Fostering well-being in parents of preterm infants in a Neonatal Intensive Care Unit

AE Gibson

23317299

Thesis submitted for the degree *Doctor Philosophiae* in Psychology at the Potchefstroom Campus of the North-West University

Promoter: Dr M van der Merwe

Co Promoter: Prof KFH Botha

November 2016

It all starts here ™

NORTH-WEST UNIVERSITY ®
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

DECLARATION

I, the undersigned, hereby declare that this research, Fostering well-being in parents of preterm infants in a Neonatal Intensive Care Unit, is my own original work and that I have not previously in its entirety or in part submitted it at any other university in order to obtain a degree. This thesis is submitted for the degree of Philosophiae Doctor in Psychology at the North-West University (Potchefstroom Campus). The information acknowledges the sources used.

_____

Name

_____

Date

DECLARATION OF LANGUAGE EDITOR

I declare that I, Jennifer Stacey, have edited the PhD thesis entitled, *Fostering Well-Being in Parents of Preterm Infants in a Neonatal Intensive Care Unit* which was written by Alison E. Gibson, student number 23317299. The edit was a general language edit that included grammatical accuracy, punctuation, spelling and fluency and clarity of expression.

Jennifer Stacey obtained the following degrees: BA (Wits) 1965, BA Hons, English Literature (Natal) 1970, BA Hons, Applied Linguistics (Wits) 1981, MA Language and Literature (by dissertation, Wits) 2000, PhD, Language and Literature (Wits) 2002. She also obtained a University Education Diploma (Natal) 1969. She has taught for nineteen years in the English Department at the University of the Witwatersrand where she lectured and was responsible for the supervision of post-graduate students. She is the co-author of *Read Well* and *Write Well.* Since retiring she has continued with academic editing of theses and journal articles as well as freelance editing of educational material and novels for Wits University Press, Jacana and Macmillan.



9th November 2016

ACKNOWLEDGMENTS

The completion of this thesis would not have been possible without the guidance, involvement, support and encouragement of many people. I wish to express my gratitude and appreciation to the following people:

- My promoter Dr. Mariette van der Merwe. No words can actually describe how much I appreciate your guidance, support, encouragement and assistance.

- My co-promoter Prof. Karel Botha, Thank you for your valuable input into the completion of this thesis.

- Jennifer Stacey for the language editing.

- The personnel from the Ferdinand Postma Library. Thank you for sending me information, books and resources when needed.

- The North-West University for the bursary.

- The Neonatal Intensive Care Unit staff at the various hospitals who completed questionnaires, assisted where necessary and allowed me to complete the research.

- The veteran parents who were willing to share their experiences with me.

- To the participants: Thank you for giving your consent to be willing to be involved in the research.

- My husband. Thank you for supporting me and the sacrifices you have made to enable me to complete this study.

- Mom. Thank you for your love, support and encouragement. And thank you mom for the many hours you spent ‘jade’-sitting.

- To Jade. Thank you. If it were not for you – this would not be.

SUMMARY

Preterm birth, defined as birth before 37 weeks gestation, is increasing worldwide. More preterm infants with ever lower birthweight are surviving due to the advances in technology. The impact of these advances in technology is that the number of infants requiring specialist care in a Neonatal Intensive Care Unit (NICU) is rising every year. Therefore, the lives of an ever-growing number of infants and families are shaped by the NICU environment, an environment which is highly technical and medically focused. In addition, hospitalisation in an NICU places great financial costs on the health care system as a whole and on the parents themselves.

With most preterm births the experiences of parents begin with complications before birth to eventual NICU admission. Relating to the NICU specifically, certain factors can be considered as protective to parental well-being or risk to parental well-being. The protective- and risk factors found in this study can be grouped into five broad categories, namely: the context of the NICU; relationships; the preterm infant; parental needs relating to information, education and communication; and lastly matters pertaining specifically to the mother. Within these five broad groupings protective factors include routine cleaning procedures, nursing support, other mothers in the unit, spousal support and extended family support, positive health of the preterm infant, KMC (Kangaroo Mother Care), education provision and for some mothers, staying at the hospital. Risk factors within the previously mentioned broad groupings include: the ‘alien’ environment of the NICU; sense of confinement; procedures; appearance and unstable health of the preterm infant; changed parental role; insensitivity of nursing staff and lack of support; extended family distress; lack of information and a juggling act to attend to responsibilities at home and at the hospital.

In the last phase, coming home with the infant was influenced by various stressors, namely, having limited knowledge of care-taking of a preterm infant, confinement to the home, maternal depression, feeding difficulties, daily challenges, peculiarities of the infant’s behaviour and misunderstanding by others. General themes which appeared in more than one phase of preterm birth from before birth to going home with the infant, related to bonding and fear of the death of the infant, which may result in changes to the self as well as the experience of guilt and trauma.

The veteran parents (parents who had previously had infants in an NICU) stated that support is necessary. Factors related to this support that were mentioned by the veteran parents include who should offer support, when to offer support as well as the content of support.

The aim of this study was to develop a support intervention. The support intervention was aimed at fostering well-being in parents who have delivered a preterm infant who is admitted to an NICU. The aim was achieved by formulating five research questions and following five objectives. The main research question involved determining what aspects should be included in a support intervention to

foster well-being in parents. Sub-questions were formulated as part of the process of answering the main research question.

This research study followed the Design and Development (D&D) intervention research model of five phases namely, problem analysis and project planning, information gathering and synthesis, design of an intervention programme, pilot testing, and evaluation. The last phase of the intervention research framework followed in this study was excluded but a plan for dissemination was discussed in the final chapter.

Elements of well-being as proposed by a number of authors were discussed as well as the theories of fostering well-being and how to recognise well-being. For this study, well-being has been defined as consisting of comprehensibility, positive relationships, engagement, manageability, accomplishment, positive emotions, self-acceptance and meaning. This forms part of both a hedonic and eudaimonic perspective. In addition to defining well-being, the bioecological theory of Bronfenbrenner and Morris (2006) is discussed as human development, including well-being, takes place within a social context.

The support intervention proceeded through an initial phase, a change-oriented phase and a termination phase. An individualised family-centred developmental care approach; a salutogenic and fortigenic approach; a solution-focused approach; and an approach developing the theory of flow were used.

The initial phase rendered useful information on the time leading up to NICU admission. Parents, particularly mothers, experience fear, anxiety, stress, and uncertainty when complications occur in the pregnancy. The preterm birth is unexpected and traumatic. The change-oriented phase differed in the quantity of contact sessions with each parent group due to individualisation and practical aspects such as the parent's availability. During the follow-up semi-structured interviews, the parents mentioned that overall the support process was useful and helpful. Unfortunately, the termination phase was not completed fully, nor with all of the parents as the majority was discharged very quickly. Thus, the post-test was completed with many parents after they had returned home with their infant. Understandably, post-test scores did not show an improvement in overall stress and anxiety, as parents had entered a new stressor situation at home.

It was not expected that significant results would be seen while the parents were still in a state of crisis in the weeks after the preterm birth of their infant however, stress and anxiety lessened with regard to certain factors and varied according to each set of parents. Discussing the parental reactions to the support intervention, it was seen that elements of well-being were starting to become evident.

Recommendations were made with regard to each phase from before birth to home and later development as well as with regards to education and further research.

Keywords: preterm; NICU; support; well-being; intervention research; positive psychology

OPSOMMING

Premature geboortes, dit wil sê geboortes voor 37 weke swangerskap, neem wêreldwyd toe. Al hoe meer vroeggebore babas met toenemend laer geboortegewig, oorleef as gevolg van tegnologiese vooruitgang. Die impak van hierdie vordering in die tegnologie is dat die aantal babas wat gespesialiseerde sorg in die Neonatale Intensiewe Sorgeenheid (NISE) ontvang jaar na jaar toeneem. Dus word die lewens van ‘n immergroeiende aantal babas en gesinne gevorm en beïnvloed deur die hoogs tegnologiese en medies-gerigte NISE opset. Daarbenewens plaas opname in die NISE groot finansiële druk op gesondheidstrukture in die geheel en ook op die ouers self.

Met die meeste premature geboortes begin die ouers se ondervinding met komplikasies voor geboorte tot uiteindelike opname in ‘n NISE. Aangaande spesifiek die NISE kan sommige faktore beskou word as beskermend rakende ouerlike welstand of bedreigend tot ouerlike welstand. Die beskermende en risiko faktore wat in hierdie studie gevind is kan in vyf breë kategorieë gegroepeer word, naamlik: die konteks van die NISE; verhoudings; die vroeggebore baba; ouers se behoefte aan inligting, opleiding en kommunikasie; en laastens aspekte met betrekking tot die moeder. Beskermende faktore in hierdie vyf breë kategorieë sluit in: roetine skoonmaak prosedures; ondersteuning van verpleegpersoneel; ander moeders in die eenheid; gade en uitgebreide familie ondersteuning; goeie gesondheid van die baba; KMS (“Kangaroo Moedersorg”); voorsiening van opleiding; en, vir sommige moeders, verblyf by die hospital. Risiko faktore in die voorafgenoemde breë kategorieë sluit in; die onbekende omgewing van die NISE; ingekluisterde gevoel; prosedures; voorkoms en onstabiele gesondheid van die vroeggebore baba; veranderde ouerskaprol; onsensitiwiteit van verpleegpersoneel en gebrek aan ondersteuning; onsteltenis van uitgebreide familie; gebrek aan inligting; en druk om verantwoordelikhede by beide die huis en die hospitaal na te kom.

In die laaste fase word die tuiskoms met die baba beïnvloed deur verskeie spanningsfaktore, naamilik: beperkte kennis van die sorg van ‘n vroeggebore baba; vasgekluister wees aan die huis; materne depressie; voedingsprobleme; daaglikse uitdagings; sonderlinge gedrag van die baba; en ander se gebrek aan insig. Algemene temas wat voorgekom het in meer as een fase van voor premature geboorte tot geboorte en tuiskoms met die baba sluit in binding en vrees vir die baba se dood wat veranderinge in die self tot gevolg kan hê, asook skuldgevoelens en trauma.

Die veteraan ouers (ouers wat vantevore babas in NISE gehad het) noem dat ondersteuning nodig is. Faktore rakende die ondersteuning, wat deur die veteraan ouers genoem is, sluit in wie die ondersteuning behoort te bied e nook die inhoud van die ondersteuning.

Die doel van hierdie studie was om ‘n ondersteuningsintervensie te ontwikkel. Die ondersteuningsintervensie was gerig op bevordering van die welstand van ouers wie se premature baba in die NISE opgeneem is. Die doel is bereik deur vyf navorsingsvrae te formuleer en nege doelwitte is nagestreef. Die hoof navorsingsvraag het behels dat bepaal moes word watter aspekte om in te sluit in ‘n ondersteuningsintervensie gerig op bevordering van welstand van ouers. Sub-vrae is geformuleer as deel van die proses om die hoof navorsingsvraag te beantwoord.

Hierdie navorsingstudie het die D&D intervensie-model van vyf fases gevolg, naamlik, probleem analise en projek beplanning; insameling van inligting en ‘n sintese of samevatting; ontwikkeling van ‘n intervensie; loodsstudie en evaluering. Die laaste fase van die intervensie navorsingsraamwerk wat in hierdie studie gevolg is, is uitgesluit maar in die laaste hoofstuk word ‘n plan vir disseminasie uiteengesit.

Elemente van welstand soos voorgestel deur verskeie outeurs, is bespreek sowel as die bevordering van welstand en hoe om welstand te herken. Vir hierdie studie word welstand gedefinieer as bestaande uit begrip, positiewe verhoudings, verbintenis, hanteerbaarheid, vervulling, positiewe emosies, self-aanvaarding en betekenis. Dit vorm deel van ‘n hedoniese en eudemoniese perspektief. Aanvullend tot die definisie van welstand, word die bioekologiese teorie van Bronfenbrenner en Morris (2006) bespreek aangesien menslike ontwikkeling, wat welstand insluit, in ‘n sosiale konteks plaasvind.

Die ondersteuningsintervensie het verloop deur ‘n aanvangsfase, ‘n veranderingsgerigte fase en ‘n termineringsfase. ‘n Individueelgerigte familie-gesentreerde ontwikkelings benadering; salutogene en fortigenies benadering; ‘n oplossingsgerigte benadering; en ‘n benadering wat die teorie van vloei, is benut.

Die aanvangsfase het waardevolle inligting verskaf oor die tydperk wat lei tot uiteindelike NISE opname. Ouers, veral moeders, ondervind vrees, angs, spanning en onsekerheid wanneer komplikasies in ‘n swangerskap voorkom. Die vroeggeboorte is onverwags en traumaties. Die veranderingsgerigte fase verskil in die aantal kontaksessies met elke ouergroep as gevolg van individualisering en praktiese aspekte soos die ouers se beskikbaarheid. Tydens die opvolg semi-gestruktureerde onderhoude het die ouers genoem dat die ondersteuningsproses in geheel nuttig en van waarde was. Ongelukkig is die termineringsfase nie ten volle voltooi nie en ook nie met al die ouers nie aangesien die meerderheid vining uit die hospitaal ontslaan is. Dus is die na-toets met ouers dikwels voltooi nadat hulle reeds huis toe is met hulle babas. Soos verwag kan word, het resultate van die na-toetse nie ‘n verbetering in algehele spanning en angstigheid getoon nie, aangesien ouers nuwe spanningsfaktore teëkom met hulle tuiskoms.

Die verwagting was nie om betekenisvolle resultate te sien terwyl ouers steeds in ‘n toestand van krisis verkeer in die weke na die vroeggeboorte van hulle baba nie, hoewel spanning en angs

verminder het rakende sekere faktore met verskille by elke ouerpaar. Tydens die bespreking van die ouers se reaksie teenoor die ondersteuningsintervensie, was dit duidelik dat aspekte van welstand na vore begin kom.

Aanbevelings word gemaak rakende elke fase van voor geboorte tot tuiskoms en latere ontwikkeling sowel as opleiding en verdere navorsing.

Sleutel terme: prematuur; NISE; ondersteuning; welstand; intervensie navorsing; positiewe sielkunde

PREFACE

The title of this study changed a number of times from the initial proposal and therefore certain documents in the addendum will have different titles such as: Support programme for parents with very low birthweight infants in a neonatal intensive care unit; Support programme for parents with preterm infants in a neonatal intensive care unit.

As part of protecting the identity of the participants involved in the study, hospital groups and names of hospitals where the research was conducted are not disclosed.

During the time of approval of the research proposal the PSI 3rd edition was available. After commencement of the research a later edition of the PSI was published. Thus, the 3rd edition of the PSI was used and not a later edition. The sources cited in the PSI subscale explanation are old as they are the original authors commenting on the scale.

Where mentioning PTSD and ASD in the text, it must be noted that these diagnoses were not based on the new Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5).

The editors of the book, Rothman and Thomas (1994), are sometimes referenced as Thomas and Rothman as indicted in the particular chapter of the book.

In the discussion of family-centred care and family-centred developmental care, older resources are used as most of the development and explanation of FCC and FCDC took place in the late 1990's and early 2000's.

An article is attached based on the research. This article will be submitted to the journal "Families in Society."

LIST OF FIGURES

Figure 1.1: First five phases of D&D model (Rothman & Thomas, 1994)

Figure 1.2: Phases of current research study (Adapted from Rothman & Thomas, 1994)

Figure 1.3: Phases of Intervention Research and Chapter Layout for Research Report (Adapted from Rothman & Thomas, 1994)

Figure 2.1 Outline of literature discussion regarding the process of preterm birth

Figure 2.2: Phases of current research study (Adapted from Rothman & Thomas, 1994)

Figure 3.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

Figure 3.2: Flow model (Nakamura & Csikszentmihalyi, Flow Theory and Research, 2009, p. 196)

Figure 3.3: Model of complete mental health (Keyes & Lopez, Toward a Science of Mental Health, 2002)

Figure 3.4: General Elements of well-being included in study

Figure 4.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

Figure 4.2: Average scores for parental stress level - Sights and sounds

Figure 4.3: Average scores for parental stress level - Infant's appearance

Figure 4.4: Average scores for parental stress level - Parental role alteration

Figure 4.5: Comparison of mothers' and fathers' overall stress scores

Figure 4.6: Most pressing needs of parents according to the nurses

Figure 5.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

Figure 5.2: Neonatal Integrative Developmental Care Model (Philips Mother and Child Care as cited in Altimier, Kenner, & Damus, 2015)

Figure 5.3: Placement of intervention phases within a salutogenic, fortigenic, family-centred developmental care

Figure 5.4: Cycle of Experience. Adapted from Siminovitch and Van Eron (2006)

Figure 5.5: Outline of intervention process

Figure 6.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

Figure 6.2: Understanding your baby (developed by researcher based on Madden, 2000)

Figure 6.3: Correct positioning of preterm infant based on Lubbe (2008) and Weaver (2014)

Figure 6.4: A Preemie's Bill of Rights (McCarty, n.d.)

Figure 7.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

Figure 7.2: Outline of research report

Figure 7.3: Outline of discussion regarding recommendations for practice

LIST OF TABLES

Table 3.1: Perspectives of well-being

Table 4.1: Demographic details of veteran parents

Table 4.2: Demographic details of nurse professionals

Table 4.3: Themes generated by veteran parents' experiences

Table 4.4: Risk and protective factors of the NICU

Table 4.5: Content for support intervention according to nurses

Table 5.1: Fundamental Human Needs (Max-Neef, 1992)

Table 6.1: Biographical details of NICU parent participants and preterm infants

Table 6.2: Support intervention sessions

Table 6.3: Pre-test scores of PSI and STAI

Table 6.4: Healing and hurting alphabet

Table 6.5: Post-test scores of the PSI and STAI

LIST OF COMMON ABBREVIATIONS USED

SA: South Africa

D&D: Design and Development

MRA: Maternal role attainment

HRP: High-risk pregnancy

PTL: Preterm labour

PTSD: Post-traumatic stress disorder

ASD: Acute stress disorder

VP: Veteran parent

NICU: Neonatal Intensive Care Unit

FCC: Family-centred care

FCDC: Family-centred developmental care

KMC: Kangaroo mother care

KC: Kangaroo care

KFC: Kangaroo father care

PPCT: The Process-Person-Context-Time Model

Table of Contents

DECLARATION ..... - 1 -

DECLARATION OF LANGUAGE EDITOR ..... - 2 -

ACKNOWLEDGMENTS ..... - 3 -

SUMMARY ..... - 4 -

OPSOMMING ..... - 7 -

PREFACE ..... - 10 -

LIST OF FIGURES ..... - 11 -

LIST OF TABLES ..... - 13 -

LIST OF COMMON ABBREVIATIONS USED ..... - 14 -

CHAPTER 1 ..... - 24 -

PROBLEM ANALYSIS AND PROJECT PLANNING ..... - 24 -

1.1 Problem Statement ..... - 25 -

1.2 Motivation for Research ..... - 28 -

1.3 Research Question ..... - 29 -

1.4 Philosophical and Theoretical Paradigms ..... - 29 -

1.5 Aim and Objectives of Research ..... - 31 -

1.6 Central Theoretical Statement ..... - 32 -

1.7 Research Methodology ..... - 32 -

1.8 Research Design ..... - 32 -

1.9 Research Phases ..... - 35 -

1.9.1. Phase One: Problem Analysis and Project Planning ..... - 35 -

1.9.1.1 Problem analysis. ..... - 35 -

1.9.1.2 Project planning. ..... - 35 -

1.9.2. Phase Two: Information Gathering and Synthesis ..... - 36 -

1.9.3. Phase Three: Design of Intervention Programme ..... - 37 -

1.9.4. Phase Four: Pilot Testing ..... - 37 -

1.9.5. Phase Five: Evaluation ..... - 37 -

1.10 Gaining Permission for Research at the Hospitals ..... - 38 -

1.11 Key Concepts ..... - 38 -
1.12 Ethical Considerations ..... - 40 -
1.13 Trustworthiness ..... - 40 -
1.14 Chapter Layout ..... - 41 -
CHAPTER 2 ..... - 43 -
PRETERM BIRTHS: A LITERATURE REVIEW ..... - 43 -
2.1 Pregnancy ..... - 44 -
2.1.1 Transition into Motherhood ..... - 44 -
2.1.2 Transition into Fatherhood ..... - 46 -
2.2 Stress and Pregnancy ..... - 47 -
2.2.1 Defining Stress ..... - 48 -
2.2.2 Stress in Pregnancy ..... - 49 -
2.2.3 Stress and its Effect on Pregnancy ..... - 49 -
2.3 High-Risk Pregnancy ..... - 50 -
2.3.1 Psychological Effects of a High-risk Pregnancy ..... - 51 -
2.3.2 Addressing the Needs of High-risk Pregnant Women ..... - 52 -
2.4 Maternal Hospitalisation and Bed Rest ..... - 53 -
2.4.1 Psychological Effects of Hospitalisation ..... - 53 -
2.4.2 Psychological Effects of Bed Rest ..... - 54 -
2.4.3 Addressing the Needs of Parents with Hospitalisation and Bed Rest ..... - 54 -
2.5 Preterm Labour ..... - 55 -
2.5.1 Psychological Effects of Preterm Labour ..... - 56 -
2.5.2 Addressing the Needs of Parents with Preterm Labour ..... - 56 -
2.6 Preterm Birth ..... - 57 -
2.6.1. Causes of Preterm Birth ..... - 57 -
2.6.2. Psychological Effects of Preterm Birth on Parents ..... - 58 -
2.6.3. Addressing the Needs of Parents with a Preterm Birth ..... - 60 -
2.7 Anticipation of Being with the Preterm Infant ..... - 61 -
2.8 Neonatal Intensive Care Unit (NICU) ..... - 61 -

2.8.1 The NICU Environment ..... - 61 -
2.8.2 Infant's Physical Appearance ..... - 62 -
2.8.3 Staff-Parent Interactions in the NICU ..... - 63 -
2.8.4 General Psychological Effects in Parents with an Infant Admitted to an NICU ..... - 64 -
2.8.5 (Altered) Parenting in NICU ..... - 65 -
2.8.5.1 Transition to motherhood with preterm infants. ..... - 65 -
2.8.5.2 Transition to fatherhood with preterm infants. ..... - 67 -
2.8.6 Bonding and Attachment ..... - 67 -
2.8.7 Kangaroo Care ..... - 69 -
2.8.8 Feeding ..... - 71 -
2.8.9 Parental Needs and Coping in the NICU ..... - 71 -
2.9 Discharge ..... - 73 -
2.9.1 Psychological Effects of Discharge on Parents ..... - 73 -
2.9.2 Needs of the Parents during Discharge ..... - 74 -
2.10 Conclusion ..... - 75 -
CHAPTER 3 ..... - 76 -
THEORETICAL PARADIGM ..... - 76 -
3.1 Well-Being ..... - 77 -
3.2 Salutogenesis and Fortigenesis ..... - 79 -
3.2.1 Sense of Coherence ..... - 79 -
3.2.1.1 Comprehensibility. ..... - 80 -
3.2.1.2 Manageability. ..... - 80 -
3.2.1.3 Meaningfulness. ..... - 80 -
3.2.2 Generalised Resistance Resources (GRR) ..... - 80 -
3.2.3 Cyclical Process ..... - 81 -
3.2.4 Fortigenesis ..... - 82 -
3.2.5. Preterm birth from a Salutogenesis and Fortigenic perspective ..... - 83 -
3.3 Positive Psychology ..... - 84 -
3.3.1 Defining Positive Psychology ..... - 85 -

3.3.2 Promoting Well-being ..... - 86 -
3.3.2.1 Broaden-and-Build Theory. ..... - 86 -
3.3.2.2 Flow. ..... - 88 -
3.3.2.3 Solution-focused brief therapy. ..... - 89 -
3.3.3 Complete State Model of Health ..... - 91 -
3.3.4. Preterm birth from a Positive Psychology perspective ..... - 93 -
3.4 Bronfenbrenner's Bioecological Systems Theory ..... - 95 -
3.4.1. Process ..... - 96 -
3.4.2. Personal Characteristics ..... - 96 -
3.4.3. Context ..... - 97 -
3.4.3.1 Microsystem. ..... - 97 -
3.4.3.2 Mesosystem. ..... - 97 -
3.4.3.3 Exosystem. ..... - 97 -
3.4.3.4 Macrosystem. ..... - 97 -
3.4.3.5 Chronosystem. ..... - 98 -
3.4.4. Time ..... - 98 -
3.4.5. Phenomenological Field and Individualisation ..... - 98 -
3.4.6. Instigative Characteristics ..... - 98 -
3.4.7. Preterm birth from a Bioecological Systems Theory perspective ..... - 98 -
3.4.7.1 Process and preterm birth. ..... - 98 -
3.4.7.2 Person and preterm birth. ..... - 99 -
3.4.7.3 Context and preterm birth. ..... - 99 -
3.4.7.4 Time and preterm birth. ..... - 100 -
3.5 General Elements of Well-Being relevant to this Study ..... - 101 -
3.6 Conclusion ..... - 103 -
CHAPTER 4 ..... - 104 -
INFORMATION GATHERING AND SYNTHESIS: VETERAN PARENTS' EXPERIENCES AND NURSING PROFESSIONALS RECOMMENDATIONS ..... - 104 -
4.1 Methodology ..... - 105 -

4.1.1 Population and Sample ..... - 105 -
4.1.2. Data Generation ..... - 106 -
4.1.3. Data Analysis ..... - 107 -
4.2 Findings Relating to Veteran Parents and Nursing Staff ..... - 110 -
4.2.1 Before Birth Experiences ..... - 111 -
4.2.1.1 Problems in pregnancy with repeated hospitalisation and bedrest. ..... - 112 -
4.2.1.2 NICU anticipation and preparation. ..... - 113 -
4.2.1.3 Eventual preterm labour. ..... - 113 -
4.2.2 The Birth Experience: Relief, Trauma and Distress ..... - 114 -
4.2.3 Neonatal Intensive Care Unit (NICU) – Risk and Protective Factors ..... - 115 -
4.2.3.1 Context of the NICU. ..... - 116 -
4.2.3.2 The preterm infant. ..... - 118 -
4.2.3.3 Relationships. ..... - 121 -
4.2.3.4 Needs for information, education and communication. ..... - 123 -
4.2.3.5 Matters relating specifically to the mother. ..... - 125 -
4.2.4 Home-coming of Infant ..... - 126 -
4.2.4.1 Important know-how. ..... - 126 -
4.2.4.2 Lonely confinement to prevent illness. ..... - 127 -
4.2.4.3 Maternal depression. ..... - 127 -
4.2.4.4 Difficult feeding. ..... - 128 -
4.2.4.5 Daily challenges and need for assistance. ..... - 129 -
4.2.4.6 Peculiarities of preterm infants and desire for normality. ..... - 129 -
4.2.4.7 Misunderstanding by others. ..... - 130 -
4.2.5 General Non-phase Specific Factors ..... - 130 -
4.3 Findings Relating to Nursing Staff Specifically ..... - 132 -
4.3.1 Parental Role and Nurses' Expectations in the NICU ..... - 132 -
4.3.2 Family-centred care (FCC) ..... - 133 -
4.4 Parental Needs for Support ..... - 134 -
4.4.1 Support Needs According to the VP ..... - 134 -

4.4.2 Support Needs According to Nursing Professionals ..... - 135 -
4.5 Identified Functional Elements ..... - 138 -
4.6 Conclusion ..... - 140 -
CHAPTER 5 ..... - 141 -
DESIGN OF INTERVENTION PROGRAMME ..... - 141 -
5.1 Current Approaches of Supportive Intervention Used in NICU'S ..... - 142 -
5.1.1 Family-Centred Care (FCC) ..... - 142 -
5.1.1.1 Parental involvement. ..... - 143 -
5.1.1.2 Collaboration between parents and nurses. ..... - 144 -
5.1.1.3 Promotion of FCC. ..... - 144 -
5.1.1.4 South African situation. ..... - 145 -
5.1.2 Family-Centred Developmental Care (FCDC) ..... - 146 -
5.2 Elements of Support Used in Other Programmes ..... - 150 -
5.2.1 The National Perinatal Association Workgroup ..... - 150 -
5.2.1.1 Use of NICU mental health professionals (NMHP). ..... - 151 -
5.2.1.2 Recommendations for layered levels of support for NICU parents. ..... - 151 -
5.2.1.3 Recommendations for screening in the NICU for emotional distress. ..... - 151 -
5.2.2 Findings from Studies Regarding Intervention Elements ..... - 152 -
5.3 Support Intervention to Foster Well-Being in Parents ..... - 153 -
5.3.1 Individualised, Family-Centred Developmental Care ..... - 153 -
5.3.2 Positive Psychology Perspectives ..... - 153 -
5.3.2.1 Salutogenic and fortigenic approach. ..... - 153 -
5.3.2.2 Theory of flow. ..... - 155 -
5.3.2.3 Solution-focused approach. ..... - 155 -
5.4 Outline of Intervention ..... - 157 -
5.4.1 Initial Phase ..... - 158 -
5.4.2 Change-Oriented Phase ..... - 160 -
5.4.2.1 Information and education. ..... - 160 -
5.4.2.2 Psycho-education. ..... - 161 -

5.4.2.3 Use of metaphor.....- 167 -
5.4.2.4 Awareness techniques.....- 168 -
5.4.3 Termination Phase.....- 168 -
5.5 Conclusion.....- 170 -
CHAPTER 6.....- 172 -
PILOT TEST.....- 172 -
6.1 Methods of Data Collection.....- 173 -
6.2 Data Analysis.....- 175 -
6.2.1. PSI Subscales Measurement Information.....- 175 -
6.2.1.1 Competence.....- 176 -
6.2.1.2 Isolation.....- 176 -
6.2.1.3 Attachment.....- 176 -
6.2.1.4 Health.....- 177 -
6.2.1.5 Role restriction.....- 177 -
6.2.1.6 Depression.....- 177 -
6.2.1.7 Spouse.....- 177 -
6.2.1.8 Life stress.....- 178 -
6.2.2 STAI Measurement Information.....- 178 -
6.2.2.1 State anxiety (S-Anxiety).....- 178 -
6.2.2.2 Trait anxiety (T-Anxiety).....- 178 -
6.2.3 Validity and Reliability of the PSI and STAI.....- 179 -
6.3 Findings of the Pilot Study.....- 179 -
6.3.1 Initial Phase.....- 180 -
6.3.1.1 Parent group NICU 1.....- 182 -
6.3.1.2 Parent group NICU 2.....- 183 -
6.3.1.3 Parent group NICU 3.....- 183 -
6.3.1.4 Parent group NICU 4.....- 184 -
6.3.1.5 Parent group NICU 5.....- 185 -
6.3.1.6 Parent group NICU 6.....- 186 -

6.3.1.7 Parent group NICU 7 ..... - 187 -
6.3.1.8 Parent group NICU 8 ..... - 188 -
6.3.1.9 Parent group NICU 9 ..... - 189 -
6.3.2 Change-oriented Phase ..... - 191 -
6.3.2.1 Information and education. ..... - 191 -
6.3.2.2 Psycho-education ..... - 195 -
6.3.2.3 The Pit Metaphor ..... - 196 -
6.3.2.4 Awareness techniques. ..... - 198 -
6.3.2.5 Positive themes generated in the change-oriented phase. ..... - 201 -
6.3.3 Termination Phase ..... - 203 -
6.3.3.1 Post-test scores and discussion. ..... - 205 -
6.4 Evaluation of Pilot Study ..... - 208 -
6.5 Suggested Refinements of Support Intervention ..... - 211 -
6.6 Ethical Aspects ..... - 212 -
6.6.1. Principles of ethical Research ..... - 212 -
6.6.1.1 Non-maleficence. ..... - 212 -
6.6.1.2 Beneficence. ..... - 212 -
6.6.1.3 Justice ..... - 213 -
6.6.1.4 Fidelity. ..... - 213 -
6.6.2. Ethical Guidelines ..... - 213 -
6.6.2.1 Ethical review. ..... - 213 -
6.6.2.2 Informed consent, voluntary participation and discontinuance. ..... - 214 -
6.6.2.3 Respect for participants' rights and dignity. ..... - 214 -
6.6.2.4 Analysis and reporting. ..... - 214 -
6.6.2.5 Use of gatekeepers. ..... - 214 -
6.6.2.6 Publication. ..... - 215 -
6.7 Conclusion ..... - 215 -
CHAPTER 7 ..... - 216 -
EVALUATION, CONCLUSION AND RECOMMENDATIONS ..... - 216 -

7.1 Findings of Study ..... - 217 -
7.2 Evaluation of Trustworthiness ..... - 223 -
7.2.1. Credibility ..... - 223 -
7.2.2. Transferability ..... - 225 -
7.2.3. Dependability ..... - 225 -
7.2.4. Confirmability ..... - 226 -
7.3 Ethical Considerations ..... - 226 -
7.4 Limitations and Obstacles ..... - 228 -
7.5 Recommendations for Practice ..... - 229 -
7.5.1. Recommendations Regarding Policy ..... - 230 -
7.5.2. Recommendations Regarding Interventions ..... - 230 -
7.5.2.1 Before birth. ..... - 230 -
7.5.2.2 During the birth. ..... - 231 -
7.5.2.3 During the NICU stay. ..... - 231 -
7.5.2.4 Discharge. ..... - 232 -
7.5.2.5 Home and later development. ..... - 233 -
7.6 Recommendations for Education among Health Care Professionals ..... - 233 -
7.7 Recommendations for Further Research ..... - 234 -
7.8 Conclusion ..... - 235 -
References ..... - 237 -
Addenda ..... - 285 -

CHAPTER 1

PROBLEM ANALYSIS AND PROJECT PLANNING

Becoming a parent is a life-changing experience that begins when a woman learns that she is pregnant. A normal full-term pregnancy can last anywhere from 38 to 42 weeks (Murkoff, 2009). However, sometimes women may deliver earlier than expected due to various factors. A premature birth or preterm birth takes place before the end of the 37th week of pregnancy (Madden, 2000). Infants born alive before 37 weeks' gestation are described as preterm infants (Tucker & McGuire, 2005).

Globally, preterm birth rates are increasing (Goldenberg, Culhane, Iams, & Romero, 2008; World Health Organization, 2012), due to growing rates of multiple births, greater use of assisted reproduction strategies, increased numbers of women over 35 years of age giving birth, and changes in clinical practices such as the increased use of caesarean sections (Beck et al., 2010). The Global Action Report on Preterm Birth, "Born Too Soon" was written in support of the Global Strategy for Women's and Children's Health and the health related Millennium Development Goals (MDG's) by providing first-ever estimates of preterm birth (World Health Organization, 2012). According to this report, 15 million babies are born prematurely every year around the world. National estimates of preterm birth prevalence for 184 countries indicated that 11% of the world's babies are born preterm (Blencowe et al., 2012).

In South Africa (SA), more than eight percent of babies are born preterm (Save the Children, 2012). However, these statistics may not be a true reflection of actual numbers of preterm births in SA to date as registration data collected by the Department of Home Affairs, which is published by Statistics SA, has a two-year delay. In addition, registration is often incomplete because of under-reporting and delayed registrations (Velaphi & Rhoda, 2012).

Due to advances in technology, greater numbers of these preterm infants survive (Melnyk, Feinstein, & Fairbanks, 2002; Melnyk et al., 2006; Zelkowitz et al., 2008) which results in the use of specialist neonatal intensive care rising year after year (Afrasiabi, Mohagheghi, Kalani, Mohades, & Farahani, 2014; Stacey, Osborn, & Salkovskis, 2015). As early as 1999, even in SA, the neonatal intensive care has improved the survival rate of preterm born infants as mentioned by Cooper, Salojee, Bolton, and Mokhachane (1999). However, surviving preterm infants lead to additional problematic circumstances. For example, the preterm infant generally needs prolonged hospitalisation in the Neonatal Intensive Care Unit (NICU) and this hospitalisation can last from a few days to many months for some preterm infants. Hospitalisation places high financial costs on the health care system (Afrasiabi et al., 2014; Hodek, von der Schulenburg, & Mittendorf, 2011) as

well as the price of separating the infant from the parents (Reddy & Mclnerney, 2007). In addition to the financial costs, parents may need to deal with adverse psychosocial and emotional effects (Lasiuk, Comeau, & Newburn-Cook, 2013). Even after discharge from the hospital there are substantial costs for special education, social services, and society as a whole (Mangham, Petrou, Doyle, Draper, & Marlow, 2009; Lasiuk et al., 2013) as preterm infants are at risk for cerebral palsy, sensory deficits, learning disabilities, and respiratory illnesses (Beck et al., 2010). Preterm birth is also the leading cause of infant mortality, paediatric morbidity, and long-term disability (Jain, Anand, & Aherwar, 2014; McCormick, Litt, Smith, & Zupanic, 2011). Globally, about 40% of deaths under the age of five years occur in the first four weeks of life, and 28% is due to preterm birth (Lawn, Cousens, & Zupan, 2005). The Neonatal Mortality Rate (NMR) in 2009 was 14/1000 live births with no reduction in the NMR from 1990 to 2009 (Lloyd & de Witt, 2013; Velaphi & Rhoda, 2012). A more current report describes the NMR for 2013 as being 14,8/1000 live births in SA (UNICEF; WHO; The World Bank; UN Population Division, Report 2014).

Clearly preterm birth and the sequelae thereof can be regarded as a significant public health problem. As stated by Arnold et al. (2013, p. 1), preterm birth is the “single most important determinant of adverse outcomes for infants and parents in terms of infant morbidity and mortality, the impact on the family and costs for health services.”

1.1 Problem Statement

Every pregnancy carries its risks but some can be regarded as high-risk pregnancies as they are complicated by a factor(s) which threaten the well-being of the mother and/or foetus (Jain et al., 2014; Lee, Ayers, & Holden, 2014). Factors placing a pregnancy at risk include, among others, existing health conditions (for example high blood pressure); age (above 35 years); lifestyle factors (for example alcohol use); and conditions of pregnancy (i.e. having multiples) (NIH: Eunice Kennedy Shriver National Institute of Child Health and Human Development, 2013). One common result of a high-risk pregnancy is a preterm delivery (Goldenberg et al., 2008).

Preterm birth has a number of associated problems for preterm infants, such as cerebral interventricular haemorrhage, sepsis, gastrointestinal infections, retinopathy of prematurity, and lung damage (Vazquez & Cong, 2014). As mentioned, one of the main causes of early neonatal death is preterm delivery (Ghosh, Wilhelm, Dunkel-Schetter, Lombardi, & Ritz, 2010; Goldenberg et al., 2008; Jain et al., 2014). Thus, as stated by Blencowe et al. (2012), preterm birth has been identified as the second largest cause of death among children under five years of age.

Preterm birth also has many consequences for parents. First of all, the parents are mostly not prepared emotionally for the birth and admission of their infant into an NICU. Emotional effects

include, among others, parental stress, anxiety (Kaaresen, Rønning, Ulvund, & Dahl, 2006) as well as guilt and depression (Hagan, Evans, & Pope, 2004; Kersting et al., 2004; Perun, 2013). Symptoms of post-traumatic stress disorder (PTSD) as well as postpartum depression (PPD) have been stated as emotional impacts (Hagan et al., 2004; Friedman et al., 2013). Family disruption, strain on relationships, alterations in self-esteem, and deterioration in the physical and mental health of the parents are also evident (Lasiuk et al., 2013). Several studies conducted over the last decade have found significantly higher rates of PTSD, depression, and anxiety disorders among parents with infants in the NICU than among parents of full-term healthy infants (Friedman et al., 2013; Novotney, 2013).

It is evident that mothers and fathers respond to, and deal with, the stress differently (Jackson, Ternestedt, & Schollin, 2003) and many factors associated with the birth of a preterm infant may put strain on the parents' relationship (Doering, Moder, & Dracup, 2000; Goutaudier, Lopez, Séjourné, Denis, & Chabrol, 2011; Nicholls & Ayers, 2007). Fowlie and McHaffie (2004) found that breakdowns in marital relationships are more common in couples during the months after a preterm delivery.

Additional problems related to the birth of a preterm infant involve parenting. While the infant is in the NICU, loss of the expected and desired parental role is cited as one of the greatest sources of stress for parents (Woodward et al., 2014). It is cited that barriers are created causing the loss of the expected and desired parental role. Barriers to parenting are defined as anything that prevents parents handling, interacting with, or providing care for their infant such as the physical NICU environment (Leonard & Mayers, 2008) as well as poor communication between the nursing staff and parents (Mertin & Watson, 1984). Vazquez and Cong (2014) state that the prevention of contact with the infant, close proximity to their infant, and a delay in the attainment of the parental role causes parental depression, anxiety, fear, anger, and frustration.

According to Lasiuk et al. (2013, p. S13), parental expectations are "shattered" by the "traumatic" event of a preterm birth. This trauma is related to the prolonged uncertainty, lack of control, modifications in one's meaning systems and, as stated, alterations in parental role expectations (Lasiuk et al., 2013). The postponement of parenting can result in extended periods of emotional and psychological distress. Jotzo and Poets (2005) and Fowlie and McHaffie (2004) state that parents are reported to experience distress, anxiety and symptoms of post-traumatic stress or complaints for several years after the preterm birth. In addition, preterm infants are at an increased risk of adverse health and developmental outcomes which results in substantial costs to the health sector after discharge from the hospital. Unfortunately the researcher could not find cost estimates in SA but a study conducted in England and Wales found that the average costs for preterm, very preterm, and extremely preterm infants are 1.56, 2.46 and 3.24 times higher respectively than the

average cost of a term infant up till 18 years of age (Mangham et al., 2009). According to Hall et al. (2015), long-term costs to families in terms of their children's cognitive, emotional and developmental outcomes, are considerable. These costs are, unfortunately, a burden to parents in SA. Even if the parents have medical aid, not all costs are covered. The situation is, understandably, significantly worse for parents in SA who do not have medical aid.

Intervention programmes are used in many countries to help parents cope after the delivery of their preterm infant. Benzies, Magill-Evans, Hayden, and Ballantyne (2013) conducted a systematic review and meta-analysis of intervention programmes used in countries such as Australia, England, Germany, Italy, Japan, the Netherlands, Norway, and the United States of America. It is seen that interventions are employed extensively worldwide. However, according to a recent article by Hall et al.(2015), care for preterm infants has made great strides but care for the parents of preterm infants has not progressed in a systemic way. To help with this problem, the National Perinatal Association (NPA) in the United States received funding to develop interdisciplinary programme standards for the psychosocial support of parents.

In SA, Ranchod et al. (2004) conducted one of the first studies of parental experience related to Very Low Birth Weight (VLBW) infants receiving intensive care in public-sector hospitals in SA. They state that increased perinatal counselling would lead to higher rates of parental satisfaction with NICU's. A further study was conducted on kangaroo care (KC) with preterm infants and asserts that "support of parents in both NICU and KC ward is essential …." (Leonard & Mayers, 2008, p. 25). Turan, Başbakkel and Özbek (2008) proved that some nurses may find the shift from traditional roles of helper and caregiver to educator, coach, and consultant challenging. Therefore, Leonard and Mayers (2008, p. 25) importantly state that "the introduction of a counsellor working exclusively in the NICU and KC ward may provide the additional support that health personnel are unable to provide owing to time constraints and excessive workloads." Just these three studies indicate the need for parental support while the infant is hospitalised to improve parental well-being. However, no descriptions of official or formal interventions in use in SA could be found. The researcher contacted NICU unit managers of 12 hospitals covering all nine provinces in SA with regard to the use of support interventions for parents of preterm infants. Not one of these 12 hospitals makes use of a formal support intervention for parents. It was, however, indicated that they are all interested in making use of some sort of support intervention.

It has been stated by a number of authors that preterm birth and prematurity are risk factors affecting the infant's development, the mother's well-being, and the early mother-infant relationship (Aarnoudse-Moens, Weisglas-Kuperus, van Goudoever, & Oosterlaan, 2009; Korja, Latva, & Lehtonen, 2012; Spinelli, Poehlmann, & Bolt, 2013). It is clearly shown that the parents' experiences of preterm birth and NICU hospitalisation of their infant negatively affect their psychological well-

being (Rossman, Greene, & Meier, 2015; Stacey et al., 2015). Ryff (2013) confirms that psychological well-being is becoming foundational to defining us as humans, and is shown to be associated with unanticipated (non-normative) family events. This research study focused on developing a support intervention to help parents cope with the birth, admittance of their preterm infant to an NICU, and the related parental stress and anxiety aimed at enhancing parental well-being. Components of successful intervention programmes used internationally that can be applied to the South African context will be included.

1.2 Motivation for Research

The researcher has personal experience of delivering a preterm infant. She experienced similar emotional reactions as stated in the literature review. Her motivation to implement a support intervention is due to the lack of adequate professional support she experienced while her infant was in the NICU. Upon visiting the hospital counsellor as instructed, the researcher perceived that the counsellor was not able to identify and comprehend what the researcher was going through. Therefore, the researcher believed the counsellor did not provide any support for her but generated further distress.

International literature indicates that intervention is needed for parents and that these intervention strategies should start early during NICU hospitalisation (Feeley, Gottlieb, & Zelkowitz, 2007; Kaaresen et al., 2006). According to Holditch-Davis, Miles, Burchinal, and Goldman (2011) the focus of interventions must be on the needs of the mother during NICU admission and on helping mothers develop their maternal role. It is interesting that these authors do not mention anything about the fathers, who are also affected in many ways by the situation of their infants. Bialoskurski, Cox, and Wiggins (2002) proved that mother-infant bonding can help promote maternal well-being and for this to occur support is needed from family, friends, and/or professionals. According to Hynan et al. (2015), NICU care has been focused on the physical health of the preterm infant but focusing on the well-being of the parents is also necessary. Health care professionals need to acknowledge the impact of preterm birth and the possible negative parental experiences and apply this knowledge (Tooten et al., 2013) in SA.

Ultimately, if parents are not adequately supported after the birth of a preterm infant, parenting can be affected negatively and core relationships may suffer leaving parents and their children vulnerable. The results of a study conducted by Boyce, Cook, Simonsmeier and Hendershot (2015) confirm this by proving that it is not only the infant risk factors but also the parent-child relationship that influences later development.

Based on the problem statement, the research questions in the next section were formulated

1.3 Research Question

The main research question is as follows:

- What aspects should be part of a support intervention to foster well-being in South African parents of preterm infants admitted to an NICU?

To answer the main research question certain sub-questions have to be answered:

- What are the experiences of veteran parents (parents who had delivered a preterm infant that was hospitalised in an NICU previously) regarding having a preterm infant hospitalised in an NICU, and what functional elements can be included in such an intervention based on their experiences?
- What elements need to be incorporated into a support intervention according to nursing professionals working in an NICU?
- How will the parents evaluate the self-developed intervention in terms of usefulness?
- How will the self-developed intervention impact on parental well-being while in the NICU?

Additionally the following hypothesis can be formulated: The pre-test and post-tests will indicate a positive effect of the support intervention on the parents' stress and anxiety. As the study commenced it was seen, however, that the effects of the support intervention cannot be isolated in the process of preterm birth and be shown by making use of a pre-test and post-test. A post-test was, however, administered to give the researcher an indication of the parents' states of mind at the time of administration.

1.4 Philosophical and Theoretical Paradigms

Chilisa and Kawulich (2012) and Merriam and Tisdell (2016) indicate that the paradigm of a researcher is embedded in beliefs about the nature of reality (ontology); ways of knowing (epistemology); and also ethics and values. According to the Oxford Dictionary, the term philosophy is defined as the "study of the nature and the meaning of the universe and of human life; a particular set or system of beliefs resulting from the search for knowledge about life and the universe; and a set of beliefs or an attitude to life that guides one's behaviour" (Turnbull, 2010, p. 1098). A philosophical paradigm is thus a set or system of beliefs, and an attitude to life guiding one's behaviour. This current study adheres to a philosophy of Positive Psychology (PP) which will be discussed here with regards to the basic tenets of PP and how these beliefs influence people and their behaviour.

The advent of PP, as known today, can be traced back to Seligman's 1998 Presidential Address to the American Psychological Association. However, the origins of PP did not begin then.

Research in PP topics can be traced back to the origins of psychology itself such as William James's writing on healthy-mindedness (James, 1902 as cited in Linley, Joseph, Harrington, & Wood, 2006). Linley et al. (2006) explains that PP has common interests with parts of humanistic psychology, with its emphasis on the fully functioning person (Rogers, 1961), as well as Maslow's (1968) self-actualisation of healthy individuals theory.

The developers of PP integrated previous knowledge, models, and theories into more rigorous scientific approaches. Current PP, thus, aims to increase research on psychological well-being and areas of human strength (Compton & Hoffman, 2013). In the early years of PP, Seligman and Csikszentmihalyi (2000, p. 6) urged psychologists to broaden their vision from "preoccupation only with repairing the worst things in life to also building positive qualities."

PP focuses on the scientific study of optimal human functioning (Linley et al., 2006) and the scientific study of the qualities and conditions permitting individuals to live a worthwhile life (Keyes, Fredrickson, & Park, 2012). PP investigates what people do correctly in life to move beyond basic adjustment and to actually flourish and thrive in the face of challenges (Compton & Hoffman, 2013). The term flourishing is used to describe high levels of well-being (Keyes & Lopez, 2002). A fundamental tenet of PP is the focus on strengths to promote growth, well-being, and happiness (Conoley, Plumb, Hawley, Spaventa-Vancil, & Hernández, 2015). Focusing on strengths which can be regarded as helpful personal assets or qualities (Conoley et al., 2015), can lead to the creation of positive emotions which can ultimately enhance well-being (Fredrickson, 2001).

Biswas-Diener, Kashdan, and Minhas (2011) state that PP is promising in its approach of assessing and building on individuals' strengths, based on the notion that greater reliance on one's strengths will lead to experiencing more positive emotions, engagement, meaning, positive relationships, and accomplishment and, therefore, well-being.

A few constructs included in the PP paradigm are positive constructs of hope, optimism, gratitude, character strengths, transcendence, empathy, and altruism (Lopez & Snyder, 2009). According to Rand and Cheavens (2009) individuals high in hope anticipate greater well-being and may be able to deal with stress more successfully. In addition, hope has been stated as being closely related to optimism as hope can be regarded as an optimistic belief that desired goals can be attained (Compton & Hoffman, 2013). In the theory of Seligman (2011), optimism can be learned if a person can focus on being more positive and thus learn to respond to stressors with an attitude of optimism and hope. Optimism is related to physical and psychological well-being (Compton & Hoffman, 2013).

Within the philosophical paradigm of Positive Psychology there are certain theoretical paradigms which relate to the Positive Psychology philosophy and to well-being. These are salutogenesis (Antonovsky, 1979; 1987; 1993; 1996), fortigenesis (Strümpfer, 1995; 2013; Wissing

& van Eeden, 1997; 2002), solution-focused approach (De Shazer & Dolan, 2012), and the Broaden-and-Build theory (Fredrickson, 1998; 2000; 2001). The theory of flow (Csikszentmihalyi, 1990; 1997) and the complete state model of mental health (Keyes & Lopez, 2002) will be discussed. These theories lay the groundwork for understanding health and how to improve well-being. The use of resources, strengths, as well as positive emotions can foster well-being. Bronfenbrenner's bioecological systems theory is included as a theory (Bronfenbrenner, 1973; 1974; 1976; 1977; 1979; 1989; 1999) relating to the effect of environmental contexts influencing individuals. The NICU is one environmental context influencing the well-being of parents. The theoretical paradigms are discussed in chapter three.

Based on the PP philosophical paradigm and the theories to be incorporated into the research study, certain aims and objectives are followed.

1.5 Aim and Objectives of Research

The aim of this research is to develop, implement, and evaluate a support intervention to foster well-being in parents of preterm infants admitted to an NICU, by utilizing the intervention research process.

In order to attain the above mentioned aim, the research objectives, which form part of the research process, include the following:

- To conduct semi-structured interviews and administer questionnaires with veteran parents of preterm infants to determine functional elements for the support intervention;
- To administer self-developed questionnaires (addendum I) with nursing professionals working in an NICU to determine functional elements for the intervention;
- To develop a support intervention to foster well-being in parents of preterm infants;
- To apply the support intervention to parents who currently have preterm infants hospitalised in an NICU after conducting a pre-test;
- To determine parents' opinions on the usefulness of the support intervention and evaluate the impact of the support intervention on the well-being of the parents who received the support through semi-structured interviews and a post-test.

Continuous dissemination will take place in the researcher's private practice and through consultation with professionals in the field and training workshops.

1.6 Central Theoretical Statement

Parents with infants in an NICU experience many negative emotions, including high levels of stress and anxiety, due to the health status of their preterm infants, the unfamiliar environment of the NICU, and changes to the parenting role. If a support intervention is provided to them it can aid the process of fostering well-being in parents of preterm infants in an NICU. Such support will probably facilitate longer term well-being and it is not expected that significant results will be seen while the parents are still in a state of crisis in the weeks after the birth of their infant. Furthermore, new adaptations and challenges will be faced when parents return to their homes with their infant. It is hoped that the support intervention will help them to find elements of growth in the difficult circumstances.

1.7 Research Methodology

This research is mainly applied as it focuses on a particular problem faced by a specific vulnerable group and has practical use (Bless, Higson-Smith, & Sithole, 2013; Wagner, 2012). It also focuses on everyday concerns people have to deal with and is aimed at improving practice (Merriam & Tisdell, 2016). The research will focus on developing an intervention to foster well-being in parents with infants in an NICU. The research will be mainly qualitative as the researcher will listen with an open-mind to the sharing of knowledge in the form of the words (Wagner, 2012) of various participant groups in order to gain a better understanding of the phenomenon which is the focus of the study. As suggested by Bless et al. (2013), the reality is then understood from the point of view of the participant.

The input of participants will be added to what is found in the literature to develop an intervention. The scientific reasoning for the qualitative part of the study will be inductive, working from specific observations to more general patterns in the data (Bertram & Christiansen, 2014; Hay, 2016). The qualitative approach in this study reflects Spinelli et al.'s (2016) statement that qualitative research is useful as topics are contextually related to the environmental conditions. There will also be a small quantitative component in the form of a pre- and post-test as will be described later.

1.8 Research Design

As stated by Mouton (2001), a research design is a plan or blueprint of how the researcher intends to conduct the research. According to Bertram and Christiansen (2014) and Hartell and Bosman (2016), the research design is determined by the research questions and is the plan to follow for collecting and analysing data to be able to answer the research question. The research questions

mentioned above are aimed at developing an intervention which implies developing tools for the profession. Merriam and Tisdell (2016) make an important point when they say that the research design must also be compatible with the worldview and skills of the researcher. The researcher is a psychologist who experienced a pre-term birth herself.

Rothman and Thomas (1994) were the first to propose a model for intervention research. Fraser (2004, p. 210) refers to the “landmark book” of Rothman and Thomas (1994). The original model was called the D&D phase model when it was pioneered by Rothman and Thomas (1994). It is now commonly referred to as intervention research, and will be used as a framework and blueprint in this study.

As more recent literature on intervention research, such as the chapter by De Vos and Strydom (2011), relies heavily on the older work of Rothman and Thomas, the researcher specifically included the original, older work. The researcher also took note of more current discourses on intervention research (Fraser, 2004; Fraser, Richman, Galinsky, & Day, 2009; Melnyk & Morrison-Beedy, 2012; Strydom, Steyn, & Strydom, 2007).

The intervention research model of Rothman and Thomas (1994) consists of six phases. According to Fawcett et al. (1994) the various phases of the D&D model are mostly described in a linear fashion but often merge in practice as researchers respond to opportunities and challenges in the shifting context of applied research. Some or many of the activities associated with each phase continue after the introduction of the next phase and there is sometimes looping back to earlier phases as difficulties are encountered or new information is obtained. The sixth and last phase of intervention research (dissemination) is not shown as it does not apply in the present research study, although a plan for dissemination will be discussed in chapter seven. The first five phases and their objectives according to Rothman and Thomas (1994) are shown in figure 1.1.

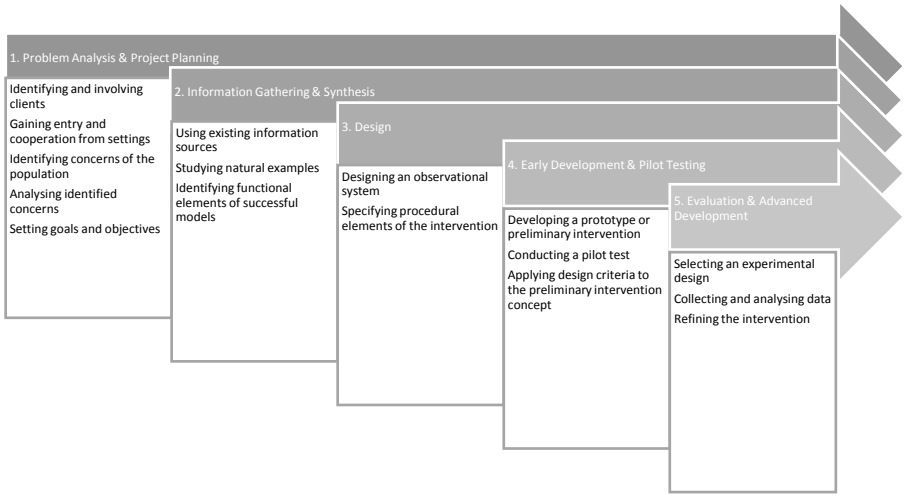


Figure 1.1: First five phases of D&D model (Rothman & Thomas, 1994)

A graphical description of the five phases of the D&D intervention model as applied in this particular study is seen in figure 1.2. Thereafter, the phases will be explained in more detail.

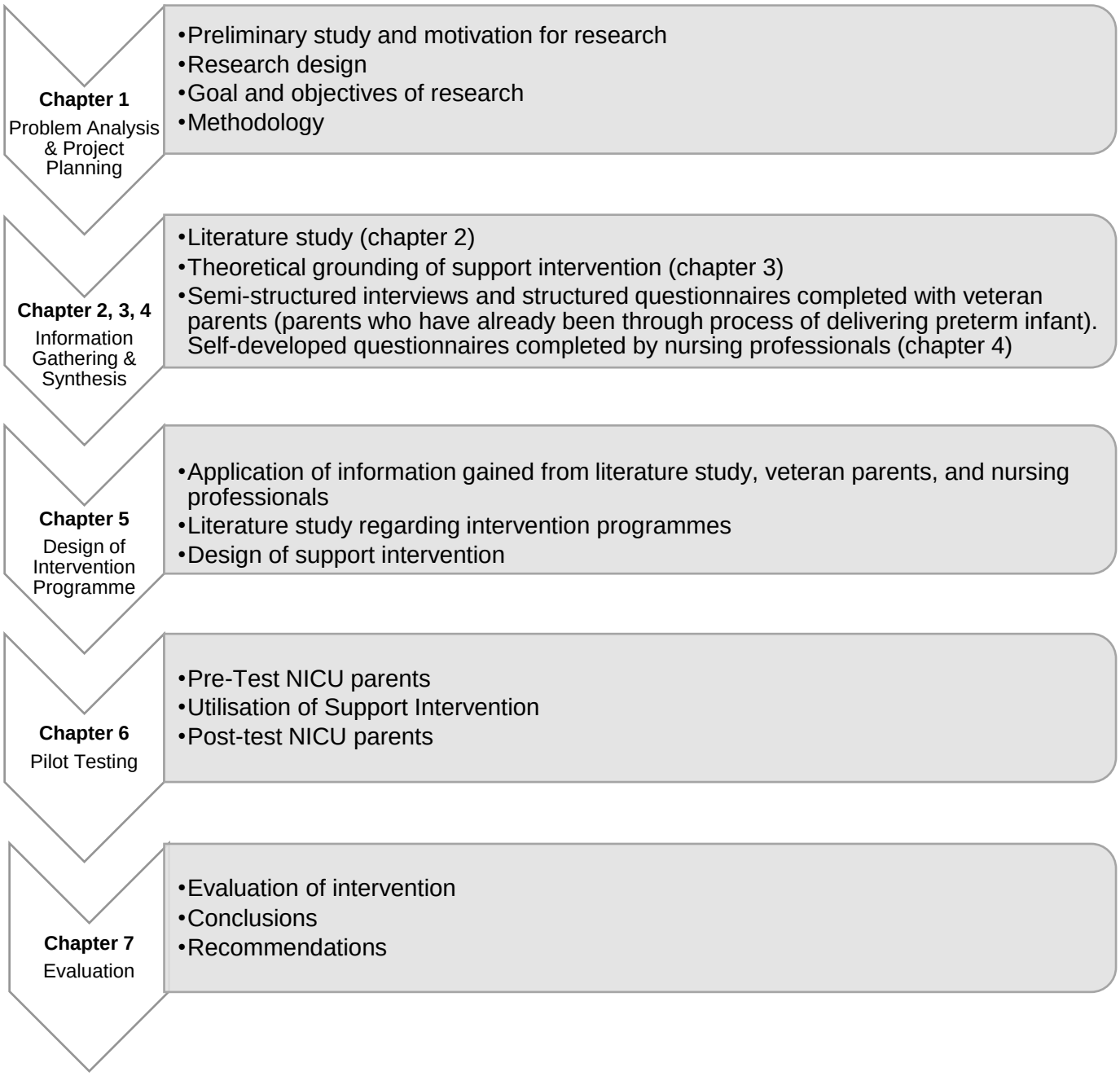


Figure 1.2: Phases of current research study (Adapted from Rothman & Thomas, 1994)

According to Thomas and Rothman (1994, p. 8), the D&D phase model typically involves "drawing on many sources of information". The different sources of information used in this study are mentioned in Figure 1.2.

1.9 Research Phases

The chapters will follow the format of the phases of intervention research as outlined in figure 1.2 and described here. The methodology will be expanded upon in a separate chapter where indicated.

In short, the following is planned:

1.9.1. Phase One: Problem Analysis and Project Planning

In this phase, key problems are identified and analysed, the project plan is prepared, goals are set, participants are identified, and entry to and co-operation from settings are coordinated (Fawcett et al., 1994).

1.9.1.1 Problem analysis.

Fraser (2004) alludes to the fact that, in the problem analysis phase, a population with heightened risk factors and vulnerability should be identified and change strategies should be directed at such risk factors. As previously discussed, preterm birth is increasing worldwide. Preterm birth is a significant health problem due to the high financial and emotional costs to parents and society. Preterm infants are admitted to the NICU and the parents of preterm infants are put into a vulnerable position where they experience various emotional problems, including trauma. The emotional problems can last for many years after the preterm birth and may affect later parenting and child development. Parents thus need support to cope with the birth of a preterm infant and deal with the related stress and anxiety. Fostering well-being in a support intervention, which is part of this study, can be regarded as an ideal goal to aim at for these parents.

1.9.1.2 Project planning.

Two different parent populations were identified for this study. The first is veteran parents (VP) who were parents of preterm infants previously admitted to an NICU, and the second is NICU parents of preterm infants currently admitted to an NICU in a private hospital(s) in the Pretoria and Johannesburg area. Another population is nursing personnel who work specifically in an NICU at a private hospital(s) in the Pretoria and Johannesburg area.

Two types of sampling are recognized, namely, probability and non-probability sampling. Non-probability sampling was used in this study and, specifically, purposive sampling (Lombard, 2016; Maree & Pietersen, 2016). To get VP's involved in the study, pamphlets (addendum B) requesting their assistance were left at gynaecologists' and paediatricians' consulting rooms with their consent. VP's were requested to contact the researcher for further details. Information was e-mailed (addendum C) to interested parents who could indicate via e-mail or telephone if they were interested in being interviewed. The time and place for the interviews were selected by the parents. Inclusion criteria for VP were any parents of preterm infant(s) that were hospitalised in an NICU no

longer than six years ago with the children being presently under the age of six years. This cut-off point was selected as the children are still young.

With regard to the nursing professionals, questionnaires were given to the unit manager of the NICU at each respective hospital who then gave the questionnaires to the nursing professionals working in the NICU. The gatekeeper for the nursing staff was the head office at each respective hospital group, and the mediators were the unit managers at each hospital.

Parents who had preterm infants hospitalised were selected using criterion sampling (Maree & Pietersen, 2016; Nieuwenhuis, 2016). They were purposively selected according to the following criteria: Married parents with preterm (< 37 weeks gestational age) infant(s) admitted to an NICU (single parents may add a further dimension affecting well-being);

- Able to speak and read English;
- Live within a 60-minute drive of the hospital (Parents are likely to be more available than when having to travel long distances).

Parents were excluded if 1) the infant was in a highly unstable medical condition that was likely to result in death, 2) had a major congenital anomaly, 3) the infant was likely to be transferred to another hospital, or 4) parents had previous experience with an NICU. Once identified, NICU parents were asked if they would be interested in being involved in the support intervention. If the NICU parents were interested, consent documentation was signed.

To gain entry to and cooperation from settings (De Vos & Strydom, 2011), written consent was obtained from the hospital management (gatekeepers), the unit manager of the NICU (mediator), as well as the participants of the study.

A final step in the problem analysis and project planning phase is setting goals and objectives (De Vos & Strydom, 2011). The goal of this study is to develop and pilot test a support intervention to foster well-being in parents of preterm infants admitted to an NICU. The objectives of this research can be seen above in section 1.6.

1.9.2. Phase Two: Information Gathering and Synthesis

Knowledge acquisition involves gaining and using relevant information (De Vos & Strydom, 2011). Data triangulation was used in this study as data was collected from multiple sources (Grove, Burns, & Gray, 2015). In this phase a literature study was first conducted. Thereafter, data was collected by using the following: findings of the semi-structured interviews and structured questionnaires with the VP and the self-developed questionnaires administered to the nursing professionals. The PSS: NICU was used as the structured questionnaire with the VP. The methodology of data collection with the VP and nursing professionals will be expanded on in chapter four.

Included in this phase, is a study of applicable theories which will be the theoretical grounding of the study, described in chapter three.

1.9.3. Phase Three: Design of Intervention Programme

In this phase, the problem is examined, the extent of the problem is determined, and the effects following the intervention are discovered (De Vos & Strydom, 2011). In this study, the synthesis of information gained through the literature study, questionnaires, and interviews with veteran parents indicated the extent of the problem and events related to the problem. Specifying the procedural elements of the intervention was made possible by observing the problem and studying naturally occurring experiences as well as other innovations and prototypes (Fawcett et al., 1994).

1.9.4. Phase Four: Pilot Testing

According to Fawcett et al. (1994) and Fraser et al. (2009), in this phase a primitive design is evolved to a form that can be evaluated under field conditions. Pilot studies are used to develop and refine an intervention (Gray, Grove, & Burns, 2013). In this research, the pilot test followed will follow the format of firstly conducting a pre-test (stress and anxiety), and then conducting a semi-structured interview, and thereafter the use of the support intervention. After use of the support intervention, a post-test and semi- structured interview were carried out. In addition, the researcher reflected after each session to capture her impressions of the sessions. (See addendum P for more information related to the researcher's reflections on the sessions).

With regards to stress and anxiety, stress has been defined as consisting of state and pregnancy anxiety (Rini, Dunkel-Schetter, Wadhwa, & Sandman, 1999). In a systematic review of sixty published studies from 1983 to 2013 which researched the use of scales for measuring pregnancy anxiety, it was found that there are currently no scales available for pregnancy related-anxiety with sound theoretical and psychometric properties (Brunton, Dryer, Saliba, & Kohlhoff, 2015). Graignic-Philippe, Dayan, Chokron, Jacquet, and Tordjman (2014) remark that in measuring state anxiety in prenatal stress the STAI inventory has been used frequently, and Brunton et al. (2015) indicate that the STAI is widely used and described as the best currently available instrument for measuring anxiety (in pregnancy) symptomatology. It is for these reasons that anxiety was measured using the STAI in this present study, and stress will be measured using the PSI. The reliability and validity of the PSI and STAI questionnaires are discussed in chapter six.

1.9.5. Phase Five: Evaluation

After the completion of the intervention, post-tests were completed using the PSI and STAI again. The pre-test, post-test and semi-structured interviews after the implementation of the intervention with the NICU parents indicated the effects of the intervention and their subjective experiences of

the intervention. Field notes were taken which enhances trustworthiness and supports observations. Audio recordings were also made for all sessions.

1.10 Gaining Permission for Research at the Hospitals

The researcher applied for permission to conduct the research at four private hospitals in the Pretoria and Johannesburg areas. Permission was granted by the head offices of these hospitals (addendum A). One of the hospitals changed management before empirical work was started and this hospital had to be excluded as new management had yet to be appointed at the time of the empirical study. In addition, the researcher collaborated with paediatricians, gynaecologists and unit managers at the hospitals where permission was granted to establish a working relationship with these health care professionals and to gain access to participants.

1.11 Key Concepts

The following terms are used in this study:

Full Term pregnancy. The average duration of a normal pregnancy is 267 days after conception or 280 days (40 weeks) from the women's first day of her last normal menstrual period (Simhan, Iams, & Romero, 2012).

Premature birth / Preterm birth. A birth that takes place before the end of the 37th week of pregnancy, also known as the 37th week of gestation (Madden, 2000).

Preterm Infant. Preterm infants are broadly described as all infants born alive before 37 weeks' gestation (Tucker & McGuire, 2005). There are sub-categories of preterm birth which are based on weeks of gestational age, namely:

- Extremely preterm (<28 weeks gestation);
- Very preterm (28 to 32 weeks gestation);
- Moderate to late preterm (32 to 37 weeks gestation) (Howson, Kinney, & Lawn, 2012).

There is often uncertainty and incomplete recording of estimates of gestation and thus birthweight may also be used in describing preterm infants:

- Low birthweight (< 2500 g)
- Very low birthweight (< 1500 g)
- Extremely low birthweight (< 1000 g) (Tucker & McGuire, 2005).

Infants born preterm are often of low birthweight (LBW) (Dunkel-Schetter, 2011). Due to a shortened gestation with preterm birth it is normal to have a LBW infant, however, preterm infants may be small for gestational age and may have neonatal problems additional to those related to shortened gestation (Tucker & McGuire, 2005). Full-term infants may be of LBW because they are 'small for gestational age.' Long-term morbidity problems increase as gestational age at birth decreases (Benzies et al., 2013). The behaviour and appearance of preterm infants also varies according to their gestational age and birthweight.

Preterm infants used in this study will include any infant born preterm (< 37 weeks gestation). Support will be individualised and be related to the parents' particular infant.

Veteran Parent (VP). This is a term used in this study and is a parent who had delivered a preterm infant that was hospitalised in an NICU previously (within the last six years). The cut-off point at approximately six years is due to the fact that the previously pre-term infant is still a young child and capturing parental perceptions should still be possible.

NICU Parent. A parent who had a preterm infant(s) in the NICU at the time of the research.

Neonatal Intensive Care Unit (NICU). The NICU is a special nursery in a hospital that provides around-the-clock care to sick or premature infants. It is also known as a level lll nursery (Madden, 2000). It has nurses who have special training and equipment to give the infant the best possible care.

Well-Being. According to Compton and Hoffman (2013), there are many definitions of happiness and well-being focusing on a variety of emotional outcomes. Well-being research has thus created models of the ways in which people define well-being (Compton & Hoffman, 2013). One-dimensional theories focus on two different perspectives, namely, the hedonic approach and the eudaimonic approach. The hedonic approach focuses on happiness and defines well-being in terms of pleasure attainment and pain avoidance, and the eudaimonic approach focuses on meaning and self-realisation and defines well-being in terms of the degree to which the person is fully functioning (Kahneman, Diener, & Schwartz, 1999; Ryan & Deci, 2001; Waterman, 1993). A further one-dimensional theory is the engagement theory which views well-being as a function of how absorbed an individual is in the activities of life (Compton & Hoffman, 2013).

Multidimensional theories describe well-being as consisting of many dimensions to capture the complexity of well-being, which include: the self-determination theory; authentic happiness and well-being theory; Ryff's (1995) six-dimensional model of psychological well-being; the modes of fulfilment; and quality of life therapy. There are common elements in each of the multidimensional theories and models. The researcher selected elements of well-being which relate to the specific context of preterm birth and the infant's admission to the NICU. Therefore, for the purpose of this

study, well-being is defined as consisting of the following aspects: positive emotion; engagement, relationships; meaning; accomplishment (PERMA); Sense of Coherence (SOC) concepts of comprehensibility and manageability as well as self-acceptance and self-esteem. Well-being thus consists of both a hedonic and eudaimonic perspective. Well-being will be discussed in more detail in chapter three.

1.12 Ethical Considerations

The goal of research ethics is to minimise the risk to participants as well as emphasise the necessity for humane and sensitive treatment of research participants (Bless et al., 2013). In chapters six and seven, the ethics related to this study will be discussed in terms of how it was applied.

1.13 Trustworthiness

Trustworthiness of research refers to the quality of the research (Rubin & Babbie, 2010). According to Barusch, Gringeri and George (2011), Lincoln and Guba (1985) posit that the trustworthiness of a research study is important in evaluating its worth. Lincoln and Guba (1985) proposed four criteria and suggested strategies to meet these criteria which provide a good starting point for evaluating qualitative work. To deem this research as being objective and of good quality, the following four concepts related to trustworthiness need to be realised:

- Credibility – confidence in the ‘truth’ of the findings;
- Transferability – findings have applicability in other contexts;
- Dependability – findings are consistent and could be repeated; and
- Confirmability – degree of neutrality (Lincoln & Guba, 1985).

These aspects are discussed in chapters 6 and 7.

1.14 Chapter Layout

This research study is organised into the following chapters (see Figure 1.3):

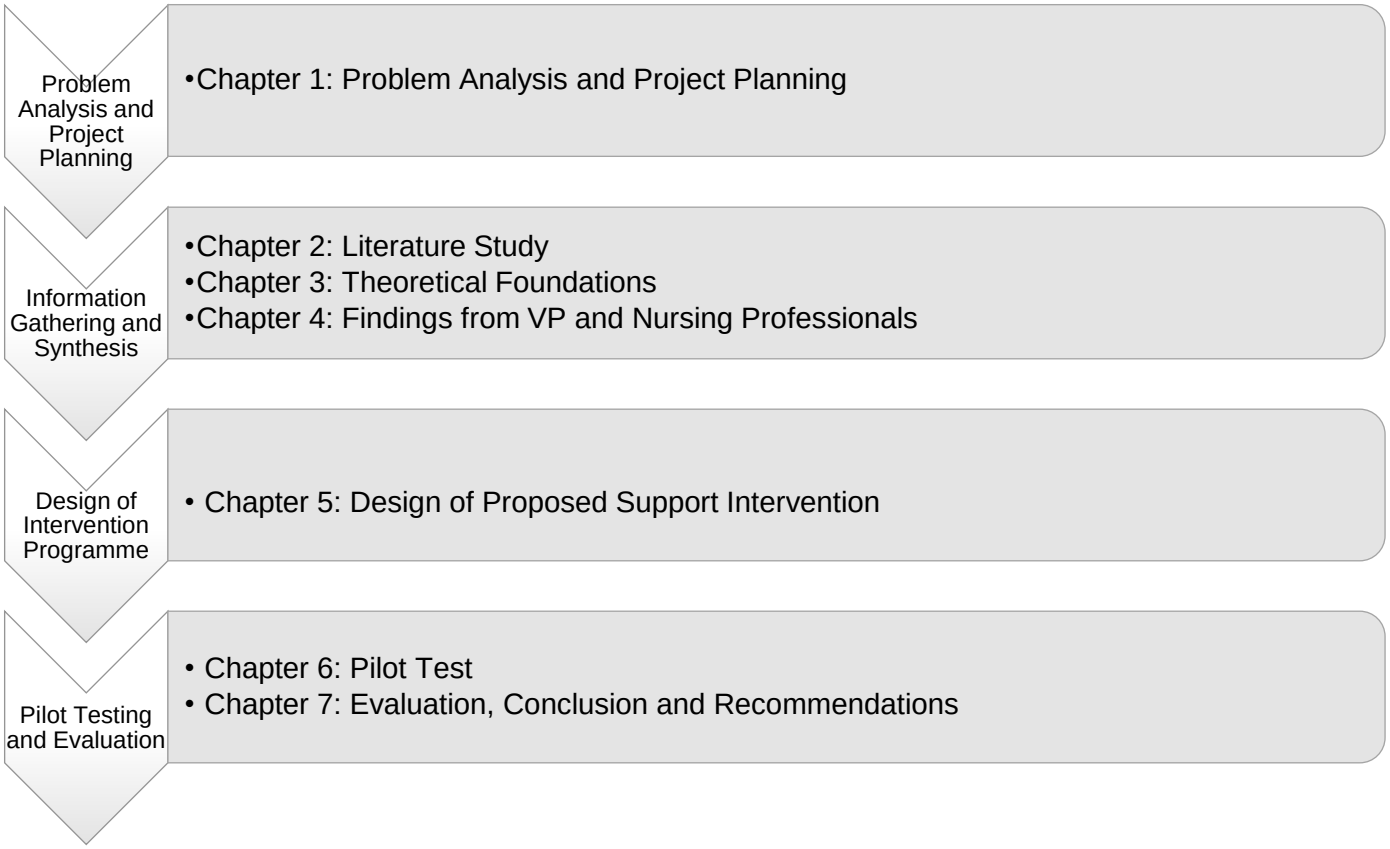


Figure 1.3: Phases of Intervention Research and Chapter Layout for Research Report (Adapted from Rothman & Thomas, 1994).

Chapter 1: This chapter covers the first phase of the intervention research process, namely, problem analysis and project planning. Prematurity and preterm birth is broadly discussed and a few problems are identified. The motivation for the research is stated as there appears to be a lack of support for parents of preterm infants. The methodological paradigm is expanded upon including the research design, goal and objectives of the study. The manner in which entry was gained is briefly explained. The philosophical paradigm of Positive Psychology is discussed with a brief overview of the theoretical paradigm which will be discussed later in chapter three.

Chapter 2: This chapter covers the information gathering and synthesis phase of the intervention research process. Existing information sources are analysed by means of a literature study. Preterm birth, its effects on parents, and the needs of parents are identified.

Chapter 3: Still within the information gathering and synthesis phase of intervention research, this chapter outlines the theoretical grounding and the various theoretical frameworks used in the research study.

Chapter 4: The study of natural examples was carried out by interviewing veteran parents and making use of self-developed and structured questionnaires to gain valuable information from nursing professionals and VP. The results of these studies are given in this chapter.

Chapter 5: In this chapter the third phase of the D&D model is executed, namely, design. Firstly, the existing programmes that were consulted with the aim of identifying valuable elements for the support intervention are discussed. Thereafter, the researcher discusses procedural elements of the intervention. Drawing together the data from the natural examples, the literature study, and findings from chapter four, an outline of a support intervention is given.

Chapter 6: Early development and pilot testing (phase four) are explained in this chapter. The results of the evaluation of the pilot test are given and discussion of research findings takes place in this chapter.

Chapter 7: Conclusions of the study are summarised and recommendations are made with regards to preterm birth and support for parents.

CHAPTER 2

PRETERM BIRTHS: A LITERATURE REVIEW

Based on a preliminary overview of preterm birth, as discussed in the previous chapter, it appears that preterm birth has many possible psychological consequences for parents. Parental well-being is one factor that may be adversely affected. This chapter investigates literature on preterm birth and its psychological consequences for parents. In addition, the needs of parents and how health care professionals can address these needs are discussed. According to the researcher, the topic-related literature predicts the theoretical paradigms and thus theoretical paradigms are discussed in the next chapter. The existing literature relating to preterm birth and its repercussions are discussed according to figure 2.1.

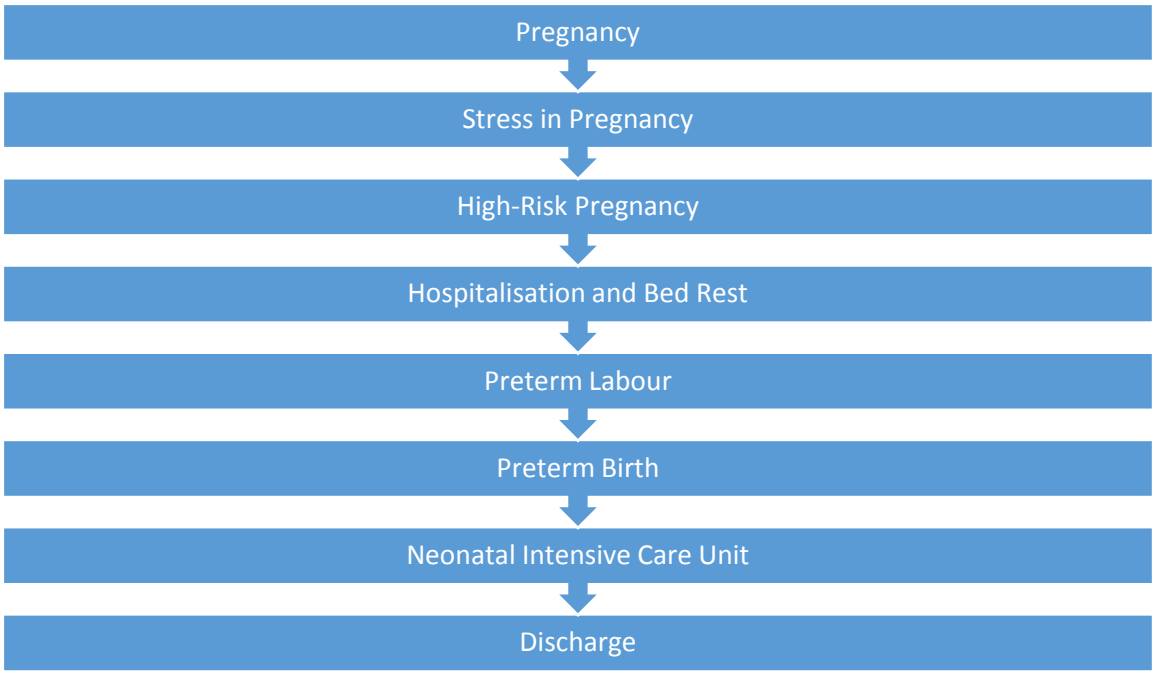


Figure 2.1: Outline of literature discussion regarding the process of preterm birth

This chapter, consisting of the literature review, is phase two of the intervention research process as indicated in figure 2.2.

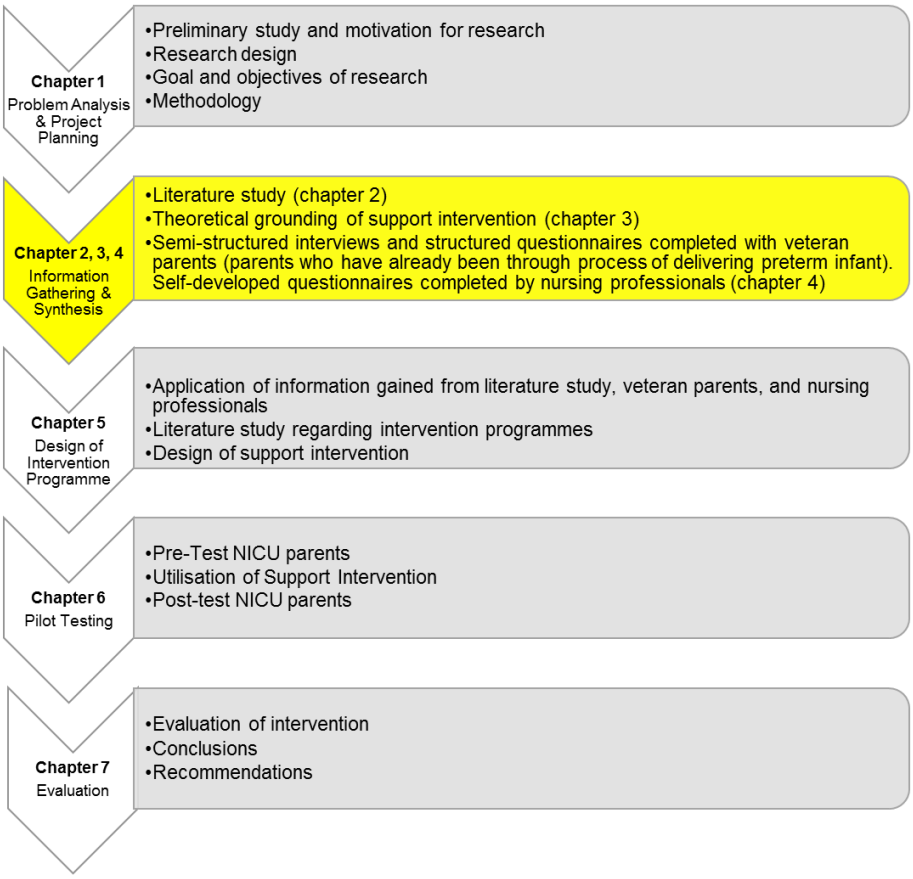


Figure 2.2: Phases of current research study (Adapted from Rothman & Thomas, 1994)

2.1 Pregnancy

Pregnancy and the transition to parenthood are major adjustment and developmental periods within a family (Deave, Johnson, & Ingram, 2008; Doss, Cicila, Hsueh, & Morrison, 2014). Transitions generally require a restructuring of goals, behaviours, and responsibilities to achieve a new concept of the self (Barba & Selder, 1995). The journey of being pregnant and the ultimate birth of a baby can certainly be regarded as a life-changing event with profound psychological and physical changes. As the focus of this study is not relating to physicality, the physical changes for a woman during pregnancy and birth are therefore not discussed. However, it is shown that mothers have to adapt to the bodily feeling of flatness as they miss the roundness of their belly and the movements of the pre-birth infant. In a Danish study some mothers just feel empty (Hall, Kronborg, Aagaard, & Brinchmann, 2013).

2.1.1 Transition into Motherhood

Transition to motherhood has been explored by a number of authors such as Rubin (1967), Mercer (1981), Nelson (2003), Parratt and Fahy (2011) and Doss et al. (2014) to name a few. Although critiqued by Parratt and Fahy (2011), the way transition to motherhood is understood today has

been influenced by the original works of Rubin (1967) and Mercer (1981). Rubin (1967) explored role theory and introduced maternal role attainment as a process leading to a woman's maternal role identity. According to Rubin (1984) four tasks need to be completed by a woman to achieve the maternal role. These are described well by Josten (1981) as:

- ensuring the physical well-being of herself and the baby;
- social acceptance of herself and her child by people who are significant to them both;
- attachment to the baby; and
- understanding the complexities of mothering.

In her later work Rubin (1984) defined maternal identity as an inseparable part of the whole personality that is more than a role. She also emphasised that maternal identity, maternal behaviour, and the quality of maternal and family life evolve as the age, physical condition, and situation of the child changes. Furthermore, with each subsequent child a new personality dimension is added into the woman's self-system due to the fact that each childbearing experience is different (Rubin, 1984).

Mercer (1985, p. 198) termed the transition to motherhood as 'maternal role attainment' (MRA) as a "process in which the mother achieves competence in the role set, so she is comfortable with her identity as a mother." McBride and Shore (2001) suggested that MRA implies a static situation rather than a fluctuating process. Thus Mercer (2006) termed the transition to motherhood as 'becoming a mother.' In addition, MRA does not include the continued expansion of the self after a maternal identity has been formed (Mercer, 2004).

Some researchers discuss MRA as having different component parts. Miles et al. (2011) as well as Holditch-Davis et al. (2011) still use the term MRA defined by components of maternal identity, maternal presence, and maternal competence. This conceptualisation is partially based on the work of Rubin (1967) and Mercer (1985). Nelson (2003) includes engagement as a component of MRA and Sawyer (1999) identified presence as part of her definition of engagement.

In sum, Mercer (2004) describes the transition to motherhood to be an intensive commitment and active involvement that begins before and during pregnancy. The woman's sense of self transforms and the result is that a woman achieves a maternal identity. An expansion of her maternal identity continues as the mother rises to new challenges in motherhood. According to Miles, Holditch-Davis, Burchinal, and Nelson (1999), the MRA components of maternal identity and maternal competence influence the mother's psychological growth. Fowles (1998), as well as Miles, Carlson and Brunssen (1999) found that MRA has effects on maternal psychological well-being.

2.1.2 Transition into Fatherhood

A transition also applies to the father where, as mentioned, a restructuring of goals, behaviours, and responsibilities to achieve a new concept of the self is necessary (Barba & Selder, 1995). In addition, research has also indicated that involvement by the prospective father has a positive effect on pregnancy and infant outcomes (Alio et al., 2011; Ghosh et al., 2010). In the study conducted in Florida, Alio et al. (2011, p. 63) found disparities in infant mortality between and within ethnic subpopulations and stated that "65–75% of excess mortality could be prevented with increased paternal involvement." Paternal support was also found to moderate the effects of chronic stress on the risk of preterm delivery in Californian women of which were mostly Latina (both US-born and immigrant) (Ghosh et al., 2010).

Transition to parenthood has largely been focused on women (Nelson, 2003) and research into the early fatherhood experience is minimal in comparison to the motherhood experience (Christie, Poulton, & Bunting, 2008; Finnbogadóttir, Svalenius, & Persson, 2003). Only in the last decade has interest been shown in the transition to fatherhood (Fenwick, Bayes, & Johansson, 2012). It is reported that (in high resource countries) pregnancy, childbirth, and parenthood also causes physical, social, emotional, and psychological changes for expectant fathers (Steen, Downe, Bamford, & Edozien, 2012). Overall, in the study conducted in Brisbane, Australia, Halle et al. (2008, p. 58) found that becoming a father is a 'profound experience.'

Genesoni and Tallandini (2009) conducted an analysis of literature from 1989-2008 in western and westernized countries, and found that there are three fatherhood stages: prenatal; labour and birth; and postpartum. Åsenhed, Kilstam, Alehagen, & Baggens (2014) describe the prenatal fatherhood stage or pregnancy stage as being a demanding period for fathers, and use the metaphor of 'roller coaster' to describe the tension between different feelings men experience about their future as fathers. Experiences of men during this stage have been characterised by feelings of being out of touch, lacking knowledge, and being fearful of labour (Draper, 2003). According to Genesoni and Tallandini (2009), pregnancy is a demanding period with regards to reorganisation of the self. Fathers want to be involved in the prenatal process (Bell et al., 2007) on the one hand, but also experience ambivalent feelings (Finnbogadóttir et al., 2003). During the next stage of labour and birth, participation is an important factor for fathers in learning to cope with the transition, because, even though the process is accompanied by feelings of helplessness, it is also typically accompanied by feelings of a sense of pleasure and pride (Chandler & Field (1997); Hallgreen, Kihlgren, Forslin, & Norberg (1999); Vehvilainen-Julkunen, and Liukkonen (1998) as cited in Genesoni & Tallandini, 2009). The postnatal period is the most interpersonally and intrapersonally challenging time for fathers where they find themselves struggling to balance work needs with the new demands of their new-father status (Genesoni & Tallandini, 2009). Genesoni and Tallandini (2009) state that if fathers struggle to reconcile their personal and work-related needs with the

family's needs, it may cause fathers to withdraw from the conflicting situation into the traditional role and end up providing little practical help to their new family. It is seen, therefore, that good couple-attunement before pregnancy can directly influence paternal identity, co-parenting relationships, and encourages a fulfilling sense of fatherhood (Rane & McBride, 2000). Mothers, thus, play key roles in helping fathers construct a triadic relationship (Genesoni & Tallandini, 2009).

Fathers also have a vital role in supporting women through the transition process, which ultimately has a longer term impact on the health and well-being of the mother and the infant (Erlandsson, Dsilna, Fagerberg, & Christensson, 2007). In the study conducted in high resource countries, Steen et al. (2012) indicated that partner support needs to work both ways. Fathers feeling excluded and fearful cannot support their partner effectively in achieving an ideal transition to a successful pregnancy, joyful birth, and parenthood experience unless they are themselves supported, included, and prepared for the reality of the uncertainty in pregnancy, labour, and parenthood, and for their role in this context.

For these reasons it is a necessity that health professionals increase their awareness of, and the involvement of expectant and new fathers (Steen et al., 2012). Fathers experience a search for answers on how to be a good father but have difficulty finding out how to support their partner (Åsenhed et al., 2014).

In sum, pregnancy and childbirth is a transition event which has profound psychological effects on both the mother and father. It has been shown that transitions, whether normative or non-normative, are critical life events that cause stress and require processes of coping (Spini, Hanappi, Bernardi, Oris, & Bickel, 2013). Pregnancy and childbirth have been cited as being stressor events (Mitnick, Heyman, & Smith Slep, 2009; Stojanovich, 2010). It is clear that pregnancy and childbirth lead to a complex interplay of roles, relationships, interactions, and adaptations within the microsystem.

2.2 Stress and Pregnancy

Research in the psychology of stress in pregnancy is progressing and increasing in quantity. Over the last two decades, interest has increased in the impact of stress and distress during pregnancy on the health and well-being of both the mother and her baby (Field, Diego, & Hernandez-Reif, 2006; Littleton, Bye, Buck, & Amacker, 2010). Various concerns relate to stress during pregnancy and the effects thereof, such as preterm birth. However, mixed findings about the relationship between prenatal stress and preterm birth have been found in the early research, partially attributed to challenges surrounding the measurement of stress, the variation in assessment tools used, study design, underlying risk differences across populations, types of stressors, and the timing of stress

assessment (Barrios, Sanchez, Qiu, Gelaye, & Williams, 2014; Gennaro & Hennessy, 2003). However, despite these challenges, Dunkel-Schetter (2011) is of the opinion that a strong body of evidence now exists about the link between stress and pregnancy outcomes.

2.2.1 Defining Stress

The concept of stress appears to have various definitions. The definition of stress based on the stress and coping theory is that “psychological stress is a particular relationship between the person in which the environment is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p. 19).

As described above, and a common perception today, stress is negative. However, some authors have suggested positive stress. In 1976, Selye introduced the concepts of eustress and distress to indicate different types of stress (Kupriyanov & Zhdanov, 2014; Simmons & Nelson, 2007). McGowan, Gardner, and Fletcher (2006) also assert that there are positive and negative aspects of stress and thus two types of stress.

Lazarus (1993) describes eustress as a positive cognitive response to a stressor and it is associated with positive feelings and a healthy physical state, while distress is severe stress associated with negative feelings and physical impairments such as muscle tension, elevated blood pressure, elevated stress hormones, and susceptibility to infection, skin problems, and pain. As cited in Kupriyanov and Zhdanov (2014), Kupriyanov and Kuzmina (2009) assert that distress is a type of stress that leads to deterioration of the adaptive capabilities of an individual and eustress initiates an increase in adaptive capabilities. According to the older work of Quick, Quick, Nelson, and Hurrell (1997), eustress is healthy, positive, and constructive.

Hersberger (2013) asserts that stress is neither positive nor negative but can be represented on a continuum with eustress being positive stress, and distress leading to negative outcomes such as short or long term anxiety:

Eustress ←----------→ Distress

Simmons and Nelson (2007) state that a major issue is to establish whether the presence of both positive and negative psychological states is possible at the same time. According to Hargrove, Nelson and Cooper (2013) stressors are characteristically neutral. Lazarus and Folkman (1984) indicate that an individual may react to any stressor with both positive and negative feelings and judgements. The individual’s appraisal of a stressor is thus the defining characteristic of a response (Hargrove, Nelson, & Cooper, 2013).

2.2.2 Stress in Pregnancy

As far back as 1999, Rini et al. (1999) define stress in pregnancy, as state and pregnancy anxiety. Later Dunkel-Schetter (2011, p. 535) use the concept 'pregnancy anxiety' for "fears about the health and well-being of one's baby, the impending childbirth, of hospital and health care experiences (including one's own health and survival in pregnancy), birth and postpartum, and of parenting or the maternal role." There appears to be a number of terms which are used interchangeably with prenatal maternal stress, such as pregnancy-specific distress, worry, anxiety, or stress (Alderdice, Lynn, & Lobel, 2012). All of these indicate negative emotional responses. Another common occurrence with literature related to pregnancy is the non-differentiation of stress and anxiety.

2.2.3 Stress and its Effect on Pregnancy

The literature on the effect of stress and/or anxiety on pregnancy can warrant a study on its own. Thus this topic is discussed briefly here with the latest findings in the research. As mentioned, eustress initiates an increase in adaptive capabilities which may help a women adapt to being pregnant. However, the presence of anxiety and stress in pregnancy has generally been associated with adverse obstetric, foetal and neonatal outcomes (Simmons & Goldberg, 2011) like preterm birth, low birthweight, and small for gestational age (Class, Lichtenstein, Långström, & D'Onofrio, 2011). Various studies have shown that prenatal maternal stress predicts preterm birth and low birthweight (Dunkel-Schetter & Glynn, 2010; Mancuso, Schetter, Rini, Roesch, & Hobel, 2004; Orr, Reiter, Blazer, & James, 2007; Kramer et al., 2009). In more recent reviews and studies, pregnancy anxiety is stated as being a key risk factor for preterm birth as pregnancy for many women is an experience characterized by a lack of socioeconomic and psychosocial resources and the presence of many stressors such as work and family responsibilities (Dunkel-Schetter, 2011). Stress is consistently significantly correlated with the incidence of adverse birth outcomes such as preterm birth or LBW (Graignic-Philippe et al., 2014).

In a literature review by Graignic-Philippe et al. (2014), life events are stated as being the most studied variable in research on prenatal stress. In the study conducted by Class et al. (2011) in Sweden, an association between risk for preterm birth and specific types of events was found. For example, experiencing the death of the father of the foetus or a relative of the mother increased the risk for preterm birth (Class et al., 2011). In other earlier studies Hedegaard, Henrikson, Sabroe, and Secher (1993) and, Hedegaard, Henriksen, Secher, Hatch, and Sabroe (1996) found that events such as physical illness or death of a family member or child, job loss, abuse, marital problems, problems with the law and financial stressors could cause stress and it was especially the women's assessment of the stress that was associated with preterm birth and not the actual occurrence of the specific events. These studies took place in Denmark. In addition to these events in life, stress at work has been researched (Lee et al., 2011) with the finding that work-related psychosocial stress in pregnant women affects birthweight and gestational age. In a systematic

review from over 80 investigations, Dunkel-Schetter and Glynn (2010) concluded that stressful life events, major catastrophes, chronic strain, state anxiety, and pregnancy anxiety contribute to the risk of preterm birth. It must be noted that the way the pregnant woman reacts to and experiences potential stressful events must be taken into account, as the particular woman in the context of her personality, past history, social and family environment may judge events differently to other women (Graignic-Philippe et al., 2014).

It is worth mentioning that the biological mechanisms of neuroendocrine, inflammatory and behavioural mechanisms are affected by stress leading to preterm birth and LBW (Dunkel-Schetter, 2011; Hobel, Goldstein, & Barrett, 2008). Maternal stressors activate the hypothalamic-pituitary-adrenal axis which is modulated by the corticotropin-releasing hormone (Cole-Lewis et al., 2014). The corticotropin-releasing hormone is likely induced by stress contributing to premature labour (Kramer et al., 2009). The study by Coussons-Read et al., (2012) provides evidence that elevated pregnancy-specific stress increases inflammatory cytokines which are associated with preterm birth and shortened gestation.

In sum, Wenzel and Stuart (2011) describe pregnancy as a time of intense physical, physiological, and psychological change that potentially increases a woman's vulnerability to anxiety. Pregnancy anxiety "is a relatively distinctive syndrome that is different from general indices of anxiety and depression" (Huizink, Mulder, de Medina, Visser, & Buitelaar, 2004, p. 89). There is evidence of a consistent association existing between pregnancy anxiety and preterm birth (Brunton et al., 2015; Ding et al., 2014). Early vulnerability combined with pregnancy-specific anxiety presents a risk for preterm birth (McDonald, Kingston, Bayrampour, Dolan, & Tough, 2014) and thus, a high-risk pregnancy can lead to the initial vulnerability and resultant anxiety with the risk of potential adverse birth outcomes.

2.3 High-Risk Pregnancy

A high-risk pregnancy (HRP) can be defined as a pregnancy where the maternal environment or past reproductive performance presents a significant risk to foetal well-being (Jain et al., 2014). Approximately 10-20% of all pregnancies are considered to be high-risk (Afrasiabi et al., 2014; Behruzi et al., 2010). Biomedical factors, usually relating to the mother's present or previous medical condition or obstetric history, can put the infant's and/or the mother's life and long-term well-being at risk (Levy-Shiff, Lerman, Har-Even, & Hod, 2002).

Many obstetrical and medical conditions may predispose women to have a HRP (Giurgescu, Penckofer, Maurer, & Bryant, 2006). Factors that may lead to a HRP can be divided into three classes, namely: antenatal factors (pregnancy); intrapartum factors (during labour and delivery); and

neonatal (infant) factors. HRP is multifactorial and high-risk mothers can have more than one factor that directly or indirectly contributes to a HRP (Jain et al., 2014). Briefly, factors can include: past reproductive performance (e.g. infertility, previous miscarriages, or stillbirths); multiple gestation; pregnancy induced hypertension; abnormal progress of labour (e.g. premature labour); birthweight and gestational age of the infant (Jain et al., 2014; Cunningham et al., 2005; Giurgescu et al., 2006; Jain et al., 2014; Lobel, Yali, Zhu, DeVincent, & Meyer, 2002).

The risk for preterm birth and low birthweight is caused by antenatal depression and this (i.e. depression) is prevalent in particular among socioeconomically disadvantaged women in developing countries, as stated by Grote et al. (2010). In SA, risk factors include HIV, alcohol abuse, poor nutrition resulting in low birthweight (<2,500 g), and maternal depression (Tomlinson et al., 2014). Bayrampour, Heaman, Duncan, and Tough (2012) state that the age 35 years or older is a maternal age where risks increase and is associated with severe pregnancy outcomes such as preterm birth and low birthweight. In addition, demographic and lifestyle factors (Gupton, Heaman, & Cheung, 2001) such as alcohol abuse, smoking, and inadequate nutrition may place a pregnancy at high-risk (Brooten, 2001). In sum, with increasing maternal high-risk status, there is a proportionate increase in the risk status of the infant, resulting in NICU admissions (Jain et al., 2014).

2.3.1 Psychological Effects of a High-risk Pregnancy

A HRP affects the whole family (Coffman & Ray, 2002). The family may react in a number of ways dependent on the significance they place on the diagnosis of high-risk, their experience with coping skills, problem-solving, and available situational supports (Aguilera, 1998).

In general, women with a high-risk pregnancy will experience more hardship and negative emotions related to their pregnancy compared to the rest of the population (Gupton et al., 2001). The main emotional characteristics include distress, anxiety, uncertainty, and depression (Clauson, 1996; Heaman, Beaton, Gupton, & Sloan, 1992; Levy-Shiff et al., 2002; Yali & Lobel, 2002). Qualitative studies of high-risk pregnant women have found uncertainty to be a complex process of denial, worry, and failure to recognise the possibility of labour (Weiss, Saks, & Harris, 2002). Uncertainty has been reported to affect the psychological well-being and coping strategies of high-risk pregnant women (Gray, 2001). Participants who reported high levels of uncertainty used avoidance to cope with their situation, and this coping strategy was related to higher levels of distress (Giurgescu et al., 2006).

In addition to the feelings of uncertainty and depression, Gilbert (2011) lists the following responses to a HRP, namely: anxiety; threat to self-esteem; self-blaming; frustration; conflict; and crisis. Anxiety results when the expectation of having a normal pregnancy and healthy infant is threatened. The strength of unmet needs and the degree of awareness about such needs determines the extent of the anxiety. The diagnosis of a HRP may affect a woman’s self-confidence

and thus she may experience a sense of low self-esteem. The mother may feel that she has failed as a woman and as a mother, which further lowers her confidence in her ability to mother. Both the mother and the father may blame each other or themselves for real or imagined wrong-doing. Frustration occurs when goals such as a healthy pregnancy, having a perfect baby, or having a perfect birth experience are impeded by the obstacles of illness, separation, and rigid rules required for health purposes. Conflict may result if the pregnancy causes physical restrictions requiring financial strains and/or it imposes difficulty in mothering tasks with siblings. Choices offered to the mother may cause conflict because they may be unappealing to her such as having a caesarean delivery for safety reasons, where she may have wanted a vaginal delivery. A crisis situation may result due to the diagnosis of a HRP with the repercussion of an inability to function and a state of disequilibrium developing (Gilbert, 2011).

Women who have suffered a perinatal loss before experience normal uncertainty associated with pregnancy, as well as uncertainty over whether their current pregnancy will end with a healthy infant (Simmons & Goldberg, 2011). Researchers have found that, after a perinatal loss, women experience more depressive symptoms and higher pregnancy-specific anxiety, which is anxiety related to the pregnancy and its outcomes (Cote-Arsenault, 2007; Cote-Arsenault & Donato, 2007). In addition, women experience a lack of communication from others as well as ambiguity, leaving these women who have experienced perinatal loss unsure of how to respond to the loss (Randolph, Hruby, & Sharif, 2015). The associated grief can lead to prolonged depression and anxiety (Lim & Cheng, 2011). Women who have experienced a perinatal loss and are experiencing psychological distress can be considered as having a high-risk pregnancy.

High-risk pregnant women are also expected to undergo more medical intervention and to encounter more difficulty coping with pain during labour and delivery (Heaman et al., 1992). If a woman perceives greater than average risk to herself and her infant, she will experience increased levels of uncertainty, higher psychological distress, and reduced well-being (Cote-Arsenault, 2007; Gray, 2006). In summary, a high-risk pregnancy leads to certain needs for the woman that need to be addressed.

2.3.2 Addressing the Needs of High-risk Pregnant Women

Parents have specific needs in the presence of obstetric complications. Most women have a desire to address the issue of being seen as women and not just as patients, and to be able to have a sincere, affirmative conversation with their health care professionals (Berg & Dahlberg, 1998). According to Behruzi et al. (2010) the following are needs of high-risk mothers: being listened to; being involved in decision making; and being offered choices. It is shown that when the health care professionals address these needs, the women generally feel more accepted as normal child-bearing women and mothers-to-be. In addition, high-risk pregnant women need to be regarded as

human beings with needs and emotions (Berg & Dahlberg, 2001). Goldberg (2007) states that authentically listening to women, being open and non-judgemental, and valuing their experiences, contributes to establishing a trust relationship between the women and health care professionals. Lindsay (2006) affirms that health care providers should assess what a high-risk pregnant woman is feeling, and what her perceptions are regarding procedures that she has to undergo. Health care professionals should be capable of identifying a mother's perception of risk and her feelings about the safety of herself and her infant. Continued information and knowledge regarding the process should be provided (Behruzi et al., 2010). According to Vila Vda and Rossi (2002) as well as Kent, Yazbek, Heyns and Coetzee (2015), most women labelled as having a high-risk pregnancy are forced to spend some part of their pregnancy in hospital.

2.4 Maternal Hospitalisation and Bed Rest

About 50% of pregnancies are affected by some type of medical complication (Bruce et al., 2008), and about 21% of women are hospitalised for these complications (Turnbull et al., 2004).

2.4.1 Psychological Effects of Hospitalisation

Admission to hospital during pregnancy may be a sudden, unexpected, and frightening event (Barber & Starkey, 2015; Barlow, Hainsworth, & Thornton, 2007). The stress associated with the hospitalisation of a high-risk pregnancy has been described in relation to separation from family, lack of privacy (Heaman & Gupton, 1998), loss of control, and a sense of isolation (Katz, 2001). Studies focusing on hospitalisation in pregnant women have found higher levels of anxiety and depression (Maloni, Kane, Suen, & Wang, 2002), lower self-image (Heaman, Gupton, & Gregory, 2004), less positive expectations for their experience of childbirth, and less optimal family functioning than in studies of non-hospitalised women (Maloni, Brezinski-Tomasi, & Johnson, 2001). In addition, women perceive their relationships as less satisfying and the presence of other children of their family is implicated in their distress (Brandon et al., 2008). Prolonged hospitalisation (more than five days) disrupts the usual adaptation to pregnancy (Kent et al., 2015). In the study of Lederman et al. (2013) in the southwestern United States, the women experienced hospitalisation as a miserable, tiring, and frustrating effort for the health of the baby, but were willing to do whatever they could to remain pregnant and to protect their baby.

When women are hospitalised during pregnancy, anxiety and worry is elevated (Barber & Starkey, 2015) as was shown among New Zealand women. Women thus may need support to identify and use coping strategies, to find hope, and bolster their social support networks (Barber & Starkey, 2015). This highlights the importance of compassionate and individualised care for women (Howarth, Swain, & Treharne, 2012).

In the South African study conducted by Kent et al. (2015), during prolonged hospitalisation, women developed social, environmental, emotional and adaptation needs. The need for social support derives from the separation from the family and the feelings of loneliness experienced. The need to improve the environment stems from women being removed from their usual environment into an environment that is unfamiliar, strange and restrictive. The long hospital stay can provoke sadness, helplessness and hopelessness, which may result in depression, hindering the woman's effectiveness in bonding with her newborn infant.

2.4.2 Psychological Effects of Bed Rest

Bed rest or maternal activity restriction is the most widely used intervention in obstetrics to prevent preterm birth in those at risk (Sciscione, 2010) despite a lack of evidence for its effectiveness (Maloni, 2010). Bed rest may exacerbate psychological effects as higher levels of anxiety, depression, and hostility are experienced during bed rest (Dunn & Shelton, 2007; Lederman et al., 2013). Financial difficulties, child care concerns related to children at home, and fear for their own outcomes and that of their baby, are causes of anxiety (Giurgescu et al., 2006). Further effects of bed rest include depression, loneliness, and separation from families causing feelings related to a lack of social and emotional support during pregnancy (Kent et al., 2015).

In contrast, Lederman et al. (2013) indicated that hospitalisation with bed rest had a positive influence on maternal development through the women's heightening identification with the motherhood protector role, an intensification or deepening of the pregnant woman's relationship with her own mother or a mother substitute, enhanced couple support, and collaboration in retaining the pregnancy and preparing for labour. Thus, it may be concluded that bed rest appears to have physical and emotional detriments but may also contribute to the woman identifying with becoming a mother.

2.4.3 Addressing the Needs of Parents with Hospitalisation and Bed Rest

Women hospitalised during pregnancy are understandably anxious and might benefit from interventions to address their anxiety. Interventions must be tailored for the unpredictable, fast-paced, and confusing environment of the medical ward. Brief interventions that place a low demand on staff and can be carried out in a self-help format, such as guided imagery or relaxation training using audio recorded instructions, music therapy, and self-guided biofeedback are, according to Barber and Starkey (2015), the most promising interventions.

Barber and Starkey (2015) state that most women will benefit from an approach that first acknowledges and contextualises their worries. Then women need a conversation about the confusing and alarming medical information they have heard so as to help them find hope and to

find the balance between caution and optimism. Information provided by the medical team can assist the women in performing well in remaining pregnant and during labour and delivery (Lederman et al., 2013). Women want to know that the medical team support their efforts to carry their babies to full term as indicated by Thornburg (2002) in an article in an American journal. Thereafter, one might then ask what usually helps and what strategies have worked for this woman before. Strategies do not have to be elaborate and can include music, reading, journaling, and prayer. Spirituality appears to mediate the relationship between environment and psychological well-being (Temane & Wissing, 2006). According to Du Toit, Wissing and Khumalo (2014) spirituality permeates subsystems such as the person and networks and finds its way across different subsystems. This is not the place to go into an in-depth discussion or conceptualisation of the term, 'spirituality', but as stated by Du Toit et al. (2014, p. 208) it presents an "expression of the inner attitude of living life directly related to the sacred." Enquiry can also be made into which strategies are practical in the current situation. For most women social support will be important. A healthcare professional can explore who is available for practical and emotional support and encourage the woman to use that support. This kind of simple intervention may be an essential investment in maternal and foetal well-being (Barber & Starkey, 2015).

Lederman et al. (2013) explains that care should include assisting the expectant mother to maintain family function. Liberal visitation hours should be considered for husbands/partners, other children, mothers and mothers-in-law and other family members. Incorporating a 'child friendly' family visitation room can facilitate interaction of the mother with her significant others.

2.5 Preterm Labour

Preterm labour (PTL) leads to 70% of preterm births, and can be regarded as a syndrome caused by multiple pathologic processes (Romero, Dey, & Fisher, 2014). Precipitating factors can include factors such as haemorrhage, cervical dysfunction, idiopathic (condition arising spontaneously where cause is unknown), contractions, infection, malnutrition, multiple pregnancy, and spontaneous preterm rupture of membranes (Liong et al., 2013). PTL is regarded as being related to maternal stress with the associated activation of the maternal-foetal stress system (Scherer et al., 2014; Romero et al., 2014). However, in the study of Seravalli, Patterson, and Nelson (2014), prenatal stress was not associated with PTL in low-income, predominantly African American women. Seravalli et al. (2014) support the understanding of the role that prenatal stress plays in the incidence of preterm birth but indicate that prenatal stress does not necessarily affect the risk of preterm labour. This is confirmed in the North Carolina studies of Dole et al. (2003) and Orr et al. (2007) where pregnancy-specific anxiety had an increased risk for preterm birth.

2.5.1 Psychological Effects of Preterm Labour

Pregnancy, which should be associated with joyful expectations, can be associated with significant distress and anxiety in the case of complications such as PTL (Brandon et al., 2008; Weidner et al., 2010). PTL is usually sudden and unexpected resulting in admission to the hospital which challenges a woman's sense of control (Barlow et al., 2007). Older literature is contrasted here with more recent literature and it seems as if previous descriptions of the feelings of women in PTL still apply today. Women hospitalised for PTL have responded emotionally to their experience by feeling scared, feeling frustrated, fearing possible bad outcomes, feeling out of control of what was happening to them, and as if their life was on hold (Coster-Schulz & Mackey, 1998; Lowenkron, 1999). Increased distress and anxieties regarding both the pregnancy and the infant's health occur (Scherer et al., 2014). Daily stress also seems to be a recurring feature in the lives of women experiencing PTL (Barlow et al., 2007). However, the diagnosis of PTL itself is linked to a wide range of emotional responses which, in turn, may increase the stress response (Brandon et al., 2008; Weidner et al., 2010) thus creating a so-called 'vicious circle.'

2.5.2 Addressing the Needs of Parents with Preterm Labour

Earlier studies on psychological interventions for women at risk for PTL focused mainly on social support components and relaxation exercises (Scherer et al., 2014). Even with inconsistent results due to limited research, studies indicate that regular applied relaxation exercises have a positive impact on a woman's emotional state (Fink, Urech, Cavelti, & Alder, 2012; Janke, 1999; Khianman, Pattanittum, Thinkhamrop, & Lumbiganon, 2012). Overall, a finding by Scherer et al. (2014) is that a chosen combination of relaxation, cognitive, and behavioural strategies have promising effects in alleviating the risks of PTL. This is consistent with the findings from Weidner et al. (2010) and Khianman et al. (2012).

In the study conducted by Barlow et al. (2007), women discussed a number of strategies to help them make sense of their situation and regain an element of control. One was to search for meaning. Women stressed how important it was that their concerns were acknowledged and taken seriously by health care staff. Equally, women needed to be given accurate and consistent information about their condition and the likely outcome. Results show that women admitted to hospital in PTL could be assisted in their search for meaning by the provision of consistent information, having their views acknowledged, getting satisfactory social support and dealing with a previous history of perceived traumatic birth experiences (Barlow et al., 2007). Other coping strategies used by women diagnosed with PTL include social support, problem-solving and positive reappraisal (Lowenkron, 1999). In addition, there is evidence that psychotherapeutic support provided to women in hospital with PTL can help avoid early preterm birth with its associated complications (Mamelle, 2001). However, the use of specific, psychological, stress-reducing interventions have not yet been evaluated systematically (Scherer et al., 2014).

2.6 Preterm Birth

Preterm birth, defined as birth before 37 weeks of gestation, is associated with 5 to 18% of pregnancies (Blencowe et al., 2012; Romero et al., 2014; World Health Organization, 2012). Preterm delivery can be spontaneous, where labour onsets prematurely, or iatrogenic where delivery is necessary for maternal or foetal conditions (Torricelli et al., 2012). Preterm birth is the leading cause of neonatal death and the second cause of childhood death below the age of five years (Lederman et al., 2013; Liu et al., 2012). Approximately 15 million neonates are born preterm every year, with the highest rates occurring in Africa and North America (Blencowe et al., 2012). It is a significant contributor to infant mortality and long-term morbidity, including an increased risk of severe impaired neurodevelopment and respiratory complications (Goldenberg et al., 2008; Stephens & Vohr, 2009; Torricelli et al., 2012). In addition, it has been stated that preterm birth is the "most single determinant of adverse outcome in terms of survival, quality of life, psychosocial and emotional impact on the family, and costs for health services" (Sawyer et al., 2013, p. 1).

2.6.1. Causes of Preterm Birth

Preterm birth appears to have multiple aetiologies not yet fully understood (Barrios et al., 2014). According to Butler and Behrman (2007), numerous psychological, social, and behavioural factors cause preterm birth. Risk factors for preterm birth based on older and more recent literature may include: very young or advanced maternal age; low pre-pregnancy body mass index; smoking; alcohol; substance abuse; increased stress; single marital status or marital strain; depression; maternal sexually transmitted infections; lower self-esteem; and inadequate social support (Berkowitz & Papiernik, 1993; Cokkinides, Coker, Sanderson, Addy, & Bethea, 1999; Neggers, Goldenberg, Cliver, & Hauth, 2004; Nkansah-Amankra, Dhawain, Hussey, & Luchok, 2010; Shumway et al., 1999). Maternal psychosocial stress is an important risk factor for preterm birth (Ghosh et al., 2010). Positive associations have been found between psychosocial stress and preterm birth (Hobel et al., 2008). Chronic stress, pregnancy-specific anxiety, stressful life events, and physical stress are all associated with increased risk (Dole et al., 2004; Hobel et al., 2008). However, some associations between psychosocial variables and preterm birth can differ by race. In the study of Dole et al. (2004) in central North Carolina, African Americans were at higher risk of preterm birth if they used distancing from problems as a coping mechanism or reported racial discrimination and white women were at higher risk if they had high counts of negative life events or were not living with a partner.

Lawn, Gravett, Nunes, Rubens, and Stanton (2010) mention some already stated causes such as infection, inflammation, placental abruption, but also maternal hypothalamic-pituitary adrenal axis activation due to acute or chronic exposure to psychological stressors. Together with known factors such as ethnicity, environmental factors, positive obstetric medical history, and maternal diseases, other aspects have assumed considerable importance such as epigenetic factors, the presence of

maternal polymorphisms associated with inflammation or thrombophilia, and gynaecological diseases such as fibromatosis, endometriosis and polycystic ovary syndrome (Torricelli et al., 2012).

All factors leading to the diagnosis of a high-risk pregnancy can also lead to preterm delivery (Giurgescu et al., 2006). As mentioned, these factors can include, among others: past reproductive performance; multiple gestation; pregnancy induced hypertension; and preterm labour (Cunningham et al., 2005; Giurgescu et al., 2006; Jain et al., 2014; Lobel et al., 2002).

A history of preterm birth and preterm labour are also significant contributors to the incidence of future preterm birth and preterm labour (Seravalli et al., 2014). Preterm birth can thus be initiated by multiple conditions and in most cases a specific mechanism cannot be established (Torricelli et al., 2012).

2.6.2. Psychological Effects of Preterm Birth on Parents

The birth of a preterm infant is usually rapid and unexpected and the infant is often immediately separated from the parents at birth and taken to the neonatal unit (Arnold et al., 2013; Sawyer et al., 2013). This may happen without the mother even seeing her infant. According to Franck, Cox, Allen, and Winter (2005), early physical separation from the infant within 24 hours of birth is related to an increase in parent's NICU-related stress. Arnold et al. (2013, p. 1) state that the parent's first experiences of the preterm birth and the time immediately thereafter is a 'blurred recall'. Parents have difficulty in remembering aspects of the birth. This aligns with the study conducted by Rossman et al. (2015) in Chicago, where mothers described feeling they were in a "haze" or a "dream" at the birth and unable to comprehend or retain what was being done to them. Fathers also report having difficulty recalling events occurring immediately after the birth (Arnold et al., 2013). Several mothers and fathers referred to the experience of the birth being a sudden or surreal experience which they did not feel part of (Arnold et al., 2013). In the study of Baum, Weidberg, Osher, and Kohelet (2012), most mothers describe the preterm delivery as a non-event as they felt that they barely participated in it and were unable to fully grasp and absorb what was happening and to give it meaning.

The surprise, suddenness, and speed of delivery and a lack of explanation give rise to feelings of shock, confusion, fear, helplessness, and loss of control (Baum et al., 2012). Goutaudier et al. (2011) as well as Baum et al. (2012) indicate that mothers experience intense feelings of frustration and emptiness. Anger towards the medical staff is also experienced at birth when no contact is given with the infant (Goutaudier et al., 2011). In the study conducted in France. Guillaume et al. (2013), reported that seeing the infant, even briefly, offered mothers the opportunity to feel like a mother.

Mothers in the study of Rossman et al. (2015) describe the pregnancy and preterm birth as being different from what they had planned, and the changes were unexpected and unwanted which left them feeling overwhelmed and unprepared psychologically for childbirth and for being a mother. The shortened pregnancy has been described by some mothers as not leaving enough time to go through the necessary psychological process of becoming a mother (Baum et al., 2012).

With regard to further negative experiences, preterm birth has been cited as being extremely stressful and traumatic for parents (Elklit, Hartvig, & Christiansen, 2007; Forcada-Guex, Borghini, Pierrehumbert, Ansermet, & Muller-Nix, 2011; Jotzo & Poets, 2005; Stacey et al., 2015). The crisis of preterm birth and the magnitude thereof is consistent with the American Psychiatric Association's (APA) definition of a trauma. APA defines trauma as exposure to actual or threatened death of a close family member (American Psychiatric Association, 2013). The parents in the study of Lasiuk et al. (2013) were described as being traumatised as the preterm birth altered their perceptions, strained their coping resources, and triggered a range of physical, emotional and behavioural responses such as fear, anxiety, grief, depression, changes in appetite and sleep patterns as well as social withdrawal. Prolonged uncertainty about the infants' survival, coupled with a lack of agency, kept the parents in the Canadian city in a heightened state of arousal (Lasiuk et al., 2013).

It is thus not surprising that symptoms of posttraumatic stress are also often reported as being experienced for several years after the preterm birth (Jotzo & Poets, 2005). As far back as 1999, Singer et al., (1999) explored the number and severity of acute stress disorder (ASD) symptoms in parents of preterm infants at seven to ten days and one month post preterm birth. In this study it was found that 25% (28% mothers and 17% of fathers) met the diagnostic criteria for ASD at both measurement times. In addition to the trauma experienced, parents often experience anxiety, guilt, incompetence, failure, and inadequacy (Lubbe, 2008; Perun, 2013). These studies were conducted in South Africa and the Ukraine. Guilt is often experienced as mothers feel they are the only ones responsible for the preterm delivery (Baum et al., 2012; Goutaudier et al., 2011). The mother's trust in her own body, her womanhood and her perception of being a mother gradually wore away due to the guilt and inadequacy she experienced (Lasiuk et al., 2013).

With regard to the fathers, few studies examine fathers' experiences of preterm birth (Arnold et al., 2013). According to the South East England study of Arnold et al. (2013), fathers reported feelings of awkwardness and exclusion during the birth, particularly during caesarean sections. In addition they feel torn between wanting to help and fear of getting in the way. Furthermore, fathers experience anguish due to having to choose between remaining with their partner or following their infant to the NICU at the time of delivery. Fathers describe the delivery as extremely stressful while at the same time worrying about their infant and wife (Guillaume et al., 2013). Interestingly, despite the fathers feeling excluded at birth, they are often the parent who sees their preterm infant for the

first time while the mother is still recovering (Arnold et al., 2013). For some fathers their experience of their first sight of the infant is both frightening and disappointing, which has been described as being a hindrance to bonding (Arnold et al., 2013). In the study of Guillaume et al. (2013) in France, several fathers reported not having been able to feel close to their infant until they had reassurance about their wife's health.

In Sweden, Lindberg, Axelsson, and Öhrling (2007), found that fathers experience three distinct themes: (1) suddenness of the preterm birth and feeling unprepared to be a father; (2) their role as being responsible for the welfare of their new family; and (3) the need to be understood by the medical staff. Fathers report confusion in finding their role in caring for the mother and infant, and tensions in the parental relationship are often attributed to this confusion (Arnold et al., 2013). Further matters which may put strain on the relationship are when mothers criticize fathers for acting tough and hiding their emotions or for being overemotional when the mothers need them to be strong (Arnold et al., 2013).

In sum, the early birth and then ultimate hospitalisation of the infant into an NICU causes chronic distress in parents (Lou, Pedersen, & Hedegaard, 2009; Kaaresen et al., 2008) and is described as being traumatic and overwhelming, leaving mothers feeling helpless, confused, and vulnerable (Rossman et al., 2015). Negative maternal experiences may have detrimental effects on parenting and the child's development (Latva, Korja, Salmelin, Lehtonen, & Tamminen, 2008). It is therefore important that health care workers acknowledge the impact of parental experiences after a preterm birth (Tooten et al., 2013). In the Netherlands study of Tooten et al. (2013), mothers and fathers do not differ in their perception and experiences. However, the way mothers and fathers cope with worry and concern differ considerably (Hughes, McCollum, Sheftel, & Sanchez, 1994; Jackson et al., 2003). According to Matud (2004), fathers use external coping strategies and women use more emotionally focused strategies when facing stressful circumstances.

2.6.3. Addressing the Needs of Parents with a Preterm Birth

Lasiuk et al. (2013) underline the importance of early identification and treatment of psychological distress related to preterm birth, and endorse the importance of support from health care providers in assisting parents to assume a parental role. The stress and uncertainty surrounding preterm birth increases the need for emotional support (Davis, Edwards, Mohay, & Wollin, 2003). According to Tooten et al. (2013), medical staff should prepare parents for what might happen during pregnancy, labour, and delivery and immediately post-birth by, for example, providing information or introducing parents to the hospital environment. In this way parents can adapt their expectations to the new situation and (re)construct their role as parents, which corresponds with the recommendations made by Lasiuk et al. (2013) in preventing ASD and PTSD. Psychological support should be offered at birth or immediately post-birth to stimulate parents to express themselves and reflect on negative

experiences they may have (Tooten et al., 2013). In the study conducted in South East England, Sawyer et al. (2013), identified four key determinants of care relating to the unique experiences of preterm birth. These are: the importance of the medical staff appearing calm during the birth; the staff portraying confidence in taking control during the birth; the mother being valued and being listened to; and the staff helping the fathers to feel involved during the birth. Thus, these determinants relate to staff professionalism, empathy, involvement of the father and birth environment.

2.7 Anticipation of Being with the Preterm Infant

Some parents see their preterm infant at birth but for others the first time will be in the NICU. In the study of Arnold et al. (2013), anticipation was felt by parents prior to seeing their infant for the first time. This anticipation is characterised by contrasting emotions, with some parents feeling scared and others feeling excited about the event. The fear experienced includes: dread of seeing the infant; wishing to stay naïve about health problems; and fear and avoidance of witnessing the seriousness of the situation.

Similar to the anticipation of seeing their infant for the first time, there is also a clear-cut distinction between parents who are worried about touching their infants for the first time and those who are more confident and excited about that experience (Arnold et al., 2013). With a preterm infant, the first contact between the parent and the infant usually takes place when the infant is in the NICU.

2.8 Neonatal Intensive Care Unit (NICU)

The first contact between the parents and the preterm infant usually takes place in the NICU. This moment is characterised by turbulent emotions (Arnold et al., 2013). According to a study conducted in New Zealand, Carter, Mulder, and Darlow (2007), determined the following four specific aspects of the NICU experience can exacerbate stress for parents: (1) the physical environment; (2) the infant's physical appearance and behaviour; (3) staff-parent interactions; and (4) alterations in the parental role. This section will be discussed according to these four aspects of the NICU as well as the general psychological effects on parents, bonding and attachment, kangaroo mother care, feeding, and parental needs and coping.

2.8.1 The NICU Environment

The experience of the NICU environment has been described as alien where parents do not speak the technical and medical language, and where every beep and light signals another crisis which, in

turn, worsens the extreme stress already experienced after the preterm birth (Altimier & Phillips, 2013; Lasiuk et al., 2013). The NICU atmosphere has been described as being cold and frightening by parents in France (Goutaudier et al., 2011) some of whom find the monitors overpowering and who have a preoccupation with the equipment covering their infants (Arnold et al., 2013). Parents face the challenge of becoming a family in a highly technological environment that is unfamiliar, challenging, and is experienced as stressful and frightening (Lee, Carter, Stevenson, & Harrison, 2014; Shin & White-Traut, 2007).

The NICU environment is highly technical and medically focused which may increase the risk of little attention being paid to the psychological needs of the parents and infant (Stacey et al., 2015). In the study of Finlayson, Dixon, Smith, Dykes, and Flacking (2014), mothers struggled to 'find their place' within this highly medicalised setting. Parent's exposure to and understanding of the NICU is crucial to their first impression, which ultimately lessens the shock at first exposure and contributes to the reassurance that their infant is in safe hands (Arnold et al., 2013). NICU tours, prior to the birth are, therefore, beneficial to ease the worry and confusion brought about by a lack of knowledge (Arnold et al., 2013; Griffin & Pickler, 2011).

2.8.2 Infant's Physical Appearance

All the women in the study of Goutaudier et al. (2011), who had no contact with their infant at birth, were shocked by the infant's physical appearance. In the study of Baum et al. (2012), many mothers expressed the initial shock and aversion on seeing their infant for the first time and experienced difficulties in accepting the infant as their own. Parents are typically overwhelmed by the infant's tiny size and fragility of the skin and have difficulty in acknowledging that the infant is a real baby (Arnold et al., 2013; Rossman et al., 2015).

Depending on the gestational age of the infant, different physical characteristics will be visible. Lubbe (2008) describes how a typical preterm infant will look like: when placed on their back, their arms fall straight to their sides and legs open like a frog's; the infant will have a weak cry or may not cry at all; their ears are soft and pliable and if a 'micro-premmie' their ears will be flat, shapeless and folded; skin will appear transparent and wrinkled; a soft, fuzzy layer of hair covers most of the body; eyelids may still be fused; fingers appear long with fingernails and toenails barely visible; ribcage soft and pliable causing chest to 'cave in' with each breath; and arms and legs are slender and skinny. Preterm infants' movements will include among other non-typical movements finger or toe splaying; squirming; jittery and jerky meaningless movements; and arching of the back.

An infant born less than eight weeks preterm will look like a small infant (Conn & Discenza, 2009; Lubbe, 2008) however, an infant born more than eight weeks preterm may not look like an infant at all (Lubbe, 2008). Conn and Discenza (2009) indicate that the appearance of a preterm infant born before 30 weeks is a shocking sight. The difference between a 34-week preterm infant and a 23-

week preterm infant is drastic. The lower the gestational age of the preterm infant, the more the infant looks like a foetus.

Parents may also find it difficult to feel a connection to their infant as their faces may be covered with masks (Arnold et al., 2013). In addition, hi-tech equipment such as monitors, wires, IV lines and leads attached to the infant make the appearance of the preterm infant difficult for parents to accept.

2.8.3 Staff-Parent Interactions in the NICU

Interaction and communication with medical staff appear to be central and influential in parental well-being. The NICU nurses, in particular, are in the unique position of being asked to practice a traditional nursing role and, in addition, help parents manage the emotional and practical consequences of having an infant in the NICU, which can be both a privilege and a burden (Stacey et al., 2015). Cleveland (2009) indicates that nurse-mother communication is complex and has the potential to either aid or hinder the mother's adaptation to the NICU. Flacking, Ewald, Nyqvist, and Starrin (2006) found that mothers of very preterm infants often keep their feelings bottled up as a result of the absorption of the hospital staff with the health of the infant. This results in mothers feeling alienated and cut off. However, according to Guillaume et al. (2013), the need for communication with the medical staff before birth, at delivery, and in the NICU, is expressed by both parents.

In the study of Stacey et al. (2015), mothers said they wanted more information at times but were reluctant to ask the staff because they worried about being bothersome. Some parents are also reluctant to ask questions due to the answer possibly being emotionally difficult to cope with, as well as their questions being perceived as stupid or redundant (Smith, SteelFisher, Salhi, & Shen, 2012). However, when not given information, more stress is created and this leads to parents feeling confused about what is best for their infant (Stacey et al., 2015).

In addition to the potential of reducing parental stress, communication makes interactions with the infant possible, and therefore can be regarded as a locus of a supportive and fulfilling encounter that reinforces the parents' perception of a developing bond with their infant (Guillaume et al., 2013). Thus, at birth and during the first weeks in the NICU, the creation of a bond with the infant is rooted in the parental relationship with the staff (Guillaume et al., 2013; Lupton & Fenwick, 2001). To help parents feel at ease in the NICU, it is important for parents to receive explanations about their infant's health status, how the NICU and equipment operate, and about changes in their infant's health status (Guillaume et al., 2013). Explanations of the infant's sensory and relational capacities and possible helpful activities are essential for parents (Guillaume et al., 2013). Fenwick, Barclay, and Schmied (2001) found that ordinary 'chatting' with staff can act as a powerful tool that can be used to assist parents in gaining confidence and becoming connected to their infants.

Guillaume et al. (2013), indicated furthermore, that in the first weeks of infant hospitalisation, the mother's self-esteem and capacity to interact with the infant is based on the relationship with the nurses and thus the nurses can compensate for, or feed into, a feeling of poor self-esteem. It is for this reason that the nurse-mother relationship has the potential to significantly affect how women perceive their mothering experience (Fenwick et al., 2001).

In a study assessing parental coping and the role of NICU staff, Smith et al. (2012) found that staff can support parents coping in the following ways: (1) facilitating participation of the parents with the infants care; (2) emphasizing documentation of the infants progress; (3) demonstrating affection for the infant; (4) addressing concerns that make parents hesitant to leave the NICU; (5) providing accurate, consistent clinical information; (6) limiting un-scheduled non-emergency phone calls by the staff; and (7) arranging voluntary activities or programmes in which parents whose infants have similar medical conditions may interact. The study of Franklin (2006) describes the unique position NICU nurses have as caring for the infants and close cooperation with the parents, being able to promote the attachment process, and stimulating the parenting role.

2.8.4 General Psychological Effects in Parents with an Infant Admitted to an NICU

Hospitalisation of preterm infants not only affects the infants but also the parents and families on physical, psychosocial, and spiritual levels (Wong, Hockenberry, Wilson, Winkelstein, & Kline, 2003). During the infant's hospitalisation in the NICU, parents are confronted with several problems such as the infant's health, its distinctive social behaviour pattern, and uncertain developmental perspectives (Goldberg & DiVitto, 2005). Parents find themselves struggling with the enormity of having an infant who is critically ill, who might die, or who may face lifelong complications (Hall et al., 2015).

In the study of Lasiuk et al. (2013) conducted in Canada, the parents' expectations of parenthood were shattered with their babies being born too early, and the consequence of NICU admission resulted in parents being frightened and helpless in the 'alien world' (p. 3), where the parents are forced to rely on strangers to safeguard the survival of their infants. The parents' normal everyday life is pushed into the background where now their only concern is their infant's survival. Parents exist in a "liminal state in which their babies had been born and yet not quite born and they are parents, but not really able to parent" (p. 3). Uncertainty remains high, parents feel horrified and helpless, and small changes in their infant's status can trigger new crises (Lasiuk et al., 2013). In the study of Rossman et al. (2015), all the mothers concurred that their infant being in the NICU was stressful, anxiety provoking, and frustrating due to uncertainties and lack of control. The unpredictability of the NICU experience is summed up in the parental feelings of guilt, anxiety, fatigue, joy, and apprehension (Stacey et al., 2015). Some mothers are overwhelmed with fears of their infant dying (Goutaudier et al., 2011), and factors contributing to the parents' psychological

state include the dependence on medical staff, the NICU's rules and organisation, and uncertainty of the infant's prognosis (Nystrom & Axelsson, 2002; Wigert, Johansson, Berg, & Hellstrom, 2006). Due to this fact, the mother often feels like an outsider (Bigelow, Littlejohn, Bergman, & McDonald, 2010). This study was conducted with South African mothers of low birth weight infants. With time and as the infant's health stabilizes, parents are able to adapt to their infant being in an NICU and rebuild their meaning systems. However this is regarded as a precarious reality that is easily disrupted by small changes in the infants condition or the NICU routine (Lasiuk et al., 2013).

2.8.5 (Altered) Parenting in NICU

It is stated that parenting affects future child health and development (Singer et al., 2003). The customary activities of parenting of holding, feeding, and bathing the infant are disrupted due to the hospitalisation of the preterm infant with its accompanying health problems and invasive treatments (Rossman et al., 2015). Parents of the hospitalised, preterm infant do not feel as though they are parents (Hutchinson, Spillett, & Cronin, 2012), which particularly affects the mother's developmental process of becoming a mother.

2.8.5.1 Transition to motherhood with preterm infants.

Maternal role attainment is a critical developmental process for the mother and mother-infant relationship (Miles & Holditch-Davis, 2003). Both the separation, direct admittance of the infant to the NICU, and the intimidating nature of the NICU, interfere with the development of the maternal role (Evans & Madsen, 2005; Fenwick, Barclay, & Schmied, 2001).

Four interrelated themes were found in a study conducted in Italy by Spinelli et al. (2016), relating to the experience of preterm mothers' transition to motherhood within the NICU. These themes were: disconnections from the child; perception of maternal inadequacy; loss of the parental role; and temporary interruption (Spinelli et al., 2016). It is shown that the mother's experience of preterm birth not only concerns the traumatic delivery but affects the entire process of becoming a mother (Spinelli et al., 2016). The normal process of transition to parenthood is disrupted due to the unexpected birth (Tooten et al., 2013). Next, the process of becoming a mother or maternal role attainment will be discussed. This is based on the work of Miles et al. (2011), Holditch-Davis et al. (2011) who refer to components of maternal role attainment, namely maternal identity, maternal presence, and maternal competence.

2.8.5.1.1. Maternal identity in mothers of preterm infants.

As discussed in 2.2.1, maternal identity can be conceptualised as the mother's perceptions and feelings of herself as the mother of her infant (Miles et al., 2011; Perun, 2013). Zabielski (1994), Mercer (1995) and Rossman et al. (2015) found that mothers of preterm infants were delayed in the early process of the attainment of their maternal role and maternal identity formation. The mother's perception of her infant influences the timing of maternal identity and the more positive the

perception, the earlier a maternal identity is formed (Zabielski, 1994). However, when mothers compare themselves to the majority of women who carry their infant to the full-term, they feel deficient, inadequate, and pained because they have not done the same (Baum et al., 2012). The mother's self-perception of inadequacy felt due to not carrying the infant to full-term, affects the mother's construction of her maternal identity (Spinelli et al., 2016). In addition, maternal identity is significantly influenced by illness-related distress and worry (Miles et al., 2011).

It is shown that certain events help trigger maternal identity such as: contact and interaction with the infant; assuming responsibilities of the maternal role; validation of their mothering by another adult or their infant's response; feelings of love for the infant; and feelings of protectiveness and concern toward the infant (Rossman et al., 2015; Zabielski, 1994). Direct physical contact between the infant and mother must be promoted (Spinelli et al., 2016) and the mother should be given the opportunity to exercise a maternal role within the NICU, which supports the natural processes of the mother-infant relationship (Fleury, Parpinelli, & Makuch, 2014).

2.8.5.1.2. Maternal engagement in mothers of preterm infants.

Maternal engagement or presence can be defined as the amount of active involvement in the child's care and the physical closeness displayed towards the infant. This concept is closely linked to the mother-infant relationship (Miles et al., 2011) which is discussed later. It is shown that greater ease in reading the infant's cues is positively related to the level of engagement (Holditch-Davis et al., 2011). MRA can be developed when mothers ask questions about their infants' health and progress, and help the nurses with tasks such as changing diapers (Baum et al., 2012). To promote the mother's feelings of motherhood, the mother should be allowed, and even encouraged, to engage in care-giving activities as soon as the infant's medical condition permits (Baum et al., 2012). Giving care to an infant is a fundamental maternal attachment behaviour, which is disrupted in the NICU (Obeidat, Bond, & Callister, 2009). However, it appears to be dependent on the mother herself. In the study of Goutaudier et al. (2011), ten women indicated that they were able to establish a strong bond with their infant while thirteen mothers considered that this bond was affected by the preterm birth.

2.8.5.1.3. Maternal competence in mothers of preterm infants.

Maternal competence can be defined as the quality of the mother's parental care-giving and interaction with her infant (Miles et al., 2011). Miles et al. (2011) as well as Zabielski (1994) found that a positive correlation exists between maternal competence and satisfaction in the maternal role. Preterm infants are often separated from the mother for prolonged periods of time causing delays in the mother interacting with, and providing care to, her infant (Kirk, Glendinning, & Gallery, 2005; Wigert et al., 2006). It has also been shown that maternal instruction affects parenting quality (Clements & Barnett, 2002; Miles et al., 2011) and thus instruction may be beneficial for parents of

preterm infants. However, research in the 1990's has shown that higher parental role stress lowers maternal competence (Zabielski, 1994). Mercer and Ferketich (1990) state that a significant correlation and interdependence exists between perceived parental competence and feelings of attachment.

2.8.5.2 Transition to fatherhood with preterm infants.

Fathers who have preterm infants may experience further challenges in gaining a paternal identity. The separation of infant and father is one of the most stressful events related to their parental role (Joseph, Mackley, Davis, Spear, & Locke, 2007). The stress fathers experience is related to them not feeling in control and struggling to gain control (Arockiasamy, Holsti, & Albersheim, 2008; Lindberg et al., 2007). Some studies have reported that fathers feel useless and uninvolved with their infant (Nirmala, Rekha, & Washington, 2006). According to the systematic review and meta-analysis conducted by Benzies and Magill-Evans (2015), the unexpected early birth of an infant may negatively affect the fathers' cognitive and emotional experiences. Fathers in the study believed that spending time with the infant, watching them grow and learn, and being recognised by the infant contributed to fathering being the "best job in the world", however, there were concerns regarding keeping the infant safe, meeting developmental milestones, self-confidence in the fathering role, providing for the family, and balancing home and work life (Benzies & Magill-Evans, 2015).

2.8.6 Bonding and Attachment

Attachment is defined as when the child uses a primary caregiver as a secure base from which to explore and, when necessary, as a haven of safety and a source of comfort (Waters & Cummings, 2000 as cited in Benoit, 2004). It is also described as the emotional and enduring bond between an infant and parent (Bowlby, 1969, 1973, 1980 as cited in Pennestri et al., 2015). Bonding is defined as the quality of the emotional tie from the parents to the infant (Hall et al., 2015; Hoffenkamp et al., 2012). According to Benoit (2004), many researchers use the terms 'attachment' and 'bonding' interchangeably and therefore these concepts will be discussed here as a whole.

Parental attachment, also called psychological bonding, is a developmental process that begins in and is strengthened during pregnancy (Habib & Lancaster, 2010) and then continues over the months following the birth of an infant (Roller, 2005). Preterm birth can influence parental bonding and impact negatively on the attachment relationship between the mother and infant (Evans, Whittingham, & Boyd, 2012; Hall et al., 2015). Studies have shown that parents who are separated from their infant and not given the chance to hold their new-borns immediately after birth can have difficulty initiating a relationship and that these early interruptions in the acquaintance process interfere with the maternal–infant relationship (Roller, 2005). According to Mercer (2006), physical contact after birth is crucial for a bond to develop into a secure attachment relationship

between parents and their infants. However, this physical contact is thwarted due to the preterm infant's need for complex technological support (Baum et al., 2012).

Further factors affecting the bonding process include uncertainties surrounding the health- and developmental outcomes of the preterm infant (DeMier et al., 2000). In addition, parents may, as a coping mechanism and a way of dealing with their emotions, keep a distance from their preterm infant (Borghini, et al., 2006; Müller-Nix & Ansermet, 2009). Mothers also withdraw from the initial contact as they feel that they cannot retain the amount of information given to them about their infant (Rossman et al., 2015). The instability of the infant's health may lead nursing staff to act as barriers to parents touching, holding and thus bonding to their infant. These physical as well as emotional separations may delay bonding (Vazquez & Cong, 2014).

According to Arnold et al. (2013), being able to touch and hold the infant are important aspects in triggering or strengthening the bond between the parents and their infant. Arnold et al (2013) and Stacey et al. (2015) assert that the first moments between the preterm infant and parent elicit a variety of feelings which are often described as a 'rollercoaster of emotions.' Research has shown that there are opposing emotions of anxious/avoidant and desperate/excited, felt in parents prior to seeing and holding their infant. The first touch for some parents is often viewed in a positive light as the parents have waited for some time for this moment to occur (Arnold et al., 2013). In the study of Arnold et al. (2013), half of the parents in the study stated that they immediately felt bonding when they touched their infant for the first time. However, when given the opportunity to hold their infant for the first time, some parents felt that they were interfering with the care, were daunted by the technology, and felt guilty for taking up staff time. The experience is, nevertheless, generally thought of as being worthwhile and the parents described that it was upsetting to return their infant to the incubator as they felt so connected to their infant. The other half of the parents in the study of Arnold et al. (2013) found the experience an ordeal and found it difficult to bond due to their fear of the infant's death. This is confirmed in the study of Guillaume et al. (2013), namely that fear of death and anxiety impedes the parent's ability to interact with the infant. The researcher is again reminded of the bioecological theory of Bronfenbrenner (1999). This theory uses the term "nested systems." In the NICU the infant is often physically out of reach of the parents in the life-giving but also restrictive medical system of the incubator. Furthermore, the family is a microsystem, existing partially in the necessary microsystem of the NICU. While this NICU environment is important to keep the infant alive, it is also directly influencing the family system on core levels such as bonding and attachment.

Both mothers and fathers, however, have described that interactions with their infant are important steps in starting to feel a bond (Guillaume et al., 2013). Fathers describe their bond with their infant as composed more of words and looking (Guillaume et al., 2013). However, fathers have

described the experience of holding their infant for the first time as unparalleled to anything else (Arnold et al., 2013). The father's relationship is marked by the need to understand monitors and treatments and to feel some control over the situation (Guillaume et al., 2013). Mothers, on the other hand, need to touch and hold the infant to experience the bond (Guillaume et al., 2013).

Notably, recent research has indicated that preterm infants and their mothers are not at higher risk of attachment difficulties than full-term infants and their mothers (Korja et al., 2012). Mothers in the study by Hall et al. (2015) reported more feelings of bonding with their preterm infants than mothers of full-term infants. The extent to which the hospital staff support the parents in the NICU contributes to parental bonding (Hall et al., 2015) and, therefore, parents need reassurance to concentrate on their infant and professional assistance on how to interact with the infant (Guillaume et al., 2013). Kangaroo Care is a procedure that affords both the mother and infant the opportunity to get to know one another even in the NICU (Roller, 2005).

2.8.7 Kangaroo Care

As mentioned, kangaroo care (KC) can help with bonding and attachment between the parents and the preterm infant. KC, also called kangaroo mother care (KMC) is defined as early, prolonged, and continuous care involving mothers or fathers holding their infant in an upright position with skin-to-skin contact (Lemmen, Fristedt, & Lundqvist, 2013; Roller, 2005). The infant is usually only dressed in a nappy and a cap, and in some cases socks, and is placed between the mothers breasts, where the infant is kept warm and has ready access to feeding, and is protected from infection and provided with stimulation and safety (Solomons & Rosant, 2012). Boundy et al. (2016) conducted a systematic review and meta-analysis with the majority of studies being from middle- or high income countries. KMC is regarded as safe and low-cost with the potential to prevent many complications associated with preterm birth. In contrast with the distance created by the incubator, KMC allows very close physical contact between parent/child subsystems with the potential of strengthening the bond and leading to more balance in the family as microsystem (Boundy, et al., 2016).

With KC, the biological and emotional needs of the infant and the mother are met (Wildner, 2012). For example, in infants the practice of KMC produces increased sleep time, decreased purposeless motor activity, decreased crying, improved weight gain, increased alertness and decreased length of stay in an NICU (Feldman, Eidelman, Sirota, & Weller, 2002). In a recent systematic review and meta-analysis between KMC and neonatal outcomes, KMC compared to conventional care was associated with 36% lower mortality, decreased risk of neonatal sepsis, hypothermia, hypoglycaemia, hospital readmission, and increased exclusive breastfeeding (Boundy et al., 2016). KMC also meets the infant's important needs for warmth, stimulation, parental contact, and love (Chen, Chang, Chang, & Mu, 2015; Johnston, Campbell-Yeo, & Filion, 2011; Nyqvist et al., 2010).

For mothers, long periods of skin-to-skin contact between the mother and her infant are regarded as one effective way to empower mothers to become familiar with their infants, strengthen their mothering at their own pace, and increase feelings of parental competence (Nyqvist et al., 2010). Other emotional benefits include enhanced bonding and lower rates of depression (Feldman et al., 2002). In addition, skin-to-skin contact is an important intervention to promote breastfeeding and enable the mother to become more confident when caring for her infant (Conde-Agudelo, Belizán, & Diaz-Rossello, 2011; Uvnäs-Moberg & Eriksson, 1996).

Fathers are also able to do KMC which is sometimes termed Kangaroo Father Care (KFC). Various authors indicate that KFC helps the father become active in their infant's care, enhances paternal feelings, and increases confidence in his paternal role (Leonard & Mayers, 2008; Lindberg, Axelsson, & Öhrling, 2008; Lundqvist, Westas, & Hallström, 2007). These studies took place in South Africa and Sweden. KFC also helps fathers develop paternal feelings, a sense of paternal competence, and an ability to handle the unexpected situation of preterm birth and NICU hospitalisation (Blomqvist, Rubertsson, Kylberg, Jöreskog, & Nyqvist, 2012). It has been shown that in studies with fathers, an association exists between early contact and feelings of emotional closeness (Sullivan, 1999).

Findings from research which are noteworthy are that most nurses believe KMC to be a positive intervention (Gabriels, 2015; Solomons & Rosant, 2012). However, according to Sellick, Chia, and Gan (2006) in an Australian study, nurses and NICU's are reluctant to institute the practice, particularly with infants requiring mechanical ventilation, umbilical catheters, or other supportive technology. In the study of Sellick et al. (2006), notable constraints to promoting KC in the NICU were heavy staff workloads, insufficient education, lack of organisational support and the absence of clear protocols, especially for low birthweight infants. It has been documented at the International Conference for Neonatal Nursing hosted by the Neonatal Nursing Association of Southern Africa (NNASA), a workshop attended by 80 participants from 13 countries, that the attitudes of nurses are considered to be the most important factor in determining whether or not the parents perceive KMC to be a positive experience (Davy, Bergh, & Van Rooyen, 2011). In a South African study conducted by Solomons and Rosant (2012), the staff did not communicate any resistance to KMC and believed that it is beneficial to the infant and the mother, but felt that the facilities in the ward were inadequate for successful implementation of KMC. The main obstacles were the mothers' lack of knowledge of KMC, lack of training in nurses, and the mothers' feelings of being isolated from their spouses and families (Solomons & Rosant, 2012). Successful implementation requires commitment from site managers and their personnel, a supportive environment, a willing mother, and dedicated staff who have been trained in all aspects of KMC (Solomons & Rosant, 2012; World Health Organization, 2003).

2.8.8 Feeding

Madden (2000) states that no other single activity of being a parent of a preterm infant absorbs as much time and emotional energy as feeding the infant. According to Flacking et al. (2006) and Sweet (2006), feeding is one of the most prominent care-giving activities in the NICU. Preterm infants require individualised feeding plans and frequent medical interventions, and their health status and physical limitations require specialised products (Neu, Bradley, Ding, Tucker, & Berseth, 2013). Many preterm infants are not capable of breastfeeding from birth due to immaturity and/or illness (Maastrup et al., 2014) and thus designing an optimal feeding programme for preterm infants can be particularly challenging (Neu et al., 2013).

Breastmilk is regarded as the best form of nutrition for infants and especially for preterm infants (Meier, Engstrom, Patel, Jegier, & Bruns, 2010; Morales & Schanler, 2007). Among other benefits, mother's milk decreases the incidence of infection and necrotizing enterocolitis (toxic inflammation in the intestine) and improves neurodevelopmental outcome (Morales & Schanler, 2007; Tudehope, 2013).

Interventions which increase the prevalence of breastfeeding for preterm infants can also improve the health of mothers (Renfrew et al., 2010). Early physical closeness and breastfeeding have been described by mothers as leading to normality and nurturing the mother-infant bond (Flacking et al., 2006; Sweet, 2006). The feeding and care of her infant may also alleviate her shock, fear and grief following the birth, and reduce the estrangement from her infant associated with care in the NICU (Flacking, Wallin, & Ewald, 2007). Furthermore feeding the infants through extracted milk can help mothers develop a maternal identity (Baum et al., 2012).

2.8.9 Parental Needs and Coping in the NICU

In the study of Guillaume et al. (2013), no differences were shown in the parents' expectations according to social, demographic characteristics or the infants' clinical data. It is mentioned that it is possible that needs become more homogeneous in the extreme situation of parenthood in the NICU.

At the outset, parents need to receive adequate, clear and concrete information and communication about expectations, their infant's condition, and care-giving activities (Johnson, 2007; Lemmen et al., 2013).

It has been show that the parents' ability to adapt to a new reality of the NICU is facilitated or constrained by the following: perceptions of their infant's survival/well-being; the suddenness, course, and duration of uncertainty about their infant's survival/ well-being; personal and family resources; quality of their relationship with health care professionals; and availability of good support (Lasiuk et al., 2013).

A commonly described coping mechanism used by most of the mothers in the study of Rossman et al. (2015), was to stay in the present moment by taking it one day at a time as each day is different. The next most commonly used coping mechanism was prayer. Other coping mechanisms used were: staying positive; believing that things happen for a reason; asking questions and staying informed; talking to someone they trust; and writing in a journal. In the study of Smith et al. (2012), parents were found to use the following coping strategies: (1) participation in care of the infant; (2) getting away from the NICU; (3) gathering information; (4) involvement of friends and family; and (5) engagement with other NICU parents.

Actions reported by parents as useful for early bonding with the preterm infant include the following: at birth (briefly reassure parents about infant's condition and reassure father about the mother's condition); between the delivery and first visit (visit the mother in her room, provide a good quality photograph of the infant, and interact directly with both parents); and in the NICU (accompany each parent on the first visit, show a gentle and attentive attitude toward the infant, explanations of the monitors, alarms, infant's capacities and ways of helping the infant, helping parents become more autonomous progressively, avoid judgements and suggest closeness with skin-to-skin contact (Guillaume et al., 2013).

Interventions are needed to support mothers as they struggle with multiple barriers and stresses in attaining their maternal role (Miles et al., 2011). The mother of an infant hospitalised in the NICU has limited opportunity for care-giving and interacting with her infant, which delays attainment of the maternal role (Rossman et al., 2015). Miles et al. (2011) state that the following can help mothers attain their maternal role: a) identity can be enhanced by focusing on the mother's critical role with her infant; b) engagement can be supported by helping mothers feel connected to their infants; and c) the teaching and facilitating of maternal care-giving roles is important during hospitalisation to increase feelings of competence. It has been shown that mothers are less assertive than fathers in verbalising their needs and concerns in the NICU environment (Fenwick et al., 2001).

Benzies and Magill-Evans (2015) found that by using interventions to increase fathers' sensitivity to their child's cues, the stress of fathers of preterm children can be reduced. According to Blomqvist et al. (2012), fathers should be given early practical information about infant care so that they can feel safe and in control when doing KFC. In addition, support and encouragement must be given to fathers in becoming primary caregivers as soon as possible after birth so as to enhance their paternal feelings.

Davy et al. (2011) report that nurses are seen as being catalysts for KMC implementation. In addition, parents need the support of nursing staff to dispel their concerns about how to handle their infant and encourage them to gain confidence in using KMC (Davanzo, 2004). In addition to KMC,

mothers should be considered vulnerable and be offered adequate lactation and breastfeeding counselling and sensitive emotional support (Nyqvist et al., 2013).

The Lasiuk et al. (2013) study explained that breastfeeding, KC, and family-centred practices are meaningful to parents with an infant in the NICU. These practices help parents (re)construct their role as parents as well give the parents a sense of agency (doing something tangible for their infant), thus moderating their own sense of helplessness.

2.9 Discharge

According to Adama, Bayes, and Sundin (2016) and Murdoch and Franck (2012), there is a paucity of research investigating parents' experience of caring for preterm infants after discharge from the NICU. However, it is necessary to understand parents' experiences during the transition from the NICU to home to promote positive experiences for parents (Hutchinson et al., 2012) as it is shown that parent perceptions and experiences can and do influence how they interact with their infants (Hutchinson et al., 2012).

2.9.1 Psychological Effects of Discharge on Parents

The discharge of a preterm infant is a stressful experience for parents as they now, for the first time, have full responsibility in caring for the infant (Spear, Leef, Epps, & Locke, 2002). Infants may still be unstable, sometimes still dependent on technology, and in need of complex care which makes parenting difficult (Buescher, Whitmire, & Brunssen, 2006). Long-term disabilities and chronic health problems may also be present (Moon, Mohay, & Gray, 2007). This transition period generates anxiety, fears of 'not being a good mother' or not being able to cope with a potential problem without the medical staff's help (Goutaudier et al., 2011). Mixed feelings are seen in the study of Goutaudier et al. (2011) where some mothers show apprehension and others anticipate the infant's discharge with impatience.

Adama et al. (2016) conducted a meta-synthesis of international literature from 1990 to 2015 regarding parental experiences of caring for preterm infants at home. The following 12 studies were used to reach the findings: (Griffin & Pickler, 2011); (Murdoch & Franck, 2012); (Phillips-Pula, Pickler, McGrath, Brown, & Dusing, 2013); (Lima de Souza et al., 2010); (Lee, Lin, Huang, Hsu, & Bartlett, 2009); (Lindberg et al., 2008); (Flacking, Ewald, & Starrin, 2007); (Jackson et al., 2003); (Sankey & Brennan, 2001); (de Oliveira Dornasbach et al., 2014); (Reyna, Pickler, & Thompson, 2006); and (Lee, Lee, & Kuo, 2009). Adama et al. (2016), group their findings of parental experiences of caring for a preterm infant after discharge into nine categories: (1) mixed feelings; (2) living in constant fear; (3) delayed joy of fatherhood and motherhood; (4) need for support; (5) guilt feelings, responsibility, and compensatory parenting; (6) developing confidence; (7) an attitude of

putting the infant first; (8) positive aspects of caring for preterm infants; and (9) parents' concerns after discharge. These are briefly discussed.

Mixed feelings are experienced with discharge. Some parents are happy for the infant to be discharged where others are scared and anxious. Care of the preterm infant is dominated by constant fear for both the mothers and fathers as they fear that something problematic will happen to the infant due to the fragile nature and health condition of the infant (Adama et al., 2016). The fear and anxiety stem from a perception of being inadequately prepared for discharge and therefore having a lack of knowledge in caring. This fear alters normal life as parents become sleep deprived in caring for the infant. This fear can still be prominent even after age one (Jackson et al., 2003). Social support from friends and family and reassurance from nurses increases the parents' confidence. Negative comments from medical staff decreases parental confidence. Support, in the form of taking care of household chores, gives mothers the opportunity to pay more attention to the infant's care which is appreciated. Parents indicate that support from their partner, formal support groups, people who have experienced preterm birth, and neonatal nurses increase their confidence and reduce their anxiety. Partner support is regarded as very necessary as the fathers became secondary carers and 'mother assistants'. For some parents confidence in caring is present after a month but for other parents it occurs much later. Confidence can result from previous new-born care, the improving health of the infant, and caring responsibilities learnt while still in the NICU. Concerns raised by parents are that they feel inadequately prepared for discharge. With regards to parenting, mothers blame themselves and compensate for the perceived harm of delivering early, and the fathers feel guilty for not providing support to the mother due to work responsibilities (Flacking et al., 2007; Griffin & Pickler, 2011). Parents as a result place the needs of the infant ahead of theirs. Eventually parents describe the experience as one that changed their perspective about life and how it can create a feeling of hope for the future.

2.9.2 Needs of the Parents during Discharge

Murdoch and Franck (2012) maintain that the emotional impact of the NICU continues through to the transition to home. Educational intervention provided to the mother before discharge has been shown to increase knowledge, change maternal behaviours, and decrease maternal stress (Browne & Talmi, 2005). The parents' perceptions can provide direction in preparing these educational materials which prepare the parents for the subsequent discharge (Hutchinson et al., 2012). Chen, Zhang, and Bai (2016) conducted studies in central China and assert that the education, and quality thereof, can improve and predict parental readiness for infant discharge. It has been shown that readiness for discharge is significantly related to infant safety, parent satisfaction, and the physical, emotional, psychological and social well-being of the family (Weiss, Ryan, & Lokken, 2006). Therefore, education and training should focus on preparing parents for the transition from hospital

to home to prevent long-term negative parenting styles and associated negative child developmental outcomes (Boykova & Kenner, 2012).

Discharge intervention programmes have been developed to promote parents' ability to care for the preterm infants such as the Creating Opportunity for Parent Empowerment (COPE), Neonatal Individual Developmental Care and Assessment Programme (NIDCAP), Mother-infant Transaction Programme (MITP), Developmental Care Programme and the Support Group Programme (Chen et al., 2016). In sum, effective support and parenting can overcome the difficulties of preterm birth.

2.10 Conclusion

One cannot generalise the psychological experiences of pregnancy, preterm birth, NICU care, and discharge into one similar experience for mothers and fathers as a whole. Pregnancy is regarded as a developmental period where both the mother and father complete psychological tasks to transition into parenthood. Some pregnancies are considered high-risk pregnancies which may lead to preterm birth. Stress also appears to be a factor related to preterm birth. The actual birth is traumatic for parents which is exaggerated when the infant is admitted into an NICU. The NICU is a strange and unfamiliar environment, making parenting difficult. Parents feel without control and are overwhelmed. In addition parents fear they cannot bond with their infant. However, KC has been shown to be beneficial for both the infant and the parents. The NICU can be regarded as being universally severe for all parents, regardless of their particular infants' health status. It must be noted however, that there is variability in the experiences as a function of many factors such as the mother's emotional state, her health and physical condition, where she lives, socioeconomic status, availability of her partner, and social support. To foster well-being in parents dealing with the preterm birth and hospitalisation of their infant, the support intervention must be grounded in theory, which is explored in the next chapter.

CHAPTER 3

THEORETICAL PARADIGM

Merriam and Tisdell (2016, p. 2), state that the theoretical paradigm provides the core structure or, as they call it, the “scaffolding” of the study. The theoretical paradigm to be used as scaffolding for the support intervention will follow the principles of Positive Psychology. The theory, therefore, provides the foundational knowledge underlying the development of a support intervention to foster well-being in parents who are in a vulnerable position due to the unexpected birth of their infant. Therefore, in this chapter the concept of well-being is introduced. Thereafter, Salutogenesis, which can be regarded as a forerunner of Positive Psychology (PP), is discussed. Then PP sub theories of Broaden-and Build theory, Flow, and Solution-focused brief therapy are discussed. Following that, the PP model of Complete Mental Health is discussed. After that, the Bioecological model is explained showing the interplay between the parents, preterm birth and the NICU environment, which all affect parental well-being. At the same time, elements of Conservation of Resources theory will be added to these discussions to illustrate the importance of resource loss and gain in the context of preterm birth. It is important to note that older literature will be used in conjunction with more recent literature, to outline the development of certain core concepts. The theoretical paradigm discussed in this chapter still forms part of phase two of the intervention research process as it involves information gathering and synthesis, as indicated in figure 3.1.

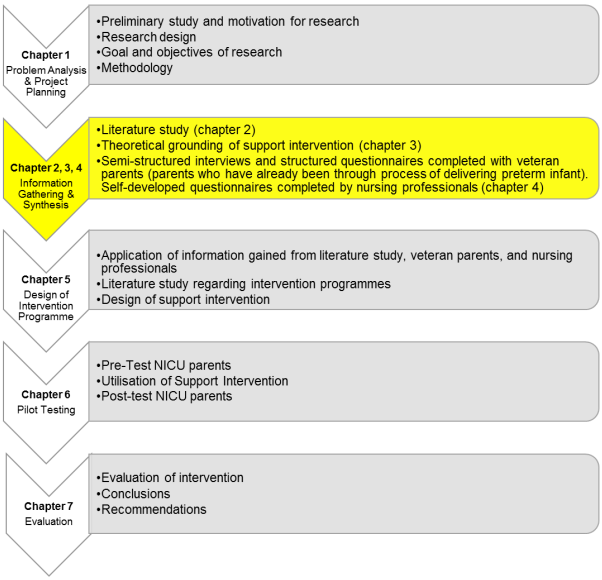


Figure 3.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

3.1 Well-Being

The World Health Organization (WHO) declares that mental health is “a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (World Health Organization, 2004, p. 2). Well-being research appears to focus on two different perspectives, namely, the hedonic approach and the eudaimonic approach. The hedonic approach focuses on happiness and defines well-being in terms of pleasure attainment and pain avoidance, and the eudaimonic approach focuses on meaning and self-realisation and defines well-being in terms of the degree to which the person is fully functioning (Kahneman et al., 1999; Ryan & Deci, 2001; Waterman, 1993). Importantly, Wissing and van Eeden (2014) link these two approaches to the development of interventions aimed at enhancing psychosocial well-being.

According to Huppert and So (2013), the earliest conceptual definition of mental health is usually attributed to Jahoda (1958) where she states that many people think that psychological health is manifested in a state of well-being. In the consequent study conducted by Jahoda (1958) six elements of positive functioning (see table 3.1) were identified. Since then, well-being has been defined by various theorists such as Ryff (1989), Antonovsky (1993), Ryan and Deci (2001), Keyes (2002), and Seligman (2002; 2011), to name a few. Psychologists who view well-being from a hedonic perspective believe that well-being consists of subjective happiness (Ryan & Deci, 2001), whereas some psychologists are more concerned with eudaimonic aspects of well-being, in other words with positive human functioning (Huppert & So, 2013). In the definition given by the WHO, mental health is equated with well-being, and a person experiencing well-being is described as being functional and self-realised. This encompasses a eudaimonic perspective. Overall, each theorist defines well-being as consisting of different elements, dimensions, or features. However, there are some similarities. Attitudes towards oneself, self-acceptance, and self-esteem are seen as features of well-being in Jahoda (1958), Diener et al. (2010), Huppert and So (2013) and Ryff’s (1989) perspectives of well-being. Keyes’s (2002) view of well-being incorporates Ryff’s (1989) six dimensions of well-being as psychological well-being. Keyes (2002) divides well-being into three components of well-being, namely: psychological, emotional, and social well-being. Positive emotion or positive feelings about life is seen in Ryff’s (1989), Seligman’s (2002; 2011), Keyes’s (2002), and Huppert and So’s (2013) perspectives. Meaningfulness or purpose in life is seen in Ryff’s (1989), Antonovsky’s (1993), Seligman’s (2002; 2011), Keyes’s (2002), Diener et al.’s (2010) and Huppert and So’s (2013) perspectives. Table 3.1 gives an indication of the different perspectives on well-being held by various theorists.

Table 3.1:

Perspectives of Well-being

Jahoda (1958) 6 elements of positive functioning: 1. Attitudes towards self 2. Self-actualisation 3. Integration 4. Autonomy 5. Perception of reality **6.** Environmental mastery	Ryff (1989; 1995) 6 dimensions of psychological well-being: 1. Self-acceptance 2. Positive relationships 3. Autonomy 4. Environmental mastery 5. Purpose in life 6. Personal growth	Antonovsky (1993) Psychological well-being = Sense of Coherence where life is seen as 1. Comprehensible 2. Manageable 3. Meaningful	Ryan and Deci (2001) Well-being is fulfilment of three basic psychological needs: 1. Autonomy 2. Competence 3. Relatedness
Seligman (2002; 2011) Well-being is defined as: PERMA 1. Positive emotion 2. Engagement 3. Positive Relationships 4. Meaningfulness 5. Accomplishment	Keyes (2002) Well-being consists of: A. <u>Psychological well-being:</u> 1. Self-acceptance 2. Positive relationships 3. Autonomy 4. Environmental mastery 5. Purpose in life 6. Personal growth B. <u>Emotional well-being:</u> Positive feelings about life C. <u>Social well-being</u> 1. Social coherence 2. Social actualization 3. Social integration 4. Social acceptance 5. Social contribution	Diener et al (2010) Subjective well-being is flourishing with the following components: 1. Purpose in life 2. Positive relationships 3. Engagement 4. Competence 5. Self-esteem 6. Optimism	Huppert and So (2013) 10 features of well-being: 1. Competence 2. Emotional stability 3. Engagement 4. Meaning 5. Optimism 6. Positive emotion 7. Positive relationships 8. Resilience 9. Self-esteem 10. Vitality

The theories of Jahoda (1958), Ryff (1989), Antonovsky (1993) and Ryan and Deci (2001) are described as being concerned with eudaimonic aspects of well-being. The perspectives of Seligman (2002; 2011), Keyes (2002) and Huppert and So (2013) include both hedonic and eudaimonic components, in other words a combination of feeling good and functioning well. Diener

et al.'s (2010) perspective on subjective well-being is regarded as only focusing on hedonic well-being.

The researcher is of the opinion that a combination of hedonic and eudaimonic perspectives on well-being will be more suitable to the research problem than happiness alone (hedonic well-being). Thus, the focus of this study will be on perspectives fostering both a eudaimonic and hedonic form of well-being. The theoretical grounding of this study therefore includes the theories of salutogenesis (Antonovsky, 1993), and Positive Psychology (Seligman, 2002; 2011) including the Broaden-and-Build theory (Fredrickson, 1998), the flow model (Csikszentmihalyi, 1990) and Keyes's (2002) complete state model of health. In addition, a solution-focused approach will guide the researcher's behaviour in the support intervention. As the support intervention takes place in a specific environment, the bioecological model (Bronfenbrenner, 1999) will be included in discussions. The theories are placed in historical context with salutogenesis, which can be regarded as a forerunner to Positive Psychology, being the first discussed.

3.2 Salutogenesis and Fortigenesis

Antonovsky (1979) developed a theory of health and illness, termed Salutogenesis, because he believed that the concept and field of health promotion was lacking in theory. His original idea was that it was more important to focus on people's resources and capacity to create health, than the classic focus on risks, ill health, and disease (Lindström & Eriksson, 2005). His work can be regarded as one of the early links in the chain leading to greater attention being placed on the positive in social sciences (Strümpfer, 2013).

3.2.1 Sense of Coherence

Antonovsky's (1987) theory of Salutogenesis focused on studying the origins of health. Antonovsky (1987) aimed to find answers to the question of how people manage stress and stay healthy. Antonovsky (1987) provided a core construct, Sense of Coherence (SOC), which reflects a person's view of life and capacity to respond to stressful situations (Lindström & Eriksson, 2005) and can be seen as an approach to coping with various stressors (Strümpfer, 2013). SOC is defined by Antonovsky (1987, p. 19) as follows:

> "The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement."

It is clear from this definition that the sense of coherence is influenced by various forces in the microsystem and the macrosystem where the individual functions as well as the interplay of resources within these systems. The constituents of the SOC definition can be described as comprehensibility, manageability, and meaningfulness (Antonovsky, 1979; 1987; 1993).

3.2.1.1 Comprehensibility.

Comprehensibility is the extent to which people perceive stimuli as making cognitive sense, in other words, information is ordered, consistent, structured, and clear (Lindström & Eriksson, 2005). People with high comprehensibility expect that stimuli they encounter will be predictable, ordered, and explicit (Antonovsky, 1987).

3.2.1.2 Manageability.

Manageability is the extent to which people perceive that they have resources available to meet the demands of the environment (Strümpfer, 2013). Related to this is Hobfoll's (1988; 1989) Conservation of Resources (COR) theory which explains that when resources are threatened, lost, believed to be unstable, or where people cannot see a path to fostering and protecting their resources people develop stress (Hobfoll, 2001). This replicates Lazarus and Folkman's (1984) definition of stress where stress results due to a person's appraisal of a situation as exceeding their resources. Thus the role of resources in fostering well-being is significant.

3.2.1.3 Meaningfulness.

Meaningfulness refers to the extent to which a person feels that life makes sense emotionally, that problems and demands are worth investing energy in, are worthy of commitment and engagement, and are seen as challenges rather than burdens (Lindström & Eriksson, 2005). Meaningfulness links to Seligmans' (2011) PERMA model as a factor promoting well-being as well as Csikszentmihalyi (1975) theory of flow. These theories are expanded upon later.

According to Antonovsky (1987) a person's SOC develops and changes through childhood and eventually at 30 years of age, the SOC becomes more or less fixed. However, the SOC can be tested, shaped, and modified throughout one's life and Antonovsky (1979) states that cataclysmic stressors have the potential of weakening the SOC.

3.2.2 Generalised Resistance Resources (GRR)

Antonovsky (1987) stated that Generalised Resistance Resources exist, which refers to any characteristic of an individual that is effective in avoiding or combating a wide variety of stressors, thus preventing tension from being transformed into stress (Strümpfer, 2013). Antonovsky (1979; 1987) considered a number of GRR's, such as:

- Culture, giving people a place in the world;

- Social support defined as a person having close ties to others and the certainty and availability thereof;
- Religion and values giving direction and meaning to life;
- Physical and biochemical resources such as a strong immune system;
- Material goods such as money, food, and clothing;
- Continuity, overview, and control which are macro-sociocultural coping resources decided by the culture and society to which the person belongs;
- Coping strategies characterised by rationality, flexibility, and foresight, including the ability for self-regulation;
- Knowledge and intelligence; and
- Self-identity (Langeland & Vinje, 2013).

Hobfoll's (1989) Conservation of Resources theory (COR) also delineates various resource categories such as objects (housing, car, clothing etc.), energy (time, money, insurance, knowledge etc.), conditions (relationships, job stability etc.), and personal resources (sense of self-esteem, optimism etc.). In later literature, it is seen that these resource categories are described differently: energy resources (time); interpersonal resources (assistance from friends); family resources (help with tasks at home); and material resources (food and shelter) (Walter, Horsey, Palmieri, & Hobfoll, 2010).

Further resources that may be regarded as helping in developing resiliency can include: a) ego related resources such as mastery or self-efficacy, perceived control, and self-esteem; b) social constructs such as social integration, connectedness, and perceived and enacted support; c) personality factors such has dispositional optimism and conscientiousness; d) beliefs and values including world views, spirituality, cultural values; and e) endowed or constitutional resources such as cognitive ability and absence of disease risks (excellent physical health) (Dunkel-Schetter, 2011).

Antonovsky (1987, p. 181) argued that an abundance of GRR's will have "consequences not only for the emergence of a strong SOC, and therefore health, but for other areas of well-being too." He maintained that there would be positive correlations between SOC and well-being, since GRR's promote well-being (Antonovsky, 1987).

3.2.3 Cyclical Process

SOC and GRR's develop through a cyclical process. For example, when the person regularly experiences the availability of GRRs, a SOC develops, and, in turn, a strong SOC mobilizes the GRR's at the person's disposal in order to avoid or overcome stressors, with such experiences reinforcing the SOC in a feedback loop (Strümpfer, 1995). Therefore, the use of resources is necessary to build the SOC which helps with alleviating stress and thus fostering well-being.

Antonovsky (1987, p. 182) also explains how a strong SOC affects task performance:

> "Particularly when the task is ambiguous and complex, the strength of the SOC will be a contributory factor. The strong SOC person will be motivated to see the task as a challenge, to impose structure, to search for appropriate resources. He or she will have more confidence that performance outcome will be reasonable. Thus, assuming that the task is within the boundaries of what matters to the person, it is indeed likely that there will be some contribution of the SOC to outcome."

Overall, Antonovsky (1996) stated that the salutogenic orientation is a viable paradigm for health promotion and, in addition, the SOC framework was offered as useful for taking a salutogenic approach to health research. One great advantage of the SOC construct is that it is not culture-bound (Antonovsky, 1996). Another advantage of the salutogenic approach is its dynamic and flexible approach and the persistent focus on ability and capacity to manage (Lindström & Eriksson, 2005). From the above it is clear that there is a strong historical link between salutogenesis and Positive Psychology as will be expanded later in this chapter.

3.2.4 Fortigenesis

South African researchers, Strümpfer (1995) as well as Wissing and van Eeden (1997) expanded the construct of salutogenesis to fortigenesis. According to Strümpfer (1995), fortigenesis is more embracing and holistic than salutogenesis. Fortigenesis thus refers to a process of producing strength at more endpoints than health only, for instance, in work, marriage, and parenthood (Strümpfer, 2006).

Strength is postulated as being aware of a demand, a goal, and a direction in which to act, as well as having the ability and energy to make the effort to do what is required (Strümpfer, 2013). Strümpfer (2013) states that fortigenesis is evident in life events such as pregnancy and child birth.

This research study follows a salutogenic and fortigenic perspective as the focus is placed on health, strengths, and well-being. Resource theories have been used in various disciplines such as cognitive psychology, biology, ecology, social psychology, community psychology, and sociology (Alvaro et al., 2010). There is a constant theme across these disciplines in that resources are key determinants of performance, adaptation, and change (Alvaro et al., 2010).

As already mentioned, Strümpfer (2013) states that Antonovsky's (1979; 1987; 1996) work can be regarded as one of the early links in the chain to greater attention being focused on the positive in social sciences. Therefore, it can be regarded as a forerunner to the focus of Positive Psychology.

3.2.5. Preterm birth from a Salutogenesis and Fortigenic perspective

As mentioned, Antonovsky's (1987) core construct, SOC, reflects a person's capacity to respond to stressful situations. By increasing a parent's SOC, parents can be helped to cope with the stressors of preterm birth. Thus, parents must be able to gain a sense of comprehensibility, manageability and meaningfulness.

Comprehensibility can be heightened if parents in this study are provided with information on what to expect with preterm birth. This includes information about the NICU and the preterm infant. Manageability can be enhanced by helping parents become aware of, and find the necessary resources within themselves and their environment to help them cope. Meaningfulness as a view that life makes sense and problems are worth investing energy in can be developed. According to the researcher, parents are put into a challenging situation with their infant being born early, but it is worth investing energy, commitment and engagement in order to have a healthy happy child with the potential to become a well-adjusted adult. Parents need to find meaning and develop skills in the situation to be able to cope.

Strümpfer (2013) describes meaningfulness being developed through belonging and participation in decision making. It has been shown that parents with their infant in the NICU, need to feel part of the team in helping their infant to health. Studies of Nyqvist et al. (2010) and Thomas (2013) have indicated that when mothers perform KMC with their infant, it can improve a mother's bonding and her feeling of being needed and comfortable with her infant.

Antonovsky (1987) further explains the role of GRR's as avoiding and combating stressors. It is envisaged by the researcher that psychosocial support and knowledge can help the parents in this research study as it has been shown that these factors help parents cope with the preterm birth and NICU hospitalisation (Benzies et al., 2013). In addition, hope, gratitude, and optimism can be regarded as psychological resources (Hobfoll, 2002) which may be fostered. Combinations of these resistance resources and their interactions are hypothesised to influence postpartum outcomes.

Regardless of all the different type of resources cited in the various theories above, overall, it is not clear or predictable what can help the individual parent as each is unique in their world. In addition, Langeland and Vinje (2013) state that due to the interaction between a person and the environment always being in flux, it is not possible to identify all possible GRR's. Resources whether according to the view of Antonovsky (1979; 1987) or Hobfoll (1989), will be of prime importance in this research as the researcher anticipates development of the parents' SOC through the use of their available resources. Antonovsky (1979, p. 99) provided a criterion to identify GRR's: "every characterization of a person, group or environment that promotes effective management of tension."

As mentioned, a relationship exists between the SOC and GRR's. Strümpfer (1995) explains the cyclical process: a strong SOC mobilizes GRR's and in turn GRR's strengthen the SOC. In

addition, a strong SOC will motivate an individual to see tasks as a challenge, if the task is what matters to the person. Once again, in the context of preterm birth, the survival and health of the infant is what matters the most to the parents (Lasiuk et al., 2013).

Antonovsky (1987) further elaborates that when a task is complex, the strength of the SOC matters. Coping with the NICU and preterm birth experience can be regarded as a complex task, specifically emotionally complex, for the parents. The preterm birth and admission to an NICU is ambiguous due to the fact that the NICU is unknown to the general population and the particular parents. It is thus important to assist the development of the parent's SOC. This can be accomplished by exploring with the parents the resources that may assist them in helping to come to a point of well-being.

Antonovsky (1979) states furthermore that cataclysmic stressors have the potential of weakening the SOC. Preterm birth, although not habitually described as cataclysmic, is often sudden and results in significant changes in the parent, and has the potential to change a parent's SOC. It is thus necessary for parents to experience comprehensibility, manageability, and meaningfulness to avoid a weakening of their SOC, which is a person's capacity to respond to stressful situations.

Strümpfer (2013) proposed that strength is being aware of a demand, a goal, and a direction in which to act, as well as having the ability and energy to make the effort to do what is required. It is the aspiration of the researcher that the parents will be able to have the strength and awareness of demands (internal and external) and be able to cope with these demands while having a preterm infant in an NICU.

The researcher is of the opinion that following a salutogenic and fortigenic perspective, creating an awareness of and utilising an individual's strengths and resources can further well-being.

3.3 Positive Psychology

Positive Psychology emerged as a new field focusing on what "makes life worth living" (Seligman & Csikszentmihalyi, 2000, p. 5) since, according to Gillham and Seligman (1999) and Seligman and Csikszentmihalyi (2000), psychology after World War II became a science focusing on identifying and repairing damage. PP thus emerged as an endeavour to balance repairing or relieving psychological problems with building strength in people as well (Gillham & Seligman, 1999; University of Pennsylvania, 2007). It appears, however, that PP's endeavour to make life worth living is not that new, as Hutchinson, Stuart and Pretorius (2010) explain that PP is not a new paradigm but rather a return to some of the ideas of earlier humanistic psychologists who focused

on human strengths. For example, Maslow (1962) and Rogers (1954, 1963) argued that psychology ignored the most important 'positive' parts of being human such as creativity, love, joy and the capacity for growth. Antonovsky's (1979) theory, as mentioned, was also a theory that focused on the positive in psychology (Wissing et al., 2014). However it was only from the 1990's that focus on a positive social science gained momentum (Gillham & Seligman, 1999).

3.3.1 Defining Positive Psychology

A critique of PP described by Lazarus (2003) is that PP lacks conceptual clarity. Historically, it is clear that defining PP was a difficult task. A number of definitions are given:

- A definition by the leading advocate of PP, Seligman (2002), indicates that PP is a science focusing on three broad areas of human experience, namely: positive subjective states, positive individual traits, and positive institutions. Seligman (2002) postulates that at the first level of subjective experience, the focus entails the study of the following: well-being; contentment and satisfaction with the past; hope and optimism for the future; and; flow and happiness in the present. With regard to the individual traits, the focus is on positive individual traits such as the capacity for love and work, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future mindedness, high talent, and wisdom. And lastly, at the group level, PP focuses on civic virtues and the institutions that move individuals toward better citizenship: responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic (Seligman & Csikszentmihalyi, 2000). This group level can also indicate activities on the macrosystem level as outlined by Bronfenbrenner (Rosa & Tudge, 2013) as will be discussed later.
- Sheldon and King (2001) state that PP is nothing more than the scientific study of ordinary human strengths and virtues. This definition is also used by the Positive Psychology Centre from where it is added that strengths and virtues are studied that enable individuals and communities to thrive (University of Pennsylvania, 2007). Wissing (2014) adds to this a focus on strengths and existing resources in the process of achieving optimal functioning.
- In 2005, Gable and Haidt (2005) indicated that PP is the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions. In the same year, Keyes (2005), a psychologist known for his work in PP, discusses flourishing in his own theory regarding mental health. This theory is discussed later.
- Later, another definition is given by Linley et al., (2006). They define PP at two levels. Firstly at the psychological level, the aim is to redress the imbalance in psychological research and practice by calling attention to the positive aspects of human functioning and experience. Secondly, to understand the sources of, processes and mechanisms that lead to more positive outcomes.

- Compton and Hoffman (2013, p. 1) indicate that PP is “concerned with the use of psychological theory, research, and intervention techniques to understand the positive, adaptive, creative and emotionally fulfilling aspects of human behaviour.”

The researcher certainly agrees with the statement of Linley et al. (2006) that in defining PP there are core themes and consistencies but also differences in emphasis and interpretation. A definition given by Hutchinson et al. (2010) is that PP emphasises developing and maintaining well-being and in a more recent article by Rusk and Waters (2013), PP is described as focusing on well-being by looking at strengths, virtues, beneficial conditions, and processes. The researcher is partial to the emphasis of PP being on developing well-being by using personal strengths and creating favourable conditions. By adopting a family-centred care approach in the intervention (further discussed in chapter six), favourable conditions can be created to foster well-being in the parents. Studies have shown that PP strength-based interventions have potential for improving well-being (Proyer, Ruch, & Buschor, 2013; Sin & Lyubomirsky, 2009). Furthermore, the definition given by Linley et al. (2006) explores the sources, processes and mechanisms leading to desirable outcomes. The researcher aims to examine sources, processes and mechanisms that can lead to fostering well-being specifically in the NICU.

3.3.2 Promoting Well-being

Rusk and Waters (2013) state that relieving disease is not sufficient in creating well-being. According to Duckworth, Steen and Seligman (2005) well-being requires the presence of factors above and beyond those that alleviate distress, such as positive emotion, engagement, positive relationships, meaning, and accomplishment. These same factors are elements described in Seligman’s (2011) PERMA Model. Seligman (2011) revised his Authentic Happiness Theory where the topic was happiness, measured through life satisfaction and increasing life satisfaction, as the goal. This original theory appears to focus on hedonic well-being only. In Seligman’s (2011) new well-being theory the focal topic of PP is well-being and the goal of PP is to increase flourishing by increasing positive emotion, engagement, meaning, positive relationships and accomplishment for which the acronym PERMA is used. This newer theory now focuses on both hedonic and eudaimonic well-being. Relating to positive emotion, a theory was developed by Fredrickson (1998), which is another perspective within Positive Psychology to promote well-being namely the Broaden-and-Build Theory.

3.3.2.1 Broaden-and-Build Theory.

According to the Broaden-and-Build theory of positive emotions (Fredrickson, 1998), certain discrete positive emotions such as joy, interest, contentment, and love share the ability to broaden people’s momentary thought-action repertoires and build their enduring personal resources, ranging from physical and intellectual resources to social and psychological resources (Fredrickson, 2001). In

other words, positive emotions broaden the scope of attention, cognition (thinking) and action as well as build resources (Fredrickson, 1998; 2001). In addition, the Broaden-and-Build model posits that positive emotions broaden a person's awareness (Garland et al., 2010). Even an incidental effect of experiencing a positive emotion, results in an increase in personal resources (Fredrickson, 2001) which as mentioned, helps in the development of a strong SOC, alleviates stress and thus fosters well-being.

Analysing how each of the positive emotions of joy, interest, contentment, and love were described in Fredrickson's (1998) initial description of the model, it is the opinion of the researcher that these positive emotions are applicable in this study. Joy can be used interchangeably with happiness (Lazarus, 1991) and, in some cases, joy can be experienced by events interpreted as accomplishments or progress towards one's goals (Izard, 1977 as cited in Fredrickson, 1998). Progress towards achieving goals has been described as hope (Compton & Hoffman, 2013) and accomplishment can be regarded as an element of fostering well-being (Seligman, 2011).

The second positive emotion described is interest, where Fredrickson (1998) states that flow (Csikszentmihalyi, 1990) represents a form of interest. Flow is discussed in the next section. In addition, openness to new ideas, experiences and actions characterises the mind-set of interest (Fredrickson, 1998). Parents in this study may or may not experience flow in the NICU but will be exposed to new experiences and actions by their interest in their infant.

The third positive emotion, contentment, "shares conceptual space" (Fredrickson, 1998, p. 306) with relief. Lazarus (cited in Fredrickson, 1998) links relief with ceasing vigilance, which can be regarded as one goal of the support intervention. Contentment can be regarded as a mindful broadening of a person's self-views and world views (Fredrickson, 1998). Similar to interest, contentment appears to be a positive emotion that follows experiences that Csikszentmihalyi (1990, p. 41) described as flow, where, when the flow episode is over, a person feels more 'together'. Contentment thus creates the urge to integrate recent events and experiences and create a new sense of self and a new world view (Frederickson, 1998). Integration of experiences is necessary when helping with traumatic experiences (Briere & Scott, 2015). This integration of experiences can also be described as similar to the Gestalt model of the Cycle of Experience where, once complete, integration occurs (Woldt & Toman, 2005). Lastly, the positive emotion of love is made up of many positive emotions including interest, joy, and contentment (Frederickson, 1998).

The Broaden-and-Build theory asserts that even small and brief positive emotions can act as catalysts for enhanced well-being. According to Affleck and Tennen (1996), Folkman and Moskowitz (2000), and Fredrickson (2000), one way people can experience positive emotions in adverse situations is by finding positive meaning in ordinary events and within the adversity itself.

In addition to positive emotions enhancing well-being and triggering positive meaning, positive emotions can undo the lingering effects of negative emotions (Fredrickson, 1998). The “undoing” hypothesis states that positive emotions help the body and mind regain a sense of balance, flexibility, and equilibrium after the impact of negative emotions (Compton & Hoffman, 2013, p. 39). In addition, after a person experiences a positive emotion, the person is more open and receptive (Kim & Franklin, 2015). Fitzpatrick and Stalikas (2008, p. 139) state “in an open state, they feel the urge to contemplate new ideas, develop alternative solutions to problems, reinterpret their situations, reflect on behaviours, and initiate new courses of action and creative endeavours.” In sum, and according to Fredrickson (2001), positive emotions are worth cultivating as a means to achieving psychological growth and improved well-being.

As mentioned above, flow represents a form of interest. Contentment follows the experience of flow. Flow will now be discussed.

3.3.2.2 Flow.

Csikszentmihalyi (1990), regarded as the founder of the flow theory, postulate that people are the happiest when in a state of flow which is described as a state of such concentration or complete absorption in an activity and situation that nothing else seems to matter. The concept of flow has also been used in the theories of Maslow and Rogers in their development of the humanistic trend (McAdams, 1990). According to Nakamura and Csikszentmihalyi (2009), flow theory is used by practitioners addressing contexts where fostering positive experience is important. For parents in the NICU, fostering positive experience is important to fostering well-being.

To experience flow, certain conditions are necessary: (1) there must be a perceived challenge or opportunity that stretches but not overmatches existing skills; and (2) there must be clear short term goals and immediate feedback on progress (Nakamura & Csikszentmihalyi, 2009). In the flow model, which Csikszentmihalyi introduced in 1997 (Figure 3.2), flow can only occur when the activity is a higher than average challenge (above the centre point) and requires above-average skills (to the right of the centre point). Flow is thus experienced when there is a fit between the skills of the self and the challenges in the environment (Csikszentmiahlyi & Rathunde, 2014).

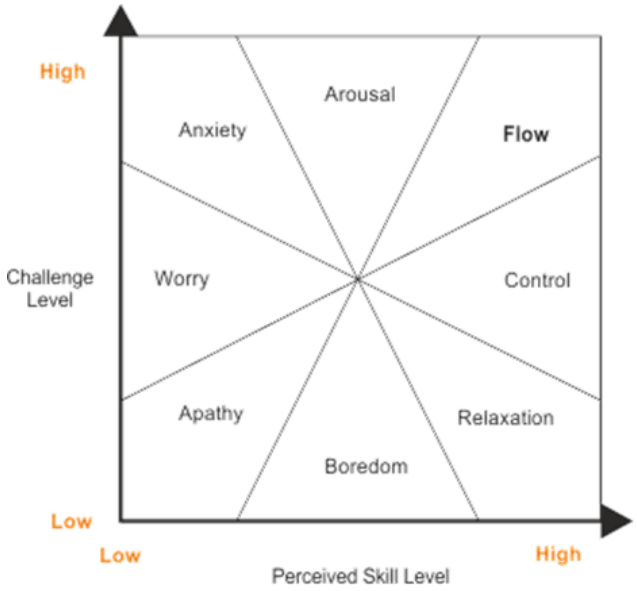


Figure 3.2: Flow model (Nakamura & Csikszentmihalyi, Flow Theory and Research, 2009, p. 196)

The model shows the emotional states that people are likely to experience when trying to complete a task, depending on the perceived difficulty of the challenge and the persons' perceptions of their skill levels. The balance between the challenges and skills is fragile and it is the person's subjective challenges and skills which influence the quality of the experience (Nakamura & Csikszentmihalyi, 2009). If challenges exceed skills, persons first become vigilant and then anxious because they feel overwhelmed, feel without control and threatened by a loss of integrity and order. Conversely, if skills exceed challenges the person relaxes, becomes bored and there is a loss of spontaneity, and a decrease in the sense of focus, urgency, curiosity, and adventure (Csikszentmiahyi & Rathunde, 2014; Nakamura & Csikszentmihalyi, 2009). Anxiety and boredom are aversive states that result from a disequilibrium between skills and challenges or the self and environment (Csikszentmiahlyi & Rathunde, 2014).

Nakamura and Csikszentmihalyi (2009) explain that the flow state is intrinsically rewarding and leads the person to want to replicate it. As individuals master challenges in an activity, they develop greater levels of skill. A flow activity thus provides a system of graded challenges, able to accommodate a person's continued and deepening enjoyment as skills grow.

3.3.2.3 Solution-focused brief therapy.

Solution-focused brief therapy (SFBT) is a future-focused, goal-directed approach to brief therapy developed in the early 1980's (De Shazer & Dolan, 2012). It is also just called solution-focused therapy (SFT). The researcher makes use of the principles of SFT as an approach in the support intervention. SFT has been described as a set of attitudes, a "stance" and a relational process (Henden, 2008; Wand, 2013). Solution-focused dialogue is about exploring past successes, current

strengths, and future hopes (Wand, 2013). Kim and Franklin (2015) state that the more a person expects a hopeful outcome, the more individuals will believe they can solve their own problems.

Main interventions, as described by De Shazer and Dolan (2012), include the following:

- A positive, collegial, solution-focused stance;
- Looking for previous solutions;
- Looking for exceptions;
- Questions versus directives or interpretations;
- Present- and future-focused questions versus past-oriented focus;
- Compliments; and
- Gentle nudging to do more of what is working.

Specific interventions of the solution-focused approach include:

- Pre-session change (asking about any health changes of infant and any changes of how parents are feeling and coping);
- Solution-focused goals;
- Miracle question;
- Scaling questions;
- Constructing solutions and exceptions;
- Coping questions;
- Is there anything I forgot to ask?
- Taking a break and reconvening;
- Experiments and homework assignments; and
- So, what is better, even a little bit, since the last time we met? (De Shazer & Dolan, 2012).

Main and specific interventions that apply and will be used in this study will be described in chapter five, which expands on the design of the support intervention.

Linked to the above, according to Wand (2013), principles common to positive health and a solution-focused approach are: normalizing, reframing, acknowledging, complimenting; use of coping questions; finding exceptions; discussing a preferred future; use of scales; and identifying resources. The researcher will make use of all of these principles in the support intervention. The method of application is discussed in chapter five. In line with a solution-focused approach, the role of the researcher involves never passing judgments on the parent's wants, needs or behaviours, and furthermore trying to expand rather than limit options (Berg & Dolan, 2001). SFT makes use of a person's strengths and resilience by focusing on his-her own previous or conceptualised solutions

and exceptions to the problem, and then, through a series of interventions, encouraging the individual to do more of those behaviours (De Shazer & Dolan, 2012).

In sum, the goal of PP is to increase the amount of flourishing (Seligman, 2011). Flourishing is used in many areas of PP to describe high levels of well-being. This is the goal of this study. However, in contrast to flourishing, there is also languishing which will be outlined with the Complete State Model of Health which follows in the next section.

3.3.3 Complete State Model of Health

Mental health has been described as a "syndrome of symptoms of positive feelings and positive functioning in life" (Keyes, 2002, p. 207). According to Keyes (2002; 2009), mental health is also equated with well-being which has three distinct and important parts, namely: emotional, psychological, and social well-being. Emotional well-being refers to positive feelings whereas positive functioning is related to psychological well-being and social well-being.

Mental illness is regarded as a deviation from normal functioning with associated emotional suffering (Keyes, 2001) and is not an antonym of mental health but a separate entity completely (Keyes, 2002). According to Keyes (2002, 2005, 2009) and Westerhof and Keyes (2010), mental health is not merely the absence of mental illnesses such as depression or anxiety but also the presence of mental health, in other words, sufficient levels of emotional, psychological, and social well-being. Mental health, according to Keyes (2002), is best viewed as a complete state consisting of the presence and the absence of mental illness and mental health symptoms.

Keyes coined the terms "flourishing" and "languishing" relating to mental health. The presence of mental health is regarded as flourishing and the absence of mental health is regarded as languishing (Keyes, 2002). A person who is flourishing is thus filled with positive emotions and functioning psychologically and socially well. People who are languishing have incomplete mental health with low well-being.

Related to the first aspect, with high emotional well-being, there is the presence of positive feelings about life and thus people are described as being happy and satisfied with their lives (Keyes, 2002; 2009; Keyes & Lopez, 2002) which links with a view encompassing hedonic well-being.

Secondly, someone with high psychological well-being will feel competent, autonomous, self-accepting, have a purpose in life, exhibit personal growth, and have positive relationships with others (Keyes & Lopez, 2002). These characteristics of positive functioning and high psychological well-being were highlighted in Ryff's (1989) study. In other words, people are thriving in their personal lives when they like most parts of themselves, have warm and trusting relationships, see

themselves developing into better people, have a direction in life, are able to shape their environments to satisfy their needs, and have a degree of self-determination (Keyes, 2002).

The third part, the social dimensions of well-being, includes social coherence, social actualization, social integration, social acceptance, and social contribution (Keyes, 2002). High social well-being is thus characterised by someone seeing society as meaningful and understandable, seeing society as possessing potential for growth, feeling they belong to, and are accepted by, their communities. Furthermore, they accept most parts of society and see themselves as contributing to society (Keyes, 2002). Social well-being relates to Bronfenbrenner's bioecological theory that an individual exists socially within a microsystem as well as a mesosystem (Bronfenbrenner, 1989).

Keyes and Lopez (2002) developed a conceptual framework called the Complete State Model of Mental Health. The model, as shown in Figure 3.3, identifies two dimensions. Mental illness and mental health lie on two separate continuums from high to low. Using this fourfold classification system, four states of mental health can be described.

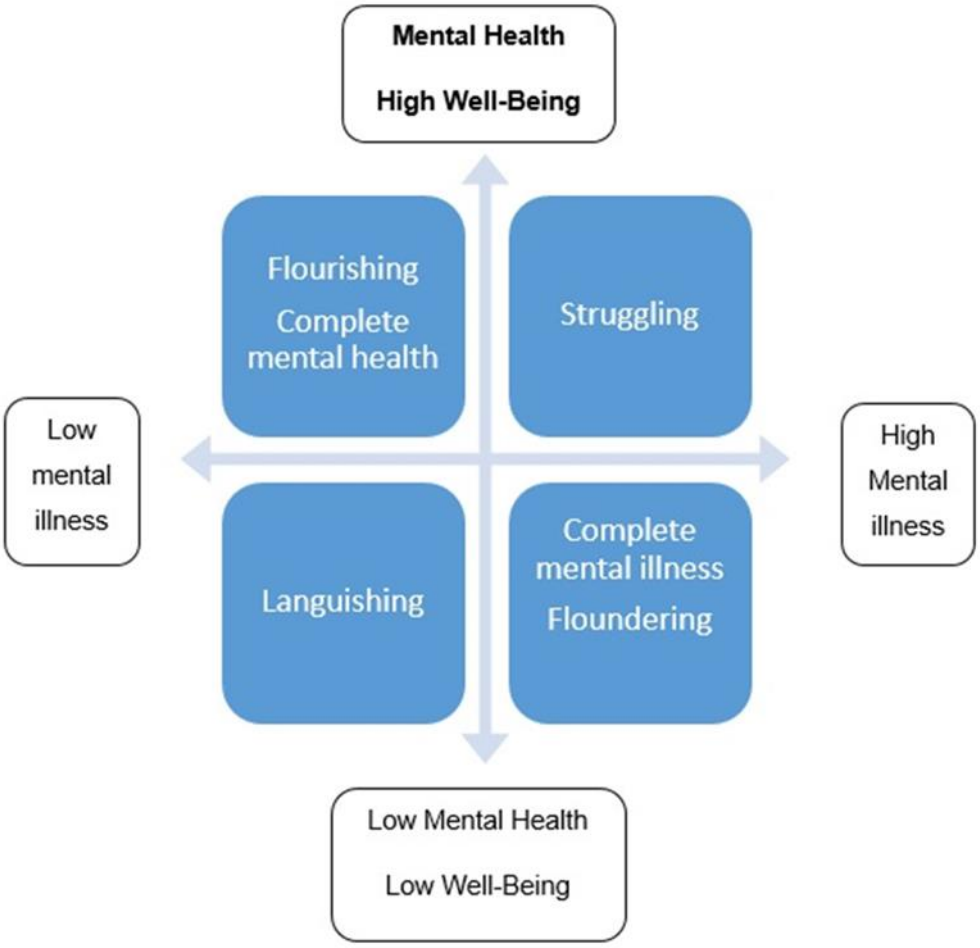


Figure 3.3: Model of complete mental health (Keyes & Lopez, Toward a Science of Mental Health, 2002)

People can be regarded as flourishing when scoring high on well-being and low on mental illness. Thus, flourishing adults experience high levels of positive emotion and function well both psychologically and socially. Flourishing individuals report, among other factors, healthy psychosocial functioning, high resilience, high intimacy, and the fewest health limitations of daily living (Keyes, 2009). Purely in terms of psychosocial functioning, this means that completely mentally healthy adults report the lowest level of perceived helplessness (e.g. high perceived control in life); the highest level of self-reported resilience (e.g. that they try to learn from adversities), and the highest level of intimacy (e.g. that they have very close relationships with family and friends). Flourishing is regarded as complete mental health.

Keyes's research (2005, 2009) found that it was possible to be relatively high in both mental illness and mental health at the same time. Someone who exhibits high well-being and high mental illness can be regarded as struggling. This person is generally doing quite well but is currently experiencing significant distress.

When someone has low well-being and low mental health, they are considered to be languishing. This describes someone with no mental illness but who is dissatisfied with life. Languishing is "conceived of as emptiness and stagnation, constituting a life of quiet despair" where individuals might describe their lives as hollow or empty (Keyes, 2002, p. 210). Languishing implies a state of being stuck, and devoid of positive functioning in life. And lastly, people who score low on well-being and high on mental illness can be regarded as floundering.

Slade (2010) postulates that as a result of the Complete State Model of Mental Health, interventions that support people into flourishing and mental health are as important as interventions focusing on mental illness.

3.3.4. Preterm birth from a Positive Psychology perspective

The birth of a preterm infant and admission to an NICU can be regarded as an adverse circumstance affecting parental well-being, but according to Frederickson (2001) positive emotions can occur in adverse circumstances. As mentioned, positive emotions broaden the scope of attention, cognition (thinking) and action, build resources (Fredrickson, 1998; 2001) and broaden a person's awareness (Garland et al., 2010). It is necessary for parents to develop awareness of available resources. This as mentioned in section 3.2.5 relates to the SOC constituent of manageability.

Fredrickson (2000) also indicates that a reciprocal relation between positive emotion and positive meaning exists, namely: finding positive meaning is a trigger for positive emotion and positive emotion should increase the likelihood of finding positive meaning, due to the broadened thinking of positive emotions. With increased comprehensibility, parental engagement and

accomplishment may be possible for parents. The resultant positive emotions can thus trigger meaningfulness for parents. Even though positive emotions may be brief and fleeting, they have lasting positive effects on a person's ability to function (Garland et al., 2010). Thus, it is important for parents to experience even small, brief, positive emotions and ideally find meaning in the preterm birth.

As mentioned by Fitzpatrick and Stalikas (2008) experiencing positive emotions leads to an open state where parents may contemplate new ideas, develop alternative solutions to problems, reinterpret situations, reflect on behaviours, and initiate new courses of action and creative endeavours. To enhance well-being, it is necessary for parents to develop solutions to their immediate problems, reinterpret their situation, reflect on their behaviour, and become more aware of their emotions and needs.

Fredrickson (1998) states that the positive emotion of interest relates to flow. Two types of intervention have been noted relating to flow theory: (1) intervention seeking to shape activity structures and environments so that they foster flow or obstruct it less; and (2) those attempting to assist individuals in finding flow. Interventions that are aimed at shaping activity structures and environments can help encourage flow. The researcher aims to shape experiences in the NICU to encourage flow as will be discussed in chapter five.

According to Nakamura and Csikszentmihalyi (2009) flow serves as a buffer against adversity and prevents pathology. By finding flow, it is hoped that distress, and anxiety, can be alleviated in the parents in this study. Also, strong SOC persons will be motivated to see their task of parenting their preterm infant in an NICU as a challenge which can be overcome by using appropriate resources (Csikszentmihalyi, 1990).

It is shown that flow is experienced similarly in different classes, genders, ages, and across various cultures (Csikszentmihalyi & Csikszentmihalyi, 1988) and thus is applicable to the participants in this research study, especially as it encompasses participants from different cultures.

As mentioned, flow can only occur where there is a perceived challenge which matches existing skills. The researcher postulates that anxiety and worry may be experienced by parents due to the preterm birth and NICU admission being perceived as a challenge which is greater than the parental skill level. Skills are required to balance the disequilibrium. Skills may include knowledge regarding the situation and how to be a parent in the NICU. The support intervention aims to develop these parental skills and provide opportunities for flow. The researcher acknowledges that flow may not be achieved while in the hospital. However, with development of knowledge and skills relating to prematurity, the opportunity for experiencing flow can be promoted, even if it only occurs at home.

As far back as 1988 it has been shown in correlational studies (Wells, 1988) that the self grows through flow experiences and time spent in flow can predict self-esteem. Early in the process, the experience and diagnosis of a HRP may affect a woman's self-confidence and self-esteem (Gilbert, 2011). Later, with the birth of a preterm infant, Guillaume et al. (2013) indicated that mothers experience a low self-esteem and that the relationship with the nurses can either compensate for, or feed into, the feeling of poor self-esteem. Developing parental skill in their parental role in the NICU and an experience of flow can improve parental self-esteem.

Being fully functional in their role as a parent (eudaimonic well-being) is shown to be important to parents who have a preterm infant in an NICU (Lasiuk et al., 2013) as loss of the expected and desired parental role is cited as one of the greatest sources of stress for parents (Woodward et al., 2014). This may then ultimately lead to more positive feelings such as happiness.

By using a solution–focused approach and applicable interventions, it is aimed that parents will expect a hopeful outcome and thus believe they can solve their own problems. Focusing on solutions, positive emotions, skill development and using available resources all relate to PP.

In the literature, it is shown that mothers who delivered a preterm infant can feel stuck, absorbed by feelings of grief or anger, and may also present with confusion and disorientation (Yaari et al., 2015) and, therefore, may be regarded as languishing. Resolution of the loss over a parent's hoped-for full-term pregnancy needs to take place and the dreamed-of infant needs to be replaced with the infant's current condition. A refocus of attention and resources on the present reality is necessary (Yaari et al., 2015) to help foster well-being. As Rashid (2009, p. 463) states: "a positive intervention does not deny distressing, unpleasant, or negative experiences." However, while not ignoring the negative and unpleasant, a support intervention can promote well-being.

Even with spectacular growth in the PP field, some authors (Fincham & Beach, 2010; Maniaci & Reis, 2010) have noted that positive psychologists have not paid enough attention to the interpersonal context in which people spend much of their lives (McNulty & Fincham, 2012). As can be seen with regard to well-being, relationships are important to humans. Humans do not exist and function in isolation but are grounded in relationships and systems. Thus, incorporating a systems perspective is necessary in this PP study.

3.4 Bronfenbrenner's Bioecological Systems Theory

A further, central theoretical model which needs to be considered in this research study is Bronfenbrenner's bioecological model. Urie Bronfenbrenner described a theory of human development with writings starting in the 1970's until his death in 2005. Bronfenbrenner (1989) originally developed a model called the 'Ecological Systems Theory' to understand a person's

development within the environment. In the original model Bronfenbrenner (1989) described four ecological systems (as will be discussed later). This model was later revised into the bioecological model. As Rosa and Tudge (2013) explain, Bronfenbrenner's theory evolved over time in three phases. In the last phase from 1993-2006, the bioecological theory or bioecological model of human development was developed. The Process-Person-Context-Time Model (PPCT), with the four elements of process, person, context and time, can be regarded as the essence of the bioecological theory (Bronfenbrenner & Morris, 2006). The four elements of process, person, context and time, simultaneously influence a person's development (Bronfenbrenner, 1999). Each of these will now be discussed.

3.4.1. Process

Process in the context of the bioecological model refers to proximal processes which are the driving forces of human development (Bronfenbrenner & Morris, 1998; 2006) and can be regarded as enduring forms of interaction in the immediate environment (Bronfenbrenner & Ceci, 1993). Proximal processes promote developmental competence in stable and advantageous environments and, in settings which are unstable and disadvantageous, they function to avoid or slow down developmental dysfunction (Bronfenbrenner & Ceci, 1993; Bronfenbrenner & Morris, 1998; 2006).

3.4.2. Personal Characteristics

The second element of the PPCT model is personal characteristics. Personal characteristics play a role in social interactions (Bronfenbrenner & Morris, 1998) and can alter environments. Three types of personal characteristics are distinguished namely: demand characteristics; resource characteristics; and force characteristics.

Firstly, demand characteristics are personal factors such as age, gender, physical appearance, as well as temperament. This will also include the important SOC as discussed above. These characteristics can invite or discourage reactions from the social environment and can thus influence the way in which proximal processes are established (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013).

Secondly, resource characteristics influence a person's ability to engage effectively in proximal processes (Bronfenbrenner & Morris, 1998; 2006). Resource characteristic include ability, experience, knowledge, and skills. This links with COR theory of personal resources.

Thirdly, force characteristics influence a person's developmental outcomes either in a generative manner or disruptive manner (Bronfenbrenner & Morris, 2006). For example, generative force characteristics involve "curiosity, tendency to initiate and engage in activity alone or with others, responsiveness to initiatives by others and readiness to defer immediate gratification to pursue long-term goals" (Bronfenbrenner & Morris, 2006, p. 810). Disruptive force characteristics

involve “impulsiveness, explosiveness, distractibility, inability to defer gratification, or in a more extreme form, resort to aggression and violence” (Bronfenbrenner & Morris, 2006, p. 810).

3.4.3. Context

The third element of the PPCT model relates to context. Five interconnected systems exist. The first four systems are from Bronfenbrenner’s (1979) original ecological systems theory. The fifth system, the chronosystem, was added into the bioecological theory and PPCT model in 1988.

3.4.3.1 Microsystem.

The microsystem is defined as the most proximal setting in which the person is situated and in which the person interacts face-to-face with others (Bronfenbrenner, 1974; 1979). Changes in roles and environments occur in people’s lives due to development, termed by Bronfenbrenner (1976; 1979) as ecological transitions. These transitions impact on the person as well as the system of which the person is part (Bronfenbrenner, 1977; 1978). Transitions may be facilitated or inhibited by a person’s personal conditions, cultural beliefs and attitudes, socioeconomic status, preparation and knowledge, and community and societal conditions (Meleis, Sawyer, Im, Messias, & Schumacher, 2000).

3.4.3.2 Mesosystem.

The mesosystem can be regarded as relationships between the microsystems of a person’s life, which is formed or widened each time a person enters a new setting. Just as within a microsystem there are activities, interpersonal roles and relationships but these now take place across settings (Bronfenbrenner, 1979).

3.4.3.3 Exosystem.

The third system, the exosystem, is an ecological system wherein the person is not situated and does not actively participate, but experiences the influence thereof. The person may also have an influence in the exosystem (Bronfenbrenner, 1979). For example, various institutions and their policies fall into the exosystem.

3.4.3.4 Macrosystem.

The macrosystem is defined as the institutional systems of a culture or subculture, such as the economic, social, education, legal, value, and political systems (Bronfenbrenner, 1976). Bronfenbrenner (1979) explains that the hallmark of the macrosystem is its overarching belief system or ideology. For this research, national and provincial health care policies can influence parents with preterm infants. This study is undertaken in private hospitals with adequate health facilities, however, in the public system this is not always the situation.

3.4.3.5 Chronosystem.

The last system, called the chronosystem, was added into the bioecological theory and describes historical circumstances that affect contexts at all other levels (Bronfenbrenner & Morris, 1998).

3.4.4. Time

The last element of the PPCT model is time. This shows that people and environments change over time. This element is organised at three levels, namely: micro-, meso- and macro-. Micro-time refers to the continuity or discontinuity of episodes of proximal processes, while meso-time refers to the extent of these episodes over the course of days and weeks. Lastly, macro-time focuses on larger society, generations, and the life course of human development (Bronfenbrenner & Morris, 2006).

In addition to the four elements of process, person, context and time influencing a person's development (Bronfenbrenner, 1999), the following factors are also worth mentioning.

3.4.5. Phenomenological Field and Individualisation

Bronfenbrenner (1976; 1978) pointed out that there are essential characteristics of ecological environments, one of them being that they are constituted in a phenomenological field. This means that the environment should be considered as it is perceived and understood by the person.

3.4.6. Instigative Characteristics

Bronfenbrenner (1993) mentioned another important factor relating to his theory. Any ecological study has certain characteristics which are described as instigative characteristics, which are reactions from the environment that can either promote or disrupt psychological growth. Instigative characteristics which disrupt psychological growth are environments characterised by instability, unpredictability and the absence of any clear structure (Bronfenbrenner, 1993).

Furthermore, instigative characteristics can serve in a constructive way. These are places or objects that invite manipulation and exploration (Bronfenbrenner, 1993). The bioecological theory shows that people and their environments constantly affect one another. Based on this relationship Bronfenbrenner and Ceci (1993) indicate that if public policy is planned on the basis of bioecological theory, ecological environments could improve and lead to developmental outcomes of competence.

3.4.7. Preterm birth from a Bioecological Systems Theory perspective

The bioecological theory model, sometimes PPCT model has four elements which will be discussed relating to preterm birth.

3.4.7.1 Process and preterm birth.

Proximal processes are enduring forms of interaction in the immediate environment (Bronfenbrenner & Ceci, 1993). These proximal processes, regarded as relationships and interactions among the medical staff and the parents, are vitally important in avoiding dysfunction

and developing well-being in parents. According to Hobfoll's (1989) Conservation of Resources theory (COR), people can move into downward spirals of resource loss when exposed to stress. Proximal processes can be used to help parents halt a downward spiral through positive, educational, supportive, and informative relationships.

3.4.7.2 Person and preterm birth.

Demand, resource, and force personal characteristics are delineated. Proximal processes are influenced by parental demand characteristics (age, gender, temperament) and well-being too. Resource characteristics of knowledge, ability, and skills can help parents engage with proximal processes. Parents however, may lack knowledge relating to their preterm infant and the NICU. With psycho-education, parents may then be able to engage effectively in proximal processes. It is hoped that parents will be interested in and responsive to the support offered, rather than being distracted and even aggressive. Force characteristics may thus influence the outcome of the support intervention. Acknowledgement needs to be made that each parent is unique in their personal characteristics and although the support intervention expects to improve parents' well-being, it must be recognised that results of the intervention may not be what is expected. In this regard, complexity thinking notes that "nonlinear, context-, and contingency-specific interactions" may influence expected research results (Rogers et al., 2013).

3.4.7.3 Context and preterm birth.

Five interconnected systems exist namely: a microsystem; mesosystem; exosystem; macro system; and chronosystem. Parents and their immediate family can be regarded as a microsystem. Individuals in this system have relationships with each other and influence each other. Proximal processes take place in this system. Transitions occur in this system and thus pregnancy and expected birth of an infant is regarded as a transition. There is a certain likelihood that this system, which may include other siblings, will be disrupted with the birth of a preterm infant. Disruptions may include changes in routines. The new infant in the parents' life is an addition to the microsystem. Fostering well-being in the parents can not only benefit the parents but also will have an influence on the rest of the family.

The relationship between the immediate family and the NICU can be regarded as a mesosystem. This mesosystem is challenging due to the strangeness of the NICU to the parents. It has even been referred to as an alien world (Conn & Discenza, 2009; Lasiuk et al., 2013). New relationships have to be forged and initially parents have to rely on the nursing and medical staff to look after their infant. The parenting role is thus delayed in the NICU, which is considered as having the most detrimental effect on parents' well-being (Woodward et al., 2014).

In this research context, the policies of the hospital and the NICU have an influence on the parents, which is characteristic of an exosystem. The NICU has certain policies and procedures that

need to be followed, with clear reason. For example, visitation rules, cleansing procedures upon entering the unit, parents being allowed or not allowed to be present for staff change-overs and, procedures relating to providing milk for the infant.

Keyes's (2009) term flourishing is a desirable condition that any government or hospital would want to protect or promote in its citizens within a macrosystem.

Historically (chronosystem), the personal reproductive history of a woman has an effect on the current pregnancy and experiences thereof. In the field of health and medicine, medical technology has advanced with survival rates of preterm infants increasing (Melnyk et al., 2006; Zelkowitz et al., 2008), and thus resulting in preterm birth being a significant health issue for parents nowadays.

It is seen therefore that preterm birth and the sequelae thereof has significance in all five systems that people exist in.

3.4.7.4 Time and preterm birth.

Environment change over time. Micro-time can be defined as episodes of proximal process and meso-time as episodes of proximal process over a course of days and weeks. With regards to this research study, it is hoped that there will be sufficient episodes of micro-time and meso-time to support parents and promote well-being.

The **phenomenological field** is significant in this study. The researcher needs to understand parental experiences and needs before a support intervention can be developed (see chapter 4). Re reactions from the environment (**instigative characteristics**) can either promote or disrupt psychological growth. In the context of this research study, the NICU has clear routines and structures, however, the health of the infant is unpredictable. Educating and informing parents regarding preterm birth and the realities of a preterm infant can circumvent at least some psychological disruption. This relates to the salutogenic term of comprehensibility. The NICU is a stressful environment where knowledge and skill is necessary to be able to function as parents in the NICU. This, according to the researcher, will ultimately lead to furthering of development as a parent of a preterm infant and thus improve well-being. It is significant to acknowledge the effect of the NICU environment on the well-being of the parents. Therefore, policies for supporting and promoting developmental competence and psychological growth (well-being) in parents with preterm infants, may need to be reviewed in hospitals as well as society in general.

3.5 General Elements of Well-Being relevant to this Study

For the purpose of this study, the researcher is of the opinion that the factors of the PERMA model are applicable to the research problem, but other factors of well-being also need to be added such as Antonovsky's (1993) SOC concepts of comprehensibility and manageability. In addition, concepts relating to the self, such as self-acceptance and self-esteem, need to be added. Therefore, there should, according to the researcher, be eight elements to foster well-being in the parents.

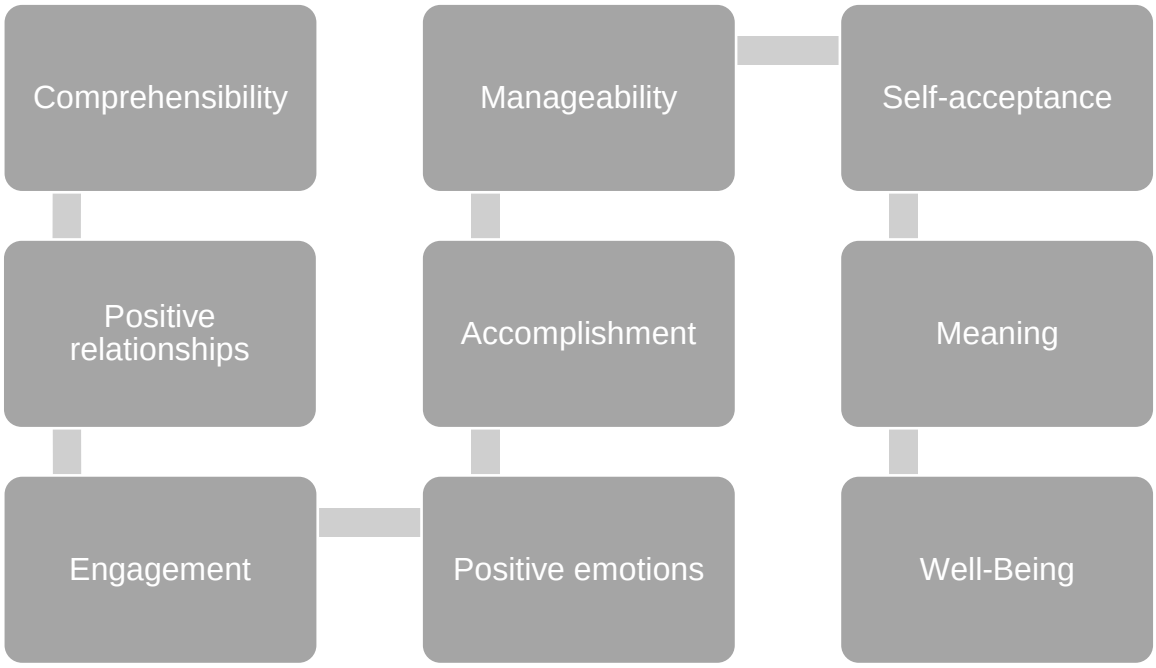


Figure 3.4: Elements of well-being included in study

Comprehensibility: As mentioned earlier, if the environment of the NICU is perceived to make cognitive sense to the parents, it is assumed by the researcher that well-being can be fostered. Thus, understanding the processes and policies of the NICU can help the parents.

Positive Relationships: People are 'social beings' and thus good relationships are the core to well-being. People who have meaningful, positive relationships with others are happier than those who do not. It is also desirable that parents can have positive relationships with the staff of the NICU. It has been shown that the parents' ability to adapt to the new reality of the NICU is facilitated or constrained by, among other factors, the quality of their relationship with health care professionals (Lasiuk et al., 2013). This links with Hobfoll's (2002) category of condition or interpersonal resources, which can be a deciding factor in terms of people moving into resource loss or gain spirals. Networking, social support and the good will of others can provide an important buffer in difficult situations.

Engagement: When engaged in a situation, task or project, a state of flow may emerge. A theory of optimal experience is based on the concept of flow, where a person is so involved in an activity that nothing else seems to matter (Csikszentmihalyi, 1990). The more a person experiences this type of engagement, the more likely the person will experience well-being (Seligman, 2011). In this research study, it is desirable that parents can experience flow.

Positive Emotion: To experience well-being, any positive emotion such as peace, gratitude, satisfaction, pleasure, inspiration, hope, curiosity, or love must be present. Obviously, it would be beneficial for participants in this study to experience some form of positive emotion.

Accomplishment / Achievement: People strive to better themselves whether seeking to master a skill, achieve a valuable goal or win in a competitive event. An aim in this study is for parents to feel competent in parenting their preterm infant in the NICU so that they can feel confident when going home. It is shown that it is necessary for parents to feel confident in parenting before going home (Adama et al., 2016) and that readiness for discharge is significantly related to infant safety, parent satisfaction and physical, emotional, psychological, and social well-being of the family (Weiss et al., 2006). Educational intervention provided to the mother before discharge has been shown to increase knowledge, change maternal behaviours, and decrease maternal stress (Browne & Talmi, 2005). Accomplishment is shown to be important in contributing to a state of flourishing (Keyes, 2009).

Manageability: This is related to the parents perceiving that they have the resources to cope. Psychological resources can include hope, gratitude, optimism (Hobfoll, 2002). As mentioned, it is not clear or predictable what resource can help the individual parent as each is unique in their world.

Self-acceptance: This concept is brought up in Jahoda's (1958), Ryff's (1989), Keyes's (2002), Diener et al's (2010) and Huppert and So's (2013) theories. Self-esteem and self-acceptance is regarded as important by the researcher as many parents, especially mothers, feel that they did something wrong to cause the preterm birth. Guilt is a common feeling among mothers (Perun, 2013) that needs to be dealt with.

Meaning: Meaning involves a sense that one's existence is purposeful (Park, 2015). Meaning has also been described by Steger, Shin, Shim, and Fitch-Martin (2013) as being central to PP as it underlies the PERMA factors. In other words, the impact of relationships and achievement are based on their significance to the person, and positive emotions as well as engagement lead to well-being only in the context of meaningful pursuits. Cohn and Fredrickson (2009) found that the experience of positive emotions results in greater flexibility and openness to experience and helps create a sense of meaning. Delivering a preterm infant needing unique caring is a cause which may be regarded as bigger than ourselves. Parents may cope better knowing that there is some meaning

to the experience. Achievement in caring for and understanding the preterm infant as a meaningful pursuit, can further meaningfulness.

According to Simmons and Nelson (2007), positive psychological states such as hope, positive affect, meaningfulness, and manageability can be regarded as eustress. Negative psychological states such as negative affect, anxiety, and anger can be regarded as distress. Hope, as defined as the belief that one has the will and knows the way to accomplish goals (Snyder et al., 1996), is, according to Simmons and Nelson (2007), their most effective indicator of eustress in their holistic stress model.

In sum, these eight factors can be regarded as elements of well-being that need to be developed in the support intervention to foster well-being in the parents of preterm infants admitted to an NICU.

3.6 Conclusion

In summation, preterm birth was seen in chapter two as being a significant stressor affecting parents and the family unit. The well-being of parents is affected and thus a possibility arises of parents moving into states of languishing or even floundering. In this study, the researcher will attempt to foster well-being in parents by firstly keeping in minds that parents are situated in a strange unfamiliar environment. The NICU exerts influences on the parents and their related families (microsystem and mesosystem). This environment needs to be understood, and thus the SOC constituent of comprehensibility needs to be developed. Parents need to be able to manage their situation and therefore resources are needed. By receiving information and learning skills, parents can start to engage with their infant and feel a sense of accomplishment. KMC is a valuable technique to engage with the preterm infant and may initiate flow. Positive emotions can result, leading to further openness, flexibility and awareness in the parents for problem-solving and building further resources. Openness to experience helps create a sense of meaning. A meaningful pursuit such as caring for and understanding a preterm infant leads to the development of meaningfulness. Positive relationships are necessary in this whole process. Knowledge, skills, engagement, accomplishment, meaningfulness and relationships can be seen as helping parents (especially mothers) learn to accept themselves again after the traumatic preterm birth. The process of exploring the experiences of parents of preterm infants previously admitted into an NICU in SA will be expanded upon in the next chapter.

CHAPTER 4

INFORMATION GATHERING AND SYNTHESIS: VETERAN PARENTS' EXPERIENCES AND NURSING PROFESSIONALS RECOMMENDATIONS

This chapter outlines the implementation, methodology, and findings related to one objective of the broader study aimed at developing a support intervention to foster well-being in parents of preterm infants admitted to an NICU. According to Gregory (2015), interventions guided by the insights and experiences of NICU families will position such interventions for the highest likelihood of success in meeting the emotional needs of parents during and after NICU hospitalisation.

The experiences of veteran parents (VP) and information gained from the nursing professionals, forms part of the information gathering and synthesis phase of the intervention research process as indicated in the figure below.

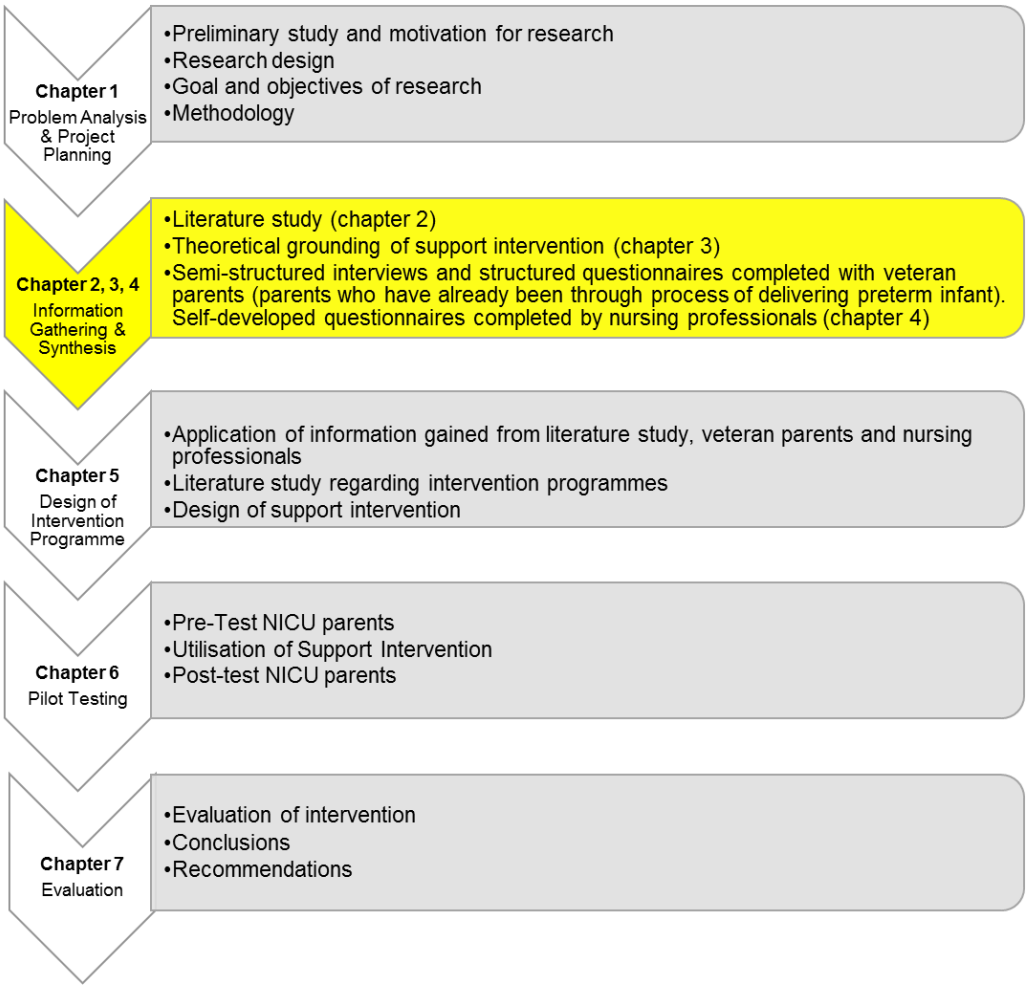


Figure 4.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

4.1 Methodology

The main aim of this chapter is to answer two sub-questions which form part of the main research question and goal of the study, namely: to create and implement a support intervention to foster well-being in parents of preterm infants admitted to an NICU, by utilizing the intervention research process. The two sub-questions questions are:

- What are the experiences of veteran parents (parents who had delivered a preterm infant that was hospitalised in an NICU previously) regarding having a preterm infant hospitalised in an NICU, and what functional elements can be included in such an intervention based on their experiences?
- What elements need to be incorporated into a support intervention according to nursing professionals working in an NICU?

These questions provide, as mentioned by Rothman and Thomas (1994), important foundational knowledge. Gilgun and Sands (2012) explain that the design and development of interventions requires descriptions of problematic situations to be as comprehensive as possible, which includes descriptions of individuals' views and experiences of their problems, as well as views of service providers familiar with the problematic situation. Thus, VP and nursing staff are included in this study.

4.1.1 Population and Sample

The VP population is parents of preterm infants previously admitted to an NICU. Non-probability sampling and specifically purposive sampling (Lombard, 2016; Maree & Pietersen, 2016) was used with inclusion criteria any parents of preterm infant(s) that were hospitalised in an NICU within the last six years. The cut-off point at approximately six years is due to the fact that the previously pre-term infant is still a young child and capturing parental perceptions should still be possible.

The sample included parents who previously had preterm infants in an NICU. Various ages up to the age of six years were included. The focus was on general parental experiences and not experiences related to a particular gestational age and/or birthweight. The researcher was sensitive to the fact that the particular gestational age and birthweight of the infant could influence the experience, for instance the appearance of an extremely low birthweight infant versus a low birthweight infant. To get VP involved in the study, pamphlets (addendum B) were left at gynaecologists' and paediatricians' consulting rooms with the doctor's consent. VP were requested to contact the researcher for further details. Information was e-mailed (addendum C) to interested parents who could indicate via e-mail or telephone if they were interested in being interviewed. The time and place for the interviews were selected by the parents.

Six mothers and two fathers were included in the semi-structured interviews. Reasons given for the absence of fathers were work commitments. Despite the fact that only six mothers and two fathers consented (addendum D) to be interviewed, thick description (Babbie & Mouton, 2009) was reached with these parents. With regard to the structured questionnaire (PSS: NICU), six mothers and five fathers completed the questionnaire (addendum F). The fathers were willing to complete the questionnaires which were left with the mothers and collected once completed. The demographic details (addendum E) of each of the six families and infants are available in Table 4.2.

To satisfy the second sub-question in this study, the population for nursing professionals included any nurse working in an NICU in the Pretoria/Johannesburg area. With regard to the nursing professionals, self-developed questionnaires (addendum I) were given to the unit manager of the NICU at each respective hospital who then gave the questionnaires to the nursing professionals working in the NICU. The gatekeeper for the nursing staff was the head office of each respective hospital group, and the mediators were the unit managers at each NICU. Twenty-three nurses, from three different hospitals, gave their consent (addendum H) and returned the questionnaire.

4.1.2. Data Generation

Data was collected from VP by using a structured questionnaire as well as semi-structured interviews. Five interviews were conducted in the parents' homes and one interview was conducted in the researcher's office. Questions asked in the semi-structured interviews with the VP were: How did you experience the preterm birth of ***?; Did you feel you were supported during those times? If so, who supported you and helped you cope?; How did you cope when you were at home?; When you think back of the experience, what is your overall feeling now?; Do you think you would have benefitted from a support intervention?; and What do you think should be included in a support intervention?

The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) (Miles, Funk, & Carlson, 1993) was also used with the VP to assess level of parental distress. Permission was obtained from the originator, Margaret Miles, via e-mail. The PSS: NICU evaluates parental perceptions of the following stressors evident in the NICU: (1) the physical environment of the NICU; (2) preterm infant's behaviour/ appearance; and (3) the relationship with the infant and their parental role. Each item is rated on a 5-point Likert scale where one means not at all stressful, two means a little stressful, three means moderately stressful, four means very stressful and five means extremely stressful in a given situation. The scale has had its validity and internal consistency confirmed in the USA (Miles et al., 1999) and the UK (Reid & Bramwell, 2003). According to Miles et al., (1993), the following steps were carried out in the development of the scale to help support its reliability and validity: Literature reviews; consultation with professionals experienced in the field;

and interviews with parents whose infants were or had been in an NICU. Construct validity was supported by linkage with theory, significant correlations with Spielberger's (1983) State-Trait Anxiety Inventory as well as factor analysis (Miles et al., 1993; Reid & Bramwell, 2003).

Data was generated from the nursing professionals, through self-developed questionnaires. The questionnaire included questions relating to the nurses' perceptions of their roles, the parents' roles, their expectations of the parents, communication and relationships with the parents, FCC and their view on the contents of a support intervention. Questionnaires were returned from three NICU's: eleven from one, nine from another, and three from the third NICU. In total there were 23 questionnaires returned from the nursing personnel. The demographic details of the nursing personnel are seen in table 4.3.

4.1.3. Data Analysis

With regard to the semi-structured interviews with the VP, the interviews were tape recorded and transcribed verbatim (for examples see addendum G). A qualitative thematic analysis was conducted following the six phase guide of Clarke and Braun (2013) which includes the following phases: gaining familiarity with data; generating initial codes; searching for; reviewing; defining; and naming themes. Although the six phase guide is presented as a linear, step-by-step procedure, analysis was done manually and iteratively. A data-driven inductive approach (Boyatzis, 1998; Braun & Clarke, 2006) was followed where analysis was a process of coding the data without trying to fit into a pre-existing coding frame.

According to Miles et al. (1993), the PSS: NICU can be scored in two ways:

- *Stress occurrence level*, is the level of stress experienced of different factors in each particular situation namely: sights and sounds of the NICU (5 factors); infants' appearance (14 factors); and parental role alteration (7 factors). Parents indicate a score from 0-5 of their experience. The average for 6 mothers and 5 fathers is determined for each factor in a particular situation. Thus, the minimum score for stress occurrence level is 0 and the maximum score will be 5 for factors within a specific situation. Stress occurrence levels are seen in figures 4.2; 4.3; 4.4.
- *Overall stress level* is the stress from each situation (sights and sounds; infants appearance; parental role alteration). Scores reflected in figure 4.5 is the total average score for each situation for 6 mothers and 5 fathers. The minimum score for overall stress is 0 and the maximum score is 5 for each situation.

Data obtained from the PSS: NICU is not used for statistical inference but only to get an indication of parental stress scores.

In addition to the thematic analysis of the semi-structured interviews with the VP, a thematic analysis was undertaken with the self-developed questionnaire completed by nursing personnel.

Table 4.1:
Demographic details of veteran parents

Veteran parent	VP 1	VP 2	VP 3	VP 4	VP 5	VP 6
Mother's age	30	34	32	27	34	28
Father's age	34	38	50	27	34	39
Previous births	1	0	0	0	0	0
Previous loss / miscarriage	No	No	No	Yes	No	Yes
Parent interviewed	Mom	Mom & Dad	Mom	Mom & Dad	Mom	Mom
Multiple birth	Yes	No	Yes	No	Yes	No
Infant's birthweight	1.2 kg 1.3 kg	2.1 kg	1.21 kg 970 g	1.22 kg	2.3 kg 1.9 kg	1.18 kg
Infant's gestational age (weeks)	30/52	36/52	29/52	31/52	34/52	27/52
Require breathing assistance	Yes	No	Yes	Yes	Yes	Yes
Length of hospitalisation for infant	59 days	13 days	69 days 154 days	39 days	14 days 35 days	69 days
Age of infant at time of interview approximate)	5 months	6 years 2 months	2 years 9 months	3 months	1 year 7 months	4 years 1 month

Table 4.2:

Demographics details of nurse professionals

Nurse	Age	Home language	Qualification	Approximate working hours in NICU per week	Experience in NICU	Total nursing experience	Hospital
N1	33	English	Masters in nursing science (neonatology)	42	5 years	9 years	A
N2	46	Afrikaans	Registered Nurse (RN)	36	9 years	27 years	A
N3	45	English	Diploma in nursing = RN	30	22 years	26 years	A
N4	34	Afrikaans	RN	30	11 years	15 years	A
N5	30	Afrikaans	RN	42	7 years	7 years	A
N6	26	English	BCur = RN	40	2 years	2 years	A
N7	36	Afrikaans	RN	42	13 years	17 years	A
N8	35	Sepedi	Enrolled Nurse = Staff nurse (1 year training)	Not filled in	1 year	3 years	A
N9	54	Afrikaans	RN	25	5 years	35 years	A
N10	38	English	RN + Midwifery	30	11 years	15 years	A
N11	37	Northern Sotho + Zulu	Enrolled Nurse Assistant	Not filled in	1 year	1 year	A
N12	35	Afrikaans	RN	Not filled in	8 years	13 years	B
N13	51	Afrikaans	M Cur Critical care (Intensive Care)	30	18 years	32 years	B
N14	40	English	BCur Diploma in neonatal nursing science = RN	36	18 years	22 years	B

N15	38	Afrikaans	BCur (Administration + education neonatal =RN	40	18 years	18 years	B
N16	63	Afrikaans	RN	24	7 years	44 years	B
N17	31	Afrikaans	RN	42	7 years	8 years	B
N18	60	Afrikaans	General Midwifery	42	10 years	40 years	B
N19	37	Ndebele	RN	42	1 year	10 years	B
N20	25	Afrikaans	RN	40	1 year	7 years	B
N21	53	English	RN (PhD)	40	26 years	35 years	C
N22	45	English	RN	42	9 months		C
N23	46	English	BCur (Honours)	36	5 years	26 years	C

This chapter can be seen as consisting of two parts. The first part relates to the experiences of VP with information from the nursing professionals integrated into the discussion. The second part relates specifically to support needed, as described by the veteran parents and nursing professionals, as well as identification of functional elements which can be included in the support intervention.

4.2 Findings Relating to Veteran Parents and Nursing Staff

In this part of the broader study, VP were interviewed regarding their experiences of delivering a preterm infant that was hospitalised in an NICU. Delivering a preterm infant appears to follow a certain path with various phases. Parents have various experiences throughout the admission phase of the preterm infant, discharge and return home. Each of these phases has specific themes (see table 4.4). Parents' experiences are discussed according to the phases and themes in each phase. In addition, the results of the questionnaires from the nursing staff are integrated, where applicable.

Table 4.3:

Themes generated by veteran parents' experiences

Phase	Themes
Before birth	Problems in pregnancy with repeated hospitalisation and bed rest NICU prediction and preparation Eventual preterm labour
Birth	A sense of relief Traumatic birth with the additional distressing separation Mothers stress in sharing room in the maternity ward Distressing separation of going home without infant
NICU (Risk and protective factors)	Context of the NICU The preterm infant Relationships Needs for, and lack of, information, education and communication Matters relating specifically to the mother
Home-coming of infant	Important know-how Lonely confinement to prevent illness of infant Maternal depression Difficult feeding Daily challenges and need for assistance Peculiarities of the infant and desire for normality Misunderstanding by others
General non-phase specific factors	Bonding Fear death of infant Changes in self Maternal guilt Trauma

4.2.1 Before Birth Experiences

A high-risk pregnancy (HRP) can be defined as a pregnancy complicated by a factor(s) which threatens the well-being of the mother and/or foetus (Jain et al., 2014; Lee et al., 2014). The majority of mothers in this study were predisposed to having a high-risk pregnancy due to factors such as having multiples (VP 1, 3, 5), previous miscarriages (VP 4, 6), previous infertility issues (VP 3, 5) and pregnancy induced hypertension (VP 6). One mother describes that she was informed that there was a problem with her foetus (VP 2): "s*o at 7 months, the gynae knew something wasn't*

right. Much as I knew something [was] *not right about it,* [it] *was a shock. Just knowing that this is your first baby and all of a sudden you are not going to be like any other parent in the hospital because they need to make observations of the baby and need to see what is the actual prognosis…at the time I just wanted her out…I did not want to wait long because anxiety was just killing me."* This mother felt different from other women, was uncertain of the outcome and experienced anxiety. The literature shows that high-risk pregnant women experience anxiety related to the potential outcomes (Lee & Lee, 2015). Stahl and Hundley (2003) found that the labelling of women to be 'at risk' results in additional stress for a women.

4.2.1.1 Problems in pregnancy with repeated hospitalisation and bedrest.

The majority of the mothers in this study (VP 1, 2, 4, 5, 6) said that they started experiencing **problems in their pregnancy** early on. This is shown by the following mothers' comments: *"it was a terrible pregnancy virtually from the day of conception… You meet women and they say how they feel when they* [are] *pregnant and I never felt anything like what they said they feel. It was not like nauseous, I was physically ill like I had some sort of disease"* (VP 5) and *"I had a difficult pregnancy, I was vomiting and nauseous and was just not well throughout the pregnancy"* (VP 6). Even looking at not so recent statistics, it is shown that in 2008 in the United States approximately 50% of pregnancies were affected by some type of medical complication (Bruce et al., 2008) and in 2004, 21% of pregnant women in Australia were hospitalised for complications at some point during pregnancy (Turnbull et al., 2004). Risk factors in pregnancy in a South African study included HIV, alcohol use, low birthweight related to poor nutrition, and depression (Tomlinson et al., 2014). In this study conducted in 24 townships in Cape Town, 66% of pregnant women experienced at least one risk factor and approximately 27% experienced more than one risk factor.

Several mothers in this study were **repeatedly hospitalised** during pregnancy (VP 1, 3, 4, 6): "*I had been in and out of hospital for two months"* (VP 1). Another mother explains: "*I went into labour at 26 weeks and then I was hospitalised for two weeks and then went home for three days and then I went into labour again"* (VP 3). Added to the actual hospitalisation, which is distressing (Barber & Starkey, 2015), women undergo medical tests and procedures. As one mother (VP 4) explains: "*I had blood tests every single day but they couldn't find the infection anywhere and at the end they did an amniocentesis"* [A medical test that involves taking some liquid from the mother's womb in order to find out if the foetus has particular illnesses or health problems (Oxford Advanced Learner's Dictionary, 2010)]. This is an invasive diagnostic procedure which results in significant anxiety (Nakić Radoš, Košec, & Gall, 2013).

Two mothers were advised **bed rest** to avoid preterm labour (VP 1, 4). The resultant immobility leads women to feel helpless: "*So if I just like lie in bed for a month, that's what the doctor wanted to do"* (VP 1). Bed rest is a commonly prescribed intervention in obstetrics to prevent

preterm birth (Maloni, 2010; Sciscione, 2010). However, it is shown that bed rest may exacerbate rather than relieve the anxiety and stress of the pregnant woman (Lederman et al., 2013; Maloni, Chance, Zhang, Betts, & Gange, 1993).

4.2.1.2 NICU anticipation and preparation.

Three sets of parents were either informed or realised themselves that they would end up in the NICU (VP 2, 4, 5): *"I was expecting the situation to lead up to the NICU and was not surprised by it. I was emotionally prepared but even so it was still hectic. It was a nasty way to start parenting… I thought I was prepared for what was going to happen but… it didn't quite work out that way"* (VP 5). One set of parents realised themselves the possibility of the impending preterm birth: *"I think we knew he was going to come early"* (VP 4). Some parents received guidance from the doctors of the risks and consequences of preterm birth (VP 4, 6). This however traumatised some of these parents: *"When I was in hospital they explained to us what was going to happen to our baby if he is born premature and what can go wrong and I think that in itself was traumatic"* (VP 4). However, the same parents also indicated that it is good in principle having these explanations.

The majority of nursing staff in this study indicated that it would be helpful to support parents by explaining what to expect (N 6, 10, 16, 17), and what to expect in the NICU (N 1, 3, 5, 6, 9, 10, 13, 15, 16, 20, 22). Nurses recommend a tour be given to the parents if possible (N 1, 2, 3, 8, 9, 16, 22). Only one set of parents received a tour of the NICU in this study: "*they took me, in a wheel chair, from obstetrics through a door. They took me for a tour there and somebody explained to us at first he will be in this incubator, then he will be moved over to that one...So I think they made an effort with us. I think that helped a lot, because if I didn't know that's what ICU looks like I would have had a heart attack when I came there the first time"* (VP 4). According to Briscoe (2015) parents need information; however, there is a gap in knowledge with regard to specific information needed. According to Cockcroft (2012), parental needs regarding access to information must be acknowledged.

4.2.1.3 Eventual preterm labour.

Eventually, preterm labour occurred with some of the mothers (VP 1, 3, 4), for example: *"my water broke and then we rushed to the hospital"* (VP 1) and *"they tried to stop the contractions and I was sent home for four days, and then my water broke and then I went back again and then it broke totally in hospital and then I was admitted again and then I was there for four days before I went into labour. So I went in to labour because I did not have any amniotic fluid"* (VP 4). It is indicated that full-term birth and spontaneous preterm birth share a 'common pathway' and are regarded as being fundamentally the same process except for the gestational age at which they occur (Romero et al., 2006). According to Voltolini et al. (2013), regardless of new scientific research it is still not possible to prevent spontaneous preterm birth as most causes and developmental processes of preterm birth

are still not completely understood. Therefore, preterm labour still leads to 70% of preterm births (Romero et al., 2014).

In some cases, preterm labour may not be the only reason for preterm birth but may be due to an iatrogenic [induced] delivery. In cases of foetal compromise, early delivery is justified by reductions in perinatal death and serious morbidity (Joseph, 2007). Thus, there are several situations when early delivery and admission to an NICU is preferable (Spong et al., 2011).

4.2.2 The Birth Experience: Relief, Trauma and Distress

For half of the mothers in this study, the early birth of the infant was due to problems with the foetus (VP 2, 3, 6): *"*[the doctor] *looked at my results and she said you need to deliver now because there is not enough blood going to the baby. He is going to be brain dead or even loose him as well, like the previous one"* (VP 6). For this mother (VP 6) the early birth was a **relief**. Another mother also felt that the preterm birth was good: "*he did not have any blood flow through the cord any more so I actually had peace because this was the best thing to do for them"* (VP 3)*.* Literature indicates that increases in iatrogenic preterm birth have occurred among women with multiple pregnancies, previous preterm births, hypertension in pregnancy, and other pregnancy complications and that these women benefit from a selective, carefully timed early delivery due to foetal complications (Joseph & D'Alton, 2013). Despite the medical risks of intentional delivery of a pregnancy before 39 weeks' gestation, it is considered to be justified in some cases to reduce the risk of stillbirth as the "emotional impact of stillbirth is considerable for families and clinicians" (Edmunds & Silver, 2013, p. 611). It is thus understandable that parents experience relief when delivering iatrogenically.

For the other half of the mothers (VP 1, 4, 5) the birth was **traumatic**: "*It was not a pleasant birth experience, you don't know if they* [the infants are] *going to live. You are just waiting to hear them scream"* (VP 1). One mother indicated that she was anticipating a preterm birth, however the emotional consequence was still traumatic: "*The birth was still traumatic, even with the awareness* [of it occurring]*"* (VP 5). This is in line with the literature as discussed in chapter two, that for some parents, a cognitive understanding exists for the potential of having a preterm birth, but shock still occurs despite this cognitive understanding (Lasiuk et al., 2013). There is an abundance of literature on the traumatic experiences of preterm birth in parents. Emotional effects include, among others, parental stress, anxiety (Kaaresen et al., 2006) as well as guilt and depression (Hagan et al., 2004; Kersting et al., 2004; Perun, 2013). Acute stress disorder and posttraumatic stress disorder are common parental reactions to preterm birth (Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Kersting et al., 2004; Lasiuk et al., 2013; Peebles-Kleiger, 2000; Pierrehumbert, Nicole, Muller-Nix, Forcada-Guex, & Ansermet, 2003; Shaw et al., 2009; Shaw et al., 2006; Vanderbilt, Bushley, Young, & Frank, 2009).

Some of the mothers (VP 3, 4, 6) were **immediately separated** from their infant when the infant was taken directly to the NICU without the mother holding or seeing her infant: "*I couldn't see or hold her"* (VP 3). This may cause mothers (VP 3, 4, 5, 6) to be worried about bonding with their infant: "*They just showed him to me and then they took him away, and you don't have that time to bond with him"* (VP 4). Even though it is not proven that a sensitive period exists for attachment (Myers, 1984; Sluckin, 1993), in some earlier studies it is shown that parents who are not given the chance to hold their new-borns immediately after birth can have difficulty initiating a relationship and that these early interruptions in the acquaintance process interfere with the attachment process (Bialoskurski, Cox, & Hayes, 1999; Mercer, 2006; Roller, 2005). More recent studies have however proven that mothers of preterm infants have higher feelings of bonding than mothers of full-term infants (Hall et al., 2015) due to parents providing more parental care in order to compensate for the negative experiences of the infant.

With regards to the maternal care mothers receive after birth, two mothers (VP 2, 4) had negative experiences relating to **sharing a room** with other mothers who had their infants with them: *"I was the only one with her child not next to me or in the crib, it was extremely stressful"* (VP 2). As a result of these negative experiences the mothers requested a private room. According to the study of Baum et al. (2012), a recommendation was made that it is helpful to place mothers in a room with other women who gave birth preterm, rather than with women who gave birth full-term to avoid the mother's sense of feeling different and inferior.

A further significant factor in the parental experience of delivering a preterm infant is the mother having to **go home without her infant**: "*One of the emotional parts for me was leaving the hospital. How do I leave when they* [the infants] *struggle, it's almost like,* [participant struggling to find the right words] *kind of makes the experience like…I didn't have a baby. It was very surreal. It was like now I have had these two babies and now where are they. I was quite frantic about that in particular"* (VP 5). The literature indicates that experiencing a preterm birth as surrealistic is not new (Baum et al., 2012). According to Phillips et al. (2013), mothers should thus be given support to prepare them for going home without their infant.

4.2.3 Neonatal Intensive Care Unit (NICU) – Risk and Protective Factors

The parental experiences relating to the NICU can be regarded as being diverse since there are factors that put the parent's well-being at risk and other additional factors that may be more protective of the parent's well-being. The parents' experiences of these risk or protective factors can be divided into five different areas of focus, namely: the environment or context of the NICU; the preterm infant; relationships; information, education, and communication needs; and matters relating to the mother specifically. These factors, with each of their risk and protective components, can be seen in table 4.4.

Table 4.4:

Risk and protective factors of the NICU

Theme	Risk Factors	Protective Factors
Context of NICU	• 'Alien' environment • Sense of confinement • Procedures	• Cleaning procedures
The preterm Infant	• Appearance • Unstable health • Changed parental role	• Positive health • Kangaroo Mother Care (KMC)
Relationships	• Insensitivity of nursing staff and lack of support • Extended family distress	• Nursing support • Other mothers in unit • Spousal support • Extended family support
Needs for information, education & communication	• Lack of information	• Education provision
Matters relating specifically to the mother	• Juggling act	• Mom stay at hospital

4.2.3.1 Context of the NICU.

The NICU is described by parents (VP 1, 2, 5) as almost being an **'alien' environment** (Conn & Discenza, 2009; Lasiuk et al., 2013): *"It's like a whole other world in there that no one else knows about"* (VP 1). In addition, in this 'alien world', another language is spoken: *"The terminology is not something I can comprehend"* (VP 5). One nurse (N 22) confirmed that terminology used in the NICU is problematic for the parent's comprehension. The NICU is also characterised by various sights and sounds. With regard to the quantitative measure (PSS: NICU), it is seen that mothers experience more stress related to the sights and sounds of the NICU than fathers generally. Certain elements can be regarded as more stressful than others (see fig 4.2). The sudden noises of monitor alarms were the most stressful event for mothers. Fathers experienced other sick infants in the unit as being most stressful. The least stressful events for the mothers were the large number of people working in the unit, and the least stressful event for the fathers were the presence of monitors and equipment.

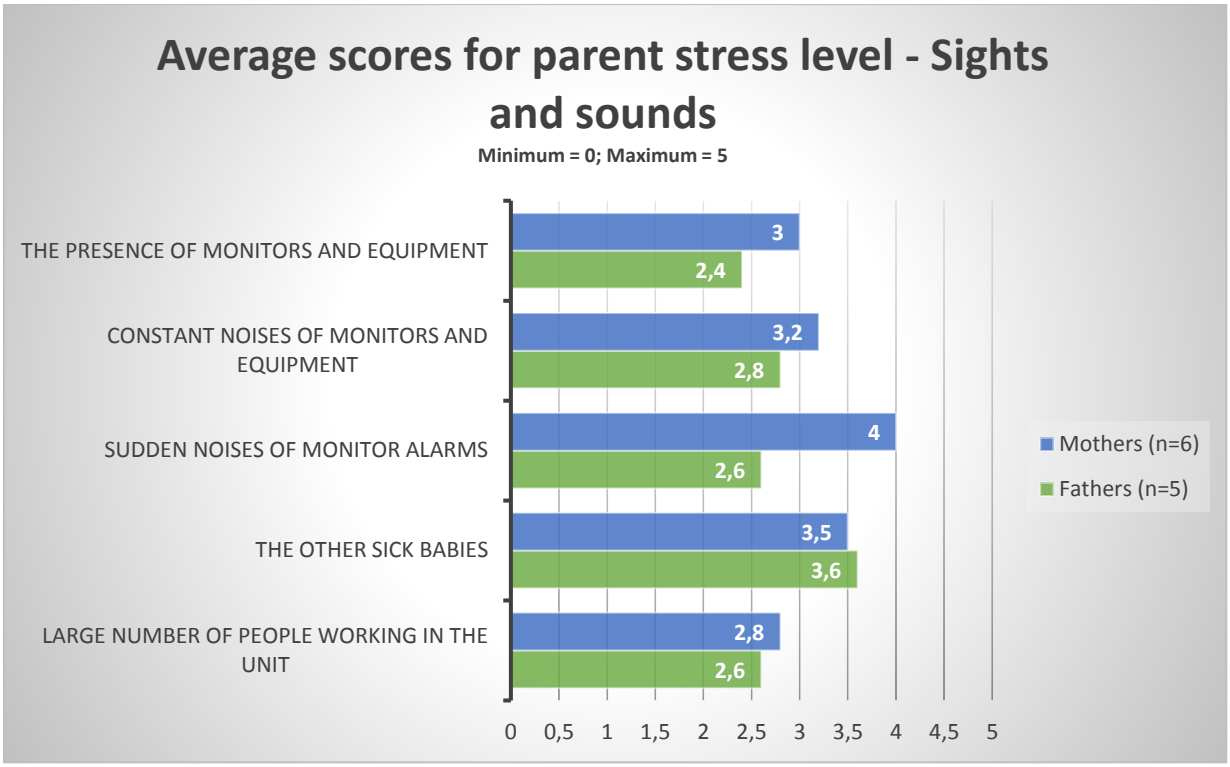


Figure 4.2: Average scores for parental stress related to sights and sounds of the NICU

A sense of **confinement** in this strange and alien 'world' is experienced as mothers (VP 1, 2, 3, 4, 6) spend entire days at the hospital. Reasons may include having to breastfeed every two hours (VP 2), express breastmilk regularly, and to be with their infant. In the study of Lasiuk et al. (2013), the parents' only concern was their infant's survival, leading to vigilance and a strong desire to stay with their infant and thus they would spend long hours at the NICU, sometimes at the cost of their own well-being. In addition, in the first few weeks after birth, mothers are forced to rely on others for transport as they are not allowed to drive which further aggravates the sense of confinement.

All hospitals and NICU's follow certain **procedures** and protocols to allow for smooth running. Procedures in the NICU include shift changes, special storage and use of expressed breastmilk, day passes, hand cleaning routines before entry and other procedures. In this study, some of these procedures acted as either risk or protective factors, based on parental perceptions. For example, routines such as staff lunch and tea-times caused irritation for one mother: "*lunch and tea time drives me insane. All of them go and have lunch and teatime at the same time. I had to look after five babies. I put dummies in their mouths, I sshh'ed this one, I had to call them on a few occasions because the babies were hysterical and I don't want to touch them"* (VP 1). A father (VP 2) expressed the **cleaning procedures** on entry as being a positive element of care in the NICU. It is evident that each NICU develops a 'culture' derived from the collective behaviours of the staff (Lefton, 2014) which will have an effect on parental experiences.

4.2.3.2 The preterm infant.

Risk and protective factors relating to the infant include appearance, roller coaster of health, parental role alteration and KMC. Mothers are *"emotional"* (VP 1) when seeing their infant for the first time. The size and **appearance** of the infant causes intense emotions: *"I was a bit afraid of him at first because he was so small and his nose was skew"* (VP 4); *"nothing prepares you…and you can see all the blood vessels and the bones. Agh, they look like little skeletons"* (VP 1). For some mothers the appearance can be a positive experience: *"My baby was fine, was pink, not blue and he cried immediately and everybody was happy and so I was relieved"* (VP 6). In the study of Meijssen et al. (2011), half of the mothers (50%) in their study described negative emotions about the first time they saw their infant, such as fear about the size of the infant, medical condition, and feelings of alienation. Of this 50%, 31% felt that the infant was not theirs as they could not relate to them. The appearance of the infant, coupled with the supportive technology surrounding the infant in the NICU, represent a source of worry for mothers making them feel disconnected from their infant (Spinelli et al., 2016).

Quantitatively, it can be seen that mothers' stress levels in this study were higher than fathers' except in relation to certain factors of the infant's appearance (see figure 4.3). Fathers were distressed more than mothers about bruises, cuts or incisions on their infant as well as the unusual colour of their infant. The most stressful event for both the parents was when their infant seemed to be in pain. The least stressful event for the fathers was the wrinkled appearance of their infant and for mothers, the colour of their infant. Many factors influence parents' stress levels related to the infant's appearance such as the infant's abnormal breathing patterns and having a machine breathe for the infant. Unusual factors such as the infant being fed with an intravenous (IV) line and seeing needles and tubes inserted into the infant can certainly cause stress in the parents.

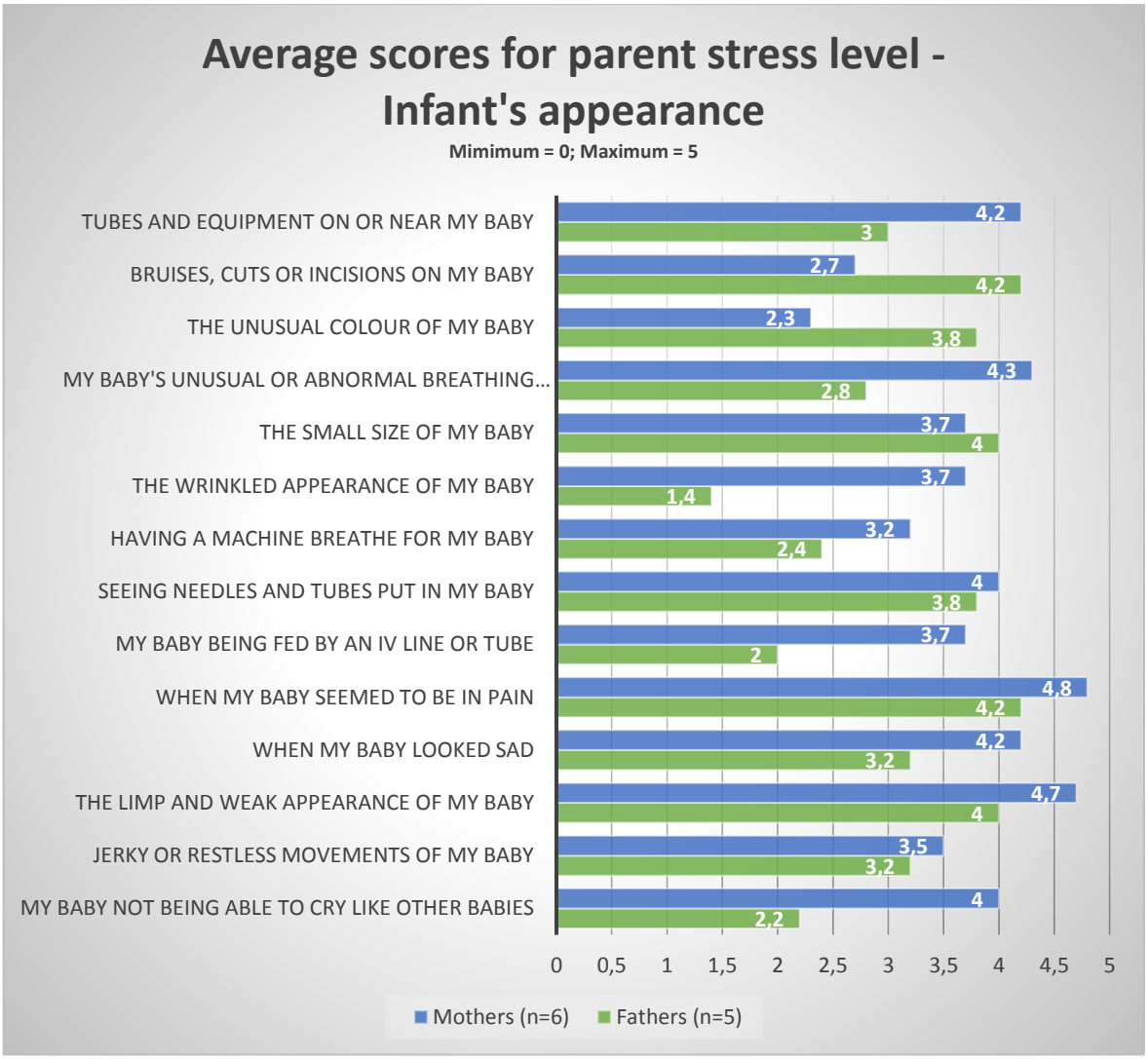


Figure 4.3: Average scores for parental stress related to the infant's appearance

Due to the nature of the preterm infant's **unstable health**, parents may experience high levels of uncertainty (Lasiuk et al., 2013). In addition a common characteristic of preterm infant's health is the unpredictability. This is often described as a roller coaster (Stacey et al., 2015). Four mothers (VP 1, 3, 4, 5) in this study expressed this phenomenon: *"you take three steps forward and two steps back, like they came off the jaundice lights and it was like yay, and then three days later they were back on the jaundice lights"* (VP 1); "*I was crying nearly every day when we went there because I was so afraid that there might be something wrong with him or he might be on oxygen or something like that"* (VP 4); and *"He was kind of doing forward steps and backward steps so it was quite difficult to understand where we are today…it was frustrating cos* [because] *I didn't know from one day to the next what was going to develop"* (VP 5).

A further risk factor to parental well-being is related to the **changed parental role**. Delayed parenthood is regarded as the greatest source of parental stress (Montirosso, Del Prete, Bellù, Tronick, & Borgatti, 2012). In this study, the altered parental role is the most stressful event for both

parents (see fig 4.4) seen quantitatively. A common factor causing the most stress in both parents is feeling helpless - firstly about protecting their infant from pain and secondly with regard to helping their infant. The least stressful event for both mothers and fathers was care-taking skills for the infant. Other stressful factors include not having time alone with the infant. According to Spinelli et al. (2016), the constant presence of the medical staff has a potential negative effect on mothers.

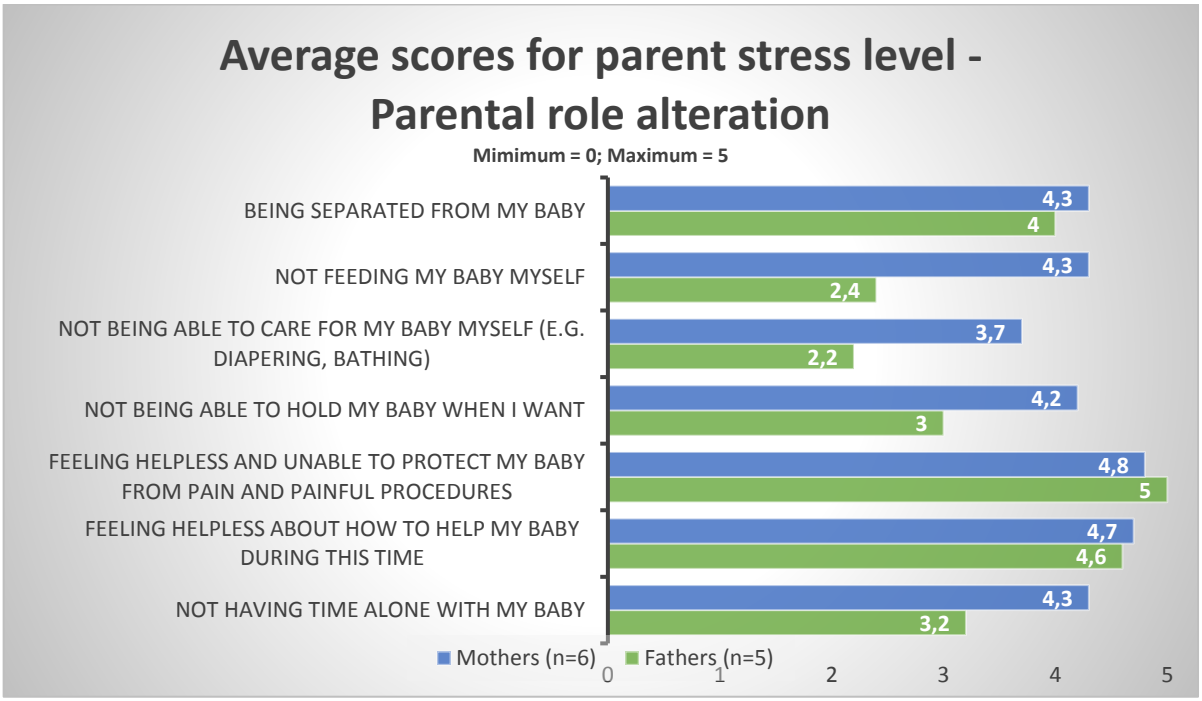


Figure 4.4: Average scores for parental stress related to parental role alteration

Positive health appears to moderate parental well-being (Stacey et al., 2015). Two mothers (VP 1, 4) were positive when describing the health status of their infant: *"they did all the x-rays and they were fine. They didn't have any stomach issues, no lung issues, no liver issues, no brain bleeds. They had nothing wrong with them. They were just tiny"* (VP 1). However, when the preterm infant's health declines, parents experience severe emotional distress. This is shown in this response: "*He was only intubated in neonatal for the medicine for his lungs. Then he went onto CPAP* [Continuous Positive Airway*] for five days and then onto nasal cannula* [oxygen tube inserted into nose] *which is actually very good of him, but after two weeks he started desaturating a lot, but it was when they increased his milk intake, then his problems started. He* [the father] *didn't think they were going to make it"* (VP 3).

A protective factor of well-being was experienced by two mothers and a father (VP 4 mother & father, VP 6). **KMC** helped mothers feel involved in the care of their infant: *"The fact that you are just there, staring at him and not doing anything for him, for me at least I felt like I'm doing*

something...every day I would kangaroo him" (VP 6). The literature (chapter 2: 2.9.7) reports many benefits of KMC for infants and parents, for example: KMC reduces procedural pain, promotes earlier infant sleep regulation, enhances bonding and attachment between the mother or father and infant, and reduces parental stress and depression (Nyqvist, 2016).

4.2.3.3 Relationships.

Relationships can also be regarded as risk or protective factors in the NICU. Risk factors for poor parental well-being include insensitivity of the nursing staff and a lack of support and distress in the extended family. Protective factors include support from the nurses, other mothers in the unit, spousal support, and support from family.

Three mothers (VP 1, 3, 5) experienced a **lack of support** from the nurses: *"the emotional support of the mother is what is lacking when you get to the NICU. They support the child, but not the mother and I understand why they do that, but at the same time I think not doing that has more major repercussions than anything else because at the end of the day that child is going to be dependent on you and wherever you are that child is going to be at"* (VP 5). Of the 23 nurses who completed questionnaires seven nurses (N 2, 6, 8, 9, 14, 17, 23) understood that their role is to support parents. However, two mothers (VP 2, 3) experienced insensitivity from the nurses: *"It felt like a prick on the heart, when I overheard when they were changing shift…they give each other a report of how progress was with all the patients…I remember hearing one of the sisters telling, um, the new staff coming through to say *** is brain damaged, and I remember one of the nurses asking her, what do you mean, and I remember her saying no she was born with a dead brain. So I just felt, how could she say that?"* (VP 2).

A further risk factor for parental well-being is **distress in other family members**. Siblings and other family members can exacerbate parental stress: *"and she* [sibling] *would scream blue murder because she wanted to go up with me. She wanted to see her brothers and she's not allowed in there, so that was bad"* (VP 1); *"everyone else was terrified because an aunt of mine, she walked in, her reaction, she actually scared me. Because she was like oh my word, like she was, held my hand so tightly and I was thinking ok, is anything wrong?"* (VP 6). It is shown that grandparents also bear emotional costs of the preterm birth (Lasiuk et al., 2013).

Protective factors include parents receiving support from nurses, other mothers in the unit, the extended family and from partners (spouses). The majority of parents (VP 2, 3, 4, 5, 6) felt they received support from some of the **nursing staff** when they answered parents questions and gave them information: *"He felt that he had support because at first they were telling us everything"* (VP 3); *"They were always there basically, very supportive, very willing, willing to answer questions"* (VP 6). Parents are exposed to other infants and parents in the unit. The presence of **other parents** in the unit can be a source of support or stress (Stacey et al., 2015). There is the possibility of further

stress for some parents: *"the one day we came there, and every single day we came there, that boy, his name was ***, every single day when we got there, there was something wrong with him. Today he's getting a blood transfusion, the next day his arm was swollen because of the drip. And then he was supposed to get eye surgery oh no, and it was terrible and I think that's what made everything 'dubbel so erg'* [made it twice as bad] "(VP 4). But it is mostly seen that other mothers and parents can be a form of support: *"and there were other mothers there that I spoke to, and there were other mothers that were there with babies that were older than mine, and at least you were there with people that travelled the same road"* (VP 6). In the findings of the study conducted by Stacey et al. (2015), positive relationships with staff and other parents in the unit are key to parental coping in the context of preterm birth and admission to the NICU.

Spousal support is particularly a protective factor for mothers before birth, during the NICU stay and on returning home. Two mothers (VP 2, 4) received spousal support before the birth of their infant: *"He was there for me emotionally"* (VP 2) and "he had to pretend like it's going to be [fine]" (VP 4 mother). The father (VP 4) indicated by saying: *"ja [yes I said], 'if he is born now its fine', because if I didn't do that she maybe would have gone into labour the first day she went into hospital, um, because she was so upset and each time she got upset the contractions started getting worse. So I tried to calm her."* The mother (VP 4) continues: *"So he was there every single day. To me, I think that made the difference"* (VP 4).

During the stay at NICU, mothers (VP 1, 2, 3, 4, 6) indicated that their spouses were supportive. Some spouses were present in the unit itself: *"He was very supportive at the time so he would come and see us every single, almost every hour. So that was exhausting for him as well, I can imagine"* (VP 2); *"He was there all the time for me"* (VP 4). Other fathers helped at home: *"he supported me well because he was the one raising her* [sibling]" (VP 3).

When returning home, two mothers (VP 3, 5) indicated that their husband was supportive: *"my husband was fantastic, I was exceptionally fortunate. My husband, he's very hands on. Um, you know obviously having the twins as well means that literally are there never enough hands to go around, um so certainly he was a huge support for me so at this moment you think all else is going to fall apart but he was there…I get up one morning early and then he gets up one morning early, so I don't know how I would have coped had I not had that"* (VP 5).

A further protective factor is **support from the extended family**. Parents (VP 1, 2, 3, 4, 6) indicated that they received this support. One mother (VP 2) gained support from a sibling before the birth of her infant: *"My sister as well played a big role…*[she] *actually knocked off work early just to be with me throughout the night. The next day she came back when we were getting ready to be hospitalised, so she was also great support."* Parents (VP 1, 4, 6) received support from their extended family during their infant's hospitalisation in the NICU with sibling care and general

emotional support: *"On weekends it was difficult because she* [sibling] *wasn't at school and we wanted to go spend time with the boys but then luckily my Mom and Dad and my in-laws are amazing. My in-laws live in *** and my parents live just down the road. And she actually sleeps out at them often"* (VP 1); *"both the families made a huge difference. Played a huge role. I don't think we would have made it without them"* (VP 4). One mother (VP 6) indicated that, although she felt supported, she also experienced difficulty relating to family being present: *"I have an aunt, my mom's sister who, 2 aunts actually who's here, they came in. I got their support quite often. My mom came in for a week – she lives in ***. I had everyone's support but it was very difficult to give them attention with the baby. I actually preferred it when they weren't there because they not allowed into the ward and it felt like a split between being with the child and your family."*

Similar to the time of NICU stay, family support continued when parents and infants were at home relating to care of the siblings and general emotional support for the parents (VP 1, 2, 3, 6). For example: *"We also had family support both from his family and my family that came through to give support. So it really kind of felt that you know help is out there. Just shout. So they were there for us"* (VP 2). One mother felt fortunate for having family support during the difficult times when fearing infant death: *"My mom's sister came through so she was there, I felt like I was happy to have someone. I won't kill the baby by myself"* (VP 6). The literature indicates that the extended family can provide certain types of support: emotional support, advice and information, prayer, and instrumental help such as child care (Kavanaugh, Nantais-Smith, Savage, Schim, & Natarajan, 2014).

4.2.3.4 Needs for information, education and communication.

The fourth theme relating to the NICU phase relates to the parents' need for information, education, and communication. A significant risk factor for parents is a **lack of information**, guidance, and education. Four parents (VP 1, 2, 4, 5) in this study experienced a need for more information. For example, some mothers felt that the staff did not prepare them for the sights and sounds of the NICU: *"It would have been nice if a nurse had come in with me and explained what this drip is for and said this pipe is for this and this is for that…No one explained what everything was"* (VP 1). Information regarding policies of the unit was also lacking: *"They don't tell you that before the time, they only jump on your head afterwards...so we were a bit scared at the beginning"* (VP 4). Furthermore, information regarding their infant was lacking: *"they should have a meeting with you, explain what his condition is, this is how things run here"* (VP 5). A significant consequence of lack of information is misunderstanding: *"I think a lot of the trauma was related to that respect. You know, not understanding and being the type of personality I am, it was very difficult. With all these different breathing apparatus you don't know which is for which at which levels in the process. The little one was on three forms of respiration – I actually can't tell you cos* [because] *I didn't*

understand it all" (VP 5). Findings from the nurses' questionnaires (N 14, 19) indicate that terminology and parental comprehension overall may be problematic. According to the nurses, language barriers appear to be a significant problem in communication (N 1, 6, 9, 12, 14, 22, 23). In addition, nurses (N 4, 11, 18) indicate that parents may be too sensitive and are unwilling to communicate with the nurses. It is seen that the quality of the relationship with the nursing personnel is one of the factors that either facilitates or constrains parents coping (Lasiuk et al., 2013).

In contrast, **information and education provision** to parents (VP 1, 2, 4, 6) contributes to parental well-being. For example, this mother appreciated information from the doctor: *"she would come to me and she would tell me that everything's fine with the breastmilk and he's doing fine, he's now on room air, and she'd come to me and she'd, ja* [yes], *just make me relax a little bit more"* (VP 4). Education is also important for mothers: *"they really taught me, I mean she was my first baby I did not know how to actually* [breastfeed]" (VP 2). Another mother explains: *"she said 'ok we going to bath them for the first time', so she told me what to bring, what time to be there. She said bring your camera, she was lovely. She helped me, she bathed them for the first time. That was lovely. She was the only one who really took an interest in explaining how to bath them"* (VP 1). Five nurses (N 6, 7, 17, 18, 23) indicated that their role is to provide education, advice, and help parents take care of their infant. Factors identified in the literature to satisfy parental needs involve: emotional support by friendly, flexible staff; parent empowerment through parental involvement in care; a welcoming, calm environment, and parent education (Cleveland, 2008; Stacey et al., 2015). A positive effect of information and education provision is seen by this mother's comment: *"They* [the grandparents] *had also never seen anything so small in their life, pipes and everything, but by then I could explain to them. This is the feeding tube, this is for this, this is for that, I could explain everything to them. So, then it was better and I had accepted it, so it wasn't so traumatic for me"* (VP 1). Education empowers parents and thus can be a positive element in developing well-being.

A further need related to information is during the discharge process. Three mothers (VP 1, 3, 5) were unhappy with the discharge process due to not being provided with information regarding possible illnesses to look out for (VP 1), information on medicines for their infant and themselves (VP 1, 5) as well as a course in CPR (VP 1). There was also no forewarning in terms of date and time of discharge, and thus sometimes no time to prepare logistics: *"with *** he was in for two weeks and everything was dire and frantic and all the rest and the next things they say ok you can take him home and we literally had to go and fetch him. We* [are] *living in a strange town, nothing at home, everything is at home, living in a B&B and suddenly here is your child"* (VP 5).

4.2.3.5 Matters relating specifically to the mother.

The fifth theme in the NICU phase is with regard to matters relating to the mother specifically. A risk factor affecting the mothers themselves was experiencing a sense of doing a **'juggling act'** (VP 1, 5, 6). Coping with all of the demands of visiting the infant, expressing breastmilk, doing KMC, self-care, and balancing family life were stressful. An example of this is described by one mother: *"It was tiring because every now and then I would have to go home and see things are going fine at home and come back to the hospital cos* [because] *I got a baby there and* [have to] *be there to express* [breastmilk] *and make sure I am eating right, and it was just difficult juggling all of that"* (VP 6); *"a juggling scenario going up and down to the hospital, feeding this one, feeding that one"* (VP 5). A factor relating to the juggling act which may act as being protective to well-being was that some mothers (VP 1, 2, 6) **stayed at the hospital**: *"hospital gave me a flat within the premises so at least I was there full time, I wasn't at home, but it was tiring"* (VP 6); *"I had a choice of leaving her and coming home and going there on a regular base, but I chose not to, I was there until the last day"* (VP 2); and *"ja* [yes] *so for a week I actually lived at the hospital. It was actually easier"* (VP 1). This factor however, may exacerbate the sense of confinement.

As mentioned before, the three focus areas of stress in the NICU according to the PSS: NICU are: sights and sounds of the NICU, the infant's appearance and parental role alteration. Overall, comparing mothers' and fathers' scores on these three focus areas (figure 4.5) it is evident that mothers generally appear to experience the NICU as more stressful than fathers. It must be noted however, that the scores do not indicate statistical significance but are only based on subjective differences. The highest form of stress for both the mothers and fathers is the altered parental role. The sights and sounds of the NICU are the least stressful factor for both the mothers and fathers.

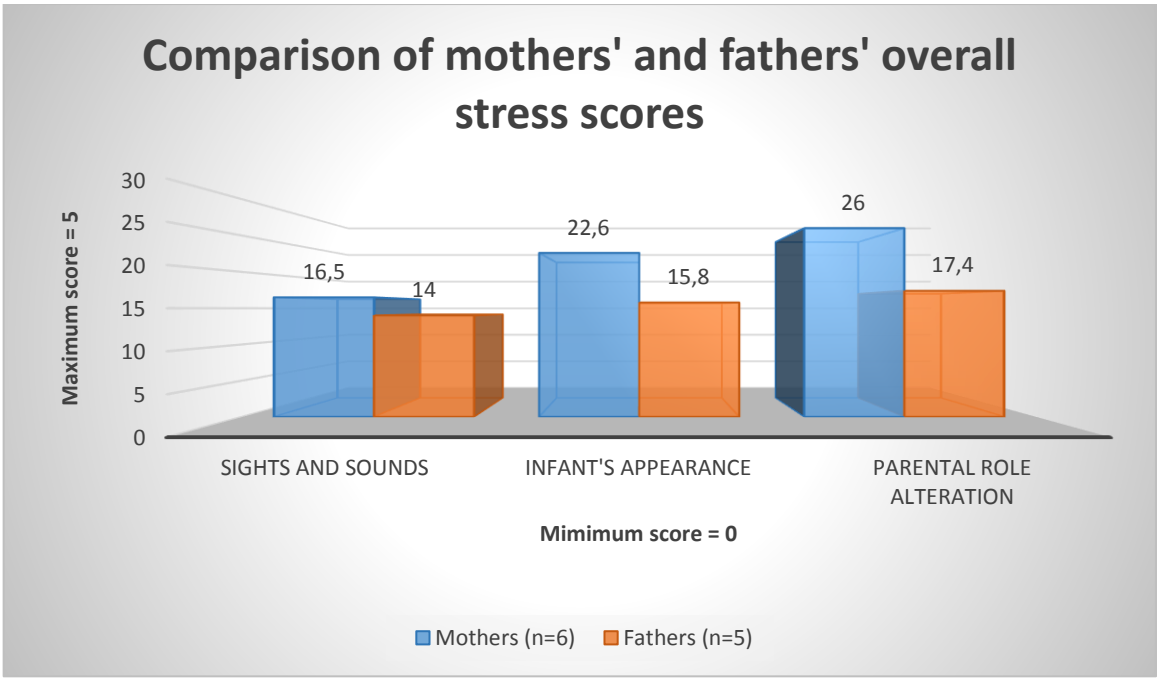


Figure 4.5: Comparison of mothers' and fathers' overall stress scores

4.2.4 Home-coming of Infant

Going home with a preterm infant is a significant milestone. Nine themes related to this phase include: (1) important know-how; (2) lonely confinement to prevent illness; (3) maternal depression; (4) difficult feeding; (5) daily challenges and need for assistance; (6) peculiarities of the infant and desire for normality; and (7) misunderstanding by others.

4.2.4.1 Important know-how.

The lack of satisfaction with the discharge process puts parents further at risk as going home is particularly stressful for parents. Two mothers (VP 5, 6) describe their experiences: *"So one moment you have a zillion doctors and nurse scurrying around your baby and the next minute they are in the room with you and now what do I do. Now you've got an underdeveloped child that is battling to suck anything and is not like a normal baby that has got substance to it. You are already dealing with all that and then coming off the back of having all this professional help, the next thing you are alone with them within two hours"* (VP 5); *"anxious, I was thinking how do I take care of this baby, I don't know how, because all the nurses are now not there"* (VP 6).The literature indicates that care of the preterm infant at home is dominated by constant fear for the parents as they fear that something problematic will happen to the infant due to the fragile nature and health condition of the infant, and that this fear and anxiety stems from a perception of being inadequately prepared for discharge and having a lack of knowledge (Adama et al., 2016; Murdoch & Franck, 2012).

4.2.4.2 Lonely confinement to prevent illness.

In addition to fears and anxieties of knowing how to care for the preterm infant, parents (VP 1, 4, 5) were vigilant and once again experienced a sense of confinement due to the risk of illness: *"for the first three weeks he was here, we didn't go anywhere and anybody that wanted to come and see him had to come and see him here"* (VP 4); *"I don't take them anywhere…I can't risk it"* (VP 1). It is seen that mothers do everything to protect their infants from illness (Griffin & Pickler, 2011), even neglecting themselves (Flacking et al., 2007).

In addition to staying at home, and being vigilant to avoid illness, parents (VP 3,4,5) undertake further measures to avoid illness: "*I didn't want lots of people holding them and breathing in their faces and I said to them here is the sterilizer bottle, wash your hands and all that kind of thing and they would think you are paranoid"* (VP 5); *"I have my Degerm* [alcohol based spray] *and I have my mask and if you come and visit me you will wash your hands and be degermed up, until they was six months old"* (VP 3). Parents fear of their infant getting ill is rooted in the fear for the lives (VP 3, 4, 6) of their infants: *"every time that he turned or he'd make a sound or whatever I would be up, and be there and wanting to know, is he breathing, is he fine, is he not lying flat on his face and like suffocate himself, so I was constantly in a panic, and I think I only relaxed I think, two or three months later"* (VP 6). However, unfortunately, preterm infants are prone to illness. Preterm infants are particularly vulnerable to life-threatening infections, with the susceptibility to infection maintained into childhood (Strunk, Currie, Richmond, Simmer, & Burgner, 2011). According to Sharma, Jen, Butler, and Lavoie (2012), preterm infants are among the most vulnerable age group for morbidity and mortality due to infections.

Parents (VP 1, 3, 6) have had their infants re-admitted to hospital due to illness. In addition to readmission to hospital, preterm infants (VP 1, 3, 6) sometimes have to repeatedly make use of health services and interventions: *"Whenever he has a temperature, there is tonsillitis. So then we decided on a tonsillectomy and he has been much better since. So we haven't been to the hospital every five weeks because of that"* (VP 6); *"we had physiotherapy going for, he was I think 18 months"* (VP 6); *"it was like a roller coaster ride because when he came home the *** September he came home with a colostomy and with oxygen and you had all this memories of when is he going to desaturate again. So I was the whole time frightened"* (VP 3).

4.2.4.3 Maternal depression.

At the same time, there is the possibility of mothers experiencing depression. Two mothers in this study (VP 1, 5) said that they suffered from depression: *"They* [the infants] *came home, then the depression kicked in. Everything was a mission. Just to get out of bed in the morning and feed my daughter* [sibling] *was like climbing Table Mountain. It's a horrible feeling"* (VP 1); *"I know it makes me sound like a terrible mother, I mean I love my boys dearly now, I can't say the same for those*

months but um, you pick up that baby and you just want to smash them against the wall. You know that is the reality of it. That kind of excessive thing is not a joke. You don't know what the problem is and I think many mothers go through this and just don't say it. You don't know what the end result of the whole neonatal experience is and what isn't. It is quite difficult to separate" (VP 5).

The literature confirms the words of VP 5 ("sound like a terrible mother") in that there is a stigma attached to an inability to cope and being a bad mother, and therefore a barrier is created to seeking help (McCarthy & McMahon, 2008). Furthermore, although mothers realised that something was wrong, they were unable to distinguish between normal levels of stress and stress that warrants help (McCarthy & McMahon, 2008). In a study conducted by Pritchard et al. (2012), maternal postnatal depression (PND) is a high maternal risk affecting up to 40% of mothers. In addition, it was shown that mothers who experienced PND at six weeks after birth were more likely to have parenting stress in the first year after discharge (Pritchard et al., 2012). Stress of parenting an infant at home aggravates the present state, or possible state, of depression. Interestingly, only two nurses (N 2, 23) indicated that their role was to look out for post-natal depression in mothers. According to Hall (2015), maternal depression can lead to worse developmental outcomes for preterm infants than full-term infants.

4.2.4.4 Difficult feeding.

Another significant factor for all the mothers (VP 1, 2, 3, 4, 5, 6) relates to feeding their infant in the NICU and at home. For some mothers feeding is a problem and for others feeding is a more positive experience. As mentioned, feeding absorbs more time and emotional energy than any other activity (Madden, 2000). Many preterm infants are not capable of breastfeeding from birth due to immaturity and/or illness (Maastrup et al., 2014) however, breastmilk is regarded as the ideal feed for preterm infants (Meier et al., 2010; Morales & Schanler, 2007). Most mothers (VP 1, 3, 4, 5, 6) in this study were forced to express while their infant was in the NICU: *"I knew and having read up about it as well how very important it was to keep it going even though they weren't sucking off me directly"* (VP 5). However, some mothers were not able to produce enough milk. In this case, mothers needed to choose between formula or applying for milk from the milk bank.

On the positive side, some mothers (VP 2, 4) were able to breastfeed: *"at first I expressed, and then after four weeks I started breastfeeding him. Ja* [Yes]. *He was able to suck as well, and they told us that on 34 weeks, ja [yes] 35 weeks they start to develop that sucking motion"* (VP4); *"*[I spent] *the entire day* [in NICU], *I had to breast feed her every 2 hours"* (VP 2).

When at home, feeding becomes very difficult for most of the mothers (VP 1, 3, 4, 5) as explained by the following comments*: "I started running out of milk. I think it was just stress. I had to put them on formula. So they started getting cramps. So they were niggly all night, for a month I didn't sleep…they were drinking painfully slowly, they were only drinking 30 mls when they came*

home, and it used to take an hour to get that in and every three hours they had to drink" (VP 1); *"At that stage they were still on 3 hourly feeds. She was drinking very slowly so she drank an hour every feed and I mean **** [he] *was having apnea* [when infant stops breathing]*. He was turning blue with every feed so it was just a terrible time. Just a terrible, terrible time"* (VP 3); *"But now the difference is because he was born premature he struggles a lot with cramps"* (VP 4); *"they couldn't suck the way other babies could suck"* (VP 5).

Battling with feeding their preterm infant can cause mothers to feel like failures: *"very sad for me, because I wanted to* [breastfeed]…*that was the one thing that I wanted to do is to breast feed the babies. I saw what *** went through - apnea every time. And she just did not want to breast feed. Ja* [yes]*, you feel like a failure, because why can't I get it right"* (VP 3).

4.2.4.5 Daily challenges and need for assistance.

Finally when the parents are at home they expect life to go on as normal but having a preterm infant easily susceptible to illness does not always allow for this normal process to take place. Parents (VP 1, 4) needed to get a nanny instead of using a crèche to help with child-care to avoid illness: "*paediatrician told us, she told us that because he was born premature he can get sick easily, so we had to get a full time nanny*" (VP 4). Some parents needed a nanny to look after the infant(s) (VP 1, 5) so that the mothers could complete the tasks of daily living: "*so many friends of mine have* [normal babies]*…You know they pop to the shops, and pick up their children from school and put them in the car seat, and the baby falls asleep in the car, you know just normal kind of behaviour. My boys have never done that and that has never been part of our life. Everything became very like, very touch and go like, you become actually a little scared, like what are they going to do next"* (VP 5). Mothers may find the process of now having to find an acceptable nanny stressful: "*We had to find a nanny and we had to, I have to make sure that she does the same things that I want. And I think that that puts a little bit of stress on me as well"* (VP 4). In addition to these stresses, the need for a nanny has financial implications too, as one father described: *"Because we paid a deposit here at *** where we go to church, there is a crèche there, and we paid a deposit to enrol him there and then we had to ask them can we have the deposit back"* (VP 4). The literature indicates that parents' concerns over the special needs of their infant and their own care-giving abilities dictate the need for greater social and professional support (McManus & Poehlmann, 2012).

4.2.4.6 Peculiarities of preterm infants and desire for normality.

Against the backdrop of vigilance and parental fears for death and illness, preterm infants are different (VP 1, 3, 5) to their full-term counterparts. Studies of mother-preterm infant interactions indicate that preterm infants are generally more passive and less alert than full-term infants (Korja et al., 2012) and do not interact in ways parents might expect (Braun, 2011). In addition, preterm

infants are at higher risk for socio-emotional, cognitive and motor delays (Hediger, Overpeck, Ruan, & Troendle, 2002; Kato et al., 2013).

This is seen in the following comments: *"I find it very difficult that because they were prem, like my daughter, after about six weeks started kind of smiling, for four and a half months I got nothing out of these two, nothing! Like that's very difficult, looking after them all day every day, you don't even get a smile back. You know. Now they smiling, and it makes me feel so much better. They smile at me, they are starting to gurgle a little bit, getting a reaction. That wait is just so much longer and you need it so much more"* (VP 1*); "my boys were not slotting into anything and I think a lot of it had to do with the development process that they had, so I could not get them into anything I thought was normal… the process of feeding, sleeping, talking was a lot longer than what most other mothers experienced… you try implement these things you've read and seen and you suddenly realize it doesn't apply whatsoever"* (VP 5).

4.2.4.7 Misunderstanding by others.

Furthermore, parents (VP 1, 3, 4, 5) do not always receive understanding from their community and social environment: *"So they don't understand why you are so cautious of him getting sick or, why you have to wash your hands so properly before you touch him"* (VP 4); *"none of my friends understand"* (VP 1); *"they have no concept of certainly* [do not understand] *of what it's like to have twins and certainly what it's like to have premature babies that are underdeveloped"* (VP 5) and *"people out there is not disability friendly"* (VP 3).

4.2.5 General Non-phase Specific Factors

Overall, it is important to note that besides the above mentioned factors in each phase of delivering and parenting a preterm infant, certain factors in this study are not phase specific and appear in more than one particular phase suggesting that they are major sources of stress for parents. These are: bonding; fear of the infant's death; changes in the self; maternal guilt; and trauma.

Bonding is a significant issue for mothers (VP 1, 3, 4, 5, 6) as they fear bonding cannot take place, firstly due to the separation at birth and, secondly, due to the infant being in the NICU. This is seen in the following comments regarding separation at birth: *"Birth itself was traumatic as well because they just showed him to me and then they took him away, and you didn't have that time to bond with him. Ja* [Yes]. *And I felt verlies* [loss], *because I couldn't spend three days with him like all the other mothers do"* (VP 4); *"There wasn't bonding. I couldn't see her or hold her"* (VP 3). Mothers experience distress and feelings of loss and grief over their hoped-for full-term pregnancy (Yaari et al., 2015). Separations at birth interfere with the maternal-infant bonding relationship (Roller, 2005) and, according to Mercer (2006), the physical contact after birth is crucial for a bond to develop into a secure attachment relationship between parents and their infants. It is also shown that skin-to-skin

contact from birth maintains the stability of preterm infants during transition to extra-uterine life (Chi Luong et al., 2015).

Bonding is also affected during hospitalisation in the NICU: *"it's difficult to bond obviously, you know when they are in ICU. You hold them a little bit but, it's not as much as you would at home"* (VP 1); *"The concept of bonding with the baby is not there at all. They were like complete little aliens…You don't feel like you've had a child to start with, besides all the aches and pains, you know, because you haven't had any bonding with it"* (VP 5). The NICU contributes to impaired bonding, with its tubes, patches, noises, bright lights, incubators and painful procedures that reduce the quality and quantity of cues and sensitivity to cues from the mother and infant (Browne & White, 2011). In addition, incubators are physical barriers to comforting touch and cause separation between the infants and parents (Kommers, Oei, Chen, Feijs, & Bambang Oetomo, 2015). Studies of KMC, have indicated that skin-to-skin care can improve a mother's bonding and her feeling of being needed and comfortable with her infant (Nyqvist et al., 2010; Thomas, 2013). Interestingly only one nurse (N 1) indicated that her role is to facilitate bonding between parent and infant.

When at home, bonding may still pose a challenge to mothers as preterm infants' cues are scarce and often unrecognisable due to their physical immaturity (Feldman, 2007). Mothers indicate that it takes time to bond with their infant at home: *"taken me a long time, long, long time to bond with my boys"* (VP 5); *"I think it is still in the process"* (VP 1); *"we wanted two or three days just alone with him, before all the family, to bond, to appreciate him, and find our feet"* (VP 4). The literature has confirmed that due to the preterm birth and long hospitalisations, fathers and mothers felt that it takes a long time to feel a bond with their infant (Flacking et al., 2007; Lindberg et al., 2008).

The majority of parents (VP 1, 3, 4, 6) experienced some form of **fear relating to the survival** of their infant. These fears can start at the time of birth: *"in theatre, that was very emotional because you don't know if they going to live"* (VP 1). These fears continue to exist in the NICU: *"I was picturing buying one of those baby little coffins"* (VP 1); *"I went through the motions that he is not going to make it. I was planning his funeral in my head. You know I thought* [my husband] *will have to, he will have to carry *** coffin to his grave, you know I was thinking of all of those things. It was actually very bad because while he was oscillated* [high frequency ventilator] *he will still desaturate too, so that was a terrible time for me"* (VP 3) and *"you don't even know what you want to ask because you don't even know what is going to happen, is he going to live?"* (VP 6). And when at home, these fears persist: *"The first night we did not sleep at all because we were listening to every little sound and we were scared maybe he is going to stop breathing or something like that, so we didn't sleep"* (VP 4) and *"I couldn't sleep, I remember I just wanted to sit next to him and listen to him breathe, and make sure that he's alive, the whole time"* (VP 6).

Having a preterm infant, going through the hospitalisation process, **changes the self**: *"we are definitely affected by it"* (VP 4) and *"coming so close to losing a child. I think it really does change you forever. I don't think I will ever be the same person again"* (VP 1). Lasiuk et al. (2013) indicate that preterm birth disrupts parents' fundamental assumptions about their selves, the world, and their place in it.

Mothers (VP 1, 4, 5) **blame themselves** for the early birth: *"I thought I'd done something to cause them to come early, which I really think I did"* (VP 1); *"I felt like it was my fault because I couldn't keep him inside, so I'm the failure, that's what it felt like"* (VP 4); and *"everything was dire, because you know, you know you get to the point when you think, what have I done"* (VP 5). Parents (VP 2, 4) do not want to have to go through the same experience again and wish ultimately for normality in their lives (VP 1, 4). The literature indicates that the stress of preterm birth is heightened by the feelings of guilt and inadequacy felt by mothers (Lasiuk et al., 2013).

Parents (VP 3, 4, 5) are **traumatised** by the incident and are affected by it months later: *"it is still traumatic; it is still traumatic, if I think about it I still get emotional"* (VP 4 mother and father). Due to lack of understanding from others, parents feel isolated in their experiences: *"having a prem is such a lonely path, such a lonely path"* (VP 3). The mostly negative experiences of preterm birth have been cited as being extremely stressful and traumatic for parents (Elklit et al., 2007; Forcada-Guex et al., 2011; Jotzo & Poets, 2005; Stacey et al., 2015). It is shown that nursing staff can help parents cope with the hospitalisation of their infant.

4.3 Findings Relating to Nursing Staff Specifically

With the use of self-developed questionnaires, it was requested that the nurses give feedback regarding their point of view and expectations of the parents and the nurses' and parents' roles. In the literature study, it is indicated that interaction and communication with medical staff appears to be central and influential in parental well-being. The nursing personnel and parents have various roles that need to be fulfilled, and the nursing personnel also have expectations of parents. These roles are separately explored with regard to the infant, nursing personnel themselves and logistical matters. Thereafter, FCC and the nurse's concept and training thereof will be discussed.

4.3.1 Parental Role and Nurses' Expectations in the NICU

With regards to the preterm infant, the majority of nurses (N 1, 2, 3, 5, 6, 7, 8, 10, 11, 20, 21, 22, 23) indicated that the parents must be involved with basic infant care where possible. Fourteen nurses (N 1, 2, 3, 7, 8, 9, 10, 12, 17, 18, 19, 20, 22, 23) indicated that parents must touch their infant and attempt KC. Nurses expect parents to initiate bonding (N 3, 6, 8, 12, 20). In addition, parents must

provide love to the infant (N 7, 8, 12), support their infant emotionally (N 2, 11), and visit often (N 2, 3, 4, 7, 10, 12, 22).

Relating to the nurses themselves, they expressed that they would like parents to: initiate conversations regarding their infant with them (N 1, 4, 5, 6); trust them (N 5, 15, 16, 18, 21); ask questions (N 23); and be honest with the nursing staff by providing correct information (N 3, 5, 18).

With regard to the parents, nurses expect parents to verbalize their needs, concerns and questions (N 7, 8, 10, 21, 22), co-operate, work with and listen to the staff (N 14, 15, 16, 19), and wash hands on entry to ensure optimal infection control (N 12, 17, 18).

Logistically, the parent's role is to provide breastmilk (N 2, 3, 7, 8, 9, 10, 15, 18, 22, 23), provide the necessities for the infant such as nappies, wipes, and toiletries (N 3, 4, 9, 12, 17, 21, 22), and adhere to the rules of the NICU (N 2, 17, 18).

4.3.2 Family-centred care (FCC)

In the questionnaire, the researcher asked the nurses what they understand FCC to mean as well as the benefits and necessity thereof, and if training had been received. The reason for researching this particular aspect is to determine the degree and extent of FCC use in the three hospitals. FCC appears to be gaining momentum in countries such as Australia, Canada, the United Kingdom, Japan, the United States of America (Skene, Gerrish, Price, Pilling, & Bayliss, 2016) and many European countries. However, it is seen that there is a variation within and between countries with regard to the intensity and means of involvement and the role played by each of the parents (Pallás-Alonso et al., 2012).

The definition of FCC is understood by thirteen nurses (N 1, 2, 3, 5, 6, 7, 13, 14, 16, 18, 21, 22, 23) as including the whole family with the care and visitation of the preterm infant. The whole family includes siblings and grandparents. Of these thirteen nurses, ten (N 1, 2, 3, 5, 6, 7, 13, 21, 22, 23) believe it is a valuable aspect of neonatal care. Interestingly, one nurses (N 6) disagreed with the value thereof (without motivation why) and two nurses did not answer the question (N 14, 16). The benefits according to the thirteen nurses, for use of FCC include:

- Earlier and better bonding between the parents and preterm infant
- Easing discharge home
- Detection of social problems
- More support for the mother
- Improved confidence in caring for infant
- Reducing stress and anxiety in parents
- Helps family feel included and not ostracised

Seven nurses (N 4, 5, 6, 13, 14, 16, 21) did indicate that undertaking FCC is risky due to the possibility of infection rates increasing. Three nurses indicated they had received training in the use of FCC. In consultations with two nurses, the researcher discovered that there is no formal training in FCC in SA but that the topic may be discussed in one of the other subjects studied. It is the opinion of the researcher that FCC is understood exactly as care involving the family, but not according to the FCC core concepts laid out by the Institute of Patient- and Family-Centred Care (2016).

4.4 Parental Needs for Support

In the literature and in this study with VP, it is seen that parents experience increased levels of stress. Stress can be characterised by a combination of negative physical and emotional effects (Busse, Stromgren, Thorngate, & Thomas, 2013). As parenting distress has been shown to have implications for adverse long-term outcomes in the infant (Arnold et al., 2013; Sawyer et al., 2013), it has been suggested that intervention during the time parents are still in the NICU may be beneficial (Shaw et al., 2013). In the following section, the findings of the VP and nurses' opinions regarding parental needs for support are discussed. Aspects from these comments will be added to the support intervention where feasible.

4.4.1 Support Needs According to the VP

During the veteran parent interviews, the researcher questioned parents about if they needed further support. All the mothers and two fathers interviewed indicated that they needed further support. This is shown by the following comments: *"I really think a support system would be great"* (VP 6); *"I would have* [liked some support], *just to, you know it is just so scary, it's just so traumatic, you've got so many questions"* (VP 1).

With regards to when the support is needed, there are diverse answers. Two parents (VP 1, 2) indicate that time may be a constraint: *"depends on, whether there would have been time. Because really the time that you had was just with your child, to feed your child, and to be there when they bath your child, so if there was time for that yes, I think that* [support] *would help"* (VP 2); *"there's just no time. The priority is your baby"* (VP 1). One mother (VP 3) indicated that support should be given during the hospital stay *"being there the first 48 hours"* and having *"weekly follow ups"* as well as after discharge in the form of a support group: *"Just a mom of a prem. Just to say yes, I also went through that feelings, and I also was scared, so also felt that like have a support group just to say what bottles worked for you, and what worked for you."* VP 1 did indicate that she would have liked information given to her early in her infant's stay in the NICU: *"I think especially when you walk in there for first time, someone to say to you ok, this is what this is, and this this this. Maybe not the first time, maybe when you have gotten over your little break down."*

Reasons given for the need for further support include, among others; helping with the many questions parents have, help in understanding their feelings, catharsis, and sharing experiences with others who have understanding of the experience. For example: *"I find it soothing to talk about it"* (VP 1); *"when you know that there are people here to help to listen to help you with any questions that you might have"* (VP 6); and *"someone could explain that to you, um someone that you could relate with on a personal entity, um, I think would be a lot, it would fill in a lot of gaps and if that person could actually also talk to the nurses, listen this is how they feeling"* (VP 5).

Parents (VP 1, 2, 3, 5, 6) indicated various people who could help or offer further support. The majority of mothers (VP 1, 2, 3, 6) indicated that another mother who has experienced preterm birth and hospitalisation would be the ideal person*: "I think that there are mothers who have gone through, walked the same road"* (VP 6); *"I think if there was some kind of programme, you know someone who can just walk the path with you, you know some kind of programme like that, I think it would been, maybe somebody who has been through it herself"* (VP 3); and *"I would love to have spoken to someone who had been through it before and could tell me this, this, and this"* (VP 1). VP 2 would have liked to meet or know how to meet someone whose child had the same condition as theirs. One mother (VP 6) mentioned that having no knowledge of the process, having someone who has been through it can help: *"sometimes you don't even know what to ask, just to have someone who knows something and to comfort you and to tell you something that you need to know, that you don't even know you need to know, it does help*." VP 5 indicated she needed someone who could communicate, connect with on a personal level and act as an intermediary: *"I think if someone were there to interpret the words."* Peer-to-peer support from parents who have been through the same process is confirmed in the literature to be a "unique and legitimate" form of support (Hall, Ryan, Beatty, & Grubbs, 2015).

4.4.2 Support Needs According to Nursing Professionals

In the self-developed questionnaire given to the nurses, one of the questions pertained to their impressions regarding the contents of a support intervention for parents during the various phases namely: before birth; just after birth; first visit to the NICU; first few days in the NICU; time in NICU; before discharge; and when at home.

According to eleven nurses (N 1, 3, 5, 6, 9, 10, 13, 15, 16, 17, 20), parents should be informed of what to expect in the NICU before the birth of a preterm infant. Some nurses (N 1, 2, 3, 8, 9, 22) believe that a tour of the NICU should be given to the parents if possible. Several nurses believe that information should be given to parents on various issues such as preterm infant's needs, conditions, and possible obstacles (N 10, 15, 19, 23). Three nurses (N 2, 13, 14) mentioned that the expected course of events can be discussed with the parents.

Nurses (N 2, 5, 13, 19, 23) stated that just after the birth of the preterm infant, parents must be given information regarding their infant's condition. Furthermore, nurses (N 3, 5, 7, 8, 17, 19, 22) indicated that parents must be given emotional support by means of chatting to put them at ease and to reassure them about the safety of their infant. Fenwick, Barclay, and Schmied (2001) found that ordinary 'chatting' acts as a powerful tool through which positive interactions are initiated, maintained and enhanced and which can be used to assist parents in gaining confidence and becoming connected to their infants. One nurse (N 4) mentioned that the mother should be given the option of psychological support. Only three nurses (N 9, 13, 22) mentioned that parents must be orientated with regard to the monitors. Nurses (N 9, 13, 15, 16, 22) said that parents must be informed about what is being done to their infant and why.

Regarding the first visit to the NICU, nurses (N 1, 2, 14, 17) further indicated that parents must receive basic explanations of the rules and routines of the unit and what to expect (N 6). Further explanations include information with regard to the infant's condition (N 1, 5, 7), interventions, and the treatment the infant is receiving (N 1, 2, 16, 19). The use of monitors and equipment should also be explained to parents (N 2, 3, 5, 7, 8, 9, 23). Nurses (N 3, 9, 19, 20, 22) stated that parents must be given emotional support. It is during this first visit that nurses (N 5, 13, 14) believe information must be provided to mothers relating to the value of breastmilk, storing thereof, and how to stimulate production. Three nurses (N 3, 7, 22) state that the parent's questions must be answered.

Furthermore, nurses indicated that during the first few days at the NICU, education about baby care should begin and, with it, attempts to involve the parents (N 1, 3, 4, 7). Breastfeeding information and information pertaining to breastmilk should be discussed (N 2, 5, 6, 9, 13). Further emotional support must be provided (N 3, 12, 14, 22, 23) and also a discussion of parental fears (N 6). Nurses (N 5, 20) recommended the initiation of bonding, possibly using KMC (N 10). Parents must be informed on the progress of their infant (N 9, 15, 16, 22, 23). Only one nurse stated that parents should be made to feel needed (N 7). Interestingly, one nurse (N 21) stated that Google should be prohibited as information provided may not relate to the parents particular preterm infant and may not be medically sound.

NICU care for preterm infants is often for long periods of time, and therefore a number of nurses (N 2, 3, 6, 7, 8, 9, 12, 14, 22) recommended emotional support. Some mentioned making use of support companions (N 6), counselling (N 12), and encouraging family support (N 22). Continued information should be given to parents regarding their infant's condition and progress (N 2, 9, 13, 16). Education on caring for the infant (N 3, 7, 10) and encouraging parental involvement (N 3, 20) should take place. Interestingly, only one nurse (N 17) stated that the journey of neonatal care and what to expect still, should be discussed at this stage.

Nurses (N 2, 5, 6, 10, 11, 12, 16, 17, 21) recommended that information must be provided to parents on routine home care before the infant is discharged from the NICU. Short courses on CPR can be given (N 2, 7, 12, 14, 17, 21). Three nurses (N 3, 7, 10) indicated that parents should be familiar with caring for their infant by the time of discharge. Further information to be provided to parents before discharge involves the use of prescribed medication, follow-ups, and immunisations (N 8, 9, 10, 13, 16, 19). Three nurses (N 1, 2, 10) indicated parents must be informed of common childhood ailments. Only one nurse stated that the following information should be given to parents at this stage: what to do in an emergency (N 5); contact number of doctor (N 19); and contact numbers of nearest clinics (N 4). In addition only two nurses indicated that parents must be informed on what to expect and the way forward (N 15, 17).

Nurses (N 3, 4, 7, 15, 16, 21) indicated that parents, when at home, must be reassured that they can contact the NICU to ask questions. Some nurses recommend that telephone numbers of who parents can contact for help are given (N 14, 15, 20).

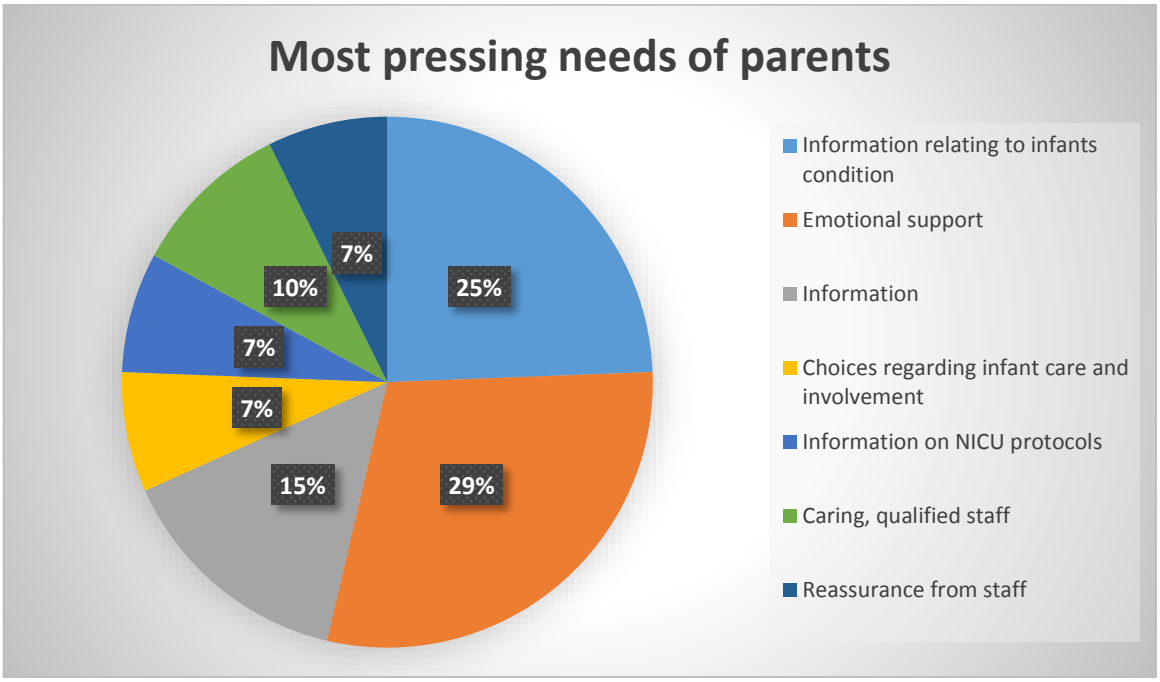


Figure 4.6: Most pressing needs of parents according to the nurses

The following nurses discussed parents' most pressing needs:

- Information relating to the infant's condition (N 1, 3, 4, 6, 9, 12, 13, 14, 20, 21);
- Emotional support (N 2, 3, 5, 6, 10, 12, 14, 17, 18, 20, 21, 22)
- Information (N 8, 10, 13, 14, 18, 19) [Without mention of what type of information]
- Be offered, within reason, choices regarding infant care and to be involved (N 1, 12, 13)

- Information on NICU protocols (Milk provision, visitors and visiting hours) (N 5, 9, 22)
- Use of caring, qualified staff (N 6, 7, 9, 15) and reassurance that staff are doing what is best for their infant (N 7, 11, 21).

However, nurses indicate that these needs are often not met due to time constraints (N 4, 5, 6, 7, 10, 12, 17, 18, 19), staff shortages (N 6, 7, 9, 11, 15, 17, 21, 23), and lack of understanding due to language barriers and cultural differences (N 15, 21).

4.5 Identified Functional Elements

In designing an intervention, information gained in the retrieval stage needs to be converted into basic action constructs so as to formulate more specific situational intervention concepts (Mullen, 1994). Thus, the insights gained through the veteran parents and nursing staff can be utilised to identify functional elements in the intervention. Various authors use different terminology in describing the same concept: Fawcett et al. (1994) mention that procedural elements need to be identified for use in the intervention; Thomas (1994) mentions intervention components; and Mullen (1994) discusses intervention elements. Thomas (1984 as cited in Mullen, 1994) states that intervention elements may be fixed or need to be designed. For example, fixed elements may be the NICU context variables, whereas elements that need to be designed are the support techniques to be used by the researcher. In this study, functional elements will be factors that can help foster well-being in parents, identified in the findings from the veteran parents, nursing professionals, and the literature. Intervention elements will be the tools and techniques used in the support intervention.

In sum, the functional elements identified with the veteran parents are as follows:

- Answering the parents questions, where possible;
- Factor in time issues with setting up appointments;
- Make provision for parents to express and understand their feelings;
- Sharing experiences with a mother who has been through the same process, often called peer counsellors;
- Provide information on the general process; and
- Act as an intermediary between the medical staff and parent, as well as ‘interpret’ medical jargon used.

Nursing professionals mentioned the factors listed in the table below as possible content for a support intervention and which can be regarded as functional elements (table 4.5). Factors are listed according to various times in the process of birth, admission to the NICU, discharge and going home:

Table 4.5:

Content for support intervention according to nurses

Phase	Possible content for support intervention
Before birth	• What to expect in the NICU • Tour of the NICU • Information on infant's needs, conditions and possible obstacles • Provision of information on expected course of events
Just after birth	• Information on the infant's condition • Reassurance of parents about the safety of their infant • Orientation regarding the use of various monitors used on their infant • Information regarding medical procedures and reasons for use
First visit to the NICU	• Basic explanations given to parents of rules and routines of the NICU • Use of monitors and equipment be explained to the parents • Emotional support be provided • Answer parents questions • Information regarding the value of breastmilk, storage thereof and how to stimulate production, must be discussed
First few days in the NICU	• Education about infant care and encouragement of parent involvement • Breastfeeding information • Further emotional support • Discussion of parental fears • Initiation of bonding such as the use of KMC • Information on progress of the infant
During the NICU stay	• Emotional support • Use of support companions (peer counsellors), counselling • Encouraging family support • Observing for post-natal depression • Information on infant's condition and progress • Education on caring and encouragement of parental involvement
Before discharge	• Information on routine home care • CPR training • Information on prescribed medication, follow-ups and immunisations • Information on common childhood ailments • Information on what to do in an emergency • Information on what to expect • Contact telephone numbers given timeously as discharge can be a very quick process

When at home	• Reassurance that parents can contact the NICU regarding any questions • Contact telephone numbers and who parents can contact for help

These identified functional elements from the veteran parents and nursing professionals that are realisable by the researcher will be included in the design of the support intervention, discussed in chapter five. Cognisance needs to be taken that certain factors to help parents cope need to be completed by the nursing staff and medical doctor. These include providing information and regular feedback on the preterm infant's health condition and reasons for certain medical measures undertaken with the infant.

4.6 Conclusion

This chapter formed part of the information gathering and synthesis phase of the intervention research framework. Themes were generated from VP experiences with regard to each phase of the healthcare journey, beginning from before birth of the preterm infant to going home. It can be seen that the delivery of a preterm infant may be caused by an initial high-risk pregnancy and/or the experience of problems during the pregnancy. Problems in pregnancy often result in repeated hospitalisation of the mother, including bed rest. The preterm birth of the infant may be traumatic or provide a sense of relief for the parents. However, separation of the mother and the preterm infant is distressing. Due to the preterm infant's dire health status, the infant is taken to the NICU. The NICU is characterised by various risk and protective factors affecting parental well-being, such as: the context of the NICU; the appearance and health of the preterm infant; relationships; needs for information, education, and communication; and matters relating to the mother specifically. When the infant is discharged from the NICU and goes home, parents experience needs related to coping with care-taking, feeding, depression, and mother-infant interaction. Furthermore, the mother's behaviour relating to her infant leads to her feeling unsupported and misunderstood by friends and the community in general. Factors that appear in more than one phase of the healthcare journey include fear of not bonding with the infant, fear of the infant's death and the mother feeling guilty for the preterm delivery. The preterm birth results in trauma and a changed sense of self. The need for support was expressed by the VP. Nursing professional's added value by confirming the need for support for parents. In addition, nurses indicated their impressions of the type of support needed during each phase. A support intervention is designed to help parents cope with the preterm birth and NICU admission, and this will be expanded on in the next chapter.

CHAPTER 5

DESIGN OF INTERVENTION PROGRAMME

As outlined in previous chapters, parents face many stresses relating to the preterm birth and hospitalisation of their preterm infant in an NICU. Stressors include the NICU environment, technology, appearance of the infant, staff-parent interactions and the loss of parental role (Cano Giménez & Sánchez-Luna, 2015; Carter et al., 2007). According to Hall (2015) and Evans et al. (2012), the preterm birth and stress result in mothers being less able to form secure attachments with their preterm infants. In addition, the psychosocial factors of stress, anxiety and depression influence maternal sensitivity and responsiveness which ultimately affects child developmental outcomes (Field, 2010; Huhtala et al., 2012). The literature thus indicates that parental psychological well-being is of importance as it may impact the long-term development of preterm children (Huhtala et al., 2014; Hall, 2015).

In this the third phase of the D&D phase model (Rothman & Thomas, 1994) of the intervention research framework followed in this study, an intervention was developed and this will be described in this chapter. Firstly, literature regarding approaches to intervention and elements of successful programmes used internationally will be discussed. Thereafter, an outline of a support intervention to be used with parents of preterm infants in an NICU, will be provided. The findings from the nurses' questionnaires and veteran parents (chapter four), were included into the design of the support intervention as further crucial content.

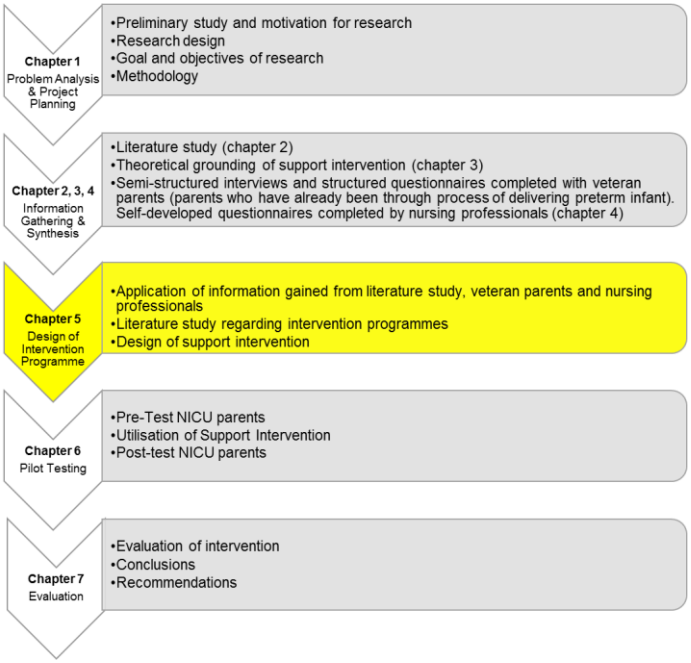


Figure 5.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

5.1 Current Approaches of Supportive Intervention Used in NICU'S

Family-Centred Care (FCC) can be regarded as a philosophy of care. It is seen, however, that some authors discuss developmental care, family-centred developmental care (FCDC) and family-centred care interchangeably. According to the researcher, there are similar tenets between FCC and FCDC such as the inclusion of the family in care-taking while the infant is in the NICU. The researcher, however, discusses FCC and FCDC separately as FCDC appears to be more related to infant development. The benefits of following a philosophy of FCC will be expanded upon first.

5.1.1 Family-Centred Care (FCC)

Family-Centred Care (FCC) is an approach or philosophy of care that recognises, embraces and acknowledges the family when caring for a preterm infant (Holditch-Davis, Blackburn, & VandenBerg, 2003; Trajkovski, Schmied, Vickers, & Jackson, 2015). Sometimes called Patient and Family-Centred Care (PFCC), the Institute for Patient and Family Centred Care (2016) defines FCC as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families." FCC acknowledges that "emotional, social and developmental support are integral components of health care and it promotes the health and well-being of individuals and families and restores dignity and control to them" (Institute for Patient and Family Centered Care, 2016). FCC is multifaceted and is applicable in different contexts and different cultures (Finlayson et al., 2014; Maria & Dasgupta, 2016). According to the Institute of Patient- and Family-Centred Care (2016), the core concepts of FCC include the following:

Respect and dignity. Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

Information sharing. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Participation. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Collaboration. Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and programme development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

According to Gooding et al. (2011), the guiding principles of FCC in the NICU are thus:

- Respect;
- Choice;
- Flexibility;
- Communication;
- Support;
- Collaboration; and
- Empowerment.

The American Academy of Pediatrics (AAP) explains these guiding principles as follows: active listening and *respect* acknowledge racial, ethnic, cultural, and socioeconomic backgrounds and how they may be used in planning for care delivery; supporting and facilitating *choice* for the infant and family about approaches to care and support; *flexibility* can be created in policies, procedures, and practices to individualise care; *communication* can be materialised by providing on-going honest and useful information; *support* can be provided for the family throughout each stage of the child's life; *collaboration* involves working with families at multiple levels of health care so their contributions can be seen in professional education, policymaking, quality improvement initiatives, medical research and family advisory councils; and, lastly, *empowerment* means helping families recognise and build on their own strengths (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012).

The researcher incorporated these core concepts/guiding principles in the support intervention.

5.1.1.1 Parental involvement.

FCC in the NICU emphasises the involvement and inclusion of both the mothers and fathers (POPPY Steering Group, 2009). Parental involvement in the care of the infant in the NICU leads to improved outcomes for the infant; for example, FCC helps with better weight gains, shorter length of hospital stay, higher breastfeeding rates, enhanced parent-infant attachment, and improved long-term outcomes (Cooper et al., 2007; Melnyk et al., 2006). Although very preterm infants can become stressed by repeated contact and stimulation, the evidence suggests a comforting touch (from parents) does not adversely affect the infant and may result in benefits when done carefully and taking into account infant behavioural cues (Arnold et al., 2013). Family presence and involvement from the parents is essential to the health, recovery, and well-being of the infant (Lee et al., 2014).

Parental involvement also reduces parental stress, facilitates parental bonding, and improves parent-infant interactions (Melnyk et al., 2006; Newnham, Milgrom, & Skouteris, 2009;

Skene et al. 2016). As mothers get involved and learn to care for their infant, they begin to cope and reduce the stress associated with their infant being in an NICU (Rossman et al., 2015). However, parents may need a lot of reassurance in the handling, bathing and feeding of their infant (Cockcroft, 2012). FCC aims to help families cope with the experienced anxiety and aid in the promotion of maternal well-being (Cockcroft, 2012). However, no assumptions should be made regarding the parents' anxieties and nurses should not be prescriptive about how long it takes to build confidence (Cockcroft, 2012). In the study of Mianaei, Karahroudy, Rassouli, and Tafreshi (2014), it was shown that irrespective of any culture, giving early and comprehensible educational-behavioural information may have positive effects on maternal psychological condition and maternal–infant interaction. Including families also leads to more satisfied, empowered, knowledgeable, and confident parents with higher levels of psychological well-being (Gooding et al., 2011; Van Riper, 2001; Verwey, Jooste, & Arries, 2008).

5.1.1.2 Collaboration between parents and nurses.

FCC involves a partnership approach between parents and nurses for the planning, implementation and evaluation of care (Cockcroft, 2012; Saunders, Abraham, Crosby, Thomas, & Edwards, 2003). In a genuine FCC culture, institutional powers are limited and the role of the staff is altered from 'doing' and supervising to becoming a resource and facilitator (Flacking et al., 2012). It has been shown that when there is a positive, trustful nurse-mother relationship, and mothers can connect with their infant (Flacking et al., 2006; Lupton & Fenwick, 2001). In addition, when parents feel supported emotionally and have trust in their relationship with the staff, the transition from traumatised onlookers to competent, confident parents is improved (Cooper et al., 2007; Fenwick et al., 2001). Improved competence and confidence strengthens the parents' ability to make decisions regarding care and treatment (Beck, Weis, Greisen, Andersen, & Zoffmann, 2009). In the study of Trajkovski et al. (2015), mothers indicated that developing a positive rapport with the nurse helped them sleep better at night and trust the nurse with their infant.

5.1.1.3 Promotion of FCC.

To promote FCC, researchers around the world have developed an extensive range of services and activities incorporating environmental, educational, psychosocial, and behavioural factors. Some strategies include support groups, parent-to-parent support (peer support), parent education, parental participation in decision-making, parent presence and participation in care, family presence in the NICU, and discharge support (Gooding et al., 2011).

It is seen in the literature that a general consensus exists regarding the value and importance of FCC, however, research also highlights that there are difficulties in incorporating FCC into daily practice (Gooding et al., 2011). In the study by Coyne and Cowley (2006), nurses were found to experience difficulties in supporting and facilitating parental participation, while at the same

time parents struggled to identify what nurses expected from them. Parents have reported that a lack of information, poor role negotiation, and unclear instructions have hindered their desire to participate in care (Blower & Morgan, 2000). In addition, the care-taking activities of parents and nursing staff evolve throughout the hospitalisation of the infant, making delineation of roles more challenging (Trajkovski et al., 2015).

Although FCC is gaining momentum in countries such as Australia, Canada, the United Kingdom, Japan, the United States of America (Skene et al., 2016) and many European countries, it is seen that there is a variation within and between countries with regard to the intensity and means of involvement and the role played by each of the parents (Pallás-Alonso et al., 2012). Research continues to demonstrate that successful implementation of key concepts of FCC remain inconsistent (Avis & Reardon, 2008; Macdonald, Liben, Carnevale, & Cohen, 2012; Shields, Young, & McCann, 2008). Hall et al. (2015, p. 25) state that FCC is optimal but "full implementation of its principles lags far behind."

5.1.1.4 South African situation.

In SA, there is minimal literature on the development of FCC for infants (Irlam & Bruce, 2002). As mentioned in chapter 4, nurses (N 4, 5, 6, 13, 14, 16, 21) believe that undertaking FCC is risky due to the possibility of infection rates increasing.

Another important factor relating to FCC is the fact that the health care systems in the UK and USA are culturally different to SA. It is indicated that there is a need to explore a definition of FCC that is unique to the SA political and socio-cultural context (Irlam & Bruce, 2002). Therefore, it is vital that FCC takes place within each cultural group's perception of rendering family care (Irlam & Bruce, 2002). Genuine FCC, if materialised, is envisioned to satisfy different cultural group's needs.

Furthermore, cognisance needs to be taken that in SA, the term 'family' may not be the same as commonly described in the literature. According to the White Paper on Families (2013), SA has various kinds of families and thus no single definition of 'family' can be comprehensive enough to cover these various kinds of families. The most common family is the nuclear family (parents with their biological or adopted children), however, various other kinds of families exist in SA such as three-generation, absent-spouse, single parent, child-headed, siblings only, elder-only, and married couple-only families (2013).

Another factor related to implementing FCC in SA relates to the formal training of nurses in FCC. Irlam and Bruce (2002) state that there is no training for neonatal nurses on models that prioritise FCC. This is still true in 2016. There is, however evidence that nurses are becoming more family- centred in caring for preterm infants, but the level of family involvement varies in each NICU. This is in line with the literature that mentions there is a variation within and between counties with

regard to the intensity and means of involvement and the role played by each of the parents in FCC (Pallás-Alonso et al., 2012).

Overall, interventions supporting a FCC approach can help in the recovery, health and well-being of the preterm infant and family in an environment of respect, love, care and hope (Lee et al., 2014).

5.1.2 Family-Centred Developmental Care (FCDC)

According to McGrath, Samra, and Kenner (2011), FCDC takes FCC one step further. Craig et al. (2015) assert that including the parents as decision-making partners and collaborators in their infant's care has been recognised as an optimal way of caring for infants in the NICU.

Several studies have shown a link between infant stress in the NICU and corresponding changes in brain architecture (Als et al., 2004; Limperopoulos et al., 2008). According to a study conducted by Smith et al. (2011), infants exposed to increasing numbers of stressors in the NICU had regional alterations in brain structure and function as well as abnormalities in motor behaviour. Stressors include exposure to painful stimuli, disruption of sleep, excessive noise and light levels, frequent handling with medical or nursing procedures, as well as maternal separation and disrupted parenting (Newnham et al., 2009). A developmental care approach includes a range of interventions designed to minimise the negative impact of these stressors.

The Universe of Developmental Care Model (UDC) was introduced in 2008 by Gibbins, Hoath, Coughlin, Gibbins, and Franck (2008). Five core measures for developmental care included:

- Protected sleep;
- Pain and stress assessment;
- Management of activities of daily living (positioning, feeding and skin care);
- Family-centred care; and
- The healing environment (Coughlin, Gibbins, & Hoath, 2009).

The Mother and Child Care team within Philip's Healthcare adapted the five core measures in the UDC model to create an Integrative Developmental Care (IDC) Model (Altimier, 2011). According to Altimier (2011), the IDC model simplified aspects from the UDC model and a more user-friendly model with developmental principles guiding practice, was developed. The neonatal integrative developmental care model (fig 5.2) proposes seven core measures for neuroprotective FCDC, which include: the healing environment; partnering with families; positioning and handling; safeguarding sleep; minimizing stress and pain; protecting skin; and optimizing nutrition (Altimier, Kenner, & Damus, 2015). The overlapping petals of the model demonstrate the integrative nature of developmental care (Altimier & Phillips, 2013).

The healing environment is considered as a core measure including key factors that must always be considered in care (Altimier, 2011). The healing environment encompasses the physical environment and the sensory environment (Altimier & Phillips, 2013). The physical environment involves space, privacy and safety. The clinical environment, in other words, the design of the NICU, noise levels, lighting, heating, ventilation and particularly available space in which to care for infants and parents are issues crucial to FCC (Nichols, 2014). Unfortunately, not all hospitals appear to have the facilities to provide true FCC. As this is not the focus of the research, the physical environment is not discussed here.

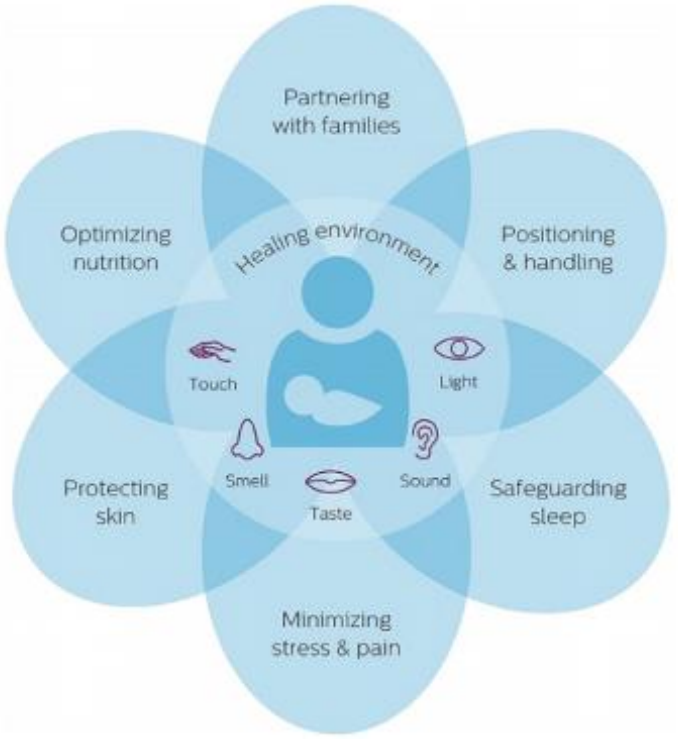


Figure 5.2: Neonatal Integrative Developmental Care Model (Philips Mother and Child Care as cited in Altimier, Kenner, & Damus, 2015)

The sensory environment encompasses temperature, touch, proprioception, smell, taste, sound, and light. The optimal environment for the preterm infant is skin-to-skin contact with a parent, known as kangaroo care. Kangaroo care meets the infant's needs for touch and supplies the needed proprioceptive sensory input to the developing brain (Altimier & Phillips, 2013). Temperature is stabilised for the infant if the infant is positioned into a flexed and contained position (Altimier, 2012). As mentioned in chapter two, KMC compared to conventional care was associated with 36% lower mortality, decreased risk of neonatal sepsis, hypothermia, hypoglycaemia, hospital readmission, and increased exclusive breastfeeding (Boundy et al., 2016). KMC also meets the

infant's important needs for warmth, stimulation, parental contact, and love (Chen et al., 2015; Johnston et al., 2011; Nyqvist et al., 2010).

With regards to the olfactory and gustatory needs of the infant, allowing the mother and infants to be together early in the NICU is essential (Altimier & Phillips, 2013). It has been shown that smell interventions could be used as alternative ways to reduce pain in preterm infants, specifically the smell of breastmilk, as it decreases the behavioural responses to pain (Badiee, Asghari, & Mohammadizadeh, 2013).

High noise levels in NICU's affect preterm infants, staff, and families by elevating stress levels (Altimier & Phillips, 2013). Reducing noise levels relates to policy in the NICU, to which the researcher had no input. With regards to light, protecting sleep cycles is critical for visual development (Altimier & Phillips, 2013).

Interventions that can be used by the researcher with regards to the healing environment thus include: encouragement of kangaroo care; correct positioning of the infant; and education regarding sleep and awake cycles of the infant. The intervention was designed to provide information regarding the benefits of KMC, correct positioning, and sleep and awake states as psycho-education.

The second core measure relates to partnering with families. According to Altimier and Phillips (2013), the most important factor impacting developmental outcomes of the preterm infant is family involvement, as the family has the greatest influence over an infant's health and well-being over time. The benefits of parental involvement can be seen under the previous section of FCC. Parent support involves interventions to support parents in their parenting role and guiding them in developmentally appropriate interactions with their infant. Notably, the separation between the mother and her infant has been shown to have a profound negative effect on the infant's physiological stability, psychosocial well-being, and brain development (Craig et al., 2015). According to Singer et al. (2007), the separation puts infants at risk for long-term developmental and behavioural problems. Unfortunately, parents lack the support and opportunities to engage in parenting, leading to frequent misperceptions of their infant's behavioural cues (Cleveland, 2008).

Thus, one component of parent support should include guidance on how to understand the behavioural communication of their infant so as to best interpret and respond to the infant's needs (Craig et al., 2015).

The third core measure relates to positioning and handling. Preterm infants exhibit increased stress and agitation when left in unsupported extended positions (Altimier & Phillips, 2013). Therapeutic positioning can influence neuromotor and musculoskeletal development as well as physiological function and stability, skin integrity, thermal regulation, bone density, sleep facilitation,

and brain development (Hunter, 2010). Thus, forming a ‘nest’ with soft boundaries provides postural, behavioural, and physiologic stability to the infant (Altimier & Phillips, 2013). Therefore, according to Altimier and Phillips (2013), the NICU can become comforting if parents are taught how to understand their infant’s behavioural cues, developmentally appropriate positioning, and handling.

The fourth core measure involves safeguarding sleep. According to Altimier and Phillips (2013), sleep is vitally important for the NICU infant as rapid eye movement (REM) sleep is essential for neurosensory and visual development. Continuous bright lights (and noise) can disrupt sleep and awake states, which need to be protected, especially REM sleep (Altimier & Phillips, 2013). The intervention was/has been designed to provide information pertaining to the sleep and awake states to parents.

The fifth core measure entails attempts to minimise stress and pain. Typical handling and care-giving tasks such as bathing, weighing, and diaper changes are perceived as stress to the preterm infant (Comaru & Miura, 2009; Liaw, Yang, Chang, Chou, & Chao, 2009). Improved outcomes are shown in the preterm infants when the stress of overstimulation is reduced (Altimier & Phillips, 2013).

Protecting skin is the sixth core measure of the Neonatal Integrative Developmental Care Model. The skin of preterm infants is very different from full-term infants and thus skin care practices such as bathing, emollient usages, humidity practices and the use of adhesives should be incorporated into unit policies (Altimier & Phillips, 2013).

The last core measure involves optimising nutrition. Research evidence indicates that breastfeeding is the optimal method of infant feeding. However, many preterm infants are not capable of breastfeeding from birth due to immaturity and/or illness (Maastrup et al., 2014). Providing support for mothers in learning to feed their infants, either through breastfeeding or bottle (with expressed breastmilk), should be provided (Altimier & Phillips, 2013). As mentioned, early physical closeness and breastfeeding have been described by mothers as leading to normality and the nurturing of the mother-infant bond (Flacking et al., 2006; Sweet, 2006). The feeding and care of her infant may also alleviate her shock, fear and grief following the birth, and reduce the estrangement from her infant associated with care in the NICU (Flacking et al., 2007).

Developmental care has thus been linked to a number of favourable clinical outcomes, for example, incorporating developmental care practices into the NICU’s conventional care can promote the neurobehavioural development of preterm infants and their capacity for regulation and resilience (Montirosso et al., 2012). Using a family-centred approach is key to supporting mutually satisfying parent-infant interaction which will empower parents to assume the natural parental role. Supporting the parents’ ability to understand their infant’s level of communication through the

infant's behaviour, will place the parents in a better position to respond to and interact with their infant in a developmentally supportive manner (Carrier, 2010). Thus, providing individualised, developmentally supportive, family-centred care can be regarded as the best practice model in the NICU (Robison, 2003).

5.2 Elements of Support Used in Other Programmes

In this section, recommendations regarding support are provided by the National Perinatal Association. In addition, common intervention elements are discussed.

5.2.1 The National Perinatal Association Workgroup

The National Perinatal Association convened at a multidisciplinary workgroup in the United States to determine programme standards for psychosocial support for parents with an infant in an NICU. The workgroup was conducted in 2015 and thus presents fairly current ideologies in the field. The group consisted of psychologists, social workers, nurses, neonatologists, a perinatologist, midwives, occupational therapists, public health workers and veteran parents. According to Hall (2015), seven recommendations were mentioned at the workgroup. Two of the recommendations are expanded below by Hynan et al. (2015). The other five recommendations were:

- Peer-to-peer support provided by trained volunteers should be offered to all parents in every NICU. According to Hynan et al. (2015), the family-centred NICU should include an active peer-to-peer support organisation with a parent support coordinator as part of the staff. NICU mental health professionals should work closely with the parent support coordinator to provide training to 'peers' in recognising parental emotional distress and perinatal mood disorders. Peers are "volunteer parents who have had a similar experience (veteran parents)" (Hall et al., 2015, p. S9).
- Family-centred developmental care should include parents as partners in the care team;
- All healthcare workers that work with pregnant women and their families should be trained in palliative and bereavement care;
- Home healthcare workers should be trained to provide psychosocial support to families as part of their services;
- All NICU staff should receive training on the normal/expected responses of parents to an NICU stay, methods of communication and of providing support to parents, and elements of self-care to minimize burnout in the nursing staff.

Hynan et al. (2015), expanded specifically on the recommendations for mental health professionals in the NICU. The following were recommended by mental health professionals as best

practices for supporting the well-being of parents while in the NICU, and preventing a deterioration of psychological functioning during the potentially traumatic NICU experience:

5.2.1.1 Use of NICU mental health professionals (NMHP).

All NICU's should have at least one full-time social worker and one full- or part-time psychologist as part of the NICU staff. The tendency of having psychologists employed in NICU's is growing and some NICU's have had psychologists on the staff for many years. The roles of social work and psychology can overlap with regard to activities of counselling, screening, providing staff education, and teaching parenting skills. NMHP's should have dedicated time to provide verbal therapeutic support to all parents and family members. In addition, NMHP's should educate NICU staff about the centrality of the parent-infant dyad relationship and communication skills. Supporting roles can also include acting as liaison between staff and families. Clinical decisions should be made with regard to implementing screening, treatment, and referral. These judgements should take into account the diversity of various cultural norms. NMHP's should attempt to create a family-centred culture of understanding and responsiveness that recognises and supports NICU parental emotional distress. Within this culture, care for the emotional and educational needs of NICU parents are outcomes equal in importance to the health and development of their preterm infants.

5.2.1.2 Recommendations for layered levels of support for NICU parents.

Layered levels of emotional support should include family-centred developmental care, mental health professional support for parents displaying acute distress, and referrals to psychologists or psychiatrists for parents who have more concerning risk factors or escalating distress (Hall, 2015). When meeting with the parents for the first time, NMHPs should explicitly state that they meet 'all parents' to (a) normalise the likelihood of parental emotional distress, (b) avoid perceptions of stigmatization of distress and (c) initiate the process of providing emotional support. Increased levels of support can be provided to parents displaying symptoms of postpartum depression and PTSD. Counselling and therapy conducted in the NICU is more likely to be successful with parents than outside referrals as parents are typically too burdened and stressed to keep appointments at outside facilities (Hynan et al., 2015).

5.2.1.3 Recommendations for screening in the NICU for emotional distress.

NMHPs should strive to meet all parents within one to three days of admission to establish a working relationship, normalise emotional distress, and evaluate risk factors for all forms of emotional distress. Screening, using standardised measures such as validated screens for PPD and PTSD (Hynan, Mounts, & Vanderbilt, 2013) can be used. According to Hynan et al. (2013), other screening methods can include (in order of complexity): quick screens for depression and PTSD; inventories such as the Psychological Assessment Tool-NICU, and interviews such as the Clinical Interview for Premature Parents. These should be conducted within the first week with both parents

(Hynan et al., 2013). Parents should then also be rescreened later whenever deemed important and within 48 hours of discharge for NICU hospitalisations longer than one week because levels of emotional distress change. NICU staff should be educated regarding the rationale for screening and follow-up. Screening should be incorporated into NICU procedures as insuring quality services to parents (American Academy of Pediatrics, Commitee on hospital Care, Institute for Patient- and Family-Centred Care, 2012; Hynan et al., 2013).

In this research study, screening has been designed as part of the pre- and post-tests. The researcher is a psychologist who can offer dedicated time to emotionally support the parent's emotional distress. The principles of family-centred developmental care that are feasible, as well as functional elements identified by the VP and nurses (chapter four) have been incorporated into the design of the intervention. The intervention design aims to have educational needs satisfied with information posters developed by the researcher (addendum M). The design of the intervention includes the researcher establishing a working relationship with the parents to normalise their emotional distress and to help parents develop awareness of their needs, resources, and coping skills which can help parents in developing well-being

5.2.2 Findings from Studies Regarding Intervention Elements

In a systematic review and meta-analysis of published early intervention programmes between 1990 to December 2011, Benzies et al. (2013) aimed to categorize key components of intervention programmes and determine the direct effects on parents as well as their preterm infants. The studies were from Australia, England, Germany, Italy, Japan, Netherlands, Norway, and the United States of America. The results indicate that interventions involving parents are complex and generally employ various components categorized as (a) psychosocial support, (b) parent education, and/or (c) therapeutic developmental interventions targeting the infant.

Psychosocial support of parents is aimed at decreasing stress, anxiety, and depressive symptoms and at increasing self-efficacy, maternal sensitivity, and responsiveness in interactions with their infants, with the hope of improving the child's developmental outcomes. Interventions that included psychosocial support resulted in better outcomes for mothers.

Educational interventions are aimed at increasing parental knowledge and skill in caring for preterm infants, thus increasing parenting self-efficacy and decreasing stress. Education may include (a) information about infant growth and development, (b) demonstrations of infant behaviour with discussion, or (c) active involvement of the parent in interaction with the infant with feedback from a professional. Some aspect of education was central to all interventions. Parenting education was a key intervention component associated with decreasing anxiety, however with varying effects on stress and depression. However, parenting education alone does not reduce stress.

Developmental interventions delivered by the parent may ultimately have an effect on infant development. The core components of FCDC are related to developmental interventions. The goal of developmental care is to provide a structured care environment which supports, encourages and guides the developmental organisation of the preterm infant (Coughlin et al., 2009). Coughlin et al. (2009) state that developmental care recognises the physical, psychological, and emotional vulnerabilities of the preterm infants and their parents and is focused on minimising potential short and long-term complications associated with the NICU experience.

5.3 Support Intervention to Foster Well-Being in Parents

The support intervention in this study follows certain theoretical approaches detailed below and includes intervention elements that are expanded on later.

5.3.1 Individualised, Family-Centred Developmental Care

As each family is unique in their composition and needs, the intervention is designed to be individualised. The intervention adheres to fostering a developmental family-centred care approach which acknowledges that emotional, social, and developmental support are integral components in promoting well-being in individuals and families. As mentioned above, FCC is applicable to different cultures and therefore suitable for the South African population. During the intervention, a climate of respect for the parents and staff will be created. Delivery of the intervention will be flexible and parents will be given choices with regards to their availability for the intervention. The aim of providing parent education is to empower parents. Parent involvement will be striven for through encouraging KMC (where feasible), using positive touch, and learning about infant behavioural cues. It is shown that parental involvement reduces parental stress and facilitates bonding (Skene et al., 2016), and the early educational-behavioural information may have a positive effect on maternal well-being (Mianaei et al., 2014). If parents understand their infant's cues, they will be in a better position to respond to their infant in a developmentally supportive way.

5.3.2 Positive Psychology Perspectives

From the Positive Psychology perspective, the use of a support intervention is not synonymous with attempting to 'fix' problems but rather to nurture what is best (Seligman, 2002) within the parents. The salutogenic model, theory of flow and solution-focused approach have all been applied in the support intervention.

5.3.2.1 Salutogenic and fortigenic approach.

With the aim of fostering both hedonic and eudaimonic well-being, a salutogenic and fortigenic perspective was adhered to. The salutogenic model, specifically, renders suggestions on how the SOC can be strengthened, contribute to coping, and thereby promote well-being (Langeland &

Vinje, 2013). The main aim of using a salutogenic approach in this study is to raise parent's awareness of their potential, their internal and external resources, and their ability to use these to increase their SOC, coping, and well-being. To avoid the weakening of a parent's SOC, the constituents of comprehensibility, manageability, and meaningfulness need to be developed.

As mentioned, comprehensibility can be developed when events in life are predictable, ordered, and explicit (Antonovsky, 1987). The rules, routines and workings of an NICU need to be discussed with the parents, with the aim of making events in the NICU more predictable, ordered, and explicit. In addition, comprehensibility involves a person perceiving the world to be understandable, static, stable, and consistent, and stimuli should make 'cognitive sense' (Antonovsky, 1987, p. 16). The intervention is designed to provide information to the parents regarding their preterm infant, as a means of developing understanding of their infant's behaviour. The information will be visually presented and the researcher will take time to discuss the information with the parents. Unfortunately, the reality of preterm infants is that their health is unstable and unpredictable, as was seen with the veteran parents. Information regarding this fact will be discussed with the parents to maintain a sense of comprehensibility.

Manageability is defined as the extent to which people have resources to meet the demands of the stressor (Antonovsky, 1987). This study explores resources that are available to help parents cope. Emotional and practical support can help parents 'manage' the situation. Other forms of social support are explored. Veteran parents indicated that family and spousal support, as well as information provision, helped them cope.

And lastly, meaningfulness is the extent to which life makes sense emotionally and the demands presented are worthy of emotional investment (Antonovsky, 1987). Meaningfulness can be perceived as a motivational element which provides individuals with the 'importance of being involved' in the life challenge (Antonovsky, 1987, p. 18). An important component in the support intervention is encouraging parents to be involved in the care-taking tasks of their preterm infant as it is shown that parental role alteration is a significant stressor. If parents can define themselves as parents in the NICU, which is a meaningful role, a positive self-image may result. A further approach to attempt to foster a positive meaningful experience, is the use of flow theory discussed in the next section.

According to the salutogenesis theory, tension and strain are seen as potentially health promoting (Langeland & Vinje, 2013). The salutogenic model makes a distinction between tension and stress. Similar to the definition of Lazarus and Folkman (1984), stress is experienced when demands exceed a person's resources leading the person to a lower level of health. Therefore, setting appropriate challenges is of great importance in creating life experiences that promote SOC and enable coping (Langeland & Vinje, 2013). Antonovsky (1987) did stress that goal attainment is

contingent on investment of effort and energy. Thus, a strong SOC is not necessarily related to everything being easy and requiring no effort; instead a state of tension can also be linked to valuable benefits in terms of the sense of achievement and direction of effort required to achieve the intended goal. Accomplishment is one of the elements of well-being in this study.

The concept of flow can shed light on the significance of appropriate challenges and the strengthening of the SOC.

5.3.2.2 Theory of flow.

According to Csikszentmihalyi (1997, p. 30), “flow tends to occur when a person’s skills are fully involved in overcoming a challenge that is just about manageable. Optimal experiences usually involve a fine balance between one’s ability to act, and the available opportunities for action.” Parents often feel overwhelmed and lacking in control (Arnold et al., 2013; Baum et al. 2012; Rossman et al. 2015) when dealing with having a preterm infant in an NICU. The challenges are high for parents and parents lack skill in this area. According to the model of flow, this causes feelings of worry and anxiety. To gain a sense of control and possibly even flow, parental skills need to be developed. By being provided with information, education, and positive experiences, parents can develop skills to cope with the challenges they may be facing. By finding a match between skills and challenges, parental anxiety and depression can be alleviated.

5.3.2.3 Solution-focused approach.

As mentioned in chapter three, principles common to positive health and a solution-focused approach are: normalising, reframing, acknowledging, complimenting; use of coping questions; finding exceptions; discussing a preferred future; use of scales and identifying resources (Wand, 2013). These principles are used in the support intervention as follows:

Normalising involves explaining to the parents that their experiences and their difficulties are not uncommon. Encouraging individuals to see their problems as ordinary difficulties is intended to reassure people but not minimise their situation (Wand, 2013). In an earlier article written by the same author, normalising is described as assisting people to perceive their problems as more manageable (Wand, 2010).

Reframing helps individuals ascribe alternative, equally valid meanings to situations and thereby become aware of more effective problem-solving strategies (Guterman, 2013). In addition, it is necessary for the researcher to *acknowledge* the distress of the situation (Wand, 2013) the parents find themselves in.

Compliments validate what the parents are doing well (De Shazer & Dolan, 2012) and are also used to draw the attention of the parents to their strengths and past successes that might be useful in coping with the present situation (Wand, 2013).

Coping questions are aimed at eliciting information about a person's strengths and resources (Wand, 2013). Questions regarding coping which the researcher uses with the parents are, for example: "what have you found helpful so far? What else do you need? How did you cope with that?"

The concept of *exceptions* is described by De Shazer and Dolan (2012) as a time when a problems could occur, but do not. De Jong and Berg (2012) have also described an exception as occasions when the problem was less severe. The goal of exploring exceptions is to help parents to develop a more positive view of themselves by being reminded of current successes when the problem experienced may be less severe.

Discussing a preferred future has been realised by making use of the miracle question as is expanded on below. The intent of the miracle question is for the person to move beyond current problems and visualise a preferred future (Wand, 2013). The miracle question communicates respect for the immensity of the problem but at the same time leads the individual to come up with smaller, more manageable goals (De Shazer & Dolan, 2012).

Scales are used to gauge hope, willingness, motivation, self-esteem, or confidence (Wand, 2010). The pit metaphor (expanded below) has been used in the support intervention as a scale (Van der Merwe, 2005). Questions regarding the pit involve coping questions as well as questions regarding resources that may help the parents in coping. Resources can be 'internal' such as the parents own skills, strengths, qualities, attitudes, and beliefs, as well as 'external' such as supportive relationships and religious or support groups (De Jong & Berg, 2012; Hobfoll, 1989).

In addition to the principles of SFT, a specific intervention that is used when the researcher sees the parents for contact sessions is the *pre-session change question*. This involves asking the parents what changes have taken place since last seeing them.

Overall, the approach in this research study consists of knowledge from Positive Psychology (Compton & Hoffman, 2013; Seligman M, 2011), including seeing well-being as flourishing (Keyes, 2002), flow as an optimal experience (Csikszentmihalyi, 1990), and using social support as a vital resistance resource (Antonovsky, 1987). In addition, interventions from the solution-focused perspective can be effective in increasing parents' awareness of their coping. The theories mentioned emphasize the operationalisation of a salutogenic approach. As mentioned, the focus of this study is on perspectives fostering both a eudaimonic and hedonic form of well-being. It is the aspiration of the researcher that the parents will be able to have the strength and awareness of demands (internal and external) and be able to cope with these demands while having a preterm infant in an NICU.

5.4 Outline of Intervention

Hepworth, Rooney, Rooney, and Strom-Gottfried (2013) describe a helping process which is used in this study as a framework for the intervention. The helping process involves three major phases, namely: (1) exploration, engagement, assessment and planning (initial phase); (2) implementation and goal attainment (change-oriented phase); and lastly (3) a termination phase (Hepworth et al., 2013). The helping process proceeds through these phases. Each of these major phases have distinct objectives, however, the activities and techniques used in the phases are not clearly delineated but may differ in frequency and intensity (Hepworth et al., 2013).

In this study, it is intended that the three phases take place within a climate of salutogenesis, fortigenesis and family-centred developmental care. This climate aligns well with the statement of Goldberg (2007) that authentically listening to women, being open and non-judgemental, and valuing their experiences, contributes to establishing a trust relationship between the woman and health care professionals. As shown in chapter four, women need conversations about the confusing and alarming medical information they hear so as to help them find hope, and to find the balance between caution and optimism (Barber & Starkey, 2015). Hope can be regarded as a psychological resource (Hobfoll, 2002) and has been defined as a human strength (Cheavens & Ritschel, 2014). Individuals high in hope anticipate greater well-being and may be able to deal with stress more successfully (Rand & Cheavens, 2009).

The VP gave reasons for the need for further support such as helping with the many questions parents have, help in understanding their feelings, catharsis, and sharing experiences with others who have understanding of the experience.

The broad process is graphically presented in figure 5.3.

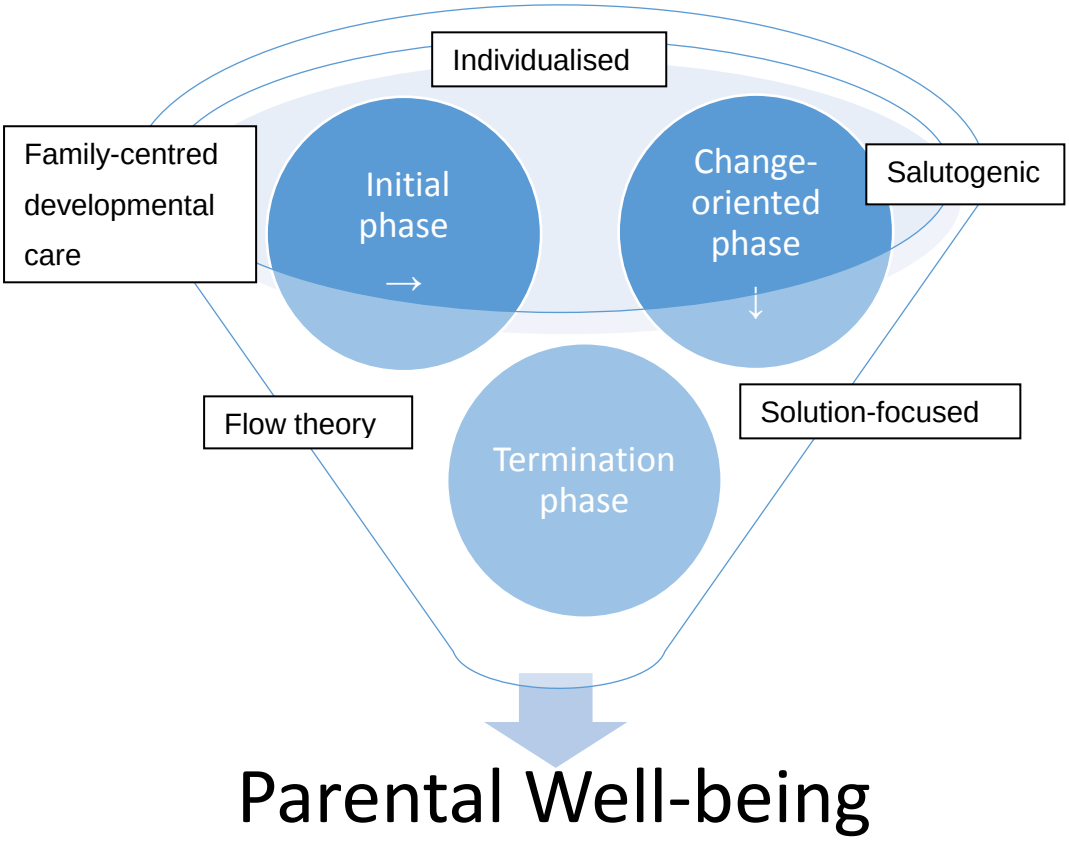


Figure 5.3: Placement of intervention phases within salutogenic, fortigenic, family-centred developmental care

Due to the nature of this support intervention being part of a research process, certain research elements were included in the helping process which will not usually form part of the counselling process, such as gaining consent, voluntary participation of the parents and the right to withdraw at any time, and pre- and post-testing. A description of the phases of the counselling process will now be provided.

5.4.1 Initial Phase

In the initial phase, processes of exploration and assessment are central. Hepworth et al. (2013) describes the processes involved, and tasks to be accomplished, during this phase as including the following:

- Exploring clients' problems by eliciting comprehensive data about the person(s), the problem, and environmental factors such as relevant aspects in the microsystem, but also in other relevant systems (medical aid health care policies);

Exploring individuals' problems will be expanded upon in chapter six. As a Positive Psychology perspective is being followed in this research study, problems are not the only focus. However, Langeland and Vinje (2013), state that a person's individual story is important because, with an awareness of one's life situation, resources that contribute to coping can be found, understood, and fostered, which can enhance and reinforce the SOC. In addition, exploring parents' problems helps "jump start" the helping process (Egan, 2013, p. 20) and as Sloan (as cited in Egan, 2013) indicates, self-disclosure is linked to psychological well-being. Further tasks in this phase include:

- Establishing rapport and enhancing motivation;
- Formulating goals to be accomplished in alleviating problems and formulating a contract;
- Making referrals if necessary;
- Formulating a multidimensional assessment of the problem, identifying systems that play a significant role in the difficulties, and identifying relevant resources that can be tapped or must be developed (Hepworth et al., 2013). Forming an assessment of resources that can be tapped or developed links with the theories of Bronfenbrenner (1993) and the COR theory of Hobfoll (2001).

In this study, the first phase of the support process involved initiating contact, motivating a reason for the intervention and contracting. Parents may be anxious about getting involved and lack knowledge of what to expect. It is for this reason that the researcher described the goals of the intervention and the benefits for the parents before contracting. Thereafter, an initial exploration of the circumstances leading to the parents to having a preterm infant in the NICU were conducted by means of a semi-structured interview. According to Egan (2013), the telling and clarifying of the story is necessary to be able to help the parents. Helpers need skills to enable clients to discuss their problem-situation and to provide support for them as they do so (Egan, 2013). Effective communication in the helping relationship is crucial as it facilitates relationship building, encourages information sharing, and establishes rapport. Building rapport through empathy and authenticity is necessary for the parents to reveal vital information and feelings. Simultaneously building rapport and exploring problems benefits both processes as exploration yields both information and a sense of trust and confidence in the researcher (Hepworth et al., 2013).

Exploration and the gathering of comprehensive information, including about the parent's emotional states and immediate concerns, are necessary. According to Hepworth et al. (2013), the exploration should gradually be broadened to encompass relevant systems such as individual, interpersonal, and environmental. Relevant systems and ecological context are explored through the biographical information form (addendum L) completed by the parents as well as by questioning the parents further.

5.4.2 Change-Oriented Phase

This phase of the intervention involved actions towards problem-solving and goal attainment. Intervention elements (tools and techniques) such as the provision of factual information regarding the NICU and the preterm infant; psycho-education; use of a metaphor; and awareness techniques were used.

Semi-structured interviews with the veteran parents rendered information regarding their support needs. In addition, the questionnaire given to the nursing professionals provided information on their ideas of content for a support intervention. Certain functional elements were identified from the interviews and questionnaires. In addition to other techniques, the following functional elements were used to help parents cope and thereby help promote well-being:

- Answering the parents questions, where possible;
- Factoring in time issues with setting up appointments as parents may be pressured to have available time for support;
- Providing information on machinery and equipment used;
- Explaining rules, routines and procedures of the NICU and the layout of the NICU;
- Interpreting confusing terminology used by the medical professionals;
- Reassuring parents that their infant is receiving good medical care;
- Providing education on infant growth and development;
- Providing information on infant behaviour;
- Encouraging active involvement of the parent with the infant.

The use of these functional elements is to improve parent's comprehensibility (Antonovsky, 1987), promote engagement and gain a sense of accomplishment (Seligman, 2011). At the outset, parents need to receive adequate, clear and concrete information and communication about expectations, their infant's condition and care-giving activities (Johnson, 2007; Lemmen et al., 2013). It is hoped that parents will experience some positive emotion through use of one or more of these functional elements and intervention elements. Positive emotions can help in broadening the scopes of attention, cognition (thinking) and action as well as build resources (Fredrickson, 1998; 2001). Furthermore, the aim of using functional elements and intervention elements is to promote coping, reduce parental stress, decrease untoward responses such as parents moving into a state of languishing or even floundering (Keyes & Lopez, 2002), and foster well-being.

5.4.2.1 Information and education.

According to Gibbs and Maguire (2011, p. 620) "it may be argued that both health and education are a human good with respect to their contribution to human flourishing." Thus, further education and information can help with advancing parental well-being. It is noted that information and education is

a key intervention component in other parental support programmes. Education can develop skills, competencies, and a knowledge base (Gibbs & Maguire, 2011) which can help parents reach a level of comprehensibility and a sense of accomplishment. This includes “A Preemie’s Bill of Rights” (McCarty) as well as education posters (addendum M) developed by the researcher. The following topics are included:

- Frequently asked questions
- NICU equipment commonly used
- Kangaroo mother care
- Developmental stages
- Sleep and awake states of the preterm infant
- Understanding your baby, specifically identifying when the infant is stressed
- Positive touch
- Positioning

Explanations of the infant’s sensory and relational capacities and possible helpful activities are essential for parents (Guillaume et al., 2013). In addition, it is shown that greater ease in reading the infant’s cues is positively related to the level of engagement (Holditch-Davis et al., 2011). Where necessary, further written information is provided to parents such as dealing with siblings at home.

5.4.2.2 Psycho-education.

The Cycle of Experience, and a theory of Fundamental Human Needs, are used as part of psycho-education.

Cycle of Experience (COE). Perls (1969) introduced a self-regulating experiential cycle that explains how the internal equilibrium in individuals is maintained. This cycle seeks to complete itself, however, due to internal and/or external influences the cycle may not be completed, causing an ‘unfinished experience/situation’ which interferes with individuals’ contact with themselves, others and/or the environment in the present (Clarkson, 2000). Perls (1973, p. 5) states that “for the individual to satisfy his needs, to close the gestalt, to move on to other business, he must be able to sense what he needs, and he must know how to manipluate himself and his environment.” The COE is generally described in the following sequence: (1) sensation and perception; (2) awareness; (3) mobilization of energy; (4) action; (5) contact/ interaction; (6) assimilation/ integration; and (7) withdrawal/ closure (Woldt & Toman, 2005). The COE is a conceptual frame for understanding natural, on-going, experiential processes of need-fulfilment and awareness-heightening in individuals (Siminovitch & Van Eron, 2006).

This cycle is used to explain to parents their experiential processes and to heighten awareness of their own needs as well as to identify where they may be ‘stuck’ in the cycle which

prevents needs satisfaction. Awareness in the present is curative because it can reinstate the need-fulfilment pattern that has been interrupted (Fernbacher, 2005). Perls, Hefferline and Goodman (1951, p. 31) aptly state that “awareness is the spontaneous sensing of what arises in you – of what you are doing, feeling, planning; introspection, in contrast, is a deliberate turning of attention to these activities in an evaluating, correcting, controlling, interfering way.” Without awareness, no effective action can be conceived, articulated or taken (Siminovitch & Van Eron, 2006).

The COE used in this study is seen in figure 5.4. Text under the line in each block indicates possible resistances that parents may be using causing ‘stuckness’ in completing the cycle. For example, in the sensation phase, parents may be desensitised to feeling and unaware of their feelings due to the trauma experienced with the preterm birth and admission to the NICU. Awareness is developed by discussing and using different techniques to discover the parent’s feelings, ideas and needs. However, they may not ‘see’ positive possibilities and the mother may especially be under the influence of guilt and how her pregnancy and birth should have been.

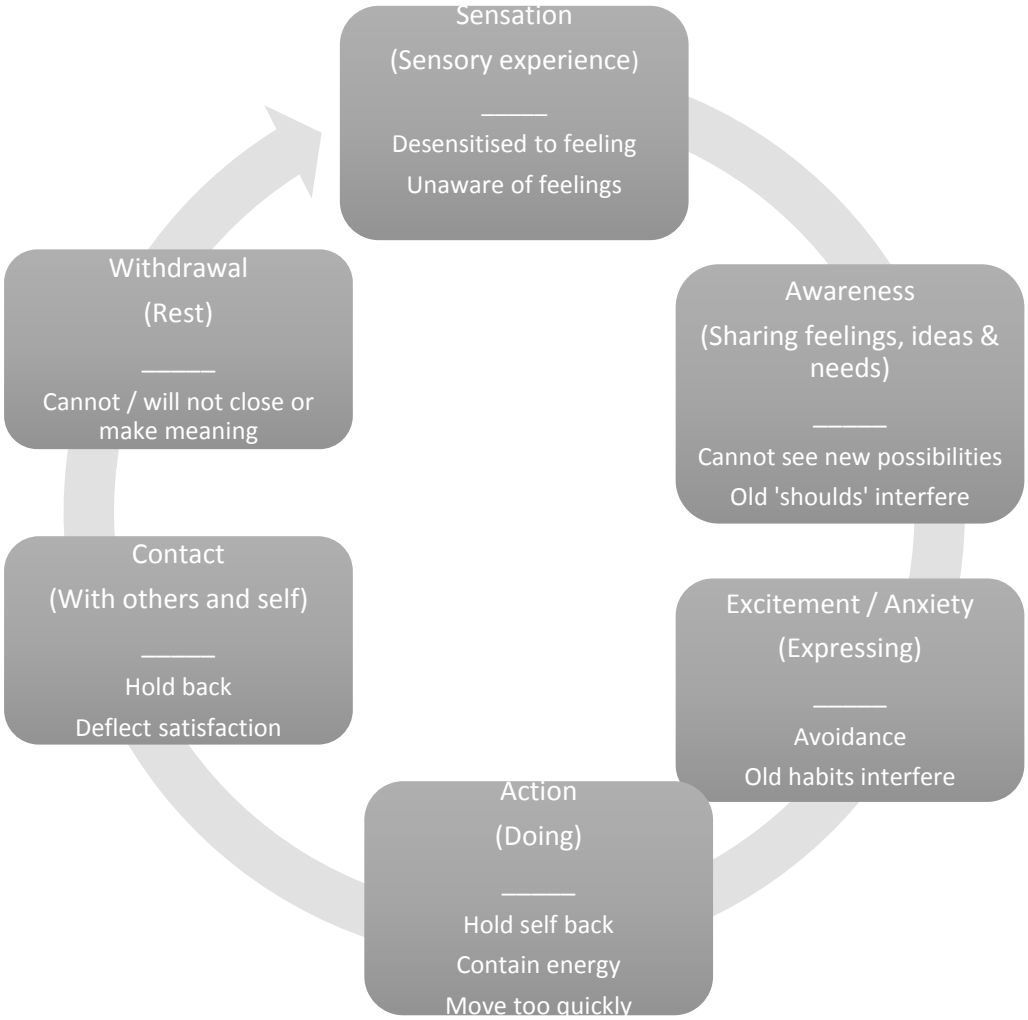


Figure 5.4: Cycle of Experience. Adapted from Siminovitch and Van Eron (2006)

Expressing excitement or anxiety may be avoided. This could be due to personality factors and upbringing. Getting involved with their infant and making contact with others may be avoided due to fear. The end result of the cycle, withdrawal and rest is thus not achieved. Meaning is not obtained.

Fundamental Human Needs. Manfred Max-Neef (1992), whose research into the diversity of cultures led to the creation of the Max-Neef Model of Human-Scale Development, which includes a matrix of fundamental needs and various satisfiers of these needs. According to Max-Neef (1992), there is no hierarchy of human needs and they do not need to be satisfied in sequential order. However, the need for subsistence or survival must be satisfied. Human needs are few, finite and classifiable and are universal and constant across historical time periods. Satisfiers, however, vary among different cultures and times and certain satisfiers can inhibit or destroy the possibility of satisfying other needs (Fisher, n.d.). According to Max-Neef (1992), human needs must be understood as a system and thus are interrelated and interactive. A satisfier may contribute simultaneously to the satisfaction of different needs or, conversely, a need may require various satisfiers in order to be met (Max-Neef, 1992). There are four types of satisfiers or ways of meeting needs namely: being, having, doing, and interacting. The researcher will thus describe the satisfiers in terms of the qualities of a need (being), things that can satisfy needs (having), actions to satisfy a need (doing) and settings (interacting) where it may be possible to satisfy a need. The relationships between satisfiers and needs are not fixed and the quality and intensity of need satisfaction all vary according to time, place and circumstance (Max-Neef, 1992). For example, breastfeeding which is a need for subsistence also satisfies the needs of protection, affection and identity. According to Max-Neef (1992), needs are satisfied within three contexts: (1) with regard to oneself (intra-personal); (2) with regard to the social group (interpersonal); and (3) with regard to the environment. The matrix can be used for purposes of diagnosis, planning, assessment and evaluation and at a preliminary stage, it can serve as an exercise of self-diagnosis (Max-Neef, 1992).

In this study, these fundamental human needs are used as psycho-education for the parents. It is shown that the model provides a useful approach that has the effect of allowing deep reflection about one’s situation leading to awareness and possibly action (Fisher, n.d.). Identifying their needs is thus important for parents to be able to eventually complete the cycle of experience related to the preterm birth and NICU hospitalisation. According to Max-Neef (1992), and used in this study, satisfiers can be selected to fully meet some fundamental needs of the parents. These satisfiers can be regarded as personal resources within and of the parents themselves, or from the external environment. According to the COR theory of Hobfoll (1989), people lacking in resources, or where resources are threatened or lost, may cause loss spirals which lead to individuals vulnerable to further loss. If parents experience loss spirals, the effects may be long-term and thus still affect the parents years later. Parents need to satisfy needs and develop resources to offset

losses and, either stabilise stress reactions, or initiate gain spirals (Hobfoll, Dunahoo, & Monnier, 1995).

Table 5.1:

Fundamental Human Needs (Max-Neef, 1992)

Fundamental Human Needs	**Being (qualities)** Attributes of need *How to be*	**Having (things)** What can satisfy need *What to have*	**Doing (actions)** Actions in satisfying need *What to do*	**Interacting (settings)** Where satisfaction can be expressed *Where to do it*
Subsistence	Physical and mental health	Food, shelter, work	Feed, clothe, rest, work	Living environment, social setting
Protection	Care, adaptability, autonomy	Social security, health systems, work	Co-operate, plan, take care of, help	Social environment, dwelling
Affection	Respect, sense of humour, generosity, sensuality	Friendships, family, relationships with nature	Share, take care of, make love, express emotions	Privacy, intimate spaces of togetherness
Understanding	Critical capacity, curiosity, Intuition	Literature, teachers, policies, education	Analyse, study, meditate, investigate	Schools, families, universities, communities
Participation	Receptiveness, dedication, sense of humour	Responsibilities, duties, work, rights	Cooperate. dissent, express opinions	Associations, parties, churches, neighbourhoods
Leisure	Imagination, tranquillity, spontaneity	Games, parties, peace of mind	Daydream, remember, relax, have fun	Landscapes, intimate spaces, places to be alone
Creation	Imagination, boldness, inventiveness, curiosity	Abilities, skills, work, techniques	Invent, build, design, work, compose, interpret	Spaces for expression, workshops, audiences
Identity	Sense of belonging, self-esteem, consistency	Language, religions, work, customs, values, norms	Get to know oneself, grow, commit oneself	Places one belongs to, everyday settings
Freedom	Autonomy, passion, self-esteem, open-mindedness	Equal rights	Dissent, choose, run risks, develop awareness	Anywhere

Each of these needs can specifically relate to the parent in the NICU. Some mothers want to breastfeed their infant which relates to subsistence. Unfortunately, sometimes the preterm infant is unable to breastfeed due to health complications. A further factor related to breastfeeding, is that the mothers own subsistence needs are controlled as it is advised that certain foods are not beneficial for the preterm infant and may cause cramping in the infant.

Still related to subsistence, is the problematic situation related to work responsibilities. It is seen in the literature that parents, and especially mothers, want to spend time with their infant (Lasiuk et al., 2013), but may prefer to use their maternity leave when the infant comes home. This can cause stress with mothers as they may need to put in leave to spend time with their infant, either during the NICU stay or when the infant goes home. Interestingly, a petition currently exists in the United Kingdom to extend maternity leave for mothers of premature babies (Ogilvy, 2016).

In addition to missing income generating work, there is the added pressure of increasing medical bills. As mentioned, the postnatal period is the most interpersonally and intra-personally challenging time for fathers where fathers find themselves struggling to balance work needs with the new demands of their new father status (Genesoni & Tallandini, 2009). It is understandable that this situation may be amplified for fathers with an infant in the NICU.

Protection, according to the researcher is a significant need related to the preterm infant in the NICU. Parents want to protect their infant from pain and harm but are often ignorant as to how to accomplish this for their infant. As was seen with the veteran parents, a common factor causing the most stress in both parents was feeling helpless in protecting their infant from pain. In addition, parents themselves need to feel protected. This implies that conducting research with the parents needs to be ethically sound. In other words, parents' rights and dignity need to be protected by gaining consent, by maintaining confidentiality, by not harming (non-maleficence) but rather promoting the well-being of parents. Following the principles of FCC can further help parents feel protected.

Parents have needs for affection related to their infant. Expectations of holding, comforting, feeding and protecting their new infant are not immediately realised due to the separation of the infant into the NICU. Parents need to be involved in care-taking as it is seen that the altered parental role is a significant stressor (Busse et al., 2013). Co-operation and practical help from the nursing staff can assist parents to be involved in care-taking tasks with their infant which, to a degree, can satisfy their need for affection.

Related to comprehensibility, parents need to understand a myriad of factors in the NICU. For example, parents need to understand reasons for the use of specific equipment with their infant, the infants need for breastmilk ideally, and the rules and procedures of the NICU. Importantly, the condition of the preterm infant needs to be understood. Related to the need of understanding, the

opposite is also true where the medical personnel need to understand the parent's desires, needs and opinions. Communication between the nursing staff and mothers can either aid or hinder the mother's adaptation to the NICU (Cleveland, 2009).

As mentioned above, parents need to be involved in care-taking tasks which can satisfy the need for participation. In addition, parents can be involved through the use of KMC. As shown in chapter four, veteran parents indicated that KMC helped mothers to feel involved in the care of their infant: *"The fact that you are just there, staring at him and not doing anything for him, for me at least I felt like I'm doing something...every day I would kangaroo him"* (VP 6).

Leisure, as a form of relaxing, may not be easily realised in the NICU. It is important for parents to try to achieve this, due to the high stress situation they find themselves in. In the study of Busse et al. (2013) evidence was provided that parents in the NICU experience a constellation of emotions as well as fatigue and sleep disruption. They recommend that nurses assist parents in developing a visiting pattern that still promotes attachment with the infant but ensures adequate rest for the parents. Furthermore, nurses can assure parents that they will phone if the infant's condition changes which can increase parents' comfort when unable to be at the infant's bedside in the evening.

The fundamental human need, creation, is described as including curiosity, and this is needed from the parents. Parents need to show an interest in understanding and learning from the nurses regarding a myriad of factors such as, their infant's health status, care-taking skills, reading behavioural cues and understanding the sleep and awake states of the preterm infant. Preterm infants communicate with bodily language and due to their poor motor stability and difficulty maintaining alertness, the preterm infant's behaviour is different to the typical full-term infant's behaviour.

The need for identity is a further significant factor related to parents in the NICU. The separation of infant and mother and altered parental role affects the mother in developing her maternal identity as discussed in chapter two. As mentioned, Rossman et al. (2015) found that mothers of preterm infants were delayed in the process of attainment of their maternal role and maternal identity formation. Contact and interaction with the infant; assuming responsibilities of the maternal role; validation of their mothering by another adult or their infant's response; feelings of love for the infant; and feelings of protectiveness and concern toward the infant (Rossman et al., 2015; Zabielski, 1994) are shown to help develop a maternal identity.

Freedom, as a fundamental human need, is related to the quality of self-esteem. It is shown that when mothers compare themselves to the majority of women who carry their infant to the full-term, they feel deficient, inadequate and pained because they had not done the same (Baum et al., 2012; Spinelli et al., 2016). Freedom also relates to do ordinary activities which no longer take place

as mothers spend many hours in the NICU. It is hoped that the elements of the support intervention can help mothers in developing their self-esteem.

In addition, and still related to freedom, is the factor of choice. Choice is related to ethics in research as the parents must be permitted to make their own decisions and their choices must be respected. Freedom as an action, is developing awareness. All in all, it is clear that the theory of Max-Neef (1992) provides a valuable framework to view the interplay of intra- and interpersonal resources in the target group. It can also be used directly in discussions to raise awareness and help parents target specific needs they would like to address.

One of the aims of the support intervention is to develop awareness in the parents regarding their own emotions, coping, and the resources available to support them. One intervention element to help with this aim is the use of the Pit metaphor.

5.4.2.3 Use of metaphor.

As stated by Lyddon, Clay, and Sparks (2001), a metaphor can be regarded as a beneficial tool in counselling. Traditionally metaphors have been used for decades in psychotherapy (Turner, 2014) and although Kopp's definition is not recent it is still regarded as applicable currently. He defined a metaphor as "a way of speaking in which one thing is expressed in terms of another, whereby this bringing together throws new light on the character of what is being described" (Kopp, 1971, p. 269). Metaphors enable an individual to express personal narratives that give meaning to past and present experiences (Bornstein & Becker-Matero, 2011). Metaphors can be used to enhance communication and the helping process as well as facilitate insight and provide new solutions (Levitt, Korman, & Angus, 2000). It is for these reasons that a metaphor is used in this study.

One metaphorical concept used is "The Pit" described in the book of Hobday and Ollier (1999). Hobday and Ollier (1999) suggest that a simple line drawing be made in the shape of a U to represent the pit. Thereafter, the parent can indicate their position in the pit. The bottom of the pit is indicative of the parents feeling dreadful and the top of the pit is indicative of the parent feeling fine. After assessing where the parent places themselves in the pit (or outside the pit), parents are then questioned about who may be standing at the top of the pit to assist them and/or who may throw a rope to assist the parent.

Van der Merwe (2005) states that the Pit metaphor helps to externalize a problem, to verbalise a situation more clearly and to move more easily to workable solutions. The Pit metaphor therefore serves the following three broad functions which are applicable in this study:

- It allows for assessment by seeing where the parents place themselves in the pit;
- It facilitates externalisation, communication and avenues for expression of feelings; and

- It advances the joint search for workable solutions by identifying social support, assets and resources (Van der Merwe, 2005).

The metaphor can also be used over time to gauge change and progress. Thus, the Pit metaphor can be regarded as a scale which is able to identify goals, coping skills, needs and resources by the researcher making use of coping questions, which forms parts of the principles of the solution-focused approach.

5.4.2.4 Awareness techniques.

Developing parental awareness is one of the focal points in this study. The existence of awareness of a demand, a goal, and a direction in which to act, as well as having the ability and energy to make the effort to do what is required is regarded as a strength by Strümpfer (2013). The awareness of the parent's own situation, needs, strengths and resources is encouraged in the parents. The COE also highlights the curative value of present self-awareness as it can restore the need-fulfilment pattern that may be interrupted (Fernbacher, 2005). One technique used to develop awareness is the Healing and Hurting Alphabet adapted from Williams and Poijula's (2016) healing alphabet. Parents are asked to try to give a word, feeling, thought to each letter of the alphabet. Through this, themes can be identified and it also provides insight into the parent's current state.

A further technique in developing awareness is developing an awareness of goals by making use of the miracle question. The words of the miracle question appear to vary, but the basic wording of the question is as follows:

> I have a strange, perhaps unusual question, a question that takes some imagination… [pause]. Suppose…[pause]. After we finish here and you go home tonight, watch TV, do your usual chores, etc., and then go to bed and to sleep…[pause]. And, while you are sleeping, a miracle happens…[pause]. And the problems that brought you here are solved, just like that!...[pause]. But this happens while you are sleeping, so you cannot know that it has happened [pause]. Once you wake up in the morning, a) how will you go about discovering that this miracle has happened to you? OR b) how will your best friend know that this miracle happened to you? [wait]. (De Shazer, The miracle question, 2006, p. 1).

The responses to the miracle question can thus be regarded as parental goals and needs. De Shazer and Dolan (2012) state that the answer to the miracle question can only be found in a person's real world and thus the miracle question can be considered as a reality question.

5.4.3 Termination Phase

According to Hepworth et al. (2013), the termination phase involves the following three major aspects: (1) assessing when the client goals have been satisfactorily attained; (2) helping the client

develop strategies that maintain change and continue growth following the termination; and (3) successfully terminating the helping relationship.

In this study, information regarding going home with a preterm infant was discussed with the parents as the literature indicates that educational intervention provided to the mother before discharge increases knowledge, changes maternal behaviours and decreases maternal stress (Browne & Talmi, 2005). According to Hutchinson et al. (2012), the parent's perceptions can direct the content of education to prepare the parents for the subsequent discharge. This can be determined by questioning parents about their informational needs. And according to Chen et al (2016) the education and quality thereof can improve and predict parental readiness for infant discharge. It has been shown that readiness for discharge is significantly related to infant safety, parent satisfaction and physical, emotional, psychological and social well-being of the family (Weiss et al., 2006).

Education and information provided at termination included information regarding expected emotional consequences for parents. It is shown in the article of Adama et al. (2016) that parental experiences of caring for a preterm infant after discharge, among other factors, include: mixed feelings; living in constant fear; a delayed joy of fatherhood and motherhood; a need for support; and an experience of guilt feelings. Murdoch and Franck (2012) also mention that mothers' experiences after discharge at home can be placed on an apprehension-confidence continuum. Apprehension is experienced with regard to the infant's fragile health, losing the support of the neonatal team, and performing medical procedures, whereas confidence can improve as the infant's health improves. With the education and information provided it is envisaged that parent's growth towards well-being will continue at home.

In summation, the outline of the intervention is summarised in figure 5.5.

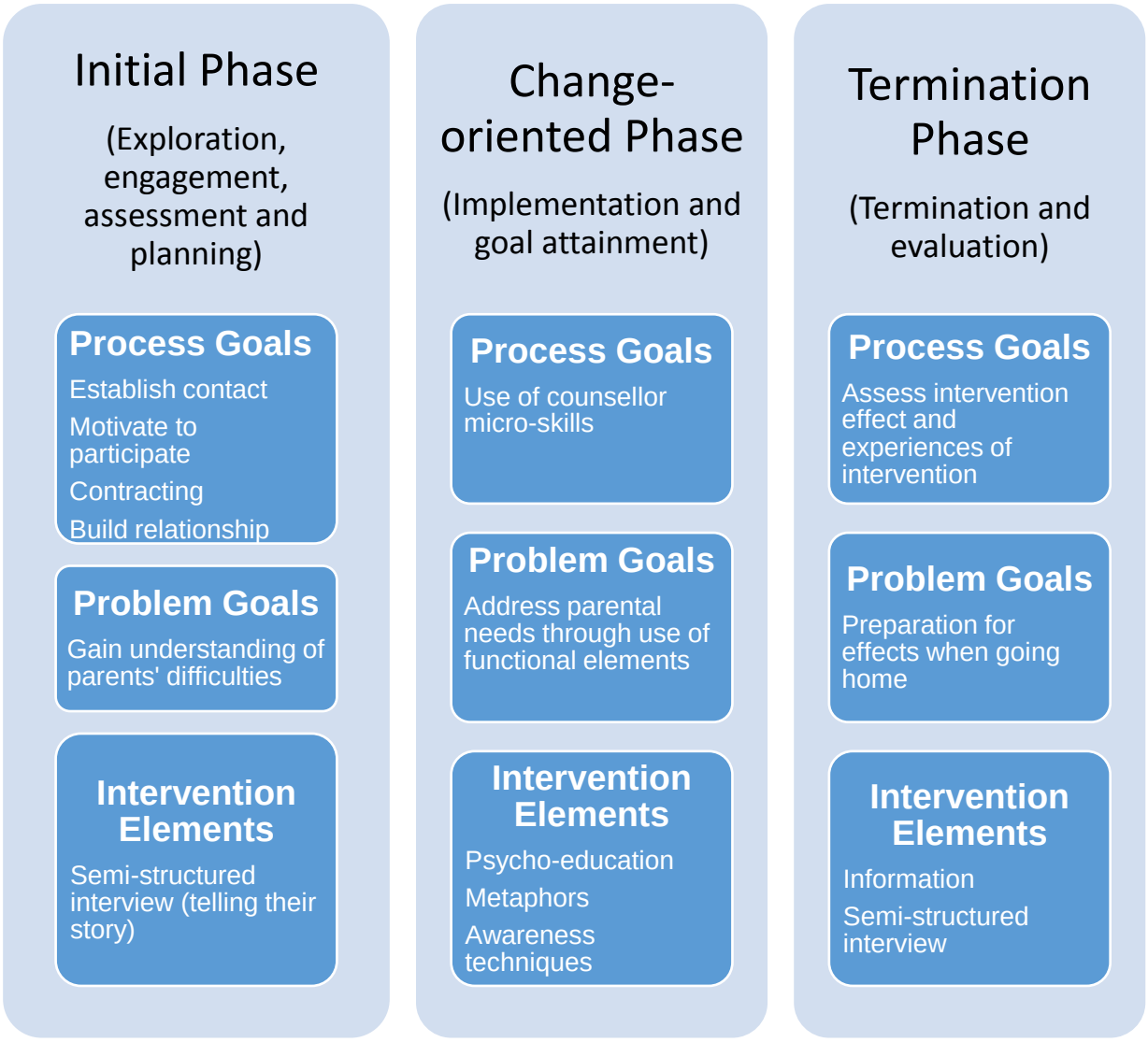


Figure 5.5: Outline of intervention process

5.5 Conclusion

As mentioned in the introduction, parents have to cope with the stressors of the NICU environment, the appearance and unstable health of their preterm infant, staff-parent interactions, and a changed parental role. In addition, parents are dealing with their own emotions of stress, anxiety, depression, guilt, and alterations in self-esteem. It is foreseen that a Positive Psychology intervention will help parents cope with these stressors and foster well-being while in the NICU. The researcher aimed to examine sources, processes and mechanisms that can lead to fostering well-being in this study. In addition, the following factors are regarded as helping foster well-being: comprehensibility, manageability; positive emotion, engagement, positive relationships, meaning, accomplishments as well as self-acceptance.

Comprehensibility can be developed through the use of information and education regarding the NICU and the preterm infant. Manageability is developed by looking for resources to help parents cope. Resources can be internal strengths of the parents or external factors. Intervention elements to help with this process include making use of awareness techniques such as the healing and hurting alphabet, the pit metaphor and the miracle question. As parents in the NICU have to deal with delayed bonding and a changed parental role, the support intervention includes factors to help parents to be more engaged with their infant such as the use of information, education and encouragement of KMC. Through these intervention elements, parents can start to be more involved in their infants care. This also represents the philosophy of FCC. When parents engage more with their infant, it is hoped they will experience positive emotion, which helps in developing meaningfulness. As the process may not be easy and may be challenging to the parents, the involvement in care can lead to a sense of accomplishment and possibly even flow. Accomplishment thus furthers meaningfulness. Relationships are core to well-being and the support intervention is based on a genuine helpful relationship between the parent and the researcher. In addition any nurse-parent problems or difficulties need to be explored. Specifically related to mothers who experience guilt, it is hoped that through engagement, accomplishment and the development of a maternal role, the mother's own self-acceptance can improve. Psycho-education related to the cycle of experience and Max-Neef's fundamental human needs are included in the support intervention to help parents identify unmet needs and develop an awareness of what may be causing these needs to not be satisfied.

FCC as a philosophy of care dictates the relationship that the researcher aimed to develop with the parents. Theories grounding the intervention elements include the salutogenic model which renders suggestions on how the SOC can be strengthened and thus contribute to coping and thereby promote well-being. A main aim is that the support intervention can aid the process of fostering well-being in the parents and help them to find elements of growth in the difficult circumstances, as discussed in the next chapter.

CHAPTER 6

PILOT TEST

In the fourth phase of the D&D model followed in this study, a pilot test was conducted. A pilot test is a primitive intervention design evolved to a form that can be evaluated under field conditions (Fawcett et al., 1994; Fraser et al., 2009). Pilot studies are used to develop and refine an intervention (Gray et al., 2013). In this chapter the pilot study of the support intervention will be discussed including the methods of data collection and data analysis. The intervention has been field tested with parents who at that stage had an infant in the NICU and the findings will be discussed according to the different phases of the helping process. Included in this chapter, as indicated in the figure below, is an evaluation of the pilot study as well as recommended refinements of the support intervention.

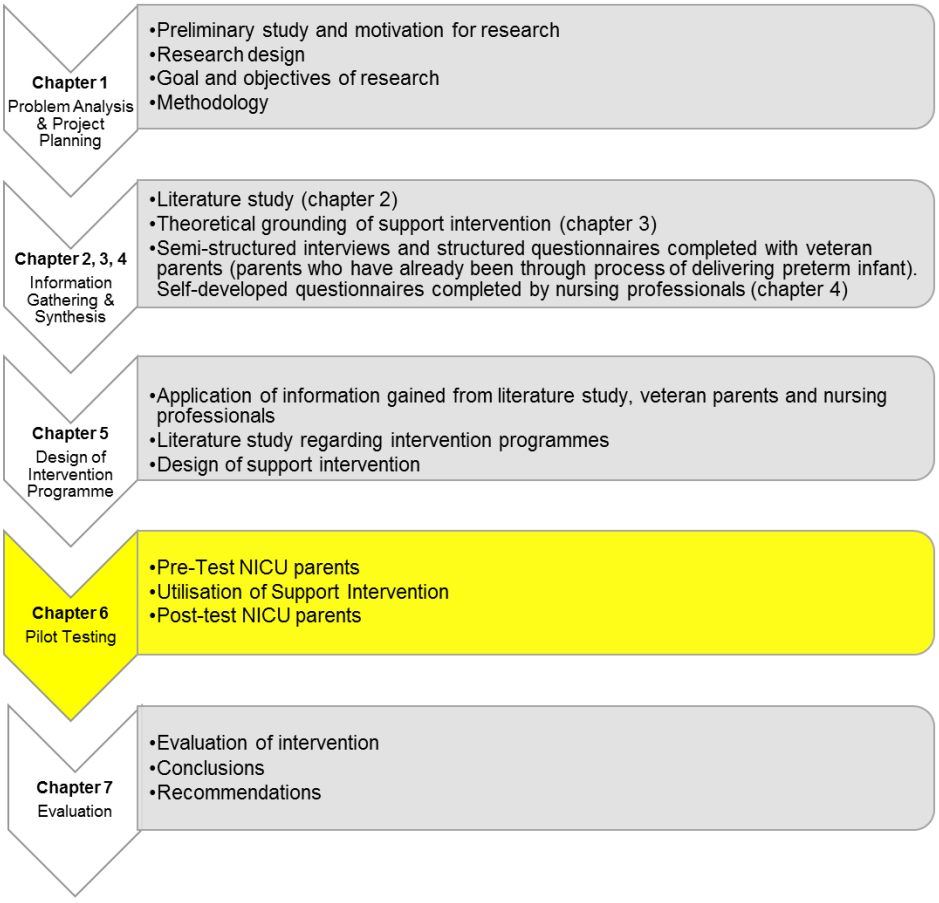


Figure 6.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

6.1 Methods of Data Collection

As previously mentioned, the gatekeepers for this part of the research plan were the head offices of two hospital groups and the hospital managers of each hospital. Gatekeepers were necessary to gain permission to approach NICU parents to participate in this study. Permission was obtained from the hospital head offices and hospital managers. The mediator was the unit manager of the specific NICU. Letters were given to the unit manager to provide to the parents in the unit which explained the purpose of, and the parents involvement in, the support intervention (addendum J). After a day or two, parents were approached in the NICU and asked if they would be part of the research study. Information was reiterated regarding the goal of the study as well as the benefits of their involvement. Five sets of parents declined involvement. Cited reasons included that they felt they were coping adequately and did not feel the need for support, or that they did not foresee having the time to be involved. According to the researcher, it seems as if there was a trend that in cases where the infant was bigger (> 31 weeks gestation), the mothers declined involvement in the study. This is affirmed by the study of Tooten et al. (2013) where, with a lower gestational age, more negative parental experiences and perceptions are experienced. The negative parental experiences relate to: the infant's current condition; pregnancy course; labour and delivery; relationship with the infant; and discharge and beyond. Nine sets of parents consented to be part of this research study.

A pre-test was conducted where two structured questionnaires were administered (see 6.2.3) namely: The Parenting Stress Index, 3rd edition (PSI) as well as the State-Trait Anxiety Inventory for Adults, Form Y (STAI). For some parents, the semi-structured interview was conducted immediately after the questionnaires were completed as parents were willing and time was available. For other parents, questionnaires were given to the parents to complete in their own time. After the questionnaires were collected, a semi-structured interview was conducted with the parents where the aim was for the parent "to tell their story" (Egan, 2013). The reason for allowing parents to explain what led up to the NICU admission of their preterm infant was to help 'jump start' the helping process (Egan, 2013, p. 20) and as Sloan (as cited in Egan, 2013) indicates, self-disclosure is linked to psychological well-being. It was requested that both parents be present for the interview, however, this was not always realised as some fathers had returned to work and others were absent. The duration of the interview was approximately 60 minutes. Upon completion of the interview, arrangements were made with the parents for when the support intervention could start. An endeavour was made to organise regular appointments. Each support session was audio recorded and field notes were taken. After the infant was discharged, which sometimes occurred unexpectedly, an appointment was made with the parents for a follow-up interview and to re-administer the PSI and STAI. All interviews were at the parent's home a few weeks after discharge except for two which were conducted in the hospital due to the infants being re-admitted for illness and one still waiting to go home the same afternoon. The interviews were again audio recorded. All

audio recordings were transcribed verbatim. Each NICU parent group was assigned a number for confidentiality reasons. Table 6.1 provides details regarding the participants.

Table 6.1:

Biographical details of NICU parent participants and preterm infants

NICU Parent Number	Age of mother	Age of father	Previous miscarriages	Siblings	Type of birth	Multiple	Gestational age	Birth-weight	Notes
NICU1	37	41	None	Yes (1)	Caesar	Yes	27 weeks 27 weeks	900 g 870 g	Deceased
NICU2	39	43	No	Yes (2)	Caesar	No	29 weeks	1038 g	
NICU3	39	39	No	Yes (1)	Caesar	No	33 weeks	2000 g	
NICU4	30	31	Yes (X1)	No	Vaginal	No	26 weeks	965 g	Deceased
NICU5	38	41	Yes (X2)	Yes (1)	Caesar	Yes	30 weeks 30 weeks	1058 g 1038 g	
NICU6	33	35	No	Yes (1)	Caesar	No	27 weeks	985 g	
NICU7	31	27	No	Yes (1)	Caesar	No	32 weeks	1295 g	Sibling deceased 6 years previously
NICU8	32	32	No	Yes (1)	Caesar	Yes	32 weeks 32 weeks	1900 g 2100 g	
NICU9	27	30	Yes (X1)	Yes (2)	Caesar	No	34 weeks	2446 g	

Notes: One of the twins of NICU 1 passed away the day after birth before the support intervention had commenced. The mother of NICU 1 consented that we continue with the support intervention. The infant of NICU 4 passed away after eight sessions of the support intervention had been completed. NICU 7 had a sibling who passed away, six years previously.

6.2 Data Analysis

The theoretical paradigms have been discussed in chapter three. These theoretical paradigms serve as lenses to interpret reality (Nieuwenhuis, 2016). The data, results, and interpretation of the pilot study will be discussed in this light.

The pre-test results of the PSI and STAI Inventory are given for each parent in table 6.3 and the post-test results are given in table 6.5. With regards to the PSI, percentiles falling within 15th and 80th percentile are regarded as normal. High scores are considered to be scores at or above the 85th percentile and are coloured in red on both the pre-test scores and post-test scores. Scores below the 15th percentile are low scores, coloured blue on the pre-test and post-test scores. Interpretations are suggested to be seen as hypotheses which can be validated by further enquiry (Abidin, 1995). Defensive responding is coloured in green on both the pre-test and post-test scores. A defensive responding score of 24 and less indicates that the parent responded in a defensive manner. It is advised in the manual that caution should thus be exercised when interpreting the remainder of the scores. Occasionally, very low defensive responding scores will be found in situations where it is obvious that the parent is very competent and existing within a supportive social situation that is economically advantaged. On the STAI, high scores are indicated for percentiles at and above the 75th percentile.

6.2.1. PSI Subscales Measurement Information

The PSI was suggested for use by, among others, researchers. The PSI was designed as a screening and diagnostic assessment technique to identify parent and child systems which are under stress, and in which deviant development of the child is likely to take place, or where dysfunctional parenting is likely to occur. Additional cited uses include pre-post measurement of intervention effectiveness and research aimed at studying the effects of stress on parent and child interactions and other psychological variables (Abidin, 1995). Abidin (1995) states that stress in the parenting system during the first years of life is critical in relation to a child's emotional/behavioural development and to the developing parent-child relationship. The researcher is aware that the literature discussing the subscales of the PSI is old, but it is because the questionnaire was developed at this time.

Three major domains of stressors include child characteristics, parent characteristics, and situational/demographic life stressors. The parent domain subscale examines some of the principal parent characteristics and family context variables that have been identified as impacting upon the parent's ability to function as a competent caregiver to his or her child. Child characteristics of adaptability, demandingness, mood, and acceptability cannot be applied with a preterm infant. The parent domain factors apply with regards to a preterm infant admitted to an NICU and thus, only the parent domain subscale of the PSI was used in the measurement.

Falling under the parent domain, eight factors are measured using subscales. The two subscales, depression and competence in the parenting role, are directly related to a parent's stress level and impact on parental attachment. There are also four additional situational subscales which are seen as major contributors to the parents stress level, namely, spouse, isolation, health, and role restriction (Abidin, 1995). Each of these will be briefly discussed.

6.2.1.1 Competence.

The competence subscale assesses the parents' sense of competence in relation to their role as parent (Abidin, 1995). According to Teti and Gelfind (as cited in Abidin, 1995), young parents with an only child and parents lacking in practical child development knowledge will have high scores. In addition, parents who do not find the parenting role as reinforcing as they had expected (Mouton & Tuma, 1988 as cited in Abidin, 1995), will also earn high scores on competence. High scores are thus indicative of a low sense of competence. High scores are also associated with a lack of acceptance and criticism from the child's other parent (Abidin, 1995) with regards to competency skills. This is most likely when the spouse's subscale is also elevated. Parents of children with major physical and mental disabilities often have elevated scores (Kazak & Marvin, 1984 as cited in Abidin, 1995). According to Abidin (1995), interventions that are most helpful for these parents are parent education classes and parent discussion groups. Personal validation and individual emotional support, particularly with new parents, is often helpful (Abidin, 1995).

6.2.1.2 Isolation.

The isolation subscale examines the parent's social isolation and the availability of social support for the role of parent (Abidin, 1995). Parents who earn high scores in this area are under considerable stress, and it is necessary to establish an intervention as soon as possible. These parents are often socially isolated from their peers, relatives, and other emotional support systems. In many instances, their relationship with their spouses is distant and lacking in support (Herzog & Kilbane, 1989 as cited in Abidin, 1995). Social support and supportive relationships can be conceptualised as available resources that can aid the individual's coping by influencing stress appraisals (Revenson & Lepore, 2012).

6.2.1.3 Attachment.

The parental attachment subscale was designed to assess the intrinsic investment the parent has in the role of parent and determines the parent's motivation level to fulfil the role of parent (Abidin, 1995). High scores on this subscale indicate two possible sources of dysfunction. First of all, the parent may not feel a sense of emotional closeness to the infant, and secondly, the parent has a real or perceived inability to understand the infants' feelings and needs. Low levels of monitoring and vigilance in relation to their infant's behaviour is a common feature of parents who earn high scores (Abidin, 1995).

6.2.1.4 Health.

The health subscale assesses the impact of the parent's current physical health in terms of his or her ability to meet the demands of parenting (Abidin, 1995). High scores are suggestive of deterioration in parental health that may be the result of either parenting stress or further independent stress in the parent-child system (Abidin & Wilfong, 1989 as cited in Abidin, 1995).

6.2.1.5 Role restriction.

The subscale role restriction addresses the impact of parenthood on the parent's personal freedom and other life roles (Abidin, 1995). A high score on this subscale indicates that the parent experiences the parental role as restricting his/her freedom and frustrating attempts to maintain their own identity (Matthews, 1989 as cited in Abidin, 1995). Parents may see themselves as being controlled and dominated by their infant's needs. In many cases, one will detect a strong note of resentment and anger toward the child and/or spouse (Abidin, 1995). Primiparous (first birth) mothers, in comparison to the fathers, report rapidly rising stress levels during the first years of their child's life (Stewart et al., 1984 as cited in Abidin, 1995). Interventions are often made difficult by an anger-guilt cycle in which efforts to change the situation stimulate feelings of guilt. Therefore an effort must be made not to minimise the reality of the parent's situation or the real limitations that occur as a function of being a parent. This validation is necessary before these parents can be assisted to recognise their options (Abidin, 1995).

6.2.1.6 Depression.

The depression subscale assesses the extent to which the parent's emotional availability to the child is impaired and the extent to which the parent's emotional and physical energy is compromised. High scores on this subscale are suggestive of the presence of significant depression in the parent (Webster-Stratton, 1988 as cited in Abidin, 1995). There are some items that relate to guilt and unhappy feelings, which, although often associated with depression, may be responded to primarily out of dissatisfaction with themselves and their life circumstances and may not signal clinically significant depression. Withdrawal is a frequent behavioural manifestation (Perez, 1989 as cited in Abidin, 1995). Individuals who score high on this subscale should be provided with parental therapy or counselling aimed at enhancing self-esteem and assessing the significance of the depressive symptoms (Abidin, 1995).

6.2.1.7 Spouse.

The spouse subscale assesses the emotional and physical support provided to facilitate functioning in the parenting role (Abidin, 1995). Parents who earn high scores on this subscale are those who are lacking the emotional and active support of the other parent (Webster-Stratton, 1989 as cited in Abidin, 1995). In general in these cases, the opposite sex parent is not available for companionship

and is unwilling to accept the responsibilities of the parental role (Guisinger, Cowan, & Schuldberg, 1989 as cited in Abidin, 1995).

6.2.1.8 Life stress.

The life stress scale provides an assessment of the global situational stressors that moderate or exacerbate parenting stress (Abidin, 1995). Parents with high life stress scores find themselves in stressful situational circumstances that are often beyond their control. This scale provides some indication of the amount of stress outside the parent-child relationship that the parent is currently experiencing. High levels of life stress should be interpreted to suggest that the task of parenting will be more difficult, and the potential for problems in the family interactions is increased (Abidin, 1995).

6.2.2 STAI Measurement Information

In this research study the STAI questionnaire was used to measure state- and trait-anxiety. The STAI, form Y (Spielberger, 1983), consists of two 20-item subscales (State and Trait Anxiety) on which respondents rate their feelings on a 1-4 scale, with totals for each subscale ranging from 20 to 80. Higher scores are representative of higher anxiety. The scales have good internal consistency and reliability (Crawford, Cayley, Lovibond, Wilson, & Hartley, 2011). This scale is reported to be psychometrically sound and has been used in several previous studies on pregnant women (Chang et al. 2008, Cheng et al. 2008).

The term anxiety on the STAI is used to refer to two related but also quite different constructs. It can be defined as an unpleasant emotional state or condition (State anxiety) as well as a relatively stable individual difference in anxiety-proneness which could be regarded as a personality trait (Trait anxiety) (Spielberger, 1983). These are described further:

6.2.2.1 State anxiety (S-Anxiety).

Anxiety states are characterised by subjective feelings of tension, apprehension, nervousness, and worry. Therefore, S-Anxiety refers to a palpable reaction or process taking place at a given time and level of intensity. The STAI S-Anxiety scale assesses how a person is feeling “right now.” Scores on the S-Anxiety scale increase in response to psychological stress. State anxiety items ask for ‘how you feel right now, at this moment’ and assess acute anxiety (Spielberger, 1983).

6.2.2.2 Trait anxiety (T-Anxiety).

Trait anxiety refers to relatively stable individual differences in anxiety-proneness, in other words, differences in people in the tendency to perceive a stressful situation as dangerous or threatening and to consequently respond with elevations in the intensity of their state anxiety. In addition, the stronger the anxiety trait, the more probable the individual will experience more intense elevations in state anxiety in a threatening situation. Therefore, T-Anxiety refers to differences between people in

the disposition to respond to stressful situations. Trait anxiety items ask how ‘you generally feel’, and assess more enduring tendencies to experience anxiety (Spielberger, 1983).

In sum, people with high T-Anxiety exhibit S-Anxiety elevations more frequently than low T-Anxiety individuals because they tend to interpret a wider range of situations as dangerous or threatening. High T-Anxiety persons are also more likely to respond with greater increases in the intensity of S-Anxiety in situations that involve interpersonal relationships and threaten self-esteem. Therefore, the individual’s perception of threat may have a greater impact on the level of S-Anxiety than the real danger associated with the situation (Spielberger, 1983). Parental scores for the PSI and STAI are presented in table 6.3 (pre-test) and table 6.5 (post-test).

6.2.3 Validity and Reliability of the PSI and STAI

Related to the PSI, the coefficient alpha reliability coefficients are sufficiently large, indicating a high degree of internal consistency (Abidin, 1995). The stability of the PSI scales is supported by the test-retest reliability coefficients obtained from four different studies. The relatively high reliability coefficients provide support for the stability of the scores across the time intervals, particularly for the parent domain. No differences were found in its factor structure or reliability across cultures. In the manual, a series of abstracts describing different studies provide evidence for the construct and predictive validity of the PSI.

Metzger (1976) conducted a study to measure the reliability and validity of the STAI. According to Metzger (1976), the inventory has an impressive set of reliability coefficients, which suggest that it would be an excellent device for research and clinical purposes. The researcher is aware that the literature discussing the reliability and validity of the STAI is old, but it is because the questionnaire was developed at this time. It was found that the STAI reflects differences between presumably stressful and non-stressful situations while it yields a reliable measure of the individual level of anxiety of the person. It may prove a useful instrument to measure changes in the anxiety of clients across therapy sessions. The State-Trait Anxiety Inventory was examined in stress- and no-stress situations and it was found that the inventory is a highly reliable measure and that it has the ability to discriminate between high- and low-stress situations.

6.3 Findings of the Pilot Study

The findings of the pilot study are discussed according to the helping process, namely, the initial phase, change-oriented phase and termination phase. The number of contact sessions with parents is shown in table 6.2 which includes the initial interview session and formal, arranged support sessions. When walking into the NICU to meet other parents, the researcher would occasionally greet parents and inquire about the progress of their infant as a form of maintaining a helping,

genuine relationship with the parents which is not added to the indicated number of contact sessions. In this regard, McLeod and McLeod (2011, p. 2) talk about useful conversations which can take place in the space of eight to ten minutes which offer a "window of opportunity" to re-connect and keep interest, support, and the relationship going.

Table 6.2:

Support intervention sessions

NICU family	Initial interview conducted with	Support sessions provided to	Number of contact sessions	Content covered during change-oriented phase (in order of content)
NICU 1	Mother and father	Mother	5	Bill of rights; Education; The Pit Technique; Miracle question; A-Z; COE
NICU 2	Mother	Mother	6	Education; The Pit Technique; Miracle question
NICU 3	Mother	Mother	2	Education; Bill of Rights
NICU 4	Mother	Mother	8	Education; The Pit Technique; A-Z; COE; Miracle question
NICU 5	Mother and father	Mother and father	4	Education; Bill of Rights; The Pit Technique; Miracle question; COE
NICU 6	Mother	Mother and father	5	Education; The Pit Technique; COE; A-Z; Fundamental Human Needs
NICU 7	Mother and father	Mother and father	3	Education; A-Z; COE
NICU 8	Mother	Mother	5	Education; The Pit Technique; Miracle question; A-Z; Fundamental Human Needs; COE
NICU 9	Mother	Mother	2	Education; The Pit Technique; COE; A-Z

6.3.1 Initial Phase

In this section, the initial phase of counselling, the period leading up to and the reason for the preterm birth are discussed. Even though the philosophical paradigm for this study is Positive Psychology and focuses on solutions and not only on problems, the description of the time leading up to and the reason for the preterm birth is provided for each family as indicative of the stress and trauma that may have already been experienced. In addition, according to Langeland and Vinje (2013), a person's individual story is important because only with an awareness of one's life situation can the resources that contribute to coping be found, understood, and fostered, which can

enhance and reinforce the SOC. Exploring the life story also links with Bronfenbrenner's theory, where he stresses the importance of history and time in the life cycle of families. This links with Bronfenbrenner's conceptualisation of the chronosystem (Couchenour & Chrisman, 2014). McLeod and McLeod (2011) allude to the fact that people create their own personal world where they live and function. However, at times, in this personal space, things can go wrong and people can find it hard to manage. Then they can benefit from a counselling space, from where they can reflect, externalise, and come to certain conclusions and plan within the safe boundary created by the professional relationship. The view of McLeod and McLeod (2011, pp. 1-2), is important here namely: "Counselling is what happens when a person consults someone else around a *problem in living* - a conflict or dilemma that is getting in the way, that is preventing people from living their lives in the way in which they would wish."

Table 6.3:

Pre-test scores of PSI and STAI

PRE TEST													
Parenting Stress Index (Raw scores and Percentiles in brackets)													
NICU	1	2	3		4	5		6		7		8	9
	M	M	M	F	M	M	F	M	F	M	F	M	M
Competence	25 (30)	30 (60)	27 (40)	Error	26 (35)	30 (60)	24 (25)	15 (1)	16 (2,5)	31 (65)	28 (45)	39 (93)	22 (15)
Isolation	14 (70)	15 (75)	8 (10)	9 (15)	10 (25)	20 (95)	10 (25)	10 (25)	13 (60)	13 (60)	21 (97)	10 (25)	7 (5)
Attachment	14 (75)	13 (65)	8 (10)	9 (15)	10 (25)	18 (95)	11 (35)	11 (35)	10 (25)	10 (25)	9 (15)	19 (96)	7 (1)
Health	14 (75)	18 (92,5)	10 (35)	10 (35)	20 (97)	16 (85)	13 (70)	12 (65)	11 (50)	12 (65)	14 (75)	19 (95)	9 (5)
Role Restriction	18 (45)	15 (25)	8 (1)	9 (2,5)	14 (20)	19 (55)	14 (20)	9 (2,5)	10 (3,5)	21 (70)	19 (55)	23 (80)	12 (10)
Depression	20 (50)	19 (45)	12 (5)	Error	28 (92)	27 (90)	9 (1)	18 (35)	17 (55)	21 (60)	22 (70)	33 (97)	14 (12,5)
Spouse	22 (85)	18 (65)	7 (1)	Error	10 (10)	17 (55)	11 (15)	14 (35)	11 (15)	14 (35)	14 (35)	26 (95)	8 (5)
Total Parent Domain Stress	127 (60-65)	128 (60-65)	80 (1-5)	Error	118 (45)	147 (80-85)	92 (10)	89 (5-10)	88 (5-10)	122 (50-55)	127 (60-65)	169 (95)	79 (1-5)

Life Stress	10 (70)	28 (99+)	8 (60)	4 (35)	13 (82,5)	11 (75)	6 (50)	12 (80)	12 (80)	19 (92,5)	14 (85)	4 (35)	26 (98,5)
Defensive Responding	38	38	19	Error	34	43	19	25	26	38	42	50	20

State Trait Anxiety Index (Raw scores and Percentiles in brackets)

NICU	1	2	3		4	5		6		7		8	9
	M	M	M	F	M	M	F	M	F	M	F	M	M
State	37 (62)	34 (52)	53 (93)	38 (61)	43 (77)	63 (98)	25 (16)	25 (13)	27 (19)	32 (44)	54 (94)	54 (92)	21 (3)
Trait	34 (50)	42 (76)	43 (80)	31 (38)	42 (76)	60 (98)	25 (14)	25 (12)	26 (16)	32 (42)	60 (99)	48 (90)	34 (50)

6.3.1.1 Parent group NICU 1.

Both the mother and father were available for the initial interview which took place 13 days after the birth of their twins, however, only the mother returned completed questionnaires. The mother indicated that initially during the pregnancy she was ill but after four months, the gynaecologist described her pregnancy as being an *"ideal twin pregnancy because both* [of the foetuses] *were in their own placentas…and they* [were] *gaining weight very well."* At approximately 27 weeks, the mother started to experience cramping. She was advised to go to the hospital to monitor the cramps. The mother stated that she was scared as she did not know what was going to happen, and felt unprepared. The gynaecologist on duty indicated that the infants were *"going to come at any time."* The mother was then rushed into theatre for a C-section. The mother described how the birth was traumatic for her due to the urgency as well as needing to have a C-section delivery. Her previous delivery was by natural means. The father mentioned that he could see it was serious but everyone looked confident. The mother expressed that it was *"bad"* that she was not able to hold her infants. The parents said that they did not think there were any complications or problems as the doctor said they were well. Unfortunately, the boy infant passed away the next morning before the mother was able to hold him. The parents were shocked and traumatised by the death of their one infant as they were under the impression that he was doing well because the previous evening he was stable. The mother's trauma is clearly indicated by her statement: *"the first time I was here* [in the NICU]*, it was on ***'s death…I didn't even look at her."* The mother understood that you can never predict outcomes for preterm infants by her statement: *"with preemies it goes* [changes] *from minute to minute."* The mother believes that her age might have been a factor causing the problems. At the interview the parents expressed that they are concerned and scared about their surviving infant but that they worry less everyday as she is doing well.

According to the pre-test results (table 6.3) of the PSI questionnaire, the highest score for the mother relates to her spouse. It is hypothesised that the mother feels she is lacking emotional and active support from her husband. All the other scores fall within the normal range.

6.3.1.2 Parent group NICU 2.

Only the mother (single parent) participated in this study. During the initial interview, ten days after the birth of the preterm infant, the mother explained that this pregnancy was unplanned and difficult compared to her other two pregnancies. The mother ascribes the difficulty to her age. She explained that she was also experiencing a lot of work and family stress at the time. During the first trimester, she did not eat well due to nausea, and indicated that she was tired and *"just a mess."* During the second trimester, the mother stated that she started bleeding. The mother visited the gynaecologist twice, first for bleeding and the second time for severe abdominal pains. Medication was given on both occasions and the mother was sent home. The mother explains: *"I was tense, because that's why I had to come in on those two occasions because I stay on my own most of the time* [live alone]*, so if anything happens I really need somebody to be next to me."* After a few days, the mother stated that her waters broke which was scary for her due to the possible risks of infection. She was alone at the time and explained that she was very scared about the infant's survival. Upon getting to the hospital via ambulance, the mother was given steroids twice to help mature the infant's lungs. This did not ease her worry though: *"I was scared, you know I was worried what would happen to my baby, is everything going to be fine, knowing the complications with prematurity, knowing that sometimes the brain's not developed."* The mother is a nurse and explained that the extra knowledge led to more apprehension for her. The following day the mother had a caesarean delivery and delivered a preterm infant weighing 1038g. The mother was able to hold her infant. Hearing him cry was very emotional and a relief for her.

According to the pre-test (table 6.3) results of the STAI, the mother's trait anxiety score is considered as being high, thus indicating a personality disposition of being prone to anxiety. On the PSI, life stress is high, indicating that the mother finds herself in stressful circumstances which are possibly beyond her control. Health is also a high score suggestive of parental health deteriorating due to parental stress.

6.3.1.3 Parent group NICU 3.

In this family, the preterm infant was the second child born via IVF (in vitro fertilisation). Before the pregnancy, the mother explained, she had various operations which could cause low placenta placement in further pregnancies. According to the mother, the first three months were good, however, at 24 weeks gestation, the mother reported experiencing severe bleeding. The mother reported that she was shocked and that it was very traumatic for her, especially also since her husband was away for work. The mother stated that she passed out due to blood loss. At the time,

the mother explained that she was experiencing a lot of work related stress too. The mother was rushed to and admitted to hospital for a week and then prescribed bed rest. The mother stated that it was *"very hard"* but she managed to complete two months of bed rest, all the while still dealing with work related matters. Bleeding started once again which, the mother explained, caused her to panic: *"I was not ready to have the baby then, because I knew he was going to be little."* The gynaecologist recommended delivery to avoid potential risks to the mother's health. At 33 weeks, an infant weighing 2000g was born via caesarean. The mother reported that: *"it was like being thrown totally off, because I had done no shopping, I was relying on the last three weeks to do things, and also my husband being nervous about work situation…I had no bag packed, nothing, no child's bag, nothing."* To help mature the lungs of the infant, steroids were given at the first hospital admission but not at birth due to the parents concern that the use of steroids while the infant is in utero leads to ADHD. They therefore expected that the lungs *"would be an issue."* The mother was able to hold her infant for a few minutes until he appeared to battle to breathe and then he was rushed to the NICU.

Results of the PSI (table 6.3) show defensive responding on the part of the mother which indicates that the questions were answered in a defensive manner. Caution is thus necessary when interpreting the remainder of the scores (Abidin, 1995). Pre-test scores are below average for isolation, attachment, role restriction, depression, spousal matters and the total parental stress. With regards to the pre-test results of the STAI, high scores were received for trait- and state-anxiety for the mother. Thus, the high trait anxiety score indicates that it is more probable that the mother will experience an elevation in her state anxiety. The father's PSI questionnaire was not fully competed as he did not answer every question and thus cannot be interpreted reliably. Anxiety scores for the father fall within the normal range.

6.3.1.4 Parent group NICU 4.

The mother was mostly involved with the study as the researcher only met the father once. She explained that she had no difficulties in falling pregnant and experienced no complications in her pregnancy up until her water broke. She expressed that she felt sick during the day and the same evening her water broke (26 weeks gestation). The mother expressed that she felt sad and was asking herself *"why?"* The Wednesday the mother went to hospital and the infant was reported to be *"fine."* The mother asked to be discharged on the Friday and went home. The same evening the mother started to experience pain and went back to the hospital. The infant was ready to be delivered and was delivered naturally. The mother was not given the chance to hold her infant. She expressed that she was *"sad, but after being told the baby is fine, she was not worried."* Unfortunately, as the weeks passed by for the little 965g infant, his health deteriorated quickly. He contracted meningitis, was put into isolation and eventually passed away. By then, the researcher had already seen the mother eight times for support.

According to the pre-test (table 6.3) results of the PSI, the mother was experiencing significant stress related to her health, as well as depression. A high score on the health subscale is suggestive of deterioration in parental health that may be the result of parenting stress or another additional independent stressor related to the parent-child system. A high score on the depression subscale is indicative of significant depression in the parent. The impact of depression results in difficulty mobilizing the psychic and physical energy needed to fulfil parenting responsibilities. Withdrawal is a further response. With regards to the pre-test results of the STAI, high scores were received for trait- and state-anxiety for the mother. The high trait anxiety score indicates that it is more probable that the mother will experience an elevation in her state anxiety which is evident.

6.3.1.5 Parent group NICU 5.

Both parents were involved in the study from the initial interview until follow-up after infant discharge from the hospital. Initially, it was a shock to the parents to be expecting twins. After the initial shock, the mother explained that she experienced no complications in her pregnancy; however she was not prepared for the effects in her body as well as getting a kidney stone. Thereafter, pregnancy proceeded as expected. At 30 weeks gestation, the mother started experiencing pain and reported experiencing fear and irrational hope for a *"normal pregnancy."* She expressed that in the previous pregnancy she had complications leading to her first born being induced, and that this occasion she *"wanted to do it right this time."* The mother decided to go to the hospital to be checked and it was indicated that she was in pre-term labour. Medication was prescribed to prevent labour, but after three days, labour started again and an emergency C-section was conducted. The mother admitted that she was experiencing significant work related stress: *"very much so, cos* [because] *it's our own company."* However, pregnancy was described as being unproblematic: *"it was actually an easy pregnancy this time round, I had high blood pressure and everything the first time round* [previous pregnancy]*, but this time nothing, absolutely no complications."* The mother described the birth as being: *"totally chaotic, I was so distracted I couldn't focus on them. I knew it was a case they had to go…I felt so bad cos* [because] *I had so few seconds with them."* The mother felt guilty that they were born early. During maternity care, the mother did not have a private room and therefore just wanted to leave the hospital as soon as possible: *"I felt claustrophobic due to the feeling of being next door in the ward to a mother who has her baby with her."* The mother was worried with regards to bonding and the infants' health: *"you worrying about eyesight, you worry about hearing, you worry about learning and you worry about all of these things."* The father was concerned about the infants being *"happy and healthy."* Delivering two infants and going home without them felt *"surreal"* to the mother.

During the initial interview which took place 18 days after the birth of the twins, it was evident that the mother was still traumatised as she was emotional. According to the pre-test (table 6.3) results of the STAI, the mothers T-anxiety score was high indicating an 'anxiety-proneness'

(Spielberger, 1983, p. 5), which explains the high score relating to S-anxiety. With regard to significant stress, the mother received a high score for isolation, attachment, health, and depression. High scores on the isolation sub-scale indicates parents who are under considerable stress and are often socially isolated from their peers, relatives and other emotional support systems. The high score on the attachment sub-scale may indicate two possible sources of distress. Firstly the mother does not feel a sense of emotional closeness to her infant and secondly, the mother may experience a real or perceived inability to observe and understand her infants. A high score in the subscale, health, is suggestive of deterioration in the mother's health that may be the result of parenting stress or another additional independent stressor related to the mother-child system. Lastly the high score on the depression subscale is indicative of significant depression which results in difficulty mobilizing the psychic and physical energy needed to fulfil parenting responsibilities and leading to withdrawal. Overall, the mother was experiencing significant distress.

The father's pre-test (table 6.3) score on the PSI indicated defensive responding which implies that the sub-scale scores needed to be interpreted with caution. Low scores were obtained for depression, spouse and total parent domain stress. Scores on the STAI for the father fall within the average range. During the initial interview, the father did appear to be more relaxed and laidback regarding the preterm birth and NICU admission.

6.3.1.6 Parent group NICU 6.

The initial interview was conducted with the mother only as the father had work commitments. However, support sessions were conducted with both parents. For this family the pre-term infant was a second pregnancy. Complications were picked up at approximately 20 weeks gestation. The gynaecologist prepared the mother for expected bleeding at approximately 28 weeks gestation. In the 27th week, the mother started to bleed and was rushed to hospital. The mother said that even though the gynaecologist informed them, it was still unexpected and the mother said she was scared and frightened. The mother states that she did not expect to go into pre-term labour. Doctors informed the parents that they need to deliver the baby quickly and within half an hour, they were in theatre and *"I was knocked out."* The mother was given a general anaesthetic. The mother explained the process as being hectic and out of her control. A day later after delivery, the mother stated she woke up in intensive care due to severe blood loss. At that time, the mother states that she was worried about her infant*: "the baby was my worry obviously at that point, but I couldn't get to see him for all the time I was in ICU."* The mother eventually only saw her infant on the 4th day. She expressed that it was *"a bit scary seeing such a small baby."* He was 985g. The mother expressed that she never had a good night's rest and was very irritable in ICU: *"as much as I wanted to see my baby and know everything was ok, I knew the first step was getting myself out of ICU, I think I spent most of the time just wanting to get out of there."* When the mother eventually was able to see her infant she stated that she was *"pretty emotionless for a while"* even though she

"is usually a very emotional person." The mother continues: *"I followed instructions and if anybody had to ask me to do something, I would say I need to sleep. If you had asked me at that point about how I felt about having a premature baby, I would have nothing to say because I was pretty emotionless."* She stated that her emotions seemed to *"kick in"* the following week. The second week was described by the mother as being traumatic because then she realised what had happened to her. Due to logistical reasons, the interview was conducted 26 days after delivery. However, the mother said it was better as she was able to at least communicate with the researcher then. The mother expressed that her way of coping is to keep busy with administration-related matters and that she was concerned about her husband as he was left with everything to do: *"my husband was the one I was worried about, especially from the 2nd week on, it couldn't have been easy on him. By the 2nd week he was worried about everybody else more than me, because I knew, ok, I was on my road to recovery and I know it couldn't have been easy for him watching a wife and child in ICU and he had my 5 year old too."* The mother recommended that the father be involved in the support intervention because she felt he needed to talk to someone other than herself due to the possible trauma he experienced: *"from what I hear, it was quite traumatic because, we were both,* [mother and infant both in intensive care] *I was bleeding, up to a point where they were telling him it was quite critical, so I don't know what he could have thought?"* Overall, the mother expressed that she *feels "emotionally weak, cos* [because] *it's like I am in, I feel like...I don't cry, although I miss him* [the infant] *and stuff like that, but then petty things set me off, you know."* Guilt was also experienced by the mother: *"I felt a little bit of guilt like I have robbed him of some time within me."*

According to the pre-tests (table 6.3) of the PSI, below average scores were obtained for competence and role restriction for the mother. No high scores were evident for the mother. The father also had below average scores for competence and role restriction with no high scores. STAI pre-test scores were in the average range for both the mother and father.

6.3.1.7 Parent group NICU 7.

This family was very happy when they conceived and were pregnant. Six years before the present pregnancy and pre-term birth, the mother delivered a sibling at 25 weeks but she only lived for one day. Thereafter, the mother was diagnosed with full stage kidney failure. After two years on medication, the mother was able to receive a kidney transplant. Eventually, after another year, the mother fell pregnant again. The parents indicated that they were a bit concerned and worried about kidney function and pregnancy but experienced no complications. The pregnancy followed the normal course up until approximately 30 weeks gestation when the mother's amniotic fluid started to dry up and problems with blood flow to the infant was experienced. The mother was clearly traumatised by the death of her first child and was worried: *"we had those problems with our little girl as well about the restriction* [of blood flow]*, it wasn't only the kidney function, we were scared because we thought, oh no, don't let this happen again, 110 things run through your head, just*

breathe, he's fine, his heart beat is fine, so it just gave flashbacks on what had already happened." The parents continually compared the present pregnancy to the previous one which *"freaked us out even more*." The mother was put on bed rest and after two weeks the gynaecologist recommended they deliver via C-section at 32 weeks. The mother expressed that she was extremely scared with having an epidural and caesarean as the first pregnancy she had a general anaesthetic. The father stated that he was nervous with the epidural as they were given a list of risks involved with an epidural. The mother stated that she was: *"freaking out before I heard him* [the infant] *cry."* The mother was able to give him a kiss before he was taken to the NICU. The parents were not worried about bonding issues. During the first few days, when the mother was still hospitalised, the father mentioned that he was worried about his wife and infant as a result of the previous loss*: "knowing what we went through with the first one, he's here* [in NICU], *she's in the hospital, it's worrying about him and worrying about her."* The father mentioned that it was *"very hard"* for him. The mother had to stay in the ICU to monitor kidney function and therefore only saw her infant on the second day which she described as being frustrating. As with pre-term infants, *"he was fine but then it went bad"* and needed to be put onto oxygen and then onto an oscillator. The mother blamed herself for the early birth and both the parents feared for his death.

According to the results of the pre-test (table 6.3) of the PSI and STAI, the only high score for the mother was life stress, which refers to distress associated with stressful situational circumstances which are often beyond a person's control. All the other results fell in the average range for the mother. With regard to the pre-test scores for the father, isolation and life stress were high. It can be assumed that the father was under considerable stress and socially isolated from peers, relatives and other emotional support systems. And similarly to the mother, the father's high life stress score refers to finding himself in stressful situational circumstances which were beyond his control. The STAI pre-test scores for the father indicate high T-anxiety as well as S-anxiety. The T-anxiety score indicates an 'anxiety-proneness' (Spielberger, 1983, p. 5), which explains the high score relating to S-anxiety.

6.3.1.8 Parent group NICU 8.

Only the mother was available to be part of the study. She stated that she was very excited when finding out at six weeks gestation that she was expecting twins. A week later the mother started feeling very *"insecure"* about being able to cope with twins. At ten weeks gestation, the mother started bleeding. The mother indicated she was scared that she might lose the infants and just wanted to know so that *"I can know what to dealt with."* She spent three days in hospital and then returned home. The mother expressed that her pregnancy was difficult as she felt sick with nausea, headaches, a kidney stone, an *"infection somewhere*" and had an anxiety attack. At 25 weeks gestation the mother had a check-up which indicated that she had high blood pressure, was dehydrated and exhausted. The mother was readmitted to hospital. Once again, the mother was

worried about the survival of her twins and just wanted to be out of hospital. She reported being in a lot of pain and felt like she was *"going to die."* However, the mother started having contractions. A C-section was organised and 20 minutes before the procedure, the mother's waters broke. The mother interpreted her waters breaking as God saying its fine for them to be born early. The gynaecologist reported that there was no more space for the twins in the womb. The little boy infant was battling to breathe and thus taken immediately to the NICU. The mother recalled: *"when he didn't scream, it was like, why isn't the boy screaming, please check that the boy is fine, because this one* [girl] *was showing off, she was screaming and fine and did all the tests and all that, so I was a bit worried about him."* The mother was able to hold the little girl infant for a few seconds before the infant was taken to the NICU. The mother reported that she was concerned about bonding with her twins but decided she would touch them, even if she was not sure she could. Another concern for the mother was that the twins were not lying together: *"everyone* [twins seminar] *is telling me like they need to be together…they should be together…are they still going to have a bond if they not lying together, are they going to grow, is it good enough if they are not lying together."* She continued: *"I didn't want to push the nurses to do something they are not supposed to or they don't want to, or feel like they don't know what to do…but still, I had it at the back of my mind."*

According to the pre-test (table 6.3) results of the PSI, the mother had high scores for all of the sub-tests except for isolation, role restriction and life stress. High scores in the competence subscale may relate to the mother feeling that she had a lack of knowledge, limited skills and her role as mother to the twins was not as she had expected. The attachment subscale relates to the mothers sense of emotional closeness to the infants which was lacking for her. Furthermore, the mother may have felt a real or perceived inability to observe and understand the infants' feelings and needs. The high score on the health subscale indicated deterioration in the mother's health as a result of stress. Depression may be related to guilt, unhappy feelings, dissatisfaction with herself and life circumstances which caused the mother to find it difficult to muster the psychic and physical energy to fulfil her parenting responsibilities. High scores on the spousal subscale related to the mother feeling a lack of emotional and active support from the father. Overall the mother had a high score on the total parenting domain stress. According to the pre-test results of the STAI, the mother had significant trait and state anxiety.

6.3.1.9 Parent group NICU 9.

Only the mother was available to participate in this study as the father was taking care of siblings at home in another city. The mother described her pregnancy as being normal where her infant was *"happy, warm and safe."* The mother stated that with her first pregnancy she experienced pre-term labour. For her second pregnancy, the mother explained she was given high blood pressure medication as it prevents contractions. With the present pregnancy, a gynaecologist in the Pretoria area prescribed medication at 32 weeks to prevent contractions. During a check-up appointment,

the gynaecologist at home recommended that the medication be discontinued. Five days later, the mother started to experience preterm labour. The mother explained*: "we trusted him, he told me it would cause damage to her, so we stopped completely and yes, that's when preterm labour started."* The mother knew from experience that it was preterm labour and she indicated that she was relaxed and fine with it. The gynaecologist explained to her that he was happy to deliver at that time. The parents trusted that the doctor had the ability to deal with the preterm birth and thus were not worried. The gynaecologist checked and indicated that there was a problem and the infant needed to be delivered by C-section. The mother was then sedated. The mother was unhappy with having a C-section as she described normal birth as being *"much better"* for her as in the case of her previous two children. She indicated that she would *"never again"* have a C-section delivery. At the time when the mother woke up from sedation, she was told that her infant would be transported to another hospital as there was a strange sound in her lungs. The ambulance took approximately eight hours before it arrived and the mother did not see her infant until *"just before they came to pick her up."* During the time waiting for the ambulance the paediatrician told the mom that *"she* [the infant] *burst her lung into the cavities."* When at the present hospital the mother indicated that *"she* [the infant] *had an infection from the ambulance and her umbilical cord was so dry they couldn't find a line on her."* The medical staff was described by the mother as being wonderful as they were able to *"get her up and running"* on drainage, oxygen, antibiotics and *"everything useful."* The mother described her husband as being furious for the apparent ignorance at birth that there was a problem and the time it took for them to transfer the infant to another hospital. The father was able to hold the infant at birth, noticing that there were problems. The mother only held her infant one week later. The mother described that she arrived to the hospital later and *"was very upset about it, the whole thing…I just wanted to get here, you know be with her, and be able to hold her, I was very anxious to get to her and also to get her some breastmilk so that they can get her feeding, so yeah I was quite anxious about getting here."* When asked about bonding, the mother indicated that she was not really worried about it as she was going to breastfeed, but even holding her was *"good enough"* for her. She also indicated that when she was not able to hold her she would *"sit and read to her books, just so she can hear my voice, just so she can know that I am there, that's also a form of bonding. That's the best form of bonding that you can have with all the tubes sticking out of her."* The mother described herself as a *"go with the flow"* person but her husband as being more emotional and that he did not cope with the whole incident.

The pre-test (table 6.3) defensive responding score on the PSI indicates that the mother answered in a defensive manner and therefore the results should be interpreted with caution. It may also be that the mother is very competent and that the parent-infant relationship exists within an economically advantaged supportive social situation. The only high pre-test score related to life

stress which associated with the mother finding herself in a stressful situation which was beyond her control. Pre-test state- and trait-anxiety scores fall within the average range.

In summation, it is clear that pregnancies can begin as normal pregnancies but complications may arise and thus lead to a high-risk pregnancy. Other pregnancies, such as having multiples, conception through IVF or previous miscarriages, are regarded as high-risk pregnancies from the beginning. Themes of fear, anxiety, stress and uncertainty appear when experiencing complications during pregnancy. High-risk status and other various factors, including stress, may cause preterm birth. The preterm birth is shown to be unexpected and traumatic for mothers. Separation of the infant from the parents is common, and the majority of mothers were not able to hold their infants at birth which concurs with literature (Arnold et al., 2013; Sawyer et al., 2013) as causing distress for mothers.

During the initial phase of the interview, the researcher purposefully used the communication skills of tuning in, listening, empathy, and summarizing to help the parents engage in dialogue. These micro-skills, personal powers, and abilities (McLeod & McLeod, 2011) help establish a working relationship and help the parents tell their stories. In this regard McLeod and McLeod (2011, p. 5) refer to “making space to talk it through.” In this counselling space, stories can be constructed, de-constructed, re-constructed and co-constructed. As mentioned, the first session of the interview was to help ‘jump start’ the helping process (Egan, 2013, p. 20). In addition, as Sloan (as cited in Egan, 2013) indicates, self-disclosure is linked to psychological well-being. Egan (2013) confirms that helping clients tell their stories should not be underestimated. A story that is brought out into the open is the starting point for possible constructive change (Egan, 2013, p. 243). Clarity of the story was gained by asking specific probing questions during the interview.

6.3.2 Change-oriented Phase

In this phase, the admission of the preterm infant into the NICU is the focus of the support intervention. Education and information regarding the NICU and the preterm infant were used to empower parents and various intervention techniques were used to develop parental awareness with regards to current feelings, coping, and need satisfaction. Through the use of intervention elements it was hoped that the elements of well-being, in other words, comprehensibility; positive relationships; engagement; manageability; accomplishment; positive emotion; self-acceptance; and meaning would be developed. Content covered and the number of contact sessions with the various parent participants can be seen in table 6.2.

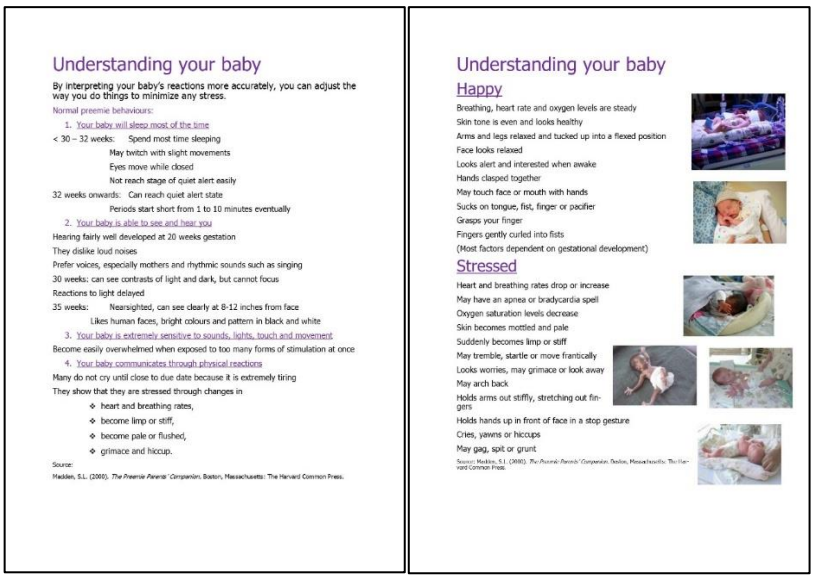
6.3.2.1 Information and education.

As outlined in chapter three comprehensibility is the extent to which people perceive stimuli as making cognitive sense, in other words, information is ordered, consistent, structured, and clear (Lindström & Eriksson, 2005). People with high comprehensibility expect that the stimuli they

encounter will be predictable, ordered, and explicit (Antonovsky, 1987). Comprehensibility was developed through the use of **education and information** regarding the NICU and the preterm infant in the support intervention. All of the parent participants were provided with education and information. A4 posters covering the following topics were developed by the researcher:

- Frequently asked questions, such as length of hospitalisation, need for blood tests, routines of hand washing etc.;
- NICU equipment commonly used;
- Understanding your baby by interpreting infant behaviours to minimise stress;
- The use of positive touch to calm, stabilise and bond;
- Sleep and awake states to protect sleep;
- Therapeutic positioning; and
- Developmental stages.

Parents did not express many words when given information but confirmed listening and understanding with their non-verbal behaviour. Parents expressed understanding when they saw evidence of the behaviour in their preterm infant that had been discussed in education regarding 'Understanding your baby': *"I have seen him twitch when someone is saying something* [loud]" *and "yeah a few times when we are carrying him and if somebody opens the cupboard door, he jumps"* (NICU 6). With regards to the psycho-education component, 'Understanding your baby' (addendum M) one mother confirmed what had just been explained: "*I saw yesterday when we dressed this one* [one of a twin]*, he was actually looking at the stripes…now it makes sense"* (NICU 8).
'Understanding your baby' covers information related to normal preterm infant behaviours as well as how to identify if the infant is happy or stressed.


Understanding your baby

By interpreting your baby's reactions more accurately, you can adjust the way you do things to minimize any stress.

Normal preemie behaviours:

1. Your baby will sleep most of the time

< 30 – 32 weeks: Spend most time sleeping
May twitch with slight movements
Eyes move while closed
Not reach stage of quiet alert easily

32 weeks onwards: Can reach quiet alert state
Periods start short from 1 to 10 minutes eventually

2. Your baby is able to see and hear you

Hearing fairly well developed at 20 weeks gestation
They dislike loud noises
Prefer voices, especially mothers and rhythmic sounds such as singing
30 weeks: can see contrasts of light and dark, but cannot focus
Reactions to light delayed
35 weeks: Nearsighted, can see clearly at 8-12 inches from face
Likes human faces, bright colours and pattern in black and white

3. Your baby is extremely sensitive to sounds, lights, touch and movement

Become easily overwhelmed when exposed to too many forms of stimulation at once

4. Your baby communicates through physical reactions

Many do not cry until close to due date because it is extremely tiring
They show that they are stressed through changes in
- heart and breathing rates,
- become limp or stiff,
- become pale or flushed,
- grimace and hiccup.

Source:
Madden, S.L. (2000). *The Preemie Parents' Companion*. Boston, Massachusetts: The Harvard Common Press.

Understanding your baby

Happy

Breathing, heart rate and oxygen levels are steady
Skin tone is even and looks healthy
Arms and legs relaxed and tucked up into a flexed position
Face looks relaxed
Looks alert and interested when awake
Hands clasped together
May touch face or mouth with hands
Sucks on tongue, fist, finger or pacifier
Grasps your finger
Fingers gently curled into fists
(Most factors dependent on gestational development)

Stressed

Heart and breathing rates drop or increase
May have an apnea or bradycardia spell
Oxygen saturation levels decrease
Skin becomes mottled and pale
Suddenly becomes limp or stiff
May tremble, startle or move frantically
Looks worries, may grimace or look away
May arch back
Holds arms out stiffly, stretching out fingers
Holds hands up in front of face in a stop gesture
Cries, yawns or hiccups
May gag, spit or grunt

Source: Madden, S.L. (2000). *The Preemie Parents' Companion*. Boston, Massachusetts: The Harvard Common Press.

Figure 6.2: Understanding your baby (developed by researcher based on Madden, 2000)

A father (NICU 7) stated that *"I couldn't hold him today, he is just not happy"* after being given information regarding the 'Developmental stages' (addendum M). After discussing 'developmental stages' (addendum M), a mother (NICU 1) confirmed seeing her infant in one stage: *"I have seen her do that a few times."* Another mother did not understand all of the common equipment used in the NICU: *"no…I don't know about it* [the CPAP]*"* (NICU 6) which was then explained to her. With regards to the 'Sleep and Awake States' (addendum M) a mother (NICU 3) mentioned *"we have actually seen him at that stage."* A father (NICU 6) mentioned that he was looking for information on the internet but as there are no medical facts he gave up with that means of gaining information. He continued stating that it can also set certain expectations which can be worrying: *"I read some more stuff and some of it is quite worrying if you start thinking about it, so I gave up on that"* (NICU 6-father). After providing information to the mother when the father was absent due to work commitments, the father (NICU 6) requested that the researcher repeat the information to him regarding 'understanding your baby' (addendum M) and the 'sleep and awake states' (addendum M). The father confirmed that he had seen his infant being stressed: *"yeah he does that and we have seen that"* (NICU 6-father). Further information regarding positioning and bedding being rolled gave a father (NICU 6) further insight and understanding.

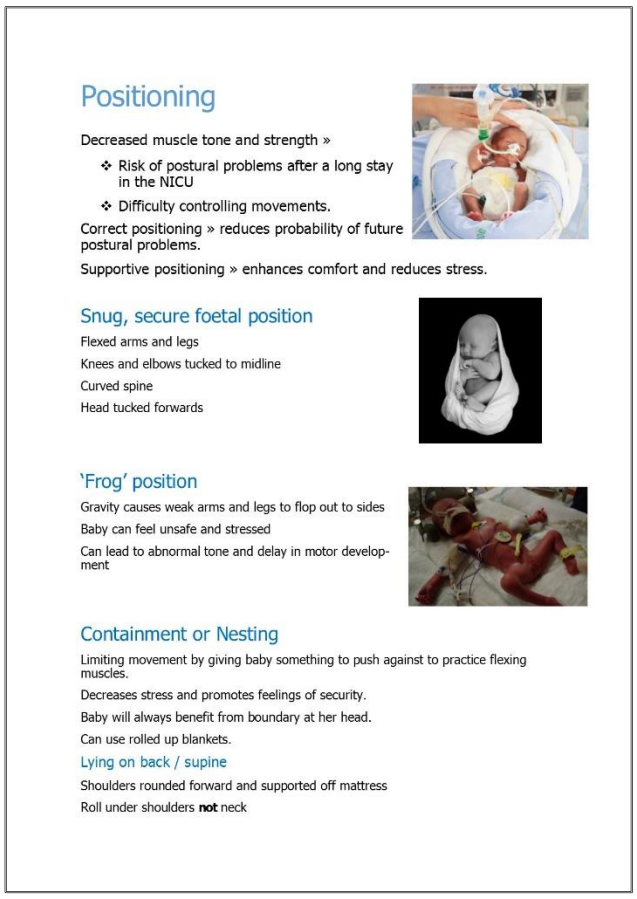
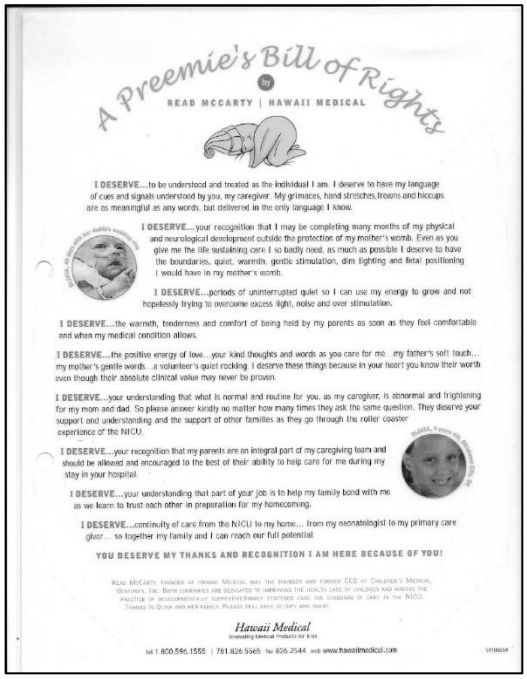


Figure 6.3: Correct positioning of preterm infant based on Lubbe (2008) and Weaver (2014)

By providing information regarding the infant, it is hoped that parents can feel more involved and engaged with their infants, by performing activities such as helping decrease stress in their infant, positioning the infant therapeutically and protecting sleep. This aligns with the core measures of FCDC. In addition, engagement may lead parents to feel less like onlookers but rather more like competent, confident parents (Cooper et al., 2007; Fenwick et al., 2001). Engagement and improved competence and confidence can foster well-being in parents.

The 'Bill of Rights' for a preterm infant (addendum M) was worked through with both parents of NICU 5 and two mothers (NICU 1,3) as an introduction and a brief summary of the preterm infant. The 'Bill of Rights' provides a quick overview of educational matters relating to a preterm infant such as, among others, understanding the preterm infant, developmental needs, and expected experiences of parents. It was used as an introduction with NICU 3 as her infant had only been in the NICU for one week. The mother became emotional and stated that it was *"so sweet."* With another mother (NICU 1) the introduction initiated a conversation about her fears relating to medical procedures, the competence of the nursing staff and procedures in the unit. The conversation moved forward and made provision for the mother to develop an awareness of her own situation with gratitude: *"most parents that lose their child don't have another one, to get them out of their* [grief] *to make them up, so she is my little miracle"* (NICU 1).



A Preemie's Bill of Rights

by

READ MCCARTY | HAWAII MEDICAL

I DESERVE...to be understood and treated as the individual I am. I deserve to have my language of cues and signals understood by you, my caregiver. My grimaces, hand stretches,frowns and hiccups are as meaningful as any words, but delivered in the only language I know.

I DESERVE...your recognition that I may be completing many months of my physical and neurological development outside the protection of my mother's womb. Even as you give me the life sustaining care I so badly need, as much as possible I deserve to have the boundaries, quiet, warmth, gentle stimulation, dim lighting and fetal positioning I would have in my mother's womb.

I DESERVE...periods of uninterrupted quiet so I can use my energy to grow and not hopelessly trying to overcome excess light, noise and over stimulation.

I DESERVE...the warmth, tenderness and comfort of being held by my parents as soon as they feel comfortable and when my medical condition allows.

I DESERVE...the positive energy of love...your kind thoughts and words as you care for me...my father's soft touch... my mother's gentle words...a volunteer's quiet rocking. I deserve these things because in your heart you know their worth even though their absolute clinical value may never be proven.

I DESERVE...your understanding that what is normal and routine for you, as my caregiver, is abnormal and frightening for my mom and dad. So please answer kindly no matter how many times they ask the same question. They deserve your support and understanding and the support of other families as they go through the roller coaster experience of the NICU.

I DESERVE...your recognition that my parents are an integral part of my caregiving team and should be allowed and encouraged to the best of their ability to help care for me during my stay in your hospital.

I DESERVE...your understanding that part of your job is to help my family bond with me as we learn to trust each other in preparation for my homecoming.

I DESERVE...continuity of care from the NICU to my home... from my neonatologist to my primary care giver... so together my family and I can reach our full potential.

YOU DESERVE MY THANKS AND RECOGNITION I AM HERE BECAUSE OF YOU!

Hawaii Medical

Figure 6.4: A Preemie's Bill of Rights (McCarty, n.d.)

Further information was provided to parents (NICU 1, 2, 5, 6, 8) who indicated problems with siblings at home (addendum N). Understandably, changes in the microsystem (Bronfenbrenner,

1979) caused some siblings to act up. Information notes were also provided to mothers (NICU 1, 4) regarding the grieving process (addendum O).

6.3.2.2 Psycho-education.

The Cycle of Experience, and a theory of Fundamental Human Needs, were used as part of psycho-education.

Cycle of Experience (COE).

The COE is used as psycho-education for parents. Discussing the COE with the parents allows the parents to develop an awareness of their needs, of potential ways of coping and how their behaviour may be possibly limiting the satisfaction of their needs. One mother (NICU 8) identified unmet needs and showed understanding of the cycle of experience as relating to her needs that are not satisfied: "it [need for affection] is going to keep popping up." Another mother (NICU 5) described that "finishing projects, putting something to order…completing goals…ticking boxes" gives her pleasure. This is indicative of the COE in use.

The COE was also used as an introduction to the A-Z alphabet discussed later, to gain awareness of parents' feelings, concerns, and needs. It was also used vice versa as a way of showing how the emotions listed in the alphabet can be dealt with to enhance coping.

Fundamental Human Needs.

Max-Neef's (1992) outline of fundamental human needs was used with two mothers (NICU 6, 8). One mother (NICU 6) stated that she was happy to talk to the researcher alone as she wanted to say certain things which she felt she could not do in front of the father. The mother spoke about her needs being related to her family's lack of understanding, lack of leisure time, rescindment of her identity and problems with her other child. The mother felt that she could freely express these needs due to the father not being present as he was not aware that she had these feelings.

Another mother (NICU 8), after discussing the COE, described a number of needs not being met that *"just keep popping up,"* such as protection and leisure time. However, one need which was more important than the other needs was the need related to affection. The mother stated that due to the time and effort spent in the NICU, her need for affection may not be satisfied: *"I don't think it's actually his behaviour, it's mine…I think I am just busy with everything else and basically I have had no time for anything else, so yes had it been a normal situation, it would have been fine, but it's not…so then I don't want to be affectionate at all because I don't have energy."* The researcher explained, using the theory of Max-Neef (1992), what actions and settings could possibly satisfy these needs. The mother and researcher discussed possible solutions to satisfy her needs.

6.3.2.3 The Pit Metaphor.

The Pit Metaphor (see chapter 5) was used to determine goals and provide a structure for progress. It was used with the majority of the parents (NICU 1, 2, 4, 5, 6, 8, 9) but at different stages in the support intervention. The researcher regarded it as being necessary at different times in the intervention process due to the parent's particular needs and the preterm infant's medical status. The Pit Metaphor was used early in the intervention process with some parents, such as during the first session after the infant had been in NICU for two weeks (NICU 9), in the second session after one and a half weeks admission (NICU 8) and after five weeks admission but then only in the second session (NICU 6). Others were later in the intervention process due to matters such as allowing parents to vent current emotions or providing education first and for logistical reasons such as lack of sufficient time. Later sessions were for parents NICU 1 (session 5 – eight weeks after birth); NICU 2 (session 7 – six weeks after birth), NICU 4 (session 6 – six weeks after birth), and NICU 5 (session 7 – five weeks after birth).

Most mothers (NICU 1, 4, 5, 8, 9) indicated that they placed themselves at zero (at the bottom of the pit) at the time of the birth. A father (NICU 6) also indicated that he was at zero at the time of birth and for the first few days, as his wife was in intensive care at the time. One mother (NICU 1) explained her placement of being at zero in the pit but also paradoxically being 'safe' by her self-generated metaphor of being in a bubble: *"I think when I just went home, after everything, obviously the first week was very difficult because I knew the funeral was coming…even after that a little bit. I think it was a period where I was like, especially with the funeral, we had everyone's prayers carrying us, I almost felt like I was in a bubble, protected and okay and then after that it's like almost the reality hit."* Similarly, another mother (NICU 5) mentioned that the reality of it all caused her to place herself at zero: *"at the birth and then just after actually, when you start realizing its happened, the difficult situation you are in and suddenly realizing that you, what's happened, reality…they are here, they are prems, and everything I didn't want."* Another mother (NICU 8) mentioned that she was at zero when leaving her infants in NICU for the first time to go home after the birth.

One mother (NICU 1) had put some thought into the Pit Metaphor and made an interesting comment regarding her placement in the pit at her next session. Initially she said the ropes of her support reached her but at the next session she said the ropes did not reach her as she had some responsibility for getting out of the pit: *"I think in some way, no one's ropes reaches me or are able to reach me because in some way I feel I also need to help myself to get out of that the situation, no one is able 100 percent to get myself out of there, I also need to will myself… that it's my responsibility to also try and stay positive and focus on the positive things to get out of the pit, it's no one's responsibility, no one can really stand in for me emotionally, in a way they can help me, but in*

a way they can't." This can be indicative of the mother developing an awareness of the need to use her own internal resources.

Another mother (NICU 2) responded differently indicating that she was fine at the birth and admission to the NICU: *"I would say at 10, reason being I was filled with uncertainty because you know after the waters broke I wasn't even sure if he was fine and then just hearing him cry was just great…and then I came here, I was still at 10 because everything was fine for about a few days."* However, the mother's placement dropped to zero when: *"he started regressing, or what should I call it, with the oxygen and stuff…they told me he was transfused and then he was on photo therapy and then zero, I just went to zero and I read about it and I know that premature babies sometimes they need photo therapy and they need transfusion because* [of the lack of] *blood."* After the setbacks with her infant she stated that *"from then I have never been at 10 honestly, have been up* [and] *down but not 10."* This is illustrative of the common roller coaster experience in the NICU.

Most mothers (NICU 1, 2, 4, 5, 9) indicated that their husband or partner was there for their support. Other significant people were grandmothers, nursing staff, friends and family. One mother (NICU 2) mentioned that the researcher was one of her supports.

A mother (NICU 8) who placed herself at a level of five indicated that certain factors such as *"knowing that they like safe and like better off here and looked after"* had improved for the positioning in the pit to change from a zero to five, however, she was still very tired having to deal with expressing breastmilk: *"expressing is like taking so much out of me…yes sterilizing, I just want to throw everything away."* The same mother indicated that her husband was at a level of six due to added responsibilities: *"definitely not himself, because now he has to look after the other one and you know help with all the stuff, because I am mostly expressing, she* [sibling] *needs to bath and yes, so all the chores and responsibility…yes, he needs to bring the milk in the morning and stuff like that, so definitely has extra stress on himself, and still his work and stuff to do."*

Various methods were indicated by the mothers and one father, as helping them get out of the pit which had worked previously with problem situations: having eye-to-eye conversations with their spouse (NICU 1); expressing and discussing emotions (NICU 2); understanding problems related to the preterm infant (NICU 4); making plans to pre-empt further problems (NICU 5-mother); asking questions and getting information (NICU 5-father) and spending more time and communicating with her husband (NICU 9).

Some mothers (NICU 5, 8) and a father (NICU 6) indicated that they would be able to be placed at ten and out of the pit when their infant is home. This is explained in the following words by a mother (NICU 5): *"getting them to my home environment where I am comfortable as well, because this is not a comfortable environment. You are not quite sure what's expected of you, you are not sure if by being away you are helping and every day is different…there is a lot of uncertainties about*

this environment…just to get home again. I know when they come home there will be less sleep, there will be less everything but somehow its comfort zone." A different response was indicated by another mother (NICU 8) who revealed that she could be placed at ten while her infants were still admitted to the NICU: *"maybe I will get to a 10 if it's like around about 24 hours breastfeeding, they are fine and they have no setbacks."*

In sum, the Pit Metaphor, worked well as a scaling technique and gave the researcher an indication of the parent's level of stress. It was also useful in helping parents to think of, and become aware of who they could use as resources for social support. Furthermore, parents became aware of the progress they had made since admission of their infant into the NICU. Through this process, the parents' attention is focused on possibilities, solutions, and resources and on what is functioning well and thus can be regarded as using a salutogenic approach with the parents.

6.3.2.4 Awareness techniques.

The A-Z healing and hurting alphabet and the Miracle Question were used to develop awareness. As mentioned in chapter five, the awareness of the parent's own situation, needs, strengths and resources is encouraged in the parents.

A-Z healing and hurting alphabet.

In conducting this technique (see chapter five) parents are provided an awareness of their thoughts, feelings, desires, concerns, and needs. With this self-examination, a salutogenic perspective is developed (Langeland & Vinje, 2013). The A-Z was conducted with three sets of parents (NICU 4, 6, 7) and three mothers (NICU 1, 8, 9). The responses of the parents to the A-Z alphabet are seen in table 6.4

Table 6.4:

Healing and hurting alphabet

Key: 1 = NICU mother 1 4 = NICU mother 4 6m = NICU mother 6 6f = NICU father 6 7m = NICU mother 7 7f = NICU father 7 9 = NICU mother 9	**A** Angry (1) Anxiety (6f, 9) Amazement (7m) Appreciation (8)	**B** Boy (1) Breathing (6m) Breathing – we can Breathe again (7m) Breastfeeding (8)	**C** Cry (1, 6m, 7m) Conflicting emotion (1) Concerns (7m) Chores (8) Comfort (8) Conscientious (9)
D	**E**	**F**	**G**

Down (1) Deprived (1) Development (6f) Drool (7m) Disappointment (7m) Discipline (7f) Damsel in distress (8)	Emotional (1) Excited (1, 6f) Experienced (4) Enough-milk, good enough? (7m) Envy (8)	Feelings-mixed (1) Future (6f) Fear (7m) Frustration (7f) Feelings-emotional (8) Funny (9)	Guilt (1, 7m) Glad (1) Grace (8) Grateful (9)
H Hope (1, 6f) Happy (4, 6m, 7m) Home? (6m) Help (8) Helpful (9)	**I** Impossible-to change anything (1) Impatience (6m) Immunisations (7m) Innocence (8)	**J** Jealousy (1, 7m, 7f, 8, 9) Jealousy-going home (7m) Joy (7f)	**K** Keeping-at home (7m) Kindness (8)
L Looking forward (1) Laughter (7m) Love (7m, 8) Long time-in hospital (9)	**M** Miracle (1) Maternity leave (6m) Mommy (7m) Money (8)	**N** Nurture (7m) Night times (8) Nervous-won't take home (9)	**O** Optimistic (1) Okay (4) Oxygen (6m) Observing-watching (7m) Options (8) Open-minded (9)
P Precious (1) Positive (1) Pure joy (7m) Perfect (7m) Patience (8, 9) Personal (9) Progress (9)	**Q** Question-what's point of having twins (1) Questions (7m) Quietness (8)	**R** Responsible (1) Relief (6f, 7m) Resting (8)	**S** Sleep (1, 7m, 8) Special (1) Strong (4) Scared-not going home (7f)
T Time (1, 8) Thankful (1) Triumph (7m) Tired (8)	**U** Understanding (7m, 8)	**V** Void (1) Voluntary (7m)	**W** Wish-turn back time (1) Worries-cope? (6m) Wondering-cope? (7m) Watch (8)

X	**Y** Yes we can (7m)	**Z** zzz-sleep (7m)	

With an analysis of the parental responses on the alphabet, it is seen that there are common emotions among a number of parents. These are: anxiety; focus on breathing in the infant; crying; excitement, guilt; hope; happiness; jealousy; questions; relief; and sleep issues. Anxiety with regards to the future and worrying about the infant's development was expressed by a father (NICU 6). With regards to breathing one mother (NICU 6) stated that *"oxygen for breathing,* [is all she] *think*[s] *about when I come in here,"* whereas another mother (NICU 7) stated that breathing is no longer a problem but *"it's a relief"* and they can breathe again too. Crying is mentioned by three mothers (NICU 1, 6, 7) clearly indicating their emotional status. Excitement was experienced by one mother (NICU 1) due to the fact that she would hopefully be going home soon: *"yes,* [I am] *thankful for her obviously, I am glad she is doing so well, I am just happy and I am excited for her to come* [home], *I think her time is coming closer and closer."* Excitement was also experienced by a father (NICU 6) but for different reasons: *"I am also happy and excited as well, to have a child and going through it again…grow him up and all of that."* As was seen with the veteran parents, guilt is common among mothers. Jealousy of other mothers going home is another common emotion experienced by three mothers (NICU 1, 7, 9). One father (NICU 7) asked if it was normal to be jealous of his wife. The mother explained that: *"we are almost jealous over each other, over him."* This indicates to the researcher the involvement and eagerness of both parents to have contact time with their infant. A mother (NICU 7) mentioned the word "questions", which related to questioning the reasons behind the early birth and the whole process of being in an NICU.

On the more positive side, hope (NICU 1, 6) and happiness (NICU 4, 6, 7) is experienced by the parents: *"yes, I am feeling hopeful. But I still feel guilty about ***"* (NICU 1). Hope can be regarded as a psychological resource (Hobfoll, 2002) and has been defined as a human strength (Cheavens & Ritschel, 2014). As mentioned earlier, individuals high in hope anticipate greater well-being and may be able to deal with stress more successfully (Rand & Cheavens, 2009). Relief is experienced by both a mother (NICU 7) relating to her infant, and a father's relief relates to his wife and infant: *"I was relieved that she is better and that he is growing" (NICU 6).* Overall, there are many negative emotions but there are also positive and healing emotions such as: amazement; gratefulness; joy; love; laughter; optimism; thankfulness; and triumph. One mother (NICU 6) describes how when she looks at her infant, *"he is quite encouraging and hopeful."*

In sum, this technique was an easy and quick way of clarifying the parents' thoughts of having a preterm infant and being in the NICU. Through the words mentioned it is evident to the researcher that there are themes of adverse as well as protective emotions. Concerns of the parents were also indicated and discussed.

Miracle question.

The Miracle Question (see chapter five) was used as a means to determine parental goals and how the parent would want things to be different. The miracle question was used with four mothers (NICU 1, 2, 4, 8) and one set of parents (NICU 5). For two mothers (NICU 1, 5), the miracle question did not work as well as expected as the mothers' response was a wish to undo the past. For example, one mother (NICU 5) indicated that she wished she was still pregnant and the whole *"hospital thing would be gone."* However, with a few mothers (NICU 2, 4, 8) the miracle question was more current and future directed. Mother, NICU 4, stated that it would be a miracle *"to see* [her] *baby is okay"* and *"taking him home."* Another mother (NICU 2) indicated a more medically related answer: *"I would want to be with him at home, off oxygen because they told me that there is a possibility that I could take him with the oxygen but I wouldn't want that, I would accept it but I can't be hoping for it, no."* It is evident and understandable that most mothers (NICU 2, 4, 8) wanted to take their infants home.

6.3.2.5 Positive themes generated in the change-oriented phase.

Through conversations and activities with the parents in the support intervention, it was evident that certain positive themes were emerging.

Strength

A mother (NICU 6) expressed her and her husband's strengths poignantly: *"it's a conclusion, life is precious, we have got a new life we need to take care of and I almost lost my life cos* [because] *it's a realisation, life is short, it's precious - we look after it, we do our best and we move forward, we are not going to let anything drag us down…and, you know the other thing, when we going through all of this, you know I can proudly say *** and I, we have strength, our family, I have my mom but ultimately is was us, we had to cope."* Compton and Hoffman (2013) indicate that a coping strategy for a person is determined by a unique combination of personality and situational variables. Resources such as physiological (better health status), psychological (greater subjective well-being) and social (social support) can aid in effective positive coping.

Hope

As mentioned, individuals experiencing hope, anticipate greater well-being and may be able to deal with stress more successfully (Rand & Cheavens, 2009). A number of parents (NICU 1, 6, 7) mentioned that they experienced hope: *"yeah I am feeling hopeful…but I still feel guilty" (*NICU 1);

"what I hope for is actually that we end up in the same path [normal as their friends' preterm infants] *like you know that everything goes right"* (NICU 6).

Meaning

As mentioned, meaning has been described by Steger et al. (2013) as being a central concept to PP. Relationships and accomplishment are based on the significance to the person, as can be seen in the following mother's statement: *"definitely not a normal experience but I normally feel that God puts you in a situation to help other people in any case, so I mean being here, I will probably use it to my advantage somewhere else"* (NICU 8). In addition, as stated by Steger et al. (2013), positive emotions and engagement lead to well-being only in the context of meaningful pursuits. Meaningful pursuits are seen in the following comments: *"*** was there for a reason, she saved my life"* (NICU 7) and *"I think they are all little miracles when they are born like early and stuff…he is our miracle baby this one"* (NICU 6-father). Compton and Hoffman (2013) explain that Viktor Frankl, a psychiatrist imprisoned in the Nazi concentration camps of Auschwitz and Dachau during World War II, believed that the creation of meaning must be a major criterion of the good life, in other words, a life of well-being, which is the aim of this research study.

Optimism

Optimism is related to well-being in that expectations of positive outcomes in the future foster better coping strategies concerning stress (Compton & Hoffman, 2013). Statements by parents (NICU 1, 5, 8) indicate optimism: "*now I can actually look forward* [to the future] *as opposed to taking each day"* (NICU 5) and *"I can go through this…I didn't think it was possible"* (NICU 8).

Positivity

As stated earlier by Seligman (2011), optimism can be learned if a person can focus on being more positive. One set of parents (NICU 6) and a mother (NICU 1) indicated that they were positive. The mothers state as follows*: "this is one of the worst years of my life…but also one of the best years. I always wanted a little girl"* (NICU 1).

Gratitude

Stated by Wood, Maltby, Gillett, Linley, and Joseph (2008, p. 854), "gratitude is perhaps the quintessential positive psychological trait, as it involves a life orientation toward the positive in the world." According to Compton and Hoffman (2013) and Guse (2014) research has indicated that gratitude has importance in contributing to well-being and that greater appreciation is one effective means of increasing positive relationships and thus creating a sense of meaning. Various parents (NICU 1, 6) expressed gratitude: *"I really am just so thankful to be honest with you, because the*

mom in the corner had been here for a year and I am just thinking I have nothing to complain about" (NICU 1) and *"now it feels like having a baby"* (NICU 6).

In sum, even though the parents were still situationally in a place of crisis, elements of well-being were starting to become evident.

6.3.3 Termination Phase

In this phase, the researcher had planned to provide education and information regarding going home, however all the parents but one (NICU 9) were discharged at times where the researcher was not present and without enough forewarning. Parents described how fast discharge was*: "it still surprised me when she came home and she wasn't 2 kilograms yet…I wasn't expecting it to happen at that point, I was expecting the following week or the week after…it all happened so fast…you are packing up their lives basically from the unit to bringing them home, so it's all the practical stuff, at that point it overwhelms you" (NICU 5);* and *"at the time of discharge, it was quite chaotic because it happened all so suddenly because you know, you still think you going to be there for a while"* (NICU 3).

Due to the infants being discharged without the researcher being present, the majority of the assessments took place after the parents (NICU 1, 2, 3, 5, 6, 7) were already home with a follow-up interview and post-test. Three mothers (NICU 4, 8, 9) were not interviewed at home. NICU 9 was interviewed while still in the NICU and going home the same afternoon. NICU 8 was interviewed in hospital as her infants were re-admitted to the pediatric ward for pneumonia. The infant of NICU 4 passed away unexpectedly and the mother did not want to see anyone. The researcher tried to contact the mother but she was not interested in seeing anyone at the time and therefore no follow-up interview was able to be completed with her. All interviews were conducted with mothers except NICU 5 where the father was also present. Interview questions related to coping in the NICU, coping at home, possible difficulties at home as well as support needs during the various phases of preterm birth and hospitalization of the infant.

Problems that were being experienced at home by the mothers included feeding-related problems, needing an extra pair of hands to help, lack of sleep, and health issues. One mother (NICU 8) mentioned that *"not knowing if they are actually ill"* caused her to be *"very scared about them, I feel like a bit uneasy,* [I] *am always so scared of,* [that] *something is going to happen."* The researcher became aware of two sets of parents (NICU 5, 8) who had their infants re-hospitalised due to health issues.

Further questions in the last interview related to coping at birth, admission to the NICU and discharge. The mothers reported various coping skills while their infant was in the NICU. Two mothers (NICU 1, 8) reported that they had no choice but to cope. This is reflected in their

comments*: "I can't remember how did I do it, like I just did it" (NICU 8)* and *"I think I was just in survival mode because thinking of it, and realizing it was 80 days, how did we manage, how did I get the time to pass, it's like I don't know how, it's like I am in a daze."* The same mother reported *"I just did what I had to do at the time…I don't know, you don't have a choice"* (NICU 1). One mother (NICU 2) reported that *"taking each day as it comes, and like talking to people, vocalizing how I was feeling,* [and] *my fears. I was scared most of the time, especially when I went home,* [I was] *not sure what's happening, if he is breathing you know, but I was talking about it."*

Various needs for support were mentioned relating to the time before the birth, such as needing more information on the medical condition the mother suffered from, and what to expect when having a multiple birth. One mother (NICU 9) indicated she needed her husband to be present during preparation for delivery. Mothers (NICU 1, 2, 5, 8, 9) indicated that they did receive support during the birth from their husbands and family. One mother (NICU 5) explained she received support from her doctor even though she was denying the reality of the preterm birth: *"I was blocking it out. Everything was going to be absolutely perfect. I decided positive thinking this time, not my normal nature. Even when I was in preterm labour and they wanted me to go to theatre, I said no, I am not going to, this is going to come right. That's how forceful I was, I was ignoring it completely."* The doctor provided support to this mother: *"*[she] *was brilliant because she explained the different birth, we are going to do this, we are going to do that, which is different from the previous Caesar, so she went and explained what was going to happen to the babies, don't expect a full cry, don't worry the baby will be out. You know she made a point of showing them to me before she took them away. She said we are not going to let you hold them but you are going to see their faces…I didn't need any more support because she was wonderful"* (NICU 5).

Needs relating to admission to the NICU included preparation for the admission. One mother (NICU 5) explained: *"I think if I had been more prepared for neonatal, I would have been less overwhelmed."* The same mother reported that it is a scary place but also a place where miracles happen and a place where you develop hope. Further needs vocalized by mothers while in the neonatal unit included various topics such as: care-taking of siblings; wishing to *"have a normal day, maybe going to the movies or lunch, you know without having to feel guilty about it"* (NICU 1); and transport to and from the hospital. One mother (NICU 3) who the researcher only managed to see twice before a sudden discharge, needed more information on policies, routines, breastfeeding and why certain procedures are recommended in the NICU. This mother's need confirms the necessity for information and education.

No support needs were indicated at the time of discharge by the mothers except one mother (NICU 8) who explained she needed more information regarding her infant's proneness to having apnea attacks: *"I would say, like especially with him. I didn't know that he had a type of apnea. When he*

came back [to hospital], *I had to ask them what's the signs of it were. I mean they knew he had issues with his oxygen, because he was on oxygen for so long, so I would have said they should have told me ok, if he has another loss of oxygen or whatever, then this and this would affect him. So a little bit more information on apnea."*

With regards to the support intervention offered by the researcher, all the parents interviewed indicated that they were thankful for the support. Some expressions relating to this point include: *"it was very helpful to know that there is someone there that has been through something similar and you are able to relate and you are there if I really need someone to talk to"* (NICU 1); *"I am very impressed because you were there, you showed me what to look for and you offered yourself that if I had any problems, I should just ask"* (NICU 2); *"yes, it did [help] definitely…I think putting the whole premature thingy into perspective"* (NICU 3); and *"I think it's really positive, just being able to talk to someone and understand the environment and understand what you going through…so yes, being able to talk, being able to ask questions. Sometimes you just get a little bit frustrated by the situation"* (NICU 5) and *"I think it helps because then you actually think about it, you get to process your thoughts, you really get to think about the stuff you have gone through, how you really feel about it, because if you don't talk about it then you don't really know what's going on in your head."* (NICU 9).

The researcher questioned whether there was anything that should be added to the intervention. Some mothers indicated that nothing should be added. Others indicated a support group of other parents (NICU 2), and a type of 'road map' of the process (NICU 5). One mother (NICU 1) mentioned that she appreciated the reading material provided regarding help with siblings and the grieving process however, she suggested that *"maybe more reading material…short and sweet bits of information that you don't have to go read through a book…the stuff you gave to me I found very helpful"* as reading the book she had bought was *"just too much"* for her (NICU 1). Further topics suggested by this mother was *"what to expect, as she is growing a little bit, like those different time frames*" and *"what to expect when you get home"* (NICU 1). As mentioned, the researcher did not get the opportunity to provide discharge information to the parents due to the lack of information provided to the researcher regarding the timing of the discharge.

6.3.3.1 Post-test scores and discussion.

The PSI and STAI were re-administered to the available parents at home after discharge of the infants from the NICU. Even though it was planned for the questionnaires to be administered before discharge, the researcher continued to use the questionnaires as an indication of the parent's level of well-being and state of mind. The scores are provided in table 6.5.

Table 6.5:

Post-test scores of the PSI and STAI

POST TEST													
Parenting Stress Index (Raw scores and Percentiles in brackets)													
NICU	1	2	3		4	5		6		7		8	9
	M	M	M	F	/	M	F	M	F	M	F	M	M
Competence	35 (85)	33 (75)	26 (35)	/	/	31 (65)	23 (20)	30 (60)	/	36 (87,5)	32 (70)	44 (98)	16 (2,5)
Isolation	14 (70)	15 (75)	7 (5)	/	/	21 (97)	13 (60)	18 (90)	/	13 (60)	21 (97)	15 (75)	6 (1)
Attachment	15 (80)	12 (50)	8 (10)	/	/	17 (90)	13 (65)	15 (80)	/	10 (25)	16 (85)	19 (96)	7 (1)
Health	13 (70)	12 (65)	9 (20)	/	/	12 (65)	12 (65)	18 (92,5)	/	12 (65)	19 (95)	21 (99+)	9 (5)
Role Restriction	28 (93)	18 (45)	10 (3,5)	/	/	21 (70)	14 (20)	22 (75)	/	24 (96,5)	25 (87,5)	30 (96,5)	11 (5)
Depression	21 (60)	20 (50)	9 (1)	/	/	25 (82,5)	14 (35)	28 (92)	/	22 (70)	34 (98)	38 (99+)	11 (2,5)
Spouse	24 (91,5)	20 (75)	12 (20)	/	/	19 (70)	10 (10)	18 (65)	/	21 (80)	21 (80)	32 (99+)	7 (1)
Total Parent Domain Stress	150 (85-90)	130 (65-70)	81 (1-5)	/	/	146 (80-85)	99 (15)	149 (85-90)	/	138 (75-80)	168 (90-95)	199 (99+)	67 (<1)
Life Stress	10 (70)	18 (91,5)	8 (60)	/	/	9 (65)	0 (<10)	18 (91,5)	/	10 (70)	14 (85)	26 (98,5)	26 (98,5)
Defensive Responding	48	34	16	/	/	47	26	49	/	41	49	61	16
State Trait Anxiety Index (Raw scores and Percentiles in brackets)													
NICU	1	2	3		4	5		6		7		8	9
	M	M	M	F	M	M	F	M	F	M	F	M	M
State	23 (9)	38 (68)	38 (68)	/	/	63 (98)	29 (27)	57 (94)	/	35 (56)	59 (98)	42 (76)	21 (3)
Trait	43 (80)	34 (50)	43 (80)	/	/	60 (98)	24 (11)	57 (95)	/	46 (86)	51 (94)	52 (93)	25 (12)

According to an analysis of pre-test scores and post-test scores, a number of stressors have increased in value, as expected, and some have decreased. These are explained in detail. Note that

NICU 3 and NICU 9 answered defensively at the post-test and thus scores should be interpreted with caution.

Competence was only a high score on the pre-test for mother NICU 8, however it remained high for NICU 8, and became a high score additionally for mothers NICU 1 and NICU 7 at the post-test. Competence scores increased in value for mothers NICU 2, 5, 6 and for the father NICU 7 but not to a level of being regarded as high. Competence scores dropped for mothers NICU 3, 9 and for the father NICU 5, thus indicating a better sense of competence.

Isolation was a high score on the pre-test for one mother (NICU 5) and one father (NICU 7). Isolation stayed as a high score for the same mother and father in the post-test but also became a high score for another mother (NICU 6). Isolation scores decreased for two mothers (NICU 3, 9), however, both these mothers answered defensively. Post-test scores increased for a father (NICU 5) and a mother (NICU 8) but not to the point of being regarded as a high score.

The *attachment* scale obtained a high score on the pre-test and post-test for two mothers (NICU 5, 8) and only on the post-test for a father (NICU 7). A low score was obtained for mothers (NICU 3, 9) and father (NICU 3) on the pre-test. These low scores were on the questionnaires where the mothers answered defensively and the father did not complete the full questionnaire. On the post-test, the attachment score for NICU 2 dropped.\

Health was a significant issue for four mothers (NICU 2, 4, 5, 8) on the pre-test. At the post-test, health became an issue for mother NICU 6, remained an issue for mother NICU 8, and became an issue for father NICU 7. Health scores dropped for four mothers (NICU 1, 2, 3, 5) and a father (NICU 5) indicating better health.

With regards to *role restriction*, none of the mothers or fathers obtained high scores at the pre-test. At the post-test, role restriction had high scores for three mothers (NICU 1, 7, 8) and a father (NICU 7). As was seen with the veteran parents, it is possible that the NICU parents felt that their freedom and involvement in other roles was impaired.

Depression was seen as a high score for mothers NICU 4, 5, 8 at the pre-test. The score remained high at the post test for NICU 5, 8 but also became a high score for mother NICU 6 and father NICU 7. Unfortunately NICU 4 did not return to the hospital or want to see the researcher after her infant's death, and thus did not complete a post-test to give an indication of her level of depression. Depression, as described in the PSI, involves the extent of the parent's emotional and physical energy and is indicative that the parents do not have strength (as described under fortigenesis) and are therefore not in a state of well-being.

Spousal support was an issue for mothers NICU 1, 8 at both the pre-test and post-test. Interestingly, scores increased but not to a high score level for most of the other parents (NICU 2, 3, 5, 6, 7) except for the father NICU 5 and mother NICU 9.

Total stress was significant at the pre-test and post-test for one mother (NICU 8) but became significant for an additional two mothers (NICU 1, 6) and a father (NICU 7) at the post-test only. With the resultant increases in stress on the other parent domains, total stress increased in level for NICU 2, 6-father, 7-mother, but remained the same for NICU 3, 5-mother. Total stress decreased for mother NICU 9 as her husband was no longer at home in a different town but living with the mother at the father's parents' house and the infant was due to go home.

Life stress was at a high level at the pre-test for both parents NICU 7 and mothers NICU 2, 9. At the post-test, life stress was still considered as a high score, but a bit lower for mother NICU 2. The scores remained the same for some parents (NICU 7-father, 9). Two mothers (NICU 6, 8) obtained a high score at the post-test only. Scores decreased for both parents (NICU 5) and a mother (NICU 7). Reasons for lowering of post-test life stress scores for mother NICU 7 include fewer problems at work and fewer legal problems. For parents NICU 5, the mother felt better regarding her health and had fewer problems at work whereas the father experienced less stress as his spouse was no longer pregnant. These factors further emphasize other mediating variables affecting parental stress values.

With regards to the post-test scores on the STAI, even with slight decreases, high scores were still obtained for *state-anxiety* for the following parents: NICU 5-mother and NICU 8. The state-anxiety pre-test scores increased to remain at a high level at the post test for a mother (NICU 6) and a father (NICU 7). State-anxiety scores decreased at the post-test for two mothers (NICU 1, 3) and stayed the same for one mother (NICU 9).

The timing of the re-administration of the PSI and STAI was not as planned but clearly illustrates the stressful impact of returning home with a preterm infant without the medical teams' support which was available for assurance at the NICU. New stressors can emerge due to the realities of caring for a pre-term infant in the home environment. It was expected that the scores would not show improvement, but indications of on-going stress. Home support is thus recommended. For this study it was important to get an idea of the state of mind of the parents; and how they are functioning in the midst of the on-going crisis.

6.4 Evaluation of Pilot Study

The general goal of this study was to create and implement a support intervention to foster well-being in parents of preterm infants admitted to an NICU. Two sub-goals included an evaluation of

the impact of the support intervention on parents' stress and anxiety as well as the parents' evaluation of the support intervention in terms of its usefulness to them.

The usefulness of the intervention was determined by the parents' statements. Parents stated that the support provided was helpful and positive. Care must however be taken in this regard as the researcher questioned the parents herself and this may have led to the 'halo effect' (Nisbett & Wilson, 1977) where the parents' impression of the support intervention can influence their feelings and thoughts about the value of the support intervention. However, based on the comments of the parent participants during the use of certain intervention elements in the support intervention, it appears as though the intervention did offer some value to the parents in coping, and there may be a movement toward well-being. It must, however, also be kept in mind that other mediating variables such as social support, and the health of the infant may help in the movement towards well-being.

Even though the pre- and post-test scores were compared qualitatively, determining the impact of the intervention itself on the parents' stress and anxiety cannot be done using the questionnaires. The timing of the re-administration of the questionnaires does not allow for this as the parents were in the new situation of being at home. Understandably, little to no improvement in well-being is shown as the parents are experiencing on-going stress upon returning home. This was expected as the parents are without the support and assurance of a medical team at home and experience the daily challenges of having a preterm infant at home. The questionnaires were, however, still administered to determine the parents' level and domains of stress.

To form an evaluation of the support intervention, the researcher explored the limitations and strengths of the intervention.

The limitations of support intervention include:

- There were some missed opportunities in seeing some parents more regularly due to logistical difficulty in having to complete the research at two separate hospitals.
- In addition, there were missed opportunities for contact with parents due to parents being busy with caregiving tasks for the infant.
- Some fathers were not able to be involved in the first semi-structured interview and support intervention due to work commitments and absence.
- The researcher was not able to complete discharge planning (termination phase) due to the quick, unexpected discharge of some of the parents. The termination phase will probably always be influenced by the suddenness of discharge and support interventions should ideally be continued when parents enter the new phase of at-home-care of their infant.

Strengths and values of intervention elements:

- Providing information and education can be regarded as a strength of the support intervention as it empowers parents and can help in answering some of the parents' questions. Parental reactions to information provision indicated enhanced comprehensibility.
- Information provided to parents regarding siblings at home made provision for parents to deal with additional problems related to sibling behaviour. Some of the siblings were acting up, confirming Bronfenbrenner's (1979) bioecological theory of the microsystem changing due to the preterm birth and hospitalisation.
- The Pit Metaphor was useful as a scaling technique forming part of the solution-focused theory. The Pit Metaphor can help in parents becoming aware of resources which can help promote manageability. The well-being element of accomplishment may also be fostered as parents can visually 'see' their progress.
- The use of the healing and hurting alphabet can be regarded as a strength of the support intervention as it is a useful technique to help parents in identifying feelings, thoughts, needs, and to promote coping. The various words allow for further discussion.

General strengths of the support intervention include:

- The individualisation of the intervention for the parents. Elements of the intervention were used according to parental need and not according to a pre-set plan. Therefore, not all the intervention elements were used with all of the parents.
- The support intervention developed awareness in the parents with the aim of strengthening their SOC to enhance their effectiveness and ability to cope.
- Even though not all fathers were able to be part of the intervention, three fathers were involved, providing some insight into the effects and coping of fathers.
- The pilot study was conducted at two different NICU's offering slightly more generalisability.
- The support intervention was conducted within a theoretical framework of Positive Psychology.
- Even though well-being cannot be proven with the use of the structured questionnaires, the process of fostering well-being may facilitate longer term well-being, however not visible when the parents had just returned home with the infant.
- As this study is a supportive counselling intervention, therapist micro-skills such as relationship building, communication, reflective listening, and empathy were used. The researcher was able to show empathy as she had previously been in a similar situation of having a preterm infant in an NICU.
- Working within the FCC philosophy, the researcher showed respect by listening to and honouring parent's perspectives, values, beliefs, and cultural backgrounds.

6.5 Suggested Refinements of Support Intervention

The following refinements to the support intervention elements are suggested:

- Parents need further explanation and discussion regarding the COE. The researcher is of the opinion that the COE is useful to explain parental experiences to parents but it appeared that parents did not quite understand it as there was minimal discussion from their side regarding the COE. The COE should be explained as it relates specifically to the parent's individual situation.
- With regard to the Fundamental Human Needs as outlined by Max-Neef (1992), further discussion is necessary with more detail including that satisfying some needs may act as being destroyers of other needs.
- When making use of the miracle question, some mothers answered that they would like to turn back time. Parents should rather be guided to think of what is possible to change such as, thoughts, coping skills, social support, and problem-solving.

The following are general recommendations and refinements to the support intervention:

- With participant parents (NICU 1, 4) it was highlighted that even though there was information provided regarding bereavement, a referral system must be put in place, when necessary.
- When in dialogue with the parents, it may be beneficial to encourage the parents to generate their own metaphors to describe their experiences in the NICU. Thus, giving a clear indication of their experience to the health professional, and a 'tool' to the helping process.
- As suggested by one mother (NICU 5), an addition to the support intervention could be information of the common 'route' that parents and preterm infants follow while in the NICU, such as timing of eye and hearing tests, timing of infants moving to open cribs, and timing of when mothers can attempt breastfeeding.
- A further addition to the support intervention could be provision of information and assistance regarding breastfeeding. If the hospital does not make use of a lactation consultant, the healthcare professional could be educated in providing lactation assistance.
- As the researcher was not part of the staff of the hospital, little attention was given to the relationships between the nursing staff and parents. More attention needs to be focused on developing positive relationships between the nursing staff and parents.
- It would be beneficial if a counsellor were appointed into the NICU as a staff member to facilitate screening, support, and referral where necessary. Provision and management of peer counsellors would be a further positive intervention for parents.
- The situation can change from minute to minute for infants in the NICU and therefore it would be ideal for a health professional to be placed at one hospital full-time so as to keep abreast of the infant's health status and be able to support parents more regularly.

- As mentioned, professional support must continue at home. Further information could be provided regarding the development of the preterm infant.
- More medically related information is necessary regarding each infant's health challenges, especially before discharge, which should be provided by nurses and/or doctors.
- The provision of satisfactory, reliable websites for further information is necessary.
- Further collaboration is needed between doctors, nurses and health personnel who offer support so that the health personnel are informed regarding the timing of discharge.
- A recommendation would be to use a specific instrument that measures well-being.

6.6 Ethical Aspects

The researcher was aware that the parents in this study are vulnerable and that ethical practice was a high priority. It is therefore important that the rules or guidelines of ethical practice be evident in the practice of conducting research.

As far back as the 1980's, Kitchener (1984) identified five moral principles regarding ethical issues with regard to counselling. The five principles of autonomy, non-maleficence, beneficence, justice and fidelity, apply to this study. Bless et al. (2013) and Du Plessis (2016) provide further explanation as to how these principles apply to research in the social sciences.

6.6.1. Principles of ethical Research

6.6.1.1 Non-maleficence.

By participation in a research project, participants must not be harmed. This is the most basic principle of research (Bless et al., 2013). According to Bless et al. (2013), withholding effective treatment may be unethical. For this reason, this research study did not use a control group.

6.6.1.2 Beneficence.

Research must potentially contribute to the well-being of others (Bless et al., 2013). Bertram and Christiansen (2014) say that the study must be to the benefit of participants. It is important to calculate the risk versus benefit. The researcher was aware, from the start of this study, that there was a chance of greater than minimal risk as the health situations of the infants were so unstable and the parents were in active states of crisis due to the circumstances surrounding the pregnancy, birth and the health of the infant. However, the benefits of being involved in a support intervention counteracted the risk to a certain extent. As mentioned by the parents, they experienced the support intervention as positive and helpful. After completion of the study the researcher is convinced that professional support is needed for parents with an infant in the NICU. This was proven by the literature review and also the contact with participants.

6.6.1.3 Autonomy.

Autonomy is the right to participate voluntarily or decline to participate in social research (Bertram & Christiansen, 2014; Bless et al., 2013). As part of this principle of autonomy, information must be provided to participants about the nature of the research project, including the risks, benefits, and expected outcomes, before the participants agree to be involved. The participants can then give their informed consent to participate. In this study, information was provided in a letter (addendum J) to be given to the parents by the mediator (unit manager of NICU) regarding the nature of the research. Parents had time to think and determine if they would be willing to participate. Once the decision was made, the parents were given an informed consent form to complete (addendum K).

NICU 4 made the decision to not return after the death of her infant and the researcher respected her choice. The researcher investigated whether the employer of NICU 4 had counselling services to offer the mother. The employer offered free, confidential counselling by psychologists which the mother could attend.

6.6.1.3 Justice.

Justice is primarily concerned with the fair distribution of services on the assumption that people are equal (McLeod, 2013). According to Bless et al. (2013) in research, people should not be discriminated against on the basis of race, disability, income level or any other characteristic. In this research study, all parents were invited to participate regardless of race, income level and other characteristics. It is for this reason that more than one ethnic group was involved in the study.

6.6.1.4 Fidelity.

According to McLeod (2013), fidelity relates to the existence of loyalty, reliability, dependability, and acting in good faith. According to Bless et al. (2013), fidelity implies faithfulness and keeping promises or agreements between the researcher and participants. In this study, the principle of fidelity was adhered to as the researcher kept to her agreements with the parents involved in the study. This related to appointments being kept and providing information which was promised to parents.

6.6.2. Ethical Guidelines

In addition to the principles of ethics regarding research, there are important ethical requirements which must be adhered to.

6.6.2.1 Ethical review.

A proposal for this study was submitted to the Human Research Ethics Council (HREC) of the North-West University. The proposal was approved and the following ethics number was given: NWU-00060-12-A1. For the duration of the study, monitoring reports were submitted to the HREC of the North-West University.

6.6.2.2 Informed consent, voluntary participation and discontinuance.

As mentioned as part of autonomy, information regarding the nature of the research and what was required of them was provided to all the participants. All parents (meeting inclusion criteria) were given a letter with information regarding the benefits and procedures to be followed if they were to participate in the study (addendum J). The parents were then asked to inform the unit manager (mediator) of their decision and she would notify the researcher. Upon first contact with the parents, parents were requested to give written consent (addendum K). As explained in the consent form, participants had the right to decline to participate or to withdraw from participation in the study at any time (Du Plessis, 2016). As mentioned earlier, NICU 4 made the decision to not return after the death of her infant and the researcher respected her choice.

6.6.2.3 Respect for participants' rights and dignity.

Bless et al. (2013), state that an important aspect of protecting people's rights and dignity is understanding and respecting their culture. The researcher endeavoured to respect each participant's culture by questioning if there were certain practices regarding pregnancy, birth and child care that it was necessary to follow in their particular culture.

6.6.2.4 Confidentiality and Anonymity.

Confidentiality was maintained in this research study by allocating numbers to participants in the research report. Confidentiality was maintained by not discussing parental matters with the staff of the NICU unless given permission by the parents and if it would help their coping. Confidentiality is maintained in the research report by not using identifying particulars. Data collected from participants was kept securely at the researcher's home.

6.6.2.4 Analysis and reporting.

According to Bless et al. (2013), when reporting the results of a study the researcher should also report on technical shortcomings, failures, limitations of the study, negative findings, and methodological constraints. In this research report, the researcher included all of the above in chapters where it applies as well as in chapter seven. In reporting, the researcher has taken care to use references correctly to avoid plagiarism. Before submitting the report for examination, the turn-it-in programme has been used to detect plagiarism.

6.6.2.5 Use of gatekeepers.

According to Ogletree and Kawulich (2012), gatekeepers help researchers to gain entry into communities. In this research study, gatekeepers were regarded as various hospital groups and hospital management that needed to provide permission for the researcher to obtain access to research participants. The researcher obtained permission from the head office of two hospital groups as well as permission from the specific hospital manager at the respective hospitals where the research was conducted.

6.6.2.6 Publication.

The researcher needs to comply with the requirements of publishing an article (addendum Q) for this research. The research participants' details will not be disclosed in the published article and confidentiality will be maintained.

6.7 Conclusion

This chapter discussed the pilot study of the support intervention according to the phases of the helping process as well as parental reactions to its use. During the initial phase, parents were requested to explain reasons for their infant being admitted to the NICU. The researcher noted that mothers especially benefitted from explaining their situation. Mothers were able to debrief and express their feelings and emotions regarding the preterm birth. During the change-oriented phase, certain intervention elements were more successful than others. Information and education was particularly successful. Parents appreciated information to help them cope in understanding their infant and the situational context of the NICU. Psycho-education consisted of discussing the COE and Fundamental Human Needs of Max-Neef (1992). The Cycle of experience was less successful and would need to be discussed and explained more to parents. It is suggested that the COE be discussed specifically in relation to the parents' situation. The outline of Fundamental Human Needs was presented to two mothers and discussed. Mothers were able to indicate their needs at the time. Possible solutions were co-created which could help the mothers. The Pit metaphor was helpful in promoting a sense of accomplishment for parents and in indicating resources available. The A-Z healing and hurting alphabet and the Miracle question were used to promote further awareness of the parent's internal and external factors affecting well-being. The A-Z healing and hurting alphabet was useful in clarifying parents' thoughts, needs, and feelings at the time. Themes could be identified with regards to the parent's current state of well-being. The Miracle question was not as successful in identifying goals for the parents. Some mothers indicated a desire to turn back time. It is suggested that parents should rather be guided to think of what is possible to change such as thoughts, coping skills, social support, and problem-solving. Even though the parents were still situationally in a place of crisis, elements of well-being were starting to become evident such as hope, optimism, gratitude, positivity and meaning. In the next chapter the whole study is evaluated and recommendations are made.

CHAPTER 7

EVALUATION, CONCLUSION AND RECOMMENDATIONS

This research study was conducted to develop a support intervention to foster well-being in parents of preterm infants in an NICU. In this section, this research study is summarised in terms of how the D&D phase model of intervention research as a strategy of enquiry facilitated the answering of the main research question and sub-questions. The first five phases were included in this research study. The last and final phase of dissemination is discussed below. In addition, limitations and obstacles are outlined and recommendations are made regarding practice, education and further research.

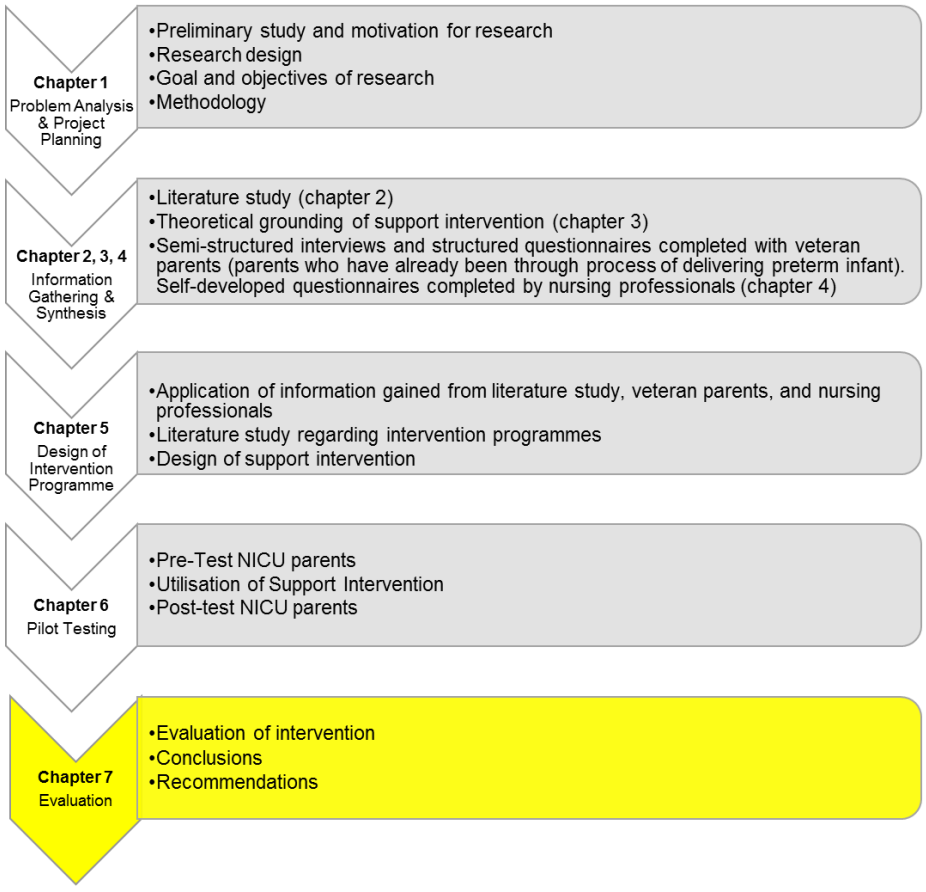


Figure 7.1: Phases of current research study (Adapted from Rothman & Thomas, 1994)

7.1 Findings of Study

The aim of the study was to develop, implement, and evaluate a support intervention to foster well-being in parents of preterm infants admitted to an NICU, by utilising the intervention research process:

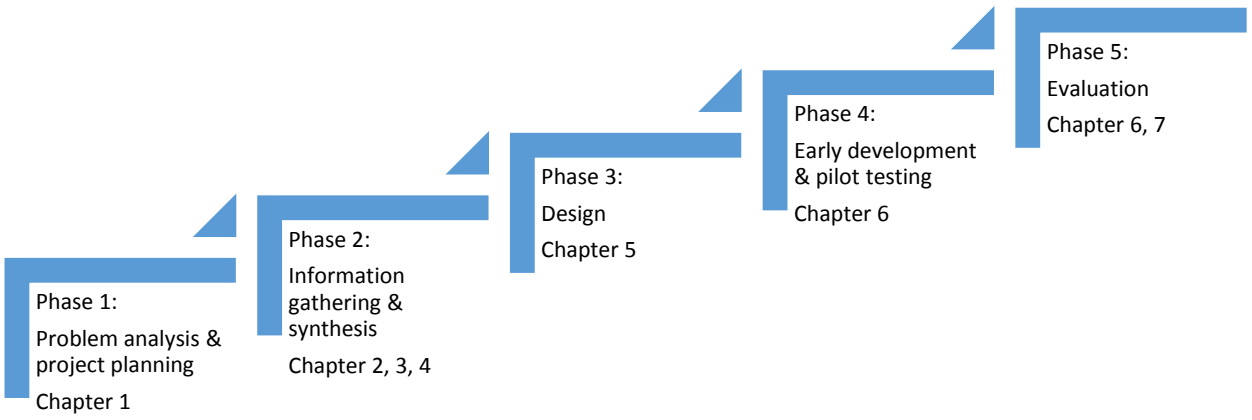


Figure 7.2: Outline of research report

In order to satisfy the aim of the research and answer the research questions, research objectives formed part of the study. Each objective is evaluated in this section and the objectives and research questions are brought together.

Problem analysis and project planning

Chapter one covered a brief analysis of preterm birth. It is evident that the numbers of preterm birth are increasing worldwide placing high financial costs on the health care system. In addition to increased financial costs for parents, parents experience adverse psychological effects. Intervention is needed for parents to cope with a preterm birth and the hospitalisation of their infant. For these reasons, this study focused on developing a support intervention to foster well-being in parents. To meet this aim, five research questions and one hypothesis were formulated as shown below and in chapter one. Positive Psychology served as the philosophical paradigm as the study is related to well-being and it is clear that people evaluate and ascribe meaning to their circumstances uniquely. An intervention research D & D process was followed as it provides clear guidelines and lends itself well to solving practical problems. The detail of each phase of the research process is seen in chapter one.

Conduct an on-going literature study of preterm birth, well-being and support

A literature study was conducted covering the time from pregnancy, the transition to parenthood until the infant's discharge. Pregnancy and transition to parenthood are described as major adjustments, developmental periods characterised by changes in goals, behaviours, the self and in different levels of stress. Various processes take place for a woman to ultimately develop a maternal identity. Fathers also undergo physical (health related), social, emotional and psychological changes. Of note is that fathers need to feel involved but may feel ambivalent with feelings of helplessness as well as pleasure and pride. Fathers play critical roles in supporting mothers in the transition process as support from the father has long term effects on the well-being of the mother and infant. Transitions are often characterised by stress, however stress can be regarded as either distress or eustress. Distress in pregnancy has negative effects which may be one factor leading to a high-risk pregnancy. High-risk pregnancies have various psychological effects on the family including uncertainty, anxiety and depression. Hospitalisation and bed rest are common practices used for problematic pregnancies with their own negative psychological effects on prospective mothers. Preterm labour may result in preterm births with as much as 70% of such births attributed to it. There are various causes of preterm birth, which is still not fully understood. Preterm birth is well described as the "most single determinant of adverse outcome in terms of survival, quality of life, psychosocial and emotional impact on the family, and costs for health services" (Sawyer, et al., 2013, p. 1). The birth is characterised by a range of feelings such as immediacy of events, shock, confusion, fear, helplessness, lack of control, as well as by blurred recall, trauma, and the separation of mother and infant. Admittance of the preterm infant immediately into an NICU is common practice. The NICU is a well organised, highly technological environment which is strange for parents. It is a stressful environment for parents to understand and it delays the expected normal parenting. The health statuses of infants in the NICU are typically unstable and described as being on a roller coaster. In addition the instability of the health status of the infant leads parents' emotions to also be on a roller coaster. As such, parents' emotions can change daily and even within one day. Bonding and attachment is delayed affecting the development of a maternal identity. It is necessary for parents to learn to understand the physical behaviours of their infant and learn care-taking skills before discharge. Each of these phases from pregnancy to discharge is characterised by certain parental needs. The on-going literature study was comprehensive and the literature is reflected in the different chapters. Objective 1 was met in chapter two and with the literature control in other chapters. Meeting objective 1 relates to answering the main research question of what aspects should be part of a support intervention to foster well-being in parents of preterm infants in an NICU.

Provide a theoretical foundation for the development of a support intervention to foster well-being in parents of preterm infants

A theoretical paradigm is necessary as it provides foundational knowledge underlying the development of the support intervention. The focus of the support intervention is to foster well-being in parents and for this reason, the concept of well-being was analysed. Positive Psychology focuses on well-being as part of its research. Well-being can be defined by two different perspectives, namely, the hedonic (pleasure attainment) and eudaimonic (fully functioning person). It is seen that various theorists define well-being as consisting of various components. The components may fit in the hedonic perspective or the eudaimonic perspective. In addition there are various theories of how to reach a state of well-being. Various elements of well-being as proposed by a number of authors were discussed in chapter three as well as the theories of fostering well-being and how to recognise well-being. For this study, well-being has been defined as consisting of comprehensibility, positive relationships, engagement, manageability, accomplishment, positive emotions, self-acceptance and meaning. This forms part of both a hedonic and eudaimonic perspective. In addition to defining well-being, the researcher discusses the bioecological theory of Bronfenbrenner and Morris (2006) as human development, including well-being, all takes place within a social context. The social context consists of various systems exerting influences on the individual and vice versa. Thus, the objective of providing a theoretical foundation for the development of a support intervention to foster well-being in parents of preterm infants was realised in chapter three. This is related to answering the main research question.

Objective 1:
Conduct semi-structured interviews and administer structured questionnaires with veteran parents of preterm infants to determine functional elements for the support intervention

Exploring the experiences of parents who had previously had infants in an NICU provided information related to parental needs when having an infant in an NICU. Information was gained from using semi-structured interviews and administering structured questionnaires to veteran parents. Themes were generated according to the different phases of preterm birth, namely, before birth, at the time of birth, during the NICU stay, and the home-coming of the infant. General non-phase specific themes were also generated. In the before birth phase, mothers experienced problematic pregnancies with repeated hospitalisations and bed rest. NICU admission was predicted. Eventually mothers experienced preterm labour. The early birth for some mothers was a relief, for others it was traumatic. The separation of the infant from the mother was distressing. In

addition, it was distressing for the mothers to share rooms with other mothers who had delivered full-time. A significant stressor for mothers was leaving the hospital without their infant. With regards to the NICU, it was found that there are certain risk and protective factors affecting the parents. Factors are classified according to the context of the NICU, the preterm infant, relationships, needs for information, and matters relating specifically to the mother. Coming home with the infant was influenced by various stressors, namely, having limited knowledge of care-taking of a preterm infant, confinement to the home, maternal depression, feeding difficulties, daily challenges, peculiarities of the infant's behaviour and misunderstanding by others. General themes which appeared in more than one phase related to bonding, fear of the death of the infant resulting in changes to the self as well as the experience of guilt and trauma.

Veteran parents stated that support is necessary and recommended that it be provided. Factors related to this support that were mentioned by the veteran parents include who should offer support, when to offer support as well as the content of support. Thus the objective of determining functional elements to include in the support intervention was achieved as discussed in chapter four. Meeting this objective answers the first sub-question, namely: what are the experiences of veteran parents (parent who had delivered a preterm infant that was hospitalised in an NICU previously) regarding having a preterm infant hospitalised in an NICU, and what functional elements can be included in such an intervention based on their experiences?

Objective 2:
Administer self-developed questionnaires with nursing professionals working in an NICU to determine functional elements for the intervention.

The researcher developed questionnaires to be administered to nursing professionals working in an NICU. The matter relating to FCC was included in the questionnaire. A definition of FCC, the need for FCC and formal training received were explored. It appears as though there are various understandings of what FCC entails among the nursing professionals. Some nurses believe in the value of FCC but are concerned about infection control. With regard to the contents of a support intervention, the nurses mentioned various elements to be included during the various phases of preterm birth to discharge. These are outlined in chapter four and show that objective 4 has been realised. Meeting objective 4 relates to answering the second sub-question of: what elements need to be incorporated into a support intervention according to nursing professionals working in an NICU?

Objective 3:
Develop a support intervention to foster well-being in parents of preterm infants

In chapter five, common approaches and functional elements presently used internationally in support interventions for parents were explored by means of a literature study. FCC and FCDC are core approaches used in interventions. In addition, there are other elements commonly used such as psychosocial support, educational intervention and developmental interventions. Recommendations were made fairly recently by the National Perinatal Association on program standards to include for psychosocial support for parents in the NICU. Based on this information and the philosophical and theoretical paradigm of Positive Psychology, the design of the support intervention proposed that various approaches and intervention elements need to be included in the support intervention. The support intervention should proceed through an initial phase, an change-oriented phase and a termination phase. Approaches to be used are: an individualised family-centred developmental care approach; a salutogenic and fortigenic approach; a solution-focused approach; and an approach developing the theory of flow. In the initial phase parents should be questioned regarding their story up to the point of NICU admission, as a means of 'jump' starting the support as well as exploring the parents' situational contexts and possible resources. Specific intervention elements need to be included in the change-oriented phase to enhance awareness in parents of their needs, available resources, strengths, and coping skills. These are: factual information and education; psycho-education including the Cycle of Experience and Fundamental Human Needs; use of a metaphor; awareness development techniques such as the Miracle question and A-Z healing and the hurting alphabet. In the termination phase, it was proposed that information be provided regarding going home including expected emotional consequences in the parents themselves. In sum, a support intervention was developed to foster well-being in parents of preterm infants, as discussed in chapter five, which serves as proof that this objective has been achieved. This objective relates to the main research question.

Objective 4:
Apply support intervention to parents who currently have preterm infants hospitalised in an NICU after conducting a pre-test

In chapter six, the pilot study of the support intervention is described. A pre-test using two structured questionnaires of parenting stress and anxiety was conducted before commencement of the support intervention with nine mothers and three fathers. Thereafter, the support intervention is described including parental reactions and comments to the support intervention elements. The initial phase

rendered useful information on the time leading up to NICU admission. Parents, particularly mothers, experience fear, anxiety, stress, and uncertainty when complications occur in the pregnancy. The preterm birth is unexpected and traumatic. The change-oriented phase differed in the quantity of contact sessions with each parent group due to individualisation and practical aspects such as their availability.

Objective 5:
Determine parents' opinions on the usefulness of the support intervention and evaluate the impact of the support intervention on the well-being of the parents who received the support through semi-structured interviews and a post-test.

During the follow-up semi-structured interviews, the parents mentioned that overall the support process was useful and helpful. Unfortunately, the termination phase was not completed fully, nor with all of the parents as the majority were discharged very quickly. Thus, the post-test was completed with many parents after they had returned home with their infant. Understandably, post-test scores did not show an improvement in overall stress and anxiety, as parents had entered a new stressor situation. It was not expected that significant results would be seen while the parents were still in a state of crisis in the weeks after the preterm birth of their infant. It was, however, hoped that the support intervention would help parents find elements of growth in the difficult circumstances.

Stress and anxiety lessened with regard to certain factors and varied according to each set of parents. Other factors became more stressful for the parents. In chapter 6, which discussed the parental reactions to the support intervention, it was seen that elements of well-being were starting to become evident.

The support intervention was evaluated according to strengths and limitations. Further refinements and elements to be added to the support intervention are described. The support intervention was implemented for parents in the target group and the objective has been met.

Thus the third and fourth sub-questions, *How will the parents evaluate the self-developed intervention in terms of usefulness*; and *How will the self-developed intervention impact on parental well-being while in the NICU*, adds insight into answering the main research question.

Make recommendations for further amendments and application

Recommendations for amendments to the support intervention are seen in chapter six. Further recommendations for practice are discussed below. The recommendations can be incorporated into the support intervention and thus satisfies the main research question.

In addition to the main research question and four sub-questions, a hypothesis was formulated that pre-tests and post-tests would indicate a positive effect of the support intervention on the parents' stress and anxiety. With regard to the hypothesis, the pre- and post-tests did not indicate that there had been a positive effect of the support intervention on the parents' stress and anxiety. This was due to the post-tests being conducted at home where parents faced additional stress in coping with the infant at home.

According to the D&D intervention research model, the first five phases namely, problem analysis and project planning, information gathering and synthesis, design, early development and pilot testing, and evaluation, were completed in this research study. The sixth and last phase includes dissemination. The results of this study will be disseminated in the following ways:

- A copy of the research report will be given to management of the hospitals from which participants were drawn
- The mediators will be informed that the research report is available
- Workshops will be conducted for nursing professionals at the two hospitals where the study was done to give feedback on the results.
- Published material [An article, addendum Q] presenting some of the findings of this research will be submitted for review to a scientific journal
- The support intervention will be applied in the researcher's own practice

7.2 Evaluation of Trustworthiness

As mentioned in chapter one, trustworthiness relates to the quality of research and the four criteria of Lincoln and Guba (1985) will be used to discuss the trustworthiness of the study:

7.2.1. Credibility

Credibility involves generating confidence in the truth value of the findings (Lincoln & Guba, 1985). According to Bertram and Christiansen (2014), credibility, as a criterion for trustworthiness, implies that the views of participants are described accurately and honestly by the researcher. Credibility is

also achieved and strengthened through prolonged engagement and triangulation (Lincoln, 1995). Babbie and Mouton (2009) mention referential adequacy in addition to the above mentioned by Lincoln (1995).

Prolonged engagement is described by Barusch et al. (2011, p. 12) as a "researcher spending sufficient time in a setting, developing trust and relationships, understanding a variety of perspectives, and co-constructing meanings with members of that setting." The researcher spent time with VP with the aim of understanding their experiences. The semi-structured interviews were conducted as a conversation with the VP so as to put them at ease in describing their experiences. In the pilot study of the support intervention, credibility was achieved by having prolonged engagement with the NICU parent participants. Relationships were formed and through the use of the researcher's micro-skills of counselling, meanings of problems and coping were co-constructed between the parent and researcher. Referential adequacy refers to materials that are available to document findings (Babbie & Mouton, 2009). Referential adequacy was accomplished by making use of audio recordings and field notes with both VP and NICU parents.

For this study, both the terms 'triangulation' and 'crystallisation' are relevant. In 2000 Richardson coined the term crystallisation after arguing that triangulation is at its core a mathematical concept which does not fit well with the search for deeper meaning so typical to qualitative research (Nieuwenhuis, 2016). In this regard Braun and Clarke (2013, p. 285) refer to triangulation as "a millennia-old mathematical process of determining the distance or location of an object". Crystallisation works from the premise that reality has many sides and angles which can be highlighted and explored in research. The term 'triangulation' is more typically used with quantitative research. Both these terms refer to more than just different ways of data collection. According to Nieuwenhuis (2016), triangulation refers to multiple data collection strategies focused on the same phenomenon, but this author also refers to Denzin (1978) who included multiple theories and multiple researchers in the quest for triangulation. This study used multiple data collection strategies, namely contact with veteran parents and nursing staff and also interviews and measurements with NICU parents. There was also a mix of qualitative and quantitative research strategies. Triangulation was also achieved by conducting a literature control related to the parental experiences and means of coping. Furthermore, the theory supporting the research was mainly based on a Positive Psychology paradigm but supported with bioecological and resource theories such as COR and the fundamental human needs of Max-Neef (1992). There was only one researcher, which could have impacted negatively on the triangulation process, but was also inevitable as an intervention had to be implemented by the researcher.

7.2.2. Transferability

According to Braun and Clarke (2013), transferability refers to the extent to which the findings can be applied in other contexts and with other participants. Lincoln and Guba (1985) recommend the use of thick description of the methodological process to strengthen transferability which involves rendering a detailed account of the work done so that readers can judge the potential for application in other contexts. Purposive sampling is also mentioned as helping the researcher gain thick description (Babbie & Mouton, 2009; Lincoln & Guba, 1985).

In this study, NICU parents were purposively selected according to the following criteria: married parents with preterm (< 37 weeks gestational age) infant(s) admitted to an NICU; able to speak and read English; and live within a 60-minute drive of the hospital. Inclusion criteria were set for the purpose of research, however, the inclusion criteria have no influence on the transferability of the value of the support intervention with other parents. Inclusion criteria were set to be able to reach thick description.

It is noteworthy that all parents are in the similar contextual situation of having their preterm infant hospitalised in an NICU. What does change is the reason behind being in the NICU. However the experiences of parents who have their infant in an NICU appear to be similar for many. This is seen with descriptions of experiences of the VP, the NICU parents, and in the literature. In addition, it is the opinion of the researcher that the support intervention can be used with other participants who are also in a private hospital NICU setting as the situational contexts are similar. As is often the case with qualitative research, transferability in this study will also be in the eye and judgement of the reader (Braun & Clarke, 2013), who will determine whether the elements of the support intervention can be transferred to use with similar groups of parents.

This study aimed to complete a pilot study of a support intervention to foster well-being in parents of preterm infants in an NICU. The support intervention cannot be regarded as a final product and will still need refinement. In addition, the support intervention was used in private hospitals in the Pretoria and Johannesburg areas. It will thus need to be adapted to be used in different contexts such as in public hospitals and in different areas of the country. However, research would be necessary to determine the protocols and procedures of public hospitals.

7.2.3. Dependability

Dependability of the support intervention relates to the degree that the findings are consistent and that the research process could be repeated (Lincoln & Guba, 1985). In order to establish dependability, an audit trail is usually outlined when describing research processes. The support intervention was based on a thoughtful and clear research strategy. In addition, the intervention research D&D model provided clear guidelines on how to conduct research to develop interventions

needed to solve practical problems. Dependability was also enhanced by discussing how the data was collected and analysed.

7.2.4. Confirmability

Confirmability is the degree of neutrality and the degree to which the findings achieve their aim and are not the product of researcher bias (Lincoln & Guba, 1985). In this regard Nieuwenhuis (2016) stresses that researchers should admit to their own possible bias. The researcher made no secret of the fact that she had had the experience of delivering and mothering a preterm infant who had been in the NICU for four months. She had to be aware of how this experience could influence her in the role of researcher and used bracketing by having two-weekly study supervision for this as well as making journal reflections. In order to establish confirmability, an audit trail of the research process is necessary which includes steps taken in the process of the research project (Barusch et al., 2011). Bertram and Christiansen (2014) indicate that it is especially important to be transparent regarding the process of data analysis, so that the findings can be confirmed by someone else.

To determine the content of the support intervention a literature study was undertaken regarding common interventions used for NICU parents. In addition, VP were interviewed regarding their experiences and needs related to support, and nursing professionals contributed by suggesting contents of a support intervention. Furthermore, the concept of well-being was researched through a literature study to determine elements of well-being. Theories to foster well-being were presented and intervention elements were selected to support and foster the elements of well-being.

In sum, the four criteria of trustworthiness of Lincoln and Guba (1985) were realised in this research study aimed at developing a support intervention for parents of preterm infants admitted to an NICU.

Similar to evaluating trustworthiness in qualitative research, validity needs to be evaluated with quantitative research. Questionnaires used in this study were the following: PSS: NICU; PSI; and STAI. The validity of the PSS: NICU is discussed in section 4.1.2, and the validity of the PSI and STAI is discussed in section 6.2.3. All the questionnaires used in this study are valid and reliable.

7.3 Ethical Considerations

Parents of preterm infants can be regarded as a vulnerable population. It is for this reason that ethical practice is vitally necessary when doing research with these parents. In research, information should never be obtained at the cost of the participants (Strydom, 2011). Bertram and Christiansen (2014) refer to the important principles of autonomy, non-maleficence and beneficence.

Principles and guidelines for ethical research were incorporated throughout the study. Permission for the research was obtained from the head offices of the hospitals where the managers served as gatekeepers. Identifying particulars of the hospitals have been removed from permission letters to protect the identity of the participants. Mediators (NICU unit managers) were also contacted to gain permission to work with NICU parents. It was intended that all participants (VP, nurses and NICU parents) not be harmed in the process.

The autonomy of all the participants was respected by providing information regarding the research process and their involvement beforehand so that participants were afforded the right to voluntarily participate or decline participation. They were assured that they could withdraw at any time, without providing reasons. One mother whose infant passed away withdrew from participation. The researcher attempted contact with the mother without success, however, the researcher discovered that her employer did provide free counselling if the mother so wished. Written consent was gained from all participants.

Another important principle is non-maleficence which in essence means that no harm will be done to the participants (Bertram & Christiansen, 2014). One of the ways of working towards non-maleficence is to ensure maximum confidentiality. Confidentiality was maintained with all the participants by assigning numbers to each participant and in so doing anonymising data as soon as possible even before transcription. In this research report and in an article to be published in a scientific journal, confidentiality will still be maintained. The names of the hospitals are withheld in all reports to ensure the confidentiality of participants.

Research should ideally benefit participants in some way (Bertram & Christiansen, 2014). In analysing a risk and benefit ratio, nursing professionals had little risk but can benefit from the findings of the research during the dissemination phase. The VP had a smaller risk than the NICU parents as they had had some time to integrate their experiences regarding the pregnancy, birth and NICU admission. Also, at the time of the research, they would have mastered many of the tasks related to caring for a pre-term infant at home. The VP's may have benefitted from sharing their story with the researcher. One VP indicated that she felt a sense of catharsis sharing her story with someone who understood. As the researcher has had experience with her own preterm infant, the researcher was able to show understanding and empathy for the VP. The NICU environment is one of high-risk as the reality of the NICU is that infants do pass away. This was evident in this study as one mother's infant passed on. Thus, working ethically is vitally important in the NICU environment. The NICU parents were, therefore, at the highest risk at the time, but could have benefitted from the support intervention. In this study the elements of well-being which were selected to develop were comprehensibility, manageability, positive emotions, positive relationships, meaning, engagement, self-acceptance, and accomplishment. By developing these elements, well-being is fostered. In

addition, the research study was approved by HREC and monitoring reports were sent to the HREC. It is hoped that the research will benefit other parents with infants in the NICU as the support intervention is used by the researcher as part of her work and also by other professionals who will be trained by the researcher.

Strydom (2011) refers to the responsibility of the researcher to the discipline of science. In this regard the researcher endeavoured to report the findings as clearly as possible. She also strove to use literature in a scientific and responsible way by not using the direct words of authors, unless in a quote, and to portray literature in the context in which it was presented.

7.4 Limitations and Obstacles

General limitations will be discussed first in this section. Thereafter, limitations and obstacles will be discussed related to VP, nursing professionals and the pilot test respectively.

A strength of this research study is the ethnic diversity of the research participants. However, not enough attention was paid to the impact of cultural differences on defining and experiencing well-being. It can be seen that cultural differences can produce effects different from what are expected. For example, one of the elements of fostering well-being includes positive emotion. However, according to Compton and Hoffman (2013), there are great variations in how people express, label, and proclaim positive emotions around the world. In addition, well-being may be defined or experienced differently based on an individual's culture. In individualistic cultures, greater emphasis is placed on individual achievement, autonomy, freedom of expression and on each person's internal thoughts, emotions, and experiences. Contrary to that, in a collectivist culture, emphasis is placed on a person's group and on the significant relationships among group members (Compton & Hoffman, 2013). The researcher is from a western background and therefore well-being is defined from an individualistic stance. In a more collectivist culture, FCC would need to be emphasised more in the support intervention but may only be realised after the infant's discharge due to infection control.

A further general limitation of this research study is that a questionnaire measuring well-being specifically was not used. At the time of approval of the researcher's proposal, the researcher was not aware of measuring instruments available for measuring well-being.

With regard to the quantitative component of the research study, results of the PSI and STAI were not what was expected. However, mediating variables are always present in qualitative work and thus one cannot isolate the effects of an intervention. The PSI and STAI were planned to be completed while the parents' infants were still in the NICU, however, due to the unexpected and quick discharge process, the questionnaires were completed at home with the majority of parents. It

is expected that once returning home with the infant, parents enter a new phase with different stressors and the possibility of additional stress. The questionnaires were, however, still conducted to determine how parents were coping.

Limitations and obstacles with regard to VP

With regards to the veteran parents, there was a disproportion between mother and father participants with regards to the semi-structured interviews. However, with the administration of the PSS: NICU there was more of balance between mother and father participants.

Limitations and obstacles with regard to nursing professionals

Initially, it was proposed that focus groups be conducted with the nursing professionals. This was not able to be completed due to lack of availability of the nursing staff.

Not all nursing professionals completed and returned the questionnaires.

Limitations and obstacles with regard to Pilot Test of support intervention

Not all the fathers were able to be present for the first semi-structured interview and support intervention. Even though not all fathers were involved, a benefit of the research study is that there was limited involvement of fathers.

Discharge of the preterm infant happened unexpectedly which led to the researcher having to complete the final semi-structured interview and post-test at home. Not all fathers involved in the support intervention were present at the follow-up interview.

7.5 Recommendations for Practice

Recommendations for practice are discussed according to policy recommendations and recommendations regarding interventions for parents.

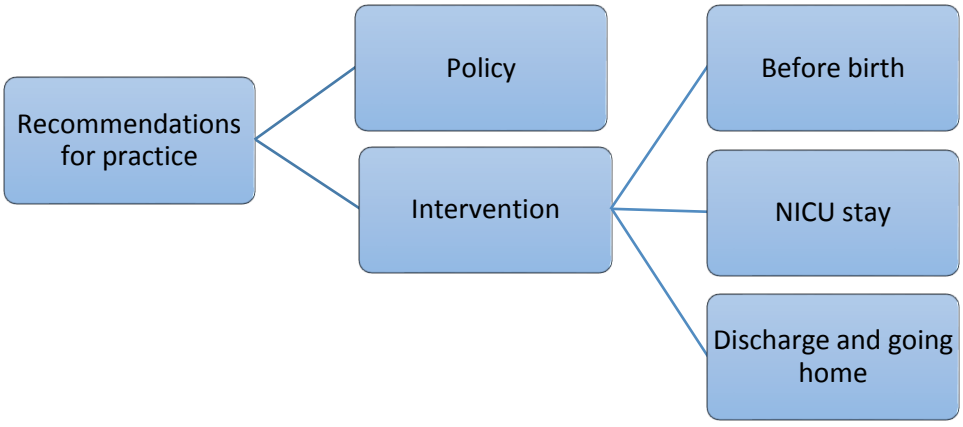


Figure 7.3: Outline of discussion regarding recommendations for practice

7.5.1. Recommendations Regarding Policy

Core concepts of FCDC show that the environment of the NICU is an important core measure for optimum preterm infant development. Aspects such as high noise levels in NICU's affect the preterm infants, staff and families by elevating stress levels (Altimier & Phillips, 2013). It should become policy to reduce noise levels as much as possible.

Screening of parents by a health professional such as a psychologist working in an NICU, should be incorporated into NICU procedures, as early depression predicts later depression, stress and anxiety (Rallis, Skouteris, McCabe, & Milgrom, 2014). By identifying women who are most vulnerable to high levels of distress, services and interventions can be designed and targeted towards parents in greatest need (Barber & Starkey, 2015; Lasiuk et al., 2013).

It was shown in this study that mothers experienced stress when roomed with other mothers who have their infants with them. According to the study of Baum et al. (2012), a recommendation was made that it is helpful to place mothers in a room with other women who gave birth preterm, or in a private room rather than with women who gave birth full-term, to avoid the mother's sense of feeling different and inferior.

7.5.2. Recommendations Regarding Interventions

7.5.2.1 Before birth.

Generally, knowledge about transition to parenthood is reported by Deave et al. (2008) to be poor. It has been recommended that parent education classes should incorporate education regarding transition to parenthood with more emotional and informational support for both parents both antenatally and postnatally (McKellar, Pincombe, & Henderson, 2006).

Identification of mothers at risk for complicated pregnancies with a possible poor outcome is, according to Jain et al. (2014), fundamental to antenatal care. It is recommended that a scoring system be used to recognise, document, and cumulate antepartum, intrapartum and neonatal risk factors in order to predict complications for the foetus and new born (Jain et al., 2014).

With the diagnosis of a high-risk pregnancy, it has been shown that the psychological care for the mother seems to be absent (Behruzi et al., 2010). It is recommended that health care providers should assess what the women is feeling, and what her perceptions are regarding the procedures she is going to undergo (Lindsay, 2006). Giurgescu et al. (2006) indicate that perinatal nurses need to assess the level of uncertainty, psychological well-being and prenatal coping strategies of high-risk pregnant women. However, the researcher believes that a social worker or psychologist should rather do this. Women hospitalised during pregnancy are understandably anxious and might benefit from interventions to address their anxiety. Interventions must be tailored for the unpredictable, fast-paced, and confusing environment of the medical ward. Brief

interventions that place a low demand on staff and can be carried out in a self-help format, such as guided imagery or relaxation training using audio recorded instructions, music therapy, and self-guided biofeedback are, according to Barber and Starkey (2015), the most promising interventions. In addition, incorporating a 'child friendly' family visitation room can facilitate interaction of the mother with her significant others.

If a woman is admitted with preterm labour, recommendations include that it is important that the women's concerns be acknowledged and taken seriously by health care staff. Equally, women need to be given accurate and consistent information about their condition and the likely outcome. The provision of consistent information, having their views acknowledged, getting satisfactory social support and dealing with a previous history of perceived traumatic birth experiences can help women in their search for meaning (Barlow et al., 2007). Other coping strategies used by women diagnosed with PTL include social support, problem-solving and positive reappraisal (Lowenkron, 1999).

Due to the buffering effect of prenatal visits, it is suggested that all parents should be encouraged to visit the NICU prior to a preterm birth if possible (Arnold, et al., 2013). Tours of an NICU should be part of ante-natal classes. This can alleviate initial distress in parents.

7.5.2.2 During the birth.

It is recommended that medical staff appear calm during the birth; the staff portray confidence in taking control during the birth; the mother be valued and listened to; and the staff help the fathers to feel involved. Sawyer et al. (2013), identified these four important key determinants of care in the unique experiences of preterm birth.

7.5.2.3 During the NICU stay.

The study of Arnold et al. (2013) show that the birth of the infant and the first contact with the NICU are critical steps and the impact of this varies between individuals. It is recommended that providing parents with a photograph of the infant before they visit the NICU may lessen the impact of seeing their baby in the NICU for the first time (Arnold et al., 2013).

The amount of time to spend with parents and the timing of the support intervention needs to be thought out innovatively as some parents feel they have no time to be involved in a support intervention. Further research is necessary in this respect.

As part of a holistic approach to care, nurses can honour the mothers' bedside rituals of praying and can arrange for pastoral visits and/or counselling during the NICU stay. Spirituality issues are important for some parents as was seen in this study with the VP.

Linking mothers with other mothers of preterm infants is one type of mutual support that can be offered to help relieve the stress of parents (Mok & Leung, 2006). It has been shown that peer-

to-peer support in the NICU can help parents cope. It should be offered by veteran parents who are trained in identifying parents who have more concerning risk factors and/or escalating distress. Peer-to-peer support can form part of a comprehensive strategy of support for parents. Friendships formed can even help parents cope when they go home.

According to Davanzo et al. (2013), breastfeeding is not adequately promoted and supported in the population of preterm infants admitted to NICU's. It is recommended that breastfeeding should be regarded for these infants as a medical and parental priority. Thus provision of practical support and encouragement from someone (peer or professional) trained in the management of breastfeeding is needed for mothers (Renfrew, et al., 2010).

The researcher noted that in the one NICU, seating was not ideal for doing KMC. It is observed that some public hospitals have specially equipped rooms for KMC. It is recommended that all hospitals with neonatal units be equipped with comfortable seating and privacy for parents to be able to do KMC.

As KMC assists parents in increasing their participation in their infant's care, the method may challenge nursing staff in their conventional role, and this might be solved with an agreed care plan about who does what in the infant's care (Blomqvist et al., 2012). This also relates to policy in the NICU.

All pregnant women attending antenatal clinics should be educated about KMC (Nyqvist et al., 2010). KMC should become a norm for all preterm infants where feasible.

As a women's maternal identity is delayed with preterm birth and NICU admission, certain events have been shown to help trigger maternal identity such as: contact and interaction with the infant (including KMC); assuming responsibilities of the maternal role (for example changing diapers); and validation of their mothering by another adult (Rossman et al., 2015; Zabielski, 1994).

Support groups should be formed to offer mothers who experienced their births as distressing the opportunity to talk through and process their experiences with a facilitator as well as other mothers who also experienced a traumatic birth. It has been shown that mothers in discussion groups with other mothers who had been through a similar situation find the discussions therapeutic (Baum et al., 2012; Goutaudier et al., 2011).

7.5.2.4 Discharge.

To optimise the mothers' engagement in infant care and attachment and to have a successful transition to home, it is recommended that parents be involved in infant care as much as possible and be fully informed about their infant's clinical needs and behavioural responses (Woodward et al., 2014).

It is recommended that telephone numbers of who parents can contact for help are given before or at discharge. In addition, parents should be prepared for sudden discharge. For this reason plans must be in place to deal with logistical issues as well as emotional readiness.

7.5.2.5 Home and later development.

Based on the results of the study it is shown that support for the parents must continue at home. The content of the support will need to be further researched.

According to O'Brien (2013), parents appreciate continuity of care and therefore, there must be pre-, peri-, and postnatal care and post discharge care (Nyqvist et al., 2013). An aspect of post-discharge care affecting parents' well-being may be the fact that the immaturity of the infant's brain and central nervous system makes parenting preterm infants more challenging as they send disorganised cues, are more irritable and difficult to soothe (Ludwig, 2007). Preterm infants are known to be less responsive and have inconsequent behaviour (Perun, 2013). The atypical responses to parental interactions, their functional immaturity due to neurological problems and developmental delays, adds to parenting difficulties (Clements & Barnett, 2002; Feldman, Eidelman, & Rotenberg, 2004) and may be associated with less positive parenting (Clark, Kochanska, & Ready, 2000). It is recommended that, as part of the discharge process and a home support intervention, information regarding the preterm infant's typical behaviour be provided to parents.

Even five to six years after the preterm birth, mothers have negative perceptions of the birth experience, and their negative experiences are also associated with subsequent behavioural and emotional child problems (Latva et al., 2008). Due to the increased risk of preterm infants developing problems in motor development, cognitive development, visual-motor integration, language development and behavioural adjustment, early intervention programmes are recommended for infants (Huber, Holditch-Davis, & Brandon, 1993).

According to Gregory (2015), interventions must be targeted at coping with both the trauma of a premature or complicated birth, and techniques must focus on enhancing parenting confidence and altering negative parental perceptions of their infant.

7.6 Recommendations for Education among Health Care Professionals

There is minimal literature on the development of FCC for infants in SA (Irlam & Bruce, 2002) and there appears to be no formal training in FCC. It is recommended that all medical staff working in the NICU be trained in FCC and FCDC that fits in with current care practices used in SA. There are various resources available to be used in teaching FCC (Horky, Levitz, Goode, Miney, & Smith, n.d.).

KMC has many benefits for both the parents and infant. Thus, for successful implementation of KMC, a supportive environment and staff who have been trained in all aspects of KMC are needed. Pattinson et al. (2005) found that the most effective training tool for KMC implementation is a combination of face-to-face facilitation and an audio-visual package. Solomons and Rosant (2012) indicated that special attention should be given to KMC training of all health care staff involved in antenatal and neonatal care. In addition, adequate resources such as beds, cupboards, dining and leisure areas should be available where KMC is to be implemented (Solomons & Rosant, 2012). KMC and breastfeeding success requires multidisciplinary staff training (Renfrew, et al., 2010).

7.7 Recommendations for Further Research

- Studies are being conducted as to the causes of preterm birth, however, given the health implications of preterm birth, it is critical to continue to identify risk factors for preterm birth so as to develop methods for intervention and prevention (Butler & Behrman, 2007).
- According to Barber and Starkey (2015), brief interventions for parents that place a low demand on staff and can be carried out in a self-help format. In this regard guided imagery or relaxation training using audio recorded instructions, music therapy, and self-guided biofeedback are promising interventions. The effect of these should be researched.
- A support intervention should be developed and researched from the beginning of the process, in other words, from the initial diagnosis of high-risk to the eventual home-coming of infant and parents.
- According to Giurgescu et al. (2006) future research also needs to develop interventions that decrease the level of uncertainty of high-risk pregnant women and counteract the coping strategy of avoidance.
- Due to the negative effects of stress in pregnancy and the possibility of preterm labour and preterm birth, specific psychological stress reducing interventions for pregnancy need to be developed and evaluated systematically (Scherer et al., 2014).
- The use of specific, psychological, stress-reducing interventions for women in preterm labour have not yet been evaluated systematically (Scherer et al., 2014).
- Further research is necessary for interventions that can be used in public hospitals. Public hospitals are completely different microsystems with other parental needs.
- Further research is necessary in exploring the use of social media platforms such as Facebook, WhatsApp groups and the use of Skype, to support parents once they are home as it is shown

that parents are confined to the home due to the risk of infection should they take the infant out. In the UK, additional support is offered to parents by means of Facebook, videos, parent information seminars and web sites on the internet.

- There is a need to explore a definition of FCC that is suitable to the SA political and socio-cultural context (Irlam & Bruce, 2002). The core concepts of FCC namely: respect and dignity; information sharing; participation; and collaboration can be used as parameters.
- In addition, according to Lohan, Spence, Parkes and Deeney (2009), there is little follow-up research in the community of the father's experience of the NICU. More research is necessary focusing on fathers' support needs and experiences.
- As various health professionals such as social workers, psychologists, occupational therapists, physical therapists, and dieticians may work in an NICU, there is a need to clarify roles and define the specialized competencies and training needed to work with the vulnerable population of parents and infants. VandenBerg (1993) described specialized knowledge and basic competencies necessary for developmental specialists from any discipline working in the NICU.
- There may be cultural differences relating to the definitions of well-being. Ryan and Deci (2001) indicate that further research needs to continue to uncover the relatively independent sources of variance in well-being owing to cultures and social contexts.
- According to Renfrew et al. (2010), gaps exist in the evidence of the care of less clinically stable infants and those with special needs, who could derive the greatest benefit from breastfeeding. Further research is recommended.
- Further research is needed regarding grief counselling for infant death in the NICU.
- According to Adama et al. (2016) and Murdoch and Franck (2012), there is a paucity of research investigating parents' experience of caring for preterm infants after discharge from the NICU.

7.8 Conclusion

The research problem in this study relates to a problem existing in World 1 which is described by Mouton (2001, p. 138) as "the ordinary social and physical reality that we exist in." It is seen that a substantial part of a person's knowledge is based on first-hand experiences (Babbie & Mouton, 2009). The researcher experienced the problem first-hand with regard to having a preterm birth with her infant being admitted to an NICU. The experiences of the researcher motivated the research. With a brief literature study, it became clear that the problem was not unique to the researcher but exists for many parents. The aim was then to develop a support intervention to support parents who

have a preterm infant admitted to an NICU. Thus, a World 1 problem was translated into a research problem to be part of the scientific field of World 2, where World 2 searches for truthful knowledge. In the world of science, the aim is to generate valid and plausible descriptions and explanations of the world (Babbie & Mouton, 2009) and science is a conscious, deliberate and rigorous method of inquiry (Babbie, 2015). In this research study the phenomenon of preterm birth and its effects were explored consciously, deliberately and rigorously to determine what aspects should be included in a support intervention to foster well-being in parents. This research was based on the collective, validated experiences of the members of the scientific community, where evidence – as the only authority accepted in science - was shown with regard to the effects of the support intervention (Babbie & Mouton, 2009). In sum, the support intervention was developed in a World 2 field to be applied in World 1 to solve the problematic situation existing in World 1.

References

Aarnoudse-Moens, C. S., Weisglas-Kuperus, N., van Goudoever, J. B., & Oosterlaan, J. (2009). Meta-analysis of neurobehavioral outcomes in very preterm and/or very low birth weight children. *Pediatrics, 124*(2), 717-728.

Abidin, R. R. (1995). *Parenting Stress Index: Professional Manual 3rd edition* (Third ed.). Florida: PAR.

Adama, E. A., Bayes, S., & Sundin, D. (2016). Parents' experiences of caring for preterm infants after discharge from Neonatal Intensive Care Unit: A meta-synthesis of the literature. *Journal of Neonatal Nursing, 22*(1), 27-51.

Affleck, G., & Tennen, H. (1996). Construing benefits from adversity: Adaptational significance and dispositional underpinnings. *Journal of personality, 64*(4), 899-922.

Afrasiabi, N., Mohagheghi, P., Kalani, M., Mohades, G., & Farahani, Z. (2014, August). The Effect of High Risk Pregnancy on Duration of Neonatal Stay in Neonatal Intensive Care Unit. *Iranian Journal of Pediatrics, 24*(4), 423-428.

Aguilera, D. (1998). *Crisis intervention: theory and methodology* (8 ed.). St Louis: Mosby.

Alderdice, F., Lynn, F., & Lobel, M. (2012). A review and psychometric evaluation of pregnancy-specific stress measures. *Journal of Psychosomatic Obstetrics & Gynecology, 33*(2), 62-77.

Alio, A. P., Mbah, A. K., Kornosky, J. L., Wathington, D., Marty, P. J., & Salihu, H. M. (2011). Assessing the impact of paternal involvement on racial/ethnic disparities in infant mortality rates. *Journal of community health, 36*(1), 63-68.

Als, H., Duffy, F. H., McAnulty, G. B., Rivkin, M. J., Vajapeyam, S., Mulkern, R. V., . . . Eichenwald, E. C. (2004). Early experience alters brain function and structure. *Pediatrics, 113*(4), 846-857.

Altimier, L. (2011). Mother and child integrative developmental care model: a simple approach to a complex population. *Newborn and Infant Nursing Reviews, 11*(3), 105-108.

Altimier, L. (2012). Thermoregulation: what's new? What's not? *Newborn and Infant Nursing Reviews, 12*(1), 51-63.

Altimier, L., & Phillips, R. M. (2013). The Neonatal Integrative Developmental Care Model: Seven neuroprotective core measures for family-centered developmental care. *Newborn and Infant Nursing Reviews, 13*(1), 9-22.

Altimier, L., Kenner, C., & Damus, K. (2015). The Wee Care Neuroprotective NICU Program (Wee Care): The effect of a comprehensive developmental care training program on seven

neuroprotective core measures for family-centered developmental care of premature neonates. *Newborn and Infant Nursing Reviews, 15*(1), 6-16.

Alvaro, C., Lyons, R. F., Warner, G., Hobfoll, S. E., Martens, P. J., Labonte, R., & Brown, E. R. (2010). Conservation of resources theory and research use in health systems. *Implementation science, 5*(79), 1-20.

American Academy of Pediatrics, Commitee on Hospital Care, Institute for Patient- and Family-Centered Care. (2012). Patient- and family-centered care and the pediatrician's role. *Pediatrics, 129*(2), 394-404.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®).* American Psychiatric Association.

Antonovsky, A. (1979). *Health, Stress and Coping.* San Francisco: Jossey-Bass.

Antonovsky, A. (1987). *Unravelling the mystery of health: how people manage stress and stay well.* San Francisco: Jossey-Bass.

Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science and Medicine, 36*, 725-733.

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International, 11*(1), 11-18.

Arnold, L., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., & Ayers, S. (2013). Parents' first moments with their very preterm babies: a qualitative study. *BMJ: British Medical Journal Open, 3*, e002487. doi:10.1136/bmjopen-2012-002487

Arockiasamy, V., Holsti, L., & Albersheim, S. (2008). Fathers' experiences in the neonatal intensive care unit: a search for control. *Pediatrics, 121*(2), e215-e222.

Åsenhed, L., Kilstam, J., Alehagen, S., & Baggens, C. (2014). Becoming a father is an emotional roller coaster–an analysis of first-time fathers′ blogs. *Journal of clinical nursing, 23*, 1309-1317.

Avis, M., & Reardon, R. (2008). Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study. *Journal of Child Health Care, 12*(1), 7-17.

Babbie, E. (2015). *The practice of social research.* Cengage Learning.

Babbie, E., & Mouton, J. (2009). *Practice of Social Research.* Southern Africa: Oxford University Press.

Badiee, Z., Asghari, M., & Mohammadizadeh, M. (2013). The calming effect of maternal breast milk odor on premature infants. *Pediatrics & Neonatology, 54*(5), 322-325.

Barba, E., & Selder, E. (1995). Life transitions theory. *Nursing Leadership Forum, 1*, 4-11.

Barber, C. C., & Starkey, N. J. (2015). Predictors of anxiety among pregnant New Zealand women hospitalised for complications and a community comparison group. *Midwifery, 31*(9), 888-896.

Barlow, J. H., Hainsworth, J. M., & Thornton, S. (2007). An exploratory, descriptive study of women's experiences of hospital admission during pre-term labor. *Acta Obstetricia et Gynecologia, 86*, 429-434.

Barrios, Y. V., Sanchez, S. E., Qiu, C., Gelaye, B., & Williams, M. A. (2014). Risk of spontaneous preterm birth in relation to maternal experience of serious life events during pregnancy. *International journal of women's health, 6*, 249-257.

Barusch, A., Gringeri, C., & George, M. (2011). Rigor in qualitative social work research: A review of strategies used in published articles. *Social Work Research, 35*(1), 11-19.

Baum, N., Weidberg, Z., Osher, Y., & Kohelet, D. (2012). No Longer Pregnant, Not Yet a Mother Giving Birth Prematurely to a Very-Low-Birth-Weight Baby. *Qualitative health research, 22*(5), 595-606.

Bayrampour, H., Heaman, M., Duncan, K. A., & Tough, S. (2012). Advanced maternal age and risk perception: A qualitative study. *BMC Pregnancy and Childbirth, 12*, 100.

Beck, S. A., Weis, J., Greisen, G., Andersen, M., & Zoffmann, V. (2009). Room for family-centered care–a qualitative evaluation of a neonatal intensive care unit remodeling project. *Journal of Neonatal Nursing, 15*(3), 88-99.

Beck, S., Wojdyla, D., Say, L., Betran, A. P., Merialdi, M., Requejo, J. H., . . . Nenon, R. (2010). The worldwide incidence of preterm birth: a systematic review of maternal mortality and morbidity. *Bulletin of the World Health Organization, 88*, 31-38.

Behruzi, R., Hatem, M., Goulet, L., Fraser, W., Leduc, N., & Misago, C. (2010). Humanized birth in high risk prenancy: barriers and facilitating factors. *Medicine, Health Care and Philosophy, 13*(1), 49-58.

Bell, L., Goulet, C., Tribble, D. S., Paul, D., Boisclair, A., & Tronick, E. Z. (2007). Mothers' and Fathers' Views of the Interdependence of Their Relationships With Their Infant. A Systems Perspective on Early Family Relationships. *Journal of Family Nursing, 13*(2), 179-200.

Benoit, D. (2004). Infant-parent attachment: Definition, types, antecedents, measurement and outcome. *Paediatrics & child health, 9*(8), 541-545.

Benzies, K. M., Magill-Evans, J. E., Hayden, K. A., & Ballantyne, M. (2013). Key components of early intervention programs for preterm infants and their parents: a systematic review and meta-analysis. *BMC Pregnancy and Childbirth, 13(Suppl 1)*, S10.

Berg, I. K., & Dolan, Y. (2001). *Tales of solutions: A collection of hope-inspiring stories.* New York: W W Norton & Co.

Berg, M., & Dahlberg, K. (1998). A phenomenological study of women's experiences of complicated childbirth. *Midwifery, 14*(1), 23-29.

Berg, M., & Dahlberg, K. (2001). Swedish midwives' care of women who are at high obstetric risk or who have obstetric complications. *Midwifery, 17*(4), 259-266.

Berkowitz, G. S., & Papiernik, E. (1993). Epidemiology of preterm birth. *Epidemiologic Reviews, 15*(2), 414-443.

Bertram, C., & Christiansen, I. (2014). *Understanding research. An introduction to reading research.* Pretoria: Van Schaik.

Bialoskurski, M. M., Cox, C. L., & Wiggins, R. D. (2002). The relationship between maternal needs and priorities in a neonatal intensive care unit. *Journal of Adanced Nursing, 37*(1), 62-69.

Bialoskurski, M., Cox, C. L., & Hayes, J. A. (1999). The nature of attachment in a neonatal intensive care unit. *The Journal of perinatal & neonatal nursing, 13*(1), 66-77.

Bigelow, A. E., Littlejohn, M., Bergman, N., & McDonald, C. (2010). The relation between early mother–infant skin-to-skin contact and later maternal sensitivity in South African mothers of low birth weight infants. *Infant Mental Health Journal, 31*(3), 358-377.

Biswas-Diener, R., Kashdan, T. B., & Minhas, G. (2011). A dynamic approach to psychological strength development and intervention. *The Journal of Positive Psychology, 6*(2), 106-118.

Blencowe, H., Cousens, S., Oestergaard, M. Z., Chou, D. C., Moller, A., Narwal, R., . . . Chou, D. (2012, June). National, regional, and worldwide estimates of preterm birth rates in the year 2010 with time trends since 1990 for selected countries: a systematic analysis and implications. *The Lancet, 379*(9832), 2162–2172.

Bless, C., Higson-Smith, C., & Sithole, S. (2013). *Fundamentals of social research methods* (5th ed.). Cape Town: Juta and Company Ltd.

Blomqvist, Y. T., Rubertsson, C., Kylberg, E., Jöreskog, K., & Nyqvist, K. H. (2012). Kangaroo Mother Care helps fathers of preterm infants gain confidence in the paternal role. *Journal of advanced nursing, 68*(9), 1988-1996.

Blower, K., & Morgan, E. (2000). Great expectations? Parental participation in care. *Journal of child health care: for professionals working with children in the hospital and community, 4*(2), 60-65.

Borghini, A., Pierrehumbert, B., Miljkovitch, R., Muller-Nix, C., Forcada-Guex, M., & Ansermet, F. (2006). Mother's attachment representations of their premature infant at 6 and 18 months after birth. *Infant mental health journal, 27*(5), 494-508.

Bornstein, R. F., & Becker-Matero, N. (2011). Reconnecting psychoanalysis to mainstream psychology: Metaphor as glue. *Psychoanalytic Inquiry, 31*(2), 172-184.

Boundy, E. O., Dastjerdi, R., Spiegelman, D., Fawzi, W. W., Missmer, S. A., Lieberman, E., . . . Chan, G. J. (2016). Kangaroo Mother Care and Neonatal Outcomes: A Meta-analysis. *Pediatrics, 137*(1), e20152238.

Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development.* Sage.

Boyce, L. K., Cook, G. A., Simonsmeier, V., & Hendershot, S. M. (2015). Academic Outcomes of Very Low Birth-Weight Infants: The Influence of Mother-child Relationships. *Infant Mental Health Journal, 36*(2), 156-166.

Boykova, M., & Kenner, C. (2012). Transition from hospital to home for parents of preterm infants. *The Journal of perinatal & neonatal nursing, 26*(1), 81-87.

Brandon, A. R., Trivedi, M. H., Hynan, L. S., Miltenberger, P. D., Labat, D. B., Rifkin, J. B., & Stringer, C. A. (2008). Prenatal depression in women hospitalized for obstetric risk. *The Journal of clinical psychiatry, 69*(4), 635-643.

Braun, K. (2011). The prefrontal-limbic system: development, neuroanatomy, function, and implications for socioemotional development. *Clinics in perinatology, 38*(4), 685-702.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Briere, J. N., & Scott, C. (2015). *Principles of trauma therapy: A guide to symptoms, evaluation, and treatment* (2nd ed.). Los Angeles: Sage Publication.

Briscoe, K. N. (2015). Information Needs of Neonatal Intensive Care Parents: A Scoping Review. *Sigma Theta Tau International's 26th International Nursing Research Congress.* Toronto: STTI.

Bronfenbrenner, U. (1973). Social ecology of human development. In F. Richardson (Ed.), *Brain and intelligence: The ecology of child development* (pp. 113-129). Hyattsville: National Education Press.

Bronfenbrenner, U. (1974). Developmental research, public policy, and the ecology of childhood. *Child Development, 45*, 1-5.

Bronfenbrenner, U. (1976). The experimental ecology of education. *Teachers College Record, 78*, 157-204.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*, 513-531.

Bronfenbrenner, U. (1978). The social role of the child in ecological perspective. *Zeitschrift fur Soziologie, 7*(1), 4-20.

Bronfenbrenner, U. (1979). Contexts of child rearing. *American Psychologist, 34*, 844-850.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* MA: Harvard University Press.

Bronfenbrenner, U. (1989). Ecological systems theory. *Annals of Child Development, 6*, 187-249.

Bronfenbrenner, U. (1993). The ecology of cognitive development: research models and fugitive findings. In R. H. Wozniak, & K. Fischer (Eds.), *Development in context: Acting and thinking in specific environments* (pp. 3-44). Hillsdale: Erlbaum.

Bronfenbrenner, U. (1999). Environments in developmental perspective: Theoretical and operational models. In S. L. Friedman, & T. D. Wachs (Eds.), *Measuring environment across the life span: Emerging methods and concepts* (pp. 3-28). Washington: American Psychological Association Press.

Bronfenbrenner, U., & Ceci, S. J. (1993). Heredity, environment, and the question "how?" A first approximation. In R. Plomin, & G. G. McClern (Eds.), *Nature, nurture, and psychology* (pp. 313-323). Washington DC: American Psychological Association.

Bronfenbrenner, U., & Morris, P. (1998). The ecology of developmental processes. *Handbook of Child Psychology, 1*, 993-1023.

Bronfenbrenner, U., & Morris, P. (2006). The bioecological model of human development. *Handbook of Child Psychology, 1*, 793-828.

Brooten, D. Y. (2001). A randomized trial of nurse specialist home care for women with high-risk pregnancies: outcomes and costs. *The American journal of managed care, 7*(8), 793-803.

Browne, J. V., & Talmi, A. (2005). Family-based intervention to enhance infant–parent relationships in the neonatal intensive care unit. *Journal of Pediatric Psychology, 30*(8), 667-677.

Browne, J. V., & White, R. D. (2011). Foundations of developmental care. *Clinics in perinatology, 38*(4), xv-xvii.

Bruce, F. B., Hornbrook, M., Whitlock, E., Callaghan, W., Bachman, D., Gold, R., & Dietz, P. (2008). Maternal morbidity rates in a managed care population. *Obstetrics & Gynecology, 111*(5), 1089-1095.

Brunton, R. J., Dryer, R., Saliba, A., & Kohlhoff, J. (2015). Pregnancy anxiety: A systematic review of current scales. *Journal of affective disorders, 176*, 24-34.

Buescher, P. A., Whitmire, J. T., & Brunssen, S. K.-H. (2006). Children who are medically fragile in North Carolina: using Medicaid data to estimate prevalence and medical care costs in 2004. *Maternal and child health journal, 10*(5), 461-466.

Busse, M., Stromgren, K., Thorngate, L., & Thomas, K. A. (2013). Parents' responses to stress in the neonatal intensive care unit. *Critical care nurse, 33*(4), 52-59.

Butler, A. S., & Behrman, R. E. (Eds.). (2007). *Preterm Birth: Causes, Consequences, and Prevention.* National Academies Press.

Cano Giménez, E., & Sánchez-Luna, M. (2015). Providing parents with individualised support in a neonatal intensive care unit reduced stress, anxiety and depression. *Acta Pædiatrica, 104*(7), e300-e305.

Carrier, C. T. (2010). Developmental Support. In M. T. Verkklan, & M. Walden (Eds.), *Core Curriculum for Neonatal Intensive Care Nursing* (Fourth ed., pp. 208-232). Missouri: Saunders Elsevier.

Carter, J. D., Mulder, R. T., & Darlow, B. A. (2007). Parental stress in the NICU: The influence of personality, psychological, pregnancy and family factors. *Personality and Mental Health, 1*(1), 40-50.

Cheavens, J., & Ritschel, L. (2014). Hope Theory. In M. Tugade, M. Shiota, & L. Kirby (Eds.), *Handbook of Positive Emotions* (pp. 396-409). New York: The Guilford Press.

Chen, Y. C., Chang, M. Y., Chang, L. Y., & Mu, P. F. (2015). Experiences of parents providing kangaroo care to a premature infant: a systematic review of the qualitative evidence protocol. *The JBI Database of Systematic Reviews and Implementation Reports, 13*(9), 112-119.

Chen, Y., Zhang, J., & Bai, J. (2016). Effect of an educational intervention on parental readiness for premature infant discharge from the neonatal intensive care units. *Journal of advanced nursing, 72*(1), 135-146.

Chi Luong, K., Long Nguyen, T., Thi, H., Huong, D., Carrara, H. P., & Bergman, N. J. (2015). Newly born low birthweight infants stabilise better in skin-to-skin contact than when separated from their mothers: a randomised controlled trial. *Acta Paediatrica, 105*, 381-390.

Chilisa, B., & Kawulich, B. (2012). Selecting a research approach: paradigm, methodology and methods. In C. Wagner, B. Kawulich, & M. Garner (Eds.), *Doing social research. A global context* (pp. 51-61). Berkshire: McGraw-Hill.

Christie, J., Poulton, B. C., & Bunting, B. P. (2008). An integrated mid-range theory of postpartum family development: a guide for research and practice. *Journal of Advanced Nursing, 61*(1), 38-50.

Clark, L. A., Kochanska, G., & Ready, R. (2000). Mothers' personality and its interaction with child temperament as predictors of parenting behavior. *Journal of Personality and Social Psychology, 79*, 274-285.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The psychologist, 26*(2), 120-123.

Clarkson, P. (2000). *Ethics: Working with ethical and moral dilemmas in psychotherapy.* John Wiley & Sons Incorporated.

Class, Q. A., Lichtenstein, P., Långström, N., & D'Onofrio, B. M. (2011). Timing of prenatal maternal exposure to severe life events and adverse pregnancy outcomes: a population study of 2.6 million pregnancies. *Psychosomatic medicine, 73*(3), 234-241.

Clauson, M. I. (1996). Uncertainty and stress in women hospitalized with high-risk pregnancy. *Clinical Nursing Research, 5*(3), 309-325.

Clements, M., & Barnett, D. (2002). Parenting and attachment among toddlers with congenital anomalies: Examining the strange situation and attachment Q-sort. *Infant Mental Health Journal, 23*, 624-625.

Cleveland, L. M. (2008). Parenting in the Neonatal Intensive Care Unit. *JOGNN, 37*, 666-691.

Cleveland, L. M. (2009). Symbolic Interactionism and Nurse–Mother Communication in the Neonatal Intensive Care Unit. *Research and theory for nursing practice, 23*(3), 216-229.

Cockcroft, S. (2012). How can family centred care be improved to meet the needs of parents with a premature baby in neonatal intensive care? *Journal of Neonatal Nursing, 18*(3), 105-110.

Coffman, S., & Ray, M. (2002). African American women describe support processes during high-risk pregnancy and postpartum. *Journal of Obstetric and Gynecological Neonatal Nursing, 31*(5), 536-544.

Cohn, M. A., & Fredrickson, B. L. (2009). Positive emotions. In C. Snyder, & S. Lopez (Eds.), *Oxford handbook of positive psychology* (2nd ed., pp. 13-24). New York: Oxford University Press.

Cokkinides, V. E., Coker, A. L., Sanderson, M., Addy, C., & Bethea, L. (1999). Physical violence during pregnancy: maternal complications and birth outcomes. *Obstetrics & Gynecology, 93*(5), 661-666.

Cole-Lewis, H. J., Kershaw, T. S., Earnshaw, V. A., Yonkers, K. A., Lin, H., & Ickovics, J. R. (2014). Pregnancy-specific stress, preterm birth, and gestational age among high-risk young women. *Health Psychology, 33*(9), 1033-1045.

Comaru, T., & Miura, E. (2009). Postural support improves distress and pain during diaper change in preterm infants. *Journal of Perinatology, 29*(7), 504-507.

Committee on Hospital Care and Institute for Patient- and Family-Centered Care. (2012). Patient- and Family-Centered Care and the Pediatrician's Role. *Pediatrics, 129*(2), 394-404.

Compton, W., & Hoffman, E. (2013). *Positive Psychology: The Science of Happiness and Flourishing* (2nd ed.). CA: Jon-David Hague.

Conde-Agudelo, A., Belizán, J. M., & Diaz-Rossello, J. (2011). Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. *Cochrane Database Syst Rev, 3*(3).

Conn, N., & Discenza, D. (2009). *The Preemie Parent's Survival Guide to the NICU.* PreemieWorld, LLC.

Conoley, C. W., Plumb, E. W., Hawley, K. J., Spaventa-Vancil, K. Z., & Hernández, R. J. (2015). Integrating Positive Psychology Into Family Therapy: Positive Family Therapy. *The Counseling Psychologist, 43*(5), 703-733.

Cooper, L. G., Gooding, J. S., Gallagher, J., Sternesky, L., Ledsky, R., & Berns, S. D. (2007). Impact of a family-centered care initiative on NICU care, staff and families. *Journal of perinatology, 27 (Supplement 2)*, S32-S37.

Cooper, P., Saloojee, H., Bolton, K., & Mokhachane, M. (1999). Survival of Low-Birth-Weight Infants at Baragwanath Hospital-1950-1996. *South African Medical Journal, 89*(11), 1179-1181.

Coster-Schulz, M. A., & Mackey, M. (1998). The preterm labor experience: A balancing act. *Clinical Nursing Research, 7*, 335-362.

Cote-Arsenault, D. (2007). Threat appraisal, coping, and emotions in pregnancy after perinatal loss. *Nursing Research, 56*, 108-116.

Cote-Arsenault, D., & Donato, K. (2007). Restrained expectations in late pregnancy following loss. *Journal of Obstetric,Gynecologic, and Neonatal Nursing, 36*, 550-557.

Couchenour, D., & Chrisman, K. (2014). *Families, schools and communities. Together for young children.* Belmont: Wadsworth.

Coughlin, M., Gibbins, S., & Hoath, S. (2009). Core measures for developmentally supportive care in neonatal intensive care units: theory, precedence and practice. *Journal of advanced nursing, 65*(10), 2239-2248.

Coussons-Read, M. E., Carey, J. C., Kreither, M. O., D'Anna, K., Argys, L., Ross, R. G., . . . Cole, S. (2012). The occurrence of preterm delivery is linked to pregnancy-specific distress and elevated inflammatory markers across gestation. *Brain, behavior, and immunity, 26*(4), 650-659.

Coyne, I., & Cowley, S. (2006). Using grounded theory to research parent participation. *Journal of Research in Nursing, 11*(6), 501-515.

Craig, J. W., Glick, C., Phillips, R., Hall, S. L., Smith, J., & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology, 35*, S5-S8.

Crawford, J., Cayley, C., Lovibond, P. F., Wilson, P. H., & Hartley, C. (2011). Percentile Norms and Accompanying Interval Estimates from an Australian General Adult Population Sample for Self-Report Mood Scales (BAI, BDI, CRSD, CES-D, DASS, DASS-21, STAI-X, STAI-Y, SRDS, and SRAS). *Australian Psychologist, 46*(1), 3-14.

Csikszentmiahlyi, M., & Rathunde, K. (2014). The Development of the Person: An Experiential Perspectives on the Ontogenesis of Psychological Complexity. In *Applications of flow in human development and education: the collected works of Mihalyi Csikszentmihalyi.* Dordrecht: Springer.

Csikszentmihalyi, M. (1975). *Beyond boredom and anxiety.* San Francisco: Jossey-Bass.

Csikszentmihalyi, M. (1990). *Flow: The Psychology of Optimal Experience.* New York: Harper & Row.

Csikszentmihalyi, M. (1997). *Finding flow: The psychology of engagement with everyday life.* New York: Basic Books.

Csikszentmihalyi, M., & Csikszentmihalyi, I. (Eds.). (1988). *Optimal Experience: Psychological Studies of Flow in Consciousness.* Cambridge: Cambridge Unoversity Press.

Cunningham, F., Leveno, K., Bloom, S., Hauth, J., Gilstrap, L., & Wenstrom, K. (2005). *Williams Obstetrics* (22th ed.). New York: McGraw Hill Professional.

Davanzo, R. (2004). Newborns in adverse conditions: issues, challenges, and interventions. *Journal of Midwifery & Women's Health, 49*(S1), 29-35.

Davanzo, R., Monasta, L., Ronfani, L., Brovedani, P., Demarini, S., & Group, B. i. (2013). Breastfeeding at NICU Discharge A Multicenter Italian Study. *Journal of Human Lactation, 29*(3), 374-380.

Davis, L., Edwards, H., Mohay, H., & Wollin, J. (2003). The impact of very premature birth on the psychological health of mothers. *Early human development, 73*(1), 61-70.

Davy, K., Bergh, A., & Van Rooyen, E. (2011). The neonatal nurse's role in kangaroo mother care: mother and child health. *Professional Nursing Today, 15*(3), 32-34.

De Jong, P., & Berg, I. K. (2012). *Interviewing for solutions* (4th ed.). Belmont: Brooks/Cole.

de Oliveira Dornasbach, J., Barbosa de Freitas, H. M., Santini Costenaro, R. G., Filipin Rangel, R., Zamberlan, C., & Ilha, S. (2014). Neonatal intensive care: feeling of parents after discharge of the child. *Journal of Nursing UFPE on line, 8*(8), 2660-2666.

De Shazer, S. (2006). *The miracle question*. Retrieved from http://www.netzwerk-ost.at

De Shazer, S., & Dolan, Y. (2012). *More than miracles: The state of the art of solution-focused brief therapy.* New York: Routledge.

De Vos, A., & Strydom, H. (2011). Intervention research. In A. De Vos, H. Strydom, C. Fouché, & C. Delport (Eds.), *Research at grassroots. For the social sciences and human service professions* (pp. 473-489). Pretoria: Van Schaik.

Deave, T., Johnson, D., & Ingram, J. (2008). Transition to parenthood: the needs of parents in pregnancy and early parenthood. *BMC Pregnancy and Childbirth, 8*, 30.

DeMier, R. L., Hynan, M. T., Hatfield, R. F., Varner, M. W., Harris, H. B., & Manniello, R. L. (2000). A measurement model of perinatal stressors: Identifying risk for postnatal emotional distress in mothers of high-risk infants. *Journal of Clinical Psychology, 56*(1), 89-100.

Department: Social Development. REPUBLIC OF SOUTH AFRICA. (2013). *White Paper on Families*. Retrieved from http://www.dsd.gov.za/index.php?option=com_docman&task=cat_view&gid=33&Itemid=39

Diener, E., Wirtz, D., Tov, W., Kim-Prieto, C., Choi, D., Oishi, S., & Biswas-Diener, R. (2010). New well-being measures: Short scales to assess flourishing and positive and negative feelings. *Social Indicators Research, 97*, 143-156.

Ding, X.-X., Wu, Y.-L., Xu, S.-J., Zhu, R.-P., Jia, X.-M., Zhang, S.-F., . . . Tao, F.-B. (2014). Maternal anxiety during pregnancy and adverse birth outcomes: a systematic review and meta-analysis of prospective cohort studies. *Journal of affective disorders, 159*, 103-110.

Doering, L., Moder, D., & Dracup, K. (2000). Correlates of Anxiety, Hostility, Depression, and Psychosocial Adjustment in Parents of NICU Infants. *Neonatal Network, 5*, 15-23.

Dole, N., Savitz, D. A., Hertz-Picciotto, I., Siega-Riz, A. M., McMahon, M. J., & Buekens, P. (2003). Maternal stress and preterm birth. *American journal of epidemiology, 157*(1), 14-24.

Dole, N., Savitz, D. A., Siega-Riz, A. M., Hertz-Picciotto, I., McMahon, M. J., & Buekens, P. (2004). Psychosocial factors and preterm birth among African American and White women in central North Carolina. *American Journal of Public Health, 94*(8), 1358-1365.

Doss, B. D., Cicila, L. N., Hsueh, A. C., & Morrison, K. R. (2014). A randomized controlled trial of brief coparenting and relationship interventions during the transition to parenthood. *Journal of Family Psychology, 28*(4), 483-494.

Draper, J. (2003). Men's passage to fatherhood: an analysis of the contemporary relevance of transition theory. *Nursing inquiry, 10*(1), 66-78.

Du Plessis, E. (2016). Etiese aspekte in navorsing. In I. Joubert, C. Hartell, & K. Lombard (Eds.), *Navorsing. 'n Gids vir die beginnernavorser* (pp. 73-92). Pretoria: Van Schaik.

Du Toit, M., Wissing, M., & Khumalo, I. (2014). Positive relationships. In M. Wissing, J. Potgieter, T. Guse, T. Khumalo, & L. Nel (Eds.), *Toward flourishing. Contextualising positive psychology* (pp. 175-219). Pretoria: Van Schaik.

Duckworth, A. L., Steen, T. A., & Seligman, M. E. (2005, April). Positive psychology in clinical practice. *Annual Review of Clinical Psychology, 1*, 629-651.

Dunkel-Schetter, C. (2011). Psychological science on pregnancy: stress processes, biopsychosocial models, and emerging research issues. *Annual review of psychology, 62*, 531-558.

Dunkel-Schetter, C., & Glynn, L. (2010). Stress in pregnancy: empirical evidence and theoretical issue to guide interdisciplinary researchers. In R. Contrada, & A. Baum (Eds.), *Handbook of Stress Science: Biology, Psychology, and Health* (2nd ed., pp. 321-344). New York: Springer.

Dunn, L. L., & Shelton, M. M. (2007). Spiritual well-being, anxiety, and depression in antepartal women on bedrest. *Issues in Mental Health Nursing, 28*(11), 1235-1246.

Edmunds, S. F., & Silver, R. M. (2013). Stillbirth Reduction Efforts and Impact on Early Births. *Clinics in perinatology, 40*(4), 611-628.

Egan, G. (2013). *The skilled helper: A problem-management and opportunity-development approach to helping* (Tenth ed.). Belmont, Canada: Brooks/Cole Cengage Learning.

Erlandsson, K., Dsilna, A., Fagerberg, I., & Christensson, K. (2007). Skin-to-skin care with the father after cesarean birth and its effect on newborn crying and prefeeding behaviour. *Birth, 34*(2), 105-114.

Evans, R., & Madsen, B. (2005). Culture clash: transitioning from the neonatal intensive care unit to the pediatric intensive care unit. *Newborn and Infant Nursing Reviews, 5*(4), 188-193.

Evans, T., Whittingham, K., & Boyd, R. (2012). What helps the mother of a preterm infant become securely attached, responsive and well-adjusted? *Infant Behavior and Development, 35*(1), 1-11.

Fawcett, S. B., Suarez-Balcazar, Y., Balcazar, F. E., White, G. W., Paine, A. L., Blanchard, K. A., & Embree, M. G. (1994). Conducting Intervention Research-The Design and Development Process. In J. Rothman, & E. J. Thomas (Eds.), *Intervention Research:Design and Development for Human Service* (pp. 25-55). New York: The Haworth Press.

Feeley, N., Gottlieb, L., & Zelkowitz, P. (2007). Mothers and Fathers of Very Low-Birthweight Infants: Similarities and Differences in the First Year After Birth. *JOGNN, 36*, 558-567.

Feldman, R. (2007). Parent–infant synchrony and the construction of shared timing; physiological precursors, developmental outcomes, and risk conditions. *Journal of Child Psychology and Psychiatry, 48*(3-4), 329-354.

Feldman, R., Eidelman, A. I., & Rotenberg, N. (2004). Parenting stress, infant emotion regulation, parental sensitivity, and the cognitive development of triplets: A model for parent and child influences in a unique ecology. *Child Development, 75*, 1774-1791.

Feldman, R., Eidelman, A. I., Sirota, L., & Weller, A. (2002). Comparison of skin-to-skin (kangaroo) and traditional care: parenting outcomes and preterm infant development. *Pediatrics, 110*(1), 16-26.

Fenwick, J., Barclay, L., & Schmied, V. (2001). 'Chatting': an important clinical tool in facilitating mothering in neonatal nurseries. *Journal of advanced nursing, 33*(5), 583-593.

Fenwick, J., Barclay, L., & Schmied, V. (2001). Struggling to mother: a consequence of inhibitive nursing interactions in the neonatal nursery. *The Journal of perinatal & neonatal nursing, 15*(2), 49-64.

Fenwick, J., Bayes, S., & Johansson, M. (2012). A qualitative investigation into pregnancy experiences and childbirth expectations of Australian fathers-to-be. *Sexual and Reproductive Health, 3*, 3-9.

Fernbacher, S. (2005). Cultural Influences and Considerations in Gestalt Therapy. In A. L. Woldt, & S. M. Toman (Eds.), *Gestalt therapy: History, theory, and practice* (pp. 117-132). California: Sage Publications.

Field, T. (2010). Postpartum depression effects on early interactions, parenting, and safety practices: a review. *Infant Behavior and Development, 33*(1), 1-6.

Field, T., Diego, M., & Hernandez-Reif, M. (2006). Prenatal depression effects on the fetus and newborn: a review. *Infant Behavior and Development, 29*(3), 445-455.

Fincham, F. D., & Beach, S. R. (2010). Marriage in the new millennium: A decade in review. *Journal of Marriage and Family, 72*, 630–649.

Fink, N. S., Urech, C., Cavelti, M., & Alder, J. (2012). Relaxation during pregnancy: what are the benefits for mother, fetus, and the newborn? A systematic review of the literature. *The Journal of perinatal & neonatal nursing, 26*(4), 296-306.

Finlayson, K., Dixon, A., Smith, C., Dykes, F., & Flacking, R. (2014). Mothers' perceptions of family centred care in neonatal intensive care units. *Sexual & Reproductive Healthcare, 5*(3), 119-124.

Finnbogadóttir, H., Svalenius, E. C., & Persson, E. K. (2003). Expectant first-time fathers' experiences of pregnancy. *Midwifery, 19*(2), 96-105.

Fisher, K. (n.d.). *Max-Neef on Human Needs and Human-scale Development*. Retrieved from http://www.rainforestinfo.org.au/background/maxneef.htm

Fitzpatrick, M. R., & Stalikas, A. (2008). Positive emotions as generators of therapeutic change. *Journal of psychotherapy integration, 18*(2), 137-154.

Flacking, R., Ewald, U., & Starrin, B. (2007). “I wanted to do a good job”: experiences of ‘becoming a mother’and breastfeeding in mothers of very preterm infants after discharge from a neonatal unit. *Social science & medicine, 64*(12), 2405-2416.

Flacking, R., Ewald, U., Nyqvist, K. H., & Starrin, B. (2006). Trustful bonds: a key to “becoming a mother” and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social science & medicine, 62*(1), 70-80.

Flacking, R., Lehtonen, L., Thomson, G., Axelin, A., Ahlqvist, S., Moran, V. H., . . . Dykes, F. (2012). Closeness and separation in neonatal intensive care. *Acta Paediatrica, 101*(10), 1032-1037.

Flacking, R., Wallin, L., & Ewald, U. (2007). Perinatal and socioeconomic determinants of breastfeeding duration in very preterm infants. *Acta Paediatrica, 96*(8), 1126-1130.

Fleury, C., Parpinelli, M. A., & Makuch, M. Y. (2014). Perceptions and actions of healthcare professionals regarding the mother-child relationship with premature babies in an intermediate neonatal intensive care unit: a qualitative study. *BMC pregnancy and childbirth, 14*(1), 1.

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American psychologist, 55*(6), 647.

Forcada-Guex, M., Borghini, A., Pierrehumbert, B., Ansermet, F., & Muller-Nix, C. (2011). Prematurity, maternal posttraumatic stress and consequences on the mother–infant relationship. *Early human development, 87*(1), 21-26.

Fowles, E. R. (1998). The relationship between maternal role attainment and postpartum depression. *Health Care for Women International, 19*, 83-94.

Fowlie, P. W., & McHaffie, H. (2004, Dec). ABC of preterm birth: Supporting parents in the neonatal unit. *BMJ: British Medical Journal, 329*(7478), 1336-1338.

Franck, L. S., Cox, S., Allen, A., & Winter, I. (2005). Measuring neonatal intensive care unit-related parental stress. *Journal of Advanced Nursing, 49*(6), 608-615.

Franklin, C. (2006). The neonatal nurse's role in parental attachment in the NICU. *Critical Care Nursing Quarterly, 29*(1), 81-85.

Fraser, M. (2004). Intervention research in social work: recent advances and continuing challenges. *Research on Social Work Practice, 14*(3), 210-222.

Fraser, M., Richman, J., Galinsky, M., & Day, S. (2009). *Intervention Research: Developing Social Programs.* New York : Oxford University Press.

Fredrickson, B. L. (1998). What good are positive emotions? *Review of general psychology, 2*(3), 300-319.

Fredrickson, B. L. (2000). Cultivating positive emotions to optimize health and well-being. *Prevention & Treatment, 3*(1), 1a.

Fredrickson, B. L. (2001). The role of positive emotions in positive psychology: The broaden-and-build theory of positive emotions. *American psychologist, 56*(3), 218-226.

Friedman, S., Kessler, A., Nagle Yang, S., Parsons, S., Friedman, H., & Martin, R. J. (2013). Delivering perinatal psychiatric services in the neonatal intensive care unit. *Acta Paediatrica, 102*(9), e392-e397.

Gable, S., & Haidt, J. (2005). What (and why) is positive psychology? *Review of General Psychology, 9*, 103-110.

Gabriels, K. B. (2015). Kangaroo Care: Experiences and Needs of Parents in Neonatal Intensive Care: A Systematic Review 'Parents' Experience of Kangaroo Care. *Pediatrics and Neonatal Nursing, 1*(1). Retrieved from http://dx.doi.org/10.16966/pnnoa.102

Garland, E. L., Fredrickson, B., Kring, A. M., Johnson, D. P., Meyer, P. S., & Penn, D. L. (2010). Upward spirals of positive emotions counter downward spirals of negativity: Insights from the broaden-and-build theory and affective neuroscience on the treatment of emotion dysfunctions and deficits in psychopathology. *Clinical psychology review, 30*(7), 849-864.

Genesoni, L., & Tallandini, M. A. (2009). Men's psychological transition to fatherhood: an analysis of the literature, 1989–2008. *Birth, 36*(4), 305-318.

Gennaro, S., & Hennessy, M. D. (2003). Psychological and physiological stress: impact on preterm birth. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 32*(5), 668-675.

Ghosh, J. K., Wilhelm, M. H., Dunkel-Schetter, C., Lombardi, C. A., & Ritz, B. R. (2010). Paternal support and preterm birth, and the moderation of effects of chronic stress: a study in Los Angeles County mothers. *Archives of women's mental health, 13*(4), 327-338.

Gibbins, S., Hoath, S. B., Coughlin, M., Gibbins, A., & Franck, L. (2008). The universe of developmental care: a new conceptual model for application in the neonatal intensive care unit. *Advances in Neonatal Care, 8*(3), 141-147.

Gibbs, P., & Maguire, K. (2011). The metaphor of therapy and its use in the learning of a workplace identity. *Journal of Vocational Education & Training, 63*(4), 619-628.

Gilbert, E. S. (2011). *Manual of High Risk Pregnancy & Delivery* (5th ed.). St. Louis: Mosby.

Gilgun, J. F., & Sands, R. G. (2012). The contribution of qualitative approaches to developmental intervention research. *Qualitative social work, 11*(4), 349-361.

Gillham, J., & Seligman, M. (1999). Footsteps on the road to a positive psychology. *Behaviour Research and Therapy, 37*(Supplement 1), S163-S173.

Giurgescu, C., Penckofer, S., Maurer, M. C., & Bryant, F. (2006). Impact of Uncertainty, Social Support, and Prenatal Coping on the Psychological Well-Being of High-risk Pregnant Women. *Nursing research, 55*(5), 356-365.

Goldberg, L. S. (2007). Embodied trust within the perinatal nursing relationship. *Midwifery, 24*, 74-82.

Goldberg, S., & DiVitto, B. (2005). Parenting children born preterm. In M. H. Bornstein (Ed.), *Handbook of parenting* (pp. 329-354). New Jersey: Erlbaum.

Goldenberg, R. L., Culhane, J. F., Iams, J. D., & Romero, R. (2008). Epidemiology and causes of preterm birth. *The Lancet, 371*, 75-84.

Gooding, J. S., Cooper, L. G., Blaine, A. I., Franck, L. S., Howse, J. L., & Berns, S. D. (2011). Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Seminars in perinatology, 35*(1), 20-28.

Goutaudier, N., Lopez, A., Séjourné, N., Denis, A., & Chabrol, H. (2011). Premature birth: subjective and psychological experiences in the first weeks following childbirth, a mixed-methods study. *Journal of Reproductive and Infant Psychology, 29*(4), 364-373.

Graignic-Philippe, R., Dayan, J., Chokron, S., Jacquet, A. Y., & Tordjman, S. (2014). Effects of prenatal stress on fetal and child development: a critical literature review. *Neuroscience & Biobehavioral Reviews, 43*, 137-162.

Gray, B. (2001). *Women's subjective appraisal of pregnancy risk and the effects of uncertainty, perceived control, coping, and emotions on maternal attachment.* Cleveland: Case Western Reserve University.

Gray, B. (2006). Hospitalization history and differences in self-related pregnancy risk. *Western Journal of Nursing Research, 28*, 216-229.

Gray, J., Grove, S., & Burns, N. (2013). *The Practice of Nursing Research: Appraisal, Synthesis, and Generation of Evidence* (Seventh ed.). Missouri: Elsevier.

Gregory, K. E. (2015). Strategies for Surviving and Thriving as Parents in the NICU. *The Journal of perinatal & neonatal nursing, 29*(4), 270-272.

Griffin, J. B., & Pickler, R. H. (2011). Hospital-to-home transition of mothers of preterm infants. *MCN: The American Journal of Maternal/Child Nursing, 36*(4), 252-257.

Grote, N. K., Bridge, J. A., Gavin, A. R., Melville, J. L., Iyengar, S., & Katon, W. J. (2010). A meta-analysis of depression during pregnancy and the risk of preterm birth, low birth weight, and intrauterine growth restriction. *Archives of general psychiatry, 67*(10), 1012-1024.

Grove, S. K., Burns, N., & Gray, J. R. (2015). *Understanding nursing research: Building an evidence-based practice* (6th ed.). St. Louis: Elsevier.

Guillaume, S., Michelin, N., Amrani, E., Benier, B., Durrmeyer, X., Lescure, S., . . . Caeymaex, L. (2013). Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. *BMC pediatrics, 13*(1), 18.

Gupton, A., Heaman, M., & Cheung, L. W. (2001). Complicated and Uncomplicated Pregnancies: Women's Perception of Risk. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 30*(2), 192-201.

Guse, T. (2014). Activities and programmes to enhance well-being. In M. Wissing, J. Potgieter, T. Guse, T. Khumalo, & L. Nel (Eds.), *Towards flourishing. Contextualising positive psychology* (pp. 291-309). Pretoria: Van Schaik.

Guterman, J. (2013). *Mastering the art of solution-focused counseling* (Second ed.). Alexandria: John Wiley & Sons.

Habib, C., & Lancaster, S. (2010). Changes in identity and paternal–foetal attachment across a first pregnancy. *Journal of Reproductive and infant Psychology, 28*(2), 128-142.

Hagan, R., Evans, S., & Pope, S. (2004). Preventing postnatal depression in mothers of very preterm infants: A randomised controlled trial. *BJOG- An International Journal of Obstetrics and Gynaecology*, 111(7), 641-647.

Hall, E. O., Kronborg, H., Aagaard, H., & Brinchmann, B. S. (2013). The journey towards motherhood after a very preterm birth: Mothers' experiences in hospital and after home-coming. *Journal of Neonatal Nursing, 19*(3), 109-113.

Hall, R. A., Hoffenkamp, H. N., Tooten, A., Braeken, J., Vingerhoets, A. J., & Van Bakel, H. J. (2015). Child-rearing history and emotional bonding in parents of preterm and full-term infants. *Journal of Child and Family Studies, 24*(6), 1715-1726.

Hall, S. (2015). Recommendations for Program Standards for Psychosocial Support of NICU Parents. *2015 AAP National Conference and Exhibition.* American Academy of Pediatrics.

Hall, S. L., Ryan, D. J., Beatty, J., & Grubbs, L. (2015). Recommendations for peer-to-peer support for NICU parents. *Journal of Perinatology, 35*, S9-S13.

Hall, S., Hynan, M., Phillips, R., Press, J., Kenner, C., & Ryan, D. J. (2015). Development of Program Standards for Psychosocial Support of Parents of Infants Admitted to a Neonatal Intensive Care Unit: A National Interdisciplinary Consensus Model. *Newborn and Infant Nursing Reviews, 15*(1), 24-27.

Halle, C., Dowd, T., Fowler, C., Rissel, K., Hennessy, K., MacNevin, R., & Nelson, M. A. (2008). Supporting fathers in the transition to parenthood. *Contemporary Nurse, 31*(1), 57-70.

Hargrove, M. B., Nelson, D. L., & Cooper, C. L. (2013). Generating eustress by challenging employees. *Organizational Dynamics, 42*(1), 61-69.

Hartell, C., & Bosman, L. (2016). Beplanning van 'n navorsingvoorstel vir nagraadse studie. In I. Joubert, C. Hartell, & K. Lombard (Eds.), *Navorsing. 'n Gids vir die beginnernavorser* (pp. 19-51). Pretoria: Van Schaik.

Hay, J. (2016). Etnografie. In I. Lombard, C. Hartell, & K. Lombard (Eds.), *Navorsing. 'n Gids vir die beginnernavorser* (pp. 201-216). Pretoria: Van Schaik.

Heaman, M., & Gupton, A. (1998). Perceptions of bed rest by women with high-risk pregnancies: A comparison between home and hospital. *Birth, 25*, 252-258.

Heaman, M., Beaton, J., Gupton, A., & Sloan, J. (1992). A comparison of childbirth expectations in high-risk and low-risk pregnant women. *Clinical Nursing Research, 1*(3), 252-265.

Heaman, M., Gupton, A., & Gregory, D. (2004). Factors influencing pregnant women's perceptions of risk. *The American Journal of Maternal/Child Nursing, 29*(2), 111-116.

Hedegaard, M., Henriksen, T. B., Secher, N. J., Hatch, M. C., & Sabroe, S. (1996). Do Stressful Life Events Affect Duration of Gestation and Risk of Preterm Delivery? *Epidemiology, 7*(4), 339-345.

Hedegaard, M., Henrikson, T. B., Sabroe, S., & Secher, N. J. (1993). Psychological distress in pregnancy and preterm delivery. *British Medical Journal, 307*, 234-239.

Hediger, M. L., Overpeck, M. D., Ruan, W., & Troendle, J. F. (2002). Birthweight and gestational age effects on motor and social development. *Paediatric and Perinatal Epidemiology, 16*(1), 33-46.

Henden, J. (2008). *Preventing suicide: The solution focused approach.* West Sussex: John Wiley & Sons.

Hepworth, D., Rooney, R., Rooney, G. D., & Strom-Gottfried, K. (2013). *Direct social work practice: Theory and skills* (Ninth ed.). Canada: Brooks/Cole Cengage Learning.

Hersberger, J. (2013). Resilience theory, information behaviour and social support in everyday life. *Proceedings of the Annual Conference of CAIS/Actes du congrès annuel de l'ACSI.* The University of North Carolina at Greensboro.

Hobday, A., & Ollier, K. (1999). *Creative therapy with children & adolescents.* California: Impact Publishers.

Hobel, C. J., Goldstein, A., & Barrett, E. S. (2008). Psychosocial stress and pregnancy outcome. *Clinical obstetrics and gynecology, 51*(2), 333-348.

Hobfoll, S. E. (1988). *The ecology of stress.* New York: Hemisphere.

Hobfoll, S. E. (1989). Conservation of resources: A new attempt at conceptualizing stress. *American Psychologist, 44*, 513-524.

Hobfoll, S. E. (2001). The influence of culture, community, and the nested self in the stress process: Advancing conservation of resources theory. *Applied Psychology: An International Review, 50*, 337-370.

Hobfoll, S. E. (2002). Social and psychological resources and adaptation. *Review of general psychology, 6*(4), 307-324.

Hobfoll, S. E., Dunahoo, C., & Monnier, J. (1995). Conservation of resources and traumatic stress. In J. Freedy, & S. Hobfoll (Eds.), *Traumatic stress: From theory to practice* (pp. 29-47). New York: Plenum Press.

Hodek, J., von der Schulenburg, J., & Mittendorf, T. (2011). Measuring economic consequences of preterm birth - Methodological recommendations for the evaluation of personal burden on children and their caregivers. *Health Economics Review, 1*, 6. Retrieved from http://www.healtheconomicsreview.com/content/1/1/6

Hoffenkamp, H., Tooten, A., Hall, R., Croon, M., Braeken, J., Winkel, F., . . . van Bakel, H. (2012). The impact of premature childbirth on parental bonding. *Evolutionary Psychology, 10*(3), 147470491201000311.

Holditch-Davis, D., Bartlett, T. R., Blickman, A. L., & Miles, M. S. (2003). Posttraumatic stress symptoms in mothers of premature infants. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 32*(2), 161-171.

Holditch-Davis, D., Blackburn, S. T., & VandenBerg, K. (2003). Newborn and infant neurobehavioral development. In C. Kenner, & J. W. Lott (Eds.), *Comprehensive Neonatal Nursing: A Physiologic Perspective* (3rd ed., pp. 236-284). St Louis, MO: Saunders.

Holditch-Davis, D., Miles, M. S., Burchinal, M. R., & Goldman, B. D. (2011). Maternal Role Attainment With Medically Fragile Infants: Part 2. Relationship to the Quality of Parenting. *Research in Nursing and Health, 34*, 35-48.

Horky, S., Levitz, B., Goode, T., Miney, A., & Smith, M. (n.d.). *Resources for Teaching Family-Centered and Family Directed Practices*. Retrieved from fttp://ftp.hrsa.gov/mchb/training/documents/grantee.../m546_fcfdp_resources05.pdf

Howarth, A. M., Swain, N. R., & Treharne, G. J. (2012). First-time mothers' perspectives on relationships with and between midwives and doctors: Insights from a qualitative study of giving birth in New Zealand. *Midwifery, 28*(4), 489-494.

Howson, C. P., Kinney, M. V., & Lawn, J. E. (Eds.). (2012). *Born Too Soon: The Global Action Report on Preterm Birth.* Geneva: World Health Organization.

Huber, C., Holditch-Davis, D., & Brandon, D. (1993). High-Risk Preterm Infants at 3 Years of Age: Parental Response to the Presence of Developmental Problems. *Children's Health Care, 22*(2), 107-124.

Hughes, M. A., McCollum, J., Sheftel, D., & Sanchez, G. (1994). How parents cope with the experience of neonatal intensive care. *Children's Health Care, 23*(1), 1-14.

Huhtala, M., Korja, R., Lehtonen, L., Haataja, L., Lapinleimu, H., & Rautava, P. (2012). Parental psychological well-being and behavioral outcome of very low birth weight infants at 3 years. *Pediatrics, 129*(4), e937-e944.

Huhtala, M., Korja, R., Lehtonen, L., Haataja, L., Lapinleimu, H., Rautava, P., & Group, P. S. (2014). Associations between parental psychological well-being and socio-emotional development in 5-year-old preterm children. *Early human development, 90*(3), 119-124.

Huizink, A. C., Mulder, E. J., de Medina, P. G., Visser, G. H., & Buitelaar, J. K. (2004). Is pregnancy anxiety a distinctive syndrome? *Early human development, 79*(2), 81-91.

Hunter, J. (2010). Therapeutic positioning: neuromotor, physiologic, and sleep implications. In J. McGrath (Ed.), *Developmental Care of Newborns and Infants: A guide for Health Professionals* (pp. 285-312). Glenview: National Association of Neonatal Nurses.

Huppert, F., & So, T. T. (2013). Flourishing Across Europe: Application of a New Conceptual Framework for Defining Well-Being. *Social Indicators Research, 110*, 837-861.

Hutchinson, A. K., Stuart, A. D., & Pretorius, H. G. (2010). Biological contributions to well-being: The relationships amongst temperament, character strengths and resilience. *South African Journal of Industrial Psychology, 36*(2).

Hutchinson, S. W., Spillett, M. A., & Cronin, M. (2012). Parents' experiences during their infant's transition from neonatal intensive care unit to home: a qualitative study. *The Qualitative Report, 17*(12), 1-20.

Hynan, M. T., Mounts, K. O., & Vanderbilt, D. L. (2013). Screening parents of high-risk infants for emotional distress: rationale and recommendations. *Journal of Perinatology, 33*(10), 748-753.

Hynan, M. T., Steinberg, Z., Baker, L., Cicco, R., Geller, P. A., Lassen, S., . . . Segre, L. (2015). Recommendations for mental health professionals in the NICU. *Journal of Perinatology, 35*, S14-S18.

Institute for Patient and Family Centered Care. (2016). Retrieved from http://www.ipfcc.org

Irlam, L. K., & Bruce, J. C. (2002). Family-centred care in paediatric and neonatal nursing-a literature review. *Curationis, 25*(3), 28-34.

Jackson, K., Ternestedt, B., & Schollin, J. (2003). From alienation to familiarity: experiences of mothers and fathers of preterm infants. *Journal of Advanced Nursing, 43*(2), 120-129.

Jahoda, M. (1958). *Current concepts of positive mental health.* New York: Basic Books.

Jain, S., Anand, S., & Aherwar, R. (2014). High risk scoring for prediction of pregnancy outcome: a prospective study. *International Journal of Reproduction, Contraception, Obstetrics and Gynecology, 3*(3), 516-522.

Janke, J. (1999). The effect of relaxation therapy on preterm labor outcomes. *Journal of obstetric, gynecologic, & neonatal nursing, 28*(3), 255-263.

Johnson, A. N. (2007). The maternal experience of kangaroo holding. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 36*(6), 568-573.

Johnston, C. C., Campbell-Yeo, M., & Filion, F. (2011). Paternal vs maternal kangaroo care for procedural pain in preterm neonates: a randomized crossover trial. *Archives of pediatrics & adolescent medicine, 165*(9), 792-796.

Joseph, K. S., & D'Alton, M. (2013). Theoretical and empirical justification for current rates of iatrogenic delivery at late preterm gestation. *Paediatric and perinatal epidemiology, 27*(1), 2-6.

Joseph, R. A., Mackley, A. B., Davis, C. G., Spear, M. L., & Locke, R. G. (2007). Stress in fathers of surgical neonatal intensive care unit babies. *Advances in Neonatal Care, 7*(6), 321-325.

Jospeh, K. (2007). Theory of obstetrics: an epidemiologic framework for justifying medically indicated early delivery. *BMC Pregnancy and Childbirth, 7*(1), 1.

Josten, L. (1981). Prenatal assessment guide for illuminating possible problems with parenting. *The American Journal of Maternal/Child Nursing, 6*(2), 113-117.

Jotzo, M., & Poets, C. F. (2005). Helping Parents Cope With the Trauma of Premature Birth: An Evaluation of a Trauma-Preventive Psychological Intervention. *Pediatrics, 115*, 915-919.

Kaaresen, P. I., Rønning, J. A., Tunby, J., Nordhov, S. M., Ulvund, S. E., & Dahl, L. B. (2008). A randomized controlled trial of an early intervention program in low birth weight children: outcome at 2 years. *Early human development, 84*(3), 201-209.

Kaaresen, P. I., Rønning, J. A., Ulvund, S. E., & Dahl, L. B. (2006, July). A Randomized, Controlled Trial of the Effectiveness of an Early-Intervention Program in Reducing Parenting Stress After Preterm Birth. *Pediatrics, 118*(1), e9-e19.

Kahneman, D., Diener, E., & Schwartz, N. (Eds.). (1999). *Well-Being: The Foundations of Hedonic Psychology.* New York: Russell Sage Found.

Kato, I., K. T., Nishida, T., Koyano, K., Nakamura, S., Nakamura, M., . . . Isobe, K. (2013). Extrauterine environment influences spontaneous low-frequency oscillations in the preterm brain. *Brain and Development, 35*(1), 17-25.

Katz, A. (2001). Waiting for something to happen: hospitalisation with placenta previa. *Birth, 28*(3), 186-191.

Kavanaugh, K., Nantais-Smith, F. L., Savage, T., Schim, S. M., & Natarajan, G. (2014). Extended Family Support for Parents Faced with Life-Support Decisions for Extremely Premature Infants. *Neonatal Network, 33*(5), 255-262.

Kent, R. A., Yazbek, M., Heyns, T., & Coetzee, I. (2015). The support needs of high-risk antenatal patients in prolonged hospitalisation. *Midwifery, 31*(1), 164-169.

Kersting, A., Dorsch, M., Wesselman, U., Lüdorff, K., Witthaut, J., Ohrmann, P., . . . Arolt, V. (2004). Maternal posttraumatic stress response after the birth of a very low-birth-weight infant. *Journal of Psychosomatic Research*, 57(5), 473-476.

Keyes, C. (2009). Toward a Science of Mental Health. In C. R. Snyder, & S. J. Lopez (Eds.), *Oxford Handbook of Positive Psychology* (2 ed., pp. 89-95). New York: Oxford University Press.

Keyes, C. L. (2001). The Encyclopedia of Criminology and Deviant Behavior. In C. E. Faupel, & P. M. Roman (Eds.). London: Taylor and Francis.

Keyes, C. L. (2002, June). The Mental Health Continuum: From Languishing to Flourishing in Life. *Journal of Health and Social Research, 43*, 207-222.

Keyes, C. L. (2005). Mental illness and/or mental health? Investigating axioms of the complete state of model of health. *Journal of Consulting and Clinical Psychology, 73*, 539-548.

Keyes, C. L., & Lopez, S. J. (2002). Toward a Science of Mental Health. In C. Snyder, & S. J. Lopez, *Handbook of Positive Psychology* (pp. 45-59). New York: Oxford University Press.

Keyes, C. L., Fredrickson, B. L., & Park, N. (2012). Positive psychology and the quality of life. In K. Land, A. Michalos, & J. Sirgy, *Handbook of social indicators and quality of life research* (pp. 99-112). Springer Netherlands.

Khianman, B., Pattanittum, P., Thinkhamrop, J., & Lumbiganon, P. (2012). Relaxation therapy for preventing and treating preterm labour. *Cochrane Database Syst Rev, 8*.

Kim, J. S., & Franklin, C. (2015). Understanding Emotional Change in Solution-Focused Brief Therapy: Facilitating Positive Emotions. *Best Practices in Mental Health, 11*(1), 25-41.

Kirk, S., Glendinning, C., & Gallery, P. (2005). Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing, 51*, 456-464.

Kitchener, K. S. (1984). Intuition, critical evaluation and ethical principles: The foundation for ethical decisions in counseling psychology. *The Counseling Psychologist, 12*, 43-45.

Kommers, D., Oei, G., Chen, W., Feijs, L., & Bambang Oetomo, S. (2015). Suboptimal bonding impairs hormonal, epigenetic and neuronal development in preterm infants, but these impairments can be reversed. *Acta Paediatrica*. doi:10.1111/apa.13254

Kopp, S. B. (1971). *Guru: Metaphors from a psychotherapist.* Palo Alto: Science & Behavior Books.

Korja, R., Latva, R., & Lehtonen, L. (2012). The effects of preterm birth on mother–infant interaction and attachment during the infant's first two years. *Acta obstetricia et gynecologica Scandinavica, 91*(2), 164-173.

Kramer, M. S., Lydon, J., Séguin, L., Goulet, L., Kahn, S. R., McNamara, H., . . . Meaney, M. J. (2009). Stress pathways to spontaneous preterm birth: the role of stressors, psychological distress, and stress hormones. *American journal of epidemiology, 169*(11), 1319-1326.

Kupriyanov, R., & Zhdanov, R. (2014). The eustress concept: problems and outlooks. *World Journal of Medical Sciences, 11*(2), 179-185.

Langeland, E., & Vinje, H. (2013). The Significance of Salutogenesis and Well-Being in Mental Health Promotion: From Theory to Practice. In C. L. Keyes (Ed.), *Mental well-being: International contributions to the study of positive mental health* (pp. 299-328). Dordrecht: Springer Science & Business Media.

Lasiuk, G. C., Comeau, T., & Newburn-Cook, C. (2013). Unexpected: an interpretive description of parental traumas' associated with preterm birth. *BMC Pregnancy and Childbirth, 13 (Suppl 1)*, S13. Retrieved from http://www.biomedcentral.com/1471-2393/13/S1/S13

Latva, R., Korja, R., Salmelin, R. K., Lehtonen, L., & Tamminen, T. (2008). How is maternal recollection of the birth experience related to the behavioral and emotional outcome of preterm infants? *Early human development, 84*(9), 587-594.

Lawn, J. E., Cousens, S., & Zupan, J. (2005). 4 million neonatal deaths: When? Where? Why? *The Lancet, 365*, 891-900.

Lawn, J. E., Gravett, M. G., Nunes, T. M., Rubens, C. E., & Stanton, C. (2010). Global report on preterm birth and stillbirth (1 of 7): definitions, description of the burden and opportunities to improve data. *BMC pregnancy and childbirth, 10(Suppl 1)*, S1.

Lazarus, R. (1991). *Emotion and adaptation.* New York: Oxford University Press.

Lazarus, R. S. (1993). From psychological stress to the emotions: A history of changing outlooks. *Annual Review of Psychology, 44*, 1-21.

Lazarus, R. S. (2003). Does the Positive Psychology Movement Have Legs? *Psychological Inquiry, 14*(2), 93-109.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Lederman, R. P., Boyd, E., Pitts, K., Roberts-Gray, C., Hutchinson, M., & Blackwell, S. (2013). Maternal development experiences of women hospitalized to prevent preterm birth. *Sexual & Reproductive Healthcare, 4*(4), 133-138.

Lee, B. E., Ha, M., Park, H., Hong, Y. C., Kim, Y., Kim, Y. J., & Ha, E. H. (2011). Psychosocial work stress during pregnancy and birthweight. *Paediatric and perinatal epidemiology, 25*(3), 246-254.

Lee, L., Carter, M., Stevenson, S., & Harrison, H. A. (2014). Improving family-centered care practices in the NICU. *Neonatal Network, 33*(3), 125-132.

Lee, S. H., & Lee, E. Y. (2015). Relationship between Pregnancy Stress and Anxiety in High-Risk Pregnant Women: The Mediating Effects of Sense of Mastery. *International Journal of Bio-Science and Bio-Technology, 8*(1), 153-162.

Lee, S., Ayers, S., & Holden, D. (2014). A metasynthesis of risk perception in women with high risk pregnancies. *Midwifery, 30*(4), 403-411.

Lee, T. Y., Lee, T. T., & Kuo, S. C. (2009). The experiences of mothers in breastfeeding their very low birth weight infants. *Journal of advanced nursing, 65*(12), 2523-2531.

Lee, T. Y., Lin, H. R., Huang, T. H., Hsu, C. H., & Bartlett, R. (2009). Assuring the integrity of the family: being the father of a very low birth weight infant. *Journal of clinical nursing, 18*(4), 512-519.

Lefton, C. (2014). Nursing Perspectives: Transforming NICU Culture: The Power of Meaningful Recognition. *NeoReviews, 15*(6), e221-e224.

Lemmen, D., Fristedt, P., & Lundqvist, A. (2013). Kangaroo care in a neonatal context: Parents' experiences of information and communication of nurse-parents. *The open nursing journal, 7*, 41.

Leonard, A., & Mayers, P. (2008). Parents' lived experience of providing kangaroo care to their preterm infants. *Heath SA Gesondheid, 13*(4), 16-28.

Leske, J. S. (1986). Needs of relatives of critically ill patients: a follow-up. *Heart & Lung, 15*(2), 189-193.

Levitt, H., Korman, Y., & Angus, L. (2000). A metaphor analysis in treatments of depression: Metaphor as a marker of change. *Counselling Psychology Quarterly, 13*(1), 23-35.

Levy-Shiff, R., Lerman, M., Har-Even, D., & Hod, M. (2002). Maternal adjustment and infant outcome in medically defined high-risk pregnancy. *Developmental Psychology, 38*(1), 93-103.

Liaw, J. J., Yang, L., Chang, L. H., Chou, H. L., & Chao, S. C. (2009). Improving neonatal caregiving through a developmentally supportive care training program. *Applied Nursing Research, 22*(2), 86-93.

Lim, C. E., & Cheng, N. C. (2011). Clinician's role of psychological support in helping parents and families with pregnancy loss. *Journal of the Australian Traditional-Medicine Society, 17*(4), 215-217.

Lima de Souza, N., Pinheiro-Fernandes, A. C., Cruz-Enders, B., Leite de Carvalho, J. B., da Silva, C., & de Lourdes, M. (2010). Domestic maternal experience with preterm newborn children. *Revista de Salud Pública, 12*(3), 356-367.

Limperopoulos, C., Gauvreau, K. K., O'Leary, H., Moore, M., Bassan, H., Eichenwald, E. C., . . . du Plessis, A. J. (2008). Cerebral hemodynamic changes during intensive care of preterm infants. *Pediatrics, 122*(5), e1006-e1013.

Lincoln, Y. (1995). Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry, 12*, 275-289.

Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry.* Newbury Park: Sage Publications.

Lindberg, B., Axelsson, K., & Öhrling, K. (2007). The birth of premature infants: experiences from the fathers' perspective. *Journal of Neonatal Nursing, 13*(4), 142-149.

Lindberg, B., Axelsson, K., & Öhrling, K. (2008). Adjusting to being a father to an infant born prematurely: experiences from Swedish fathers. *Scandinavian Journal of Caring Sciences, 22*(1), 79-85.

Lindsay, P. (2006). Creating normality in a high-risk pregnancy. *The practising midwife, 9*(1), 16.

Lindström, B., & Eriksson, M. (2005). Salutogenesis. *Journal of Epidemiology and Community Health, 59*, 440-442.

Linley, P., Joseph, S., Harrington, S., & Wood, A. M. (2006). Positive psychology: Past, present, and (possible) future. *The Journal of Positive Psychology, 1*(1), 3-16.

Liong, S., Di Quinzio, M. K., Fleming, G., Permezel, M., Rice, G. E., & Georgiou, H. M. (2013). Prediction of spontaneous preterm labor in at-risk pregnant women. *Reproduction, 146*, 335-345.

Littleton, H. L., Bye, K., Buck, K., & Amacker, A. (2010). Psychosocial stress during pregnancy and perinatal outcomes: a meta-analytic review. *Journal of Psychosomatic Obstetrics & Gynecology, 31*(4), 219-228.

Liu, L., Johnson, H. L., Cousens, S., Perin, J., Scott, S., Lawn, J. E., . . . Mathers, C. (2012). Global, regional, and national causes of child mortality: an updated systematic analysis for 2010 with time trends since 2000. *The Lancet, 379*(9832), 2151-2161.

Lloyd, L. G., & de Witt, T. W. (2013, August). Editorial: Neonatal mortality in South Africa: How are we doing and can we do better? *South African Medical Journal, 103*(8), 518-519.

Lobel, M., Yali, A. M., Zhu, W., DeVincent, C. J., & Meyer, B. (2002). Beneficial association between optimistic disposition and emotional distress in high-risk pregnancy. *Psychology and Health, 17*, 77-95.

Lohan, M., Spence, D., Parkes, J., & Deeney, K. (2009). Experiences of fathers of babies in intensive care. *Paediatric Nursing, 21*(1).

Lombard, K. (2016). Steekproefneming. In I. Lombard, C. Hartell, & K. Lombard (Eds.), *Navorsing. 'n Gids vir die beginnernavorser* (pp. 93-106). Pretoria: Van Schaik.

Lopez, S., & Snyder, C. (2009). *Handbook of positive psychology* (2nd ed.). New York: Oxford University Press.

Lou, H., Pedersen, B. D., & Hedegaard, M. (2009). Questions never asked. Positive family outcomes of extremely premature childbirth. *Quality of Life Research, 18*(5), 567-573.

Lowenkron, A. H. (1999). Coping with the stress of premature labour. *Health Care Women International, 20*(6), 547-561.

Lubbe, W. (2008). *Prematurity: Adjusting your dream.* Pretoria: Little Steps.

Ludwig, S. M. (2007). Oral feeding and the late preterm infant. *Newborn and Infant Nursing Reviews, 7*(2), 72-75.

Lundqvist, P., Westas, L. H., & Hallström, I. (2007). From distance toward proximity: fathers lived experience of caring for their preterm infants. *Journal of pediatric nursing, 22*(6), 490-497.

Lupton, D., & Fenwick, J. (2001). 'They've forgotten that I'm the mum': constructing and practising motherhood in special care nurseries. *Social science & medicine, 53*(8), 1011-1021.

Lyddon, W. J., Clay, A. L., & Sparks, C. L. (2001). Metaphor and change in counseling. *Journal of Counseling & Development, 79*(3), 269-274.

Maastrup, R., Hansen, B., Kronborg, H., Bojesen, S., Hallum, K., Frandsen, A., . . . Hallström, I. (2014). Breastfeeding progression in preterm infants is influenced by factors in infants, mothers and clinical practice: the results of a national cohort study with high breastfeeding initiation rates. *PLoS ONE, 9*(9), e108208.

Macdonald, M. E., Liben, S., Carnevale, F. A., & Cohen, S. R. (2012, Feb). An office or a bedroom? Challenges for family-centered care in the pediatric intensive care unit. *Journal of Child Health Care*, 1367493511430678.

Madden, S. L. (2000). *The Preemie Parents' Companion.* Massachusetts: The Harvard Common Press.

Maloni, J. A. (2010). Antepartum bed rest for pregnancy complications: efficacy and safety for preventing preterm birth. *Biological research for nursing, 12*(2), 106-124.

Maloni, J. A., Brezinski-Tomasi, J. E., & Johnson, L. A. (2001). Antepartum bed-rest: effect upon the family. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 30*(2), 165-173.

Maloni, J. A., Chance, B., Zhang, C., Betts, A. W., & Gange, S. J. (1993). Physical and psychosocial side effects of antepartum hospital bed rest. *Nursing research, 42*(4), 202-203.

Maloni, J. A., Kane, J. H., Suen, L., & Wang, K. K. (2002). Dysphoria among high-risk pregnant hospitalized women on bed rest. *Nursing Research, 51*, 92-99.

Mamelle, N. J. (2001). Psychological prevention of early pre-term birth: A reliable benefit. *Biology of the neonate, 79*(3-4), 268-273.

Mancuso, R. A., Schetter, C. D., Rini, C. M., Roesch, S. C., & Hobel, C. J. (2004). Maternal prenatal anxiety and corticotropin-releasing hormone associated with timing of delivery. *Psychosomatic Medicine, 66*(5), 762-769.

Mangham, L. J., Petrou, S., Doyle, L. W., Draper, E. S., & Marlow, N. (2009). The Cost of Preterm Birth Throughout Childhood in England and Wales. *Pediatrics, 123*(2). Retrieved from www.peditrics.org

Maniaci, M. R., & Reis, H. T. (2010). The marriage of positive psychology and relationship science: A reply to Fincham and Beach. *Journal of Family Theory and Review, 2*, 47–53.

Maree, K., & Pietersen, J. (2016). Sampling. In K. Maree (Ed.), *First Steps in Research* (pp. 171-181). Pretoria: Van Schaik.

Maria, A., & Dasgupta, R. (2016). Family-centered care for sick newborns: A thumbnail view. *Indian Journal of Community Medicine, 41*(1), 11-15.

Matud, M. P. (2004). Gender differences in stress and coping styles. *Personality and individual differences, 37*(7), 1401-1415.

Max-Neef, M. (1992). Development and human needs. In M. Max-Neef, A. Elizalde, & M. Hopenhayn, *Real-life economics: Understanding wealth creation* (pp. 197-213).

McAdams, D. (1990). *The person.* San Diego: Harcourt Brace Jovanovich.

McBride, A. B., & Shore, C. P. (2001). Women as mothers and grandmothers. *Annual Review of Nursing Research, 19*, 63-85.

McCarthy, M., & McMahon, C. (2008). Acceptance and experience of treatment for postnatal depression in a community mental health setting. *Health Care for Women International, 29*(6), 618-637.

McCarty, R. (n.d.). A Preemie's Bill of Rights. Hawaii Medical. Retrieved April 2014, from www.natus.com/.../5110805B%20SANDBOX%20MED%20Preemie%20Bill%20of%2..

McCormick, M., Litt, J., Smith, V., & Zupanic, J. (2011). Prematurity: an overview and public health implications. *Annual Review of Public Health, 32*, 367-379.

McDonald, S. W., Kingston, D., Bayrampour, H., Dolan, S. M., & Tough, S. C. (2014). Cumulative psychosocial stress, coping resources, and preterm birth. *Archives of women's mental health, 17*(6), 559-568.

McGowan, J., Gardner, D., & Fletcher, R. (2006). Positive and negative affective outcomes of occupational stress. *New Zealand Journal of Psychology, 35*(2), 92.

McGrath, J. M., Samra, H. A., & Kenner, C. (2011). Family-centered developmental care practices and research: what will the next century bring? *The Journal of perinatal & neonatal nursing, 25*(2), 165-170.

McKellar, L. V., Pincombe, j. L., & Henderson, A. M. (2006). Insights from Australian parents into educational experiences in the early postnatal period. *Midwifery, 22*(4), 356-364.

McLeod, J. (2013). *An introduction to counselling* (Fifth ed.). Berkshire: McGraw-Hill Education .

McLeod, J., & McLeod, J. (2011). *Counselling skills. A practical guide for counsellors and helping professionals.* Berkshire: Open University Press.

McManus, B. M., & Poehlmann, J. (2012). Maternal depression and perceived social support as predictors of cognitive function trajectories during the first 3 years of life for preterm infants in Wisconsin. *Child: care, health and development, 38*(3), 425-434.

McNulty, J. K., & Fincham, F. D. (2012). Beyond positive psychology? Toward a contextual view of psychological processes and well-being. *American Psychologist, 67*(2), 101-110.

Meier, P. P., Engstrom, J. L., & Rossman, B. (2013). Breastfeeding peer counselors as direct lactation care providers in the neonatal intensive care unit. *Journal of Human Lactation, 29*, 313-322.

Meier, P. P., Engstrom, J. L., Mingolelli, S. S., Miracle, D. J., & Kiesling, S. (2004). The Rush Mothers' Milk Club: Breastfeeding Interventions for Mothers With Very-Low-Birth-Weight Infants. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 33*(2), 164-174.

Meier, P. P., Engstrom, J. L., Patel, A. L., Jegier, B. J., & Bruns, N. E. (2010). Improving the use of human milk during and after the NICU stay. *Clinics in perinatology, 37*(1), 217-245.

Meijssen, D., Wolf, M. J., van Bakel, H., Koldewijn, K., Kok, J., & van Baar, A. (2011). Maternal attachment representations after very preterm birth and the effect of early intervention. *Infant Behavior and Development, 34*(1), 72-80.

Meleis, A. I., Sawyer, L. M., Im, E., Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science, 23*, 12-28.

Melnyk, B. M., Feinstein, N. F., & Fairbanks, E. (2002). arents of Low Birth Weight (LBW) Premature Infants: An Evidence Base toi Guide Clinical Practice. *Pediatric Nursing, 28*(5), 511.

Melnyk, B. M., Feinstein, N. F., Alpert-Gillis, L., Fairbanks, E., Crean, H. F., Sinkin, R. A., & ... & Gross, S. J. (2006). Reducing Premature Infant's Length of Stay and Improving Parents' Mental Health Outcomes With the Creating opportunities for Parent Empowerment (COPE) Neonatal Intensive Care Unit Program: A Randomised, Controlled Trial. *Pediatrics, 118*(5). Retrieved from http://www.pediatrics.org/cgi/content/full/118/5/e1414

Melnyk, B., & Morrison-Beedy, D. (2012). *Intervention research. Designing, conducting, analyzing and funding.* New York: Springer.

Mercer, J. (2006). *Understanding attachment: Parenting, child care, and emotional development.* Westport: Praeger.

Mercer, R. (1995). *Becoming a mother.* New York: Springer.

Mercer, R. T. (1981). A theoretical framework for studying factors that impact on the maternal role. *Nursing Research, 30*, 73-77.

Mercer, R. T. (1985). The process of maternal role attainment over the first year. *Nursing Research, 34*, 198-204.

Mercer, R. T. (2004). Becoming a Mother Versus Maternal Role Attainment. *Journal of Nursing Scholarship, 36*(3), 226-232.

Mercer, R. T. (2006). Nursing support of the process of becoming a mother. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 35*, 649-651.

Mercer, R. T., & Ferketich, S. L. (1990). Predictors of parental attachment during early parenthood. *Journal of Advanced Nursing, 15*, 268-280.

Merriam, S., & Tisdell, E. (2016). *Qualitative research: A guide to design and implementation* (4th ed.). San Francisco: John Wiley & Sons.

Mertin, P., & Watson, J. M. (1984). Stress in the neonatal intensive care unit. *The Australian Nurses Journal, 13*(10), 43-44.

Metzger, R. L. (1976). A reliability and validity study of the State-Trait Anxiety Inventory. *Journal of Clinical Psychology, 32*(2), 276-278.

Mianaei, S. J., Karahroudy, F. A., Rassouli, M., & Tafreshi, M. Z. (2014). The effect of Creating Opportunities for Parent Empowerment program on maternal stress, anxiety, and participation in NICU wards in Iran. *Iranian journal of nursing and midwifery research, 19*(1), 94-100.

Miles, M. S., & Holditch-Davis, D. (2003). Enhancing nursing research with children and families using a developmental science perspective. In J. J. Fitzpatrick, M. S. Miles, & D. Holditch-Davis (Eds.), *Annual Review of Nursing Research* (Vol. 21, pp. 1-20). New York: Springer Publishing Company.

Miles, M. S., Carlson, J., & Brunssen, S. (1999). The nurse parent support tool. *Journal of Pediatric Nursing, 14*(1), 44-50.

Miles, M. S., Funk, S. G., & Carlson, J. (1993). Parental Stressor Scale: neonatal intensive care unit. *Nursing research, 42*(3), 148-152.

Miles, M., Holditch-Davis, D., Burchinal, M. R., & Brunssen, S. (2011). Maternal Role Attainment With Medically Fragile Infants: Part 1. Measurement and Correlates During the First Year of Life. *Research in Nursing and Health, 34*, 20-34.

Miles, M., Holditch-Davis, D., Burchinal, M., & Nelson, D. (1999). Distress and growth in mothers of medically fragile infants. *Nursing Research, 48*, 129-140.

Mitnick, D., Heyman, R., & Smith Slep, A. (2009). Changes in relationship satisfaction across the transition to parenthood: A meta-analysis. *Journal of Family Psychology, 23*, 848-852.

Mok, E., & Leung, S. F. (2006). Nurses as providers of support for mothers of premature infants. *Journal of clinical nursing, 15*(6), 726-734.

Montirosso, R., Del Prete, A., Bellù, R., Tronick, E., & Borgatti, R. (2012). Level of NICU quality of developmental care and neurobehavioral performance in very preterm infants. *Pediatrics, 129*(5), 1-9.

Moon, n. M., Mohay, H. A., & Gray, P. H. (2007). Developmental patterns from 1 to 4 years of extremely preterm infants who required oxygen therapy. *Early Human Development, 83*, 209-216.

Morales, Y., & Schanler, R. J. (2007). Human milk and clinical outcomes in VLBW infants: how compelling is the evidence of benefit? *Seminars in perinatology, 31*(2), 83-88.

Mouton, J. (2001). *How to succeed in your Maser's & Doctoral Studies.* Pretoria: Van Schaik.

Mullen, E. (1994). Design of Social Intervention. In J. Rothman, & E. J. Thomas (Eds.), *Intervention research: design and development for the human service* (pp. 163-193). New York: Routledge.

Müller-Nix, C., & Ansermet, F. (2009). Prematurity, risk and protective factors. In C. H. Zeanah (Ed.), *Handbook of Infant Mental Health* (3rd ed., pp. 180-196). New York: Guilford Press.

Murdoch, M. R., & Franck, L. S. (2012). Gaining confidence and perspective: a phenomenological study of mothers' lived experiences caring for infants at home after neonatal unit discharge. *Journal of advanced nursing, 68*(9), 2008-2020.

Murkoff, H. (2009). *What to Expect when you're expecting.* London: Simon & Schuster UK Ltd.

Myers, B. J. (1984). Mother—infant bonding: The status of this critical-period hypothesis. *Developmental Review, 4*(3), 240-274.

Nakamura, J., & Csikszentmihalyi, M. (2009). Flow Theory and Research. In C. R. Snyder, & S. J. Lopez (Eds.), *Oxford Handbook of Positive Psychology* (2 ed., pp. 195-206). New York: Oxford University Press.

Nakić Radoš, S., Košec, V., & Gall, V. (2013). The psychological effects of prenatal diagnostic procedures: maternal anxiety before and after invasive and noninvasive procedures. *Prenatal Diagnosis, 33*, 1194-1200.

Neggers, Y., Goldenberg, R., Cliver, S., & Hauth, J. (2004). Effects of domestic violence on preterm birth and low birth weight. *Acta Obstetricia et Gynecologica Scandinavica, 83*(5), 455-460.

Nelson, A. M. (2003). Transition to motherhood. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 32*, 465-477.

Neu, J., Bradley, C. L., Ding, Z. Y., Tucker, H. N., & Berseth, C. L. (2013). Feeding the preterm infant: opportunities and challenges of bringing science to the bedside. *The Journal of pediatrics, 162*(3), S101-S106.

Newborn Care: Managing normal and high-risk infants in the newborn nursery. (2009). Retrieved from http://www.scribd.com/doc/11980413/Newborn-Care-Free-online-edition#download.

Newnham, C. A., Milgrom, J., & Skouteris, H. (2009). Effectiveness of a modified mother–infant transaction program on outcomes for preterm infants from 3 to 24 months of age. *Infant behavior and development, 32*(1), 17-26.

Nicholls, K., & Ayers, S. (2007). Childbirth-related post-traumatic stress disorder in couples: A qualitative study. *British journal of health psychology, 12*(4), 491-509.

Nichols, A. (2014). The impact of the clinical environment on family centred care in the neonatal unit: A qualitative investigation. *Journal of Neonatal Nursing, 20*(5), 230-235.

Nieuwenhuis, J. (2016). Introducing qualitative research. In K. Maree (Ed.), *First Steps in Research* (2nd ed., pp. 50-69). Pretoria: Van Schaik.

Nieuwenhuis, J. (2016). Qualitative research designs and data gathering techniques. In K. Maree (Ed.), *First steps in research* (pp. 69-97). Pretoria: Van Schaik.

NIH: Eunice Kennedy Shriver National Institute of Child Health and Human Development. (2013). *What are the factors that put a pregnancy at risk?* Retrieved from www.nichd.nih.gov/health/topics/high-risk/conditioninfo/Pages/factors.aspx

Nirmala, P., Rekha, S., & Washington, M. (2006). Kangaroo mother care: effect and perception of mothers and health personnel. *Journal of Neonatal Nursing, 12*(5), 177-184.

Nisbett, R., & Wilson, T. (1977). The halo effect: Evidence for unconsciuos alteration of judgments. *Journal of personality and social psychology, 35*(4), 250-256.

Nkansah-Amankra, S., Dhawain, A., Hussey, J. R., & Luchok, K. J. (2010). Maternal social support and neighbourhood income inequality as predictors of low birth weight and preterm birth outcome disparities: analysis of South Carolina Pregnancy Risk Assessment and Monitoring System survey, 2000–2003. *Maternal and child health journal, 14*(5), 774-785.

Novotney, A. (2013, July/August). *Supporting psychologists' youngest clients*. Retrieved from American Psychological Association: www.apa.org/monitor/2013/07-08/youngest-clients.aspx

Nyqvist, K. (2016). Given the benefits of Kangaroo mother care, why has its routine uptake been so slow? *Acta Paediatrica, 105*(4), 341-342.

Nyqvist, K. H. (2016). Given the benefits of Kangaroo mother care, why has its routine uptake been so slow?. *Acta Paediatrica, 105*(4), 341-342.

Nyqvist, K. H., Anderson, G. C., Bergman, N., Cattaneo, A., Charpak, N., Davanzo, R., . . . Pallás-Allonso, C. (2010). Towards universal kangaroo mother care: recommendations and report from the first European conference and seventh international workshop on kangaroo mother care. *Acta Paediatrica, 99*(6), 820-826.

Nyqvist, K. H., Bergman, N., Cattaneo, A., Charpak, N., Davanzo, R., Ewald, U., . . . Widström, A. M. (2010). State of the art and recommendationsKangaroo mother care: application in a high-tech environment. *Acta paediatrica, 99*(6), 812-819.

Nyqvist, K., Häggkvist, A., Hansen, M., Kylberg, E., Frandsen, A., Maastrup, R., . . . Haiek, L. (2013). Expansion of the Baby-Friendly Hospital Initiative Ten Steps to Successful Breastfeeding into Neonatal Intensive Care Expert Group Recommendations. *Journal of Human Lactation, 29*(3), 0890334413489775.

Nystrom, K., & Axelsson, K. (2002). Mothers' experience of being separated from their newborns. *Journal of Obstetric, Gynecologic and Neonatal Nursing, 31*, 275-282.

O'Brien, K. B. (2013). A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC pregnancy and childbirth, 13*(Suppl 1), S12.

Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *The Journal of perinatal education, 18*(3), 23.

Ogilvy, C. (2016). *Extend maternity leave for mothers of premature babies*. Retrieved from Change.org, Inc.: https://www.change.org/p/extend-maternity-leave-for-mothers-of-premature-babies?recruiter=332532147&utm_source=share_petition&utm_medium=email&utm_campaign=share_email_responsive

Ogletree, T., & Kawulich, B. (2012). Ethical considerations in conducting research. In C. Wagner, B. Kawulich, & M. Garner (Eds.), *Doing social research: A global context* (pp. 62-72). New York: McGraw-Hill.

Orr, S. T., Reiter, J. P., Blazer, D. G., & James, S. A. (2007). Maternal prenatal pregnancy-related anxiety and spontaneous preterm birth in Baltimore, Maryland. *Psychosomatic Medicine, 69*, 566-570.

Oxford Advanced Learner's Dictionary (8th ed.). (2010). Oxford University Press.

Pallás-Alonso, C., Losacco, V., Maraschini, A., Greisen, G., Pierrat, V., Warren, I., . . . Cuttini, M. (2012). Parental involvement and kangaroo care in European neonatal intensive care units: a policy survey in eight countries. *Pediatric critical care medicine, 13*(5), 568-577.

Park, C. L. (2015). Integrating positive psychology into health-related quality of life research. *Quality of Life Research, 24*(7), 1645-1651.

Parratt, J. A., & Fahy, K. M. (2011). A feminist critique of foundational nursing research and theory on transition to motherhood. *Midwifery, 27*, 445-451.

Pattinson, R. C., Arsalo, I., Bergh, A. M., Malan, A. F., Patrick, M., & Phillips, N. (2005). Implementation of kangaroo mother care: a randomized trial of two outreach strategies. *Acta Paediatrica, 94*(7), 924-927.

Peebles-Kleiger, M. J. (2000). Pediatric and neonatal intensive care hospitalization as traumatic stressor: Implications for intervention. *Bulletin of the Menninger Clinic, 64*(2), 257.

Pennestri, M. H., Gaudreau, H., Bouvette-Turcot, A. A., Moss, E., Lecompte, V., & Atkinson, L. (2015). Attachment disorganization among children in neonatal intensive care unit: Preliminary results. *Early human development, 91*(10), 601-606.

Perls, F. (1973). *The Gestalt approach & eye witness to therapy.* New York: Bantam.

Perls, F. S. (1969). *Ego, hunger and aggression: The beginning of Gestalt therapy.*

Perls, F. S., Hefferline, R., & Goodman, P. (1951). *Gestalt therapy: Excitement and growth in the human personality.* New York: Julian.

Perun, M. B. (2013). Maternity of Women in the Postpartum Period. *Journal of Education Culture and Society, 1*, 95-105.

Phillips, R. M., Goldstein, M., Hougland, K., Nandyal, R., Pizzica, A., Santa-Donato, A., & ... & Yost, E. (2013). Multidisciplinary guidelines for the care of late preterm infants. *Journal of Perinatology, 33*, S5-S22.

Phillips-Pula, L., Pickler, R., McGrath, J. M., Brown, L. F., & Dusing, S. C. (2013). Caring for a Preterm Infant at Home: A Mother's Perspective. *The Journal of perinatal & neonatal nursing, 27*(4), 335-344.

Pierrehumbert, B., Nicole, A., Muller-Nix, C., Forcada-Guex, M., & Ansermet, F. (2003). Parental post-traumatic reactions after premature birth: implications for sleeping and eating problems in the infant. *Archives of Disease in Childhood-Fetal and Neonatal Edition, 88*(5), F400-F404.

POPPY Steering Group. (2009). Family-centred care in neonatal units. London: National Childbirth Trust.

Pritchard, M. A., Colditz, P. B., Cartwright, D., Gray, P. H., Tudehope, D., & Beller, E. (2012). Six-week postnatal depression predicts parenting stress profiles in mothers of preterm children. *Journal of Reproductive and Infant Psychology, 30*(3), 303-311.

Proyer, R. T., Ruch, W., & Buschor, C. (2013). Testing Strengths-Based Interventions: A Preliminary Study on the Effectiveness of a Program Targeting Curiosity, Gratitude, Hope, Humor, and Zest for Enhancing Life Satisfaction. *Journal of happiness Studies, 14*, 275-292.

Quick, J. C., Quick, J. D., Nelson, D. L., & Hurrell, J. J. (1997). *Preventive stress management in organizations.* Washington DC: American Psychological Association.

Rallis, S., Skouteris, H., McCabe, M., & Milgrom, J. (2014). A prospective examination of depression, anxiety and stress throughout pregnancy. *Women and Birth, 27*(4), e36-e42.

Ranchod, T. M., Ballot, D. E., Martinez, A. M., Cory, B. J., Davies, V. A., & Partridge, J. C. (2004). Parental perception of neonatal intensive care in public sector hospitals in South Africa. *South African Medical Journal, 94*(11), 913-916.

Rand, K., & Cheavens, J. (2009). Hope theory. In S. Lopez, & C. Snyder (Eds.), *Oxford handbook of positive psychology* (2nd ed., pp. 323-333). New York: Oxford University Press.

Randolph, A. L., Hruby, B. T., & Sharif, S. (2015). Counseling Women Who Have Experienced Pregnancy Loss: A Review of the Literature. *Adultspan Journal, 14*(1), 2-10.

Rane, T. R., & McBride, B. A. (2000). Identity theory as a guide to understanding fathers' involvement with their children. *Journal of family issues, 21*(3), 347-366.

Rashid, T. (2009). Positive Interventions in Clinical Practice. *Journal of Clinical Psychology: In Session, 65*(5), 461-466.

Reddy, J., & Mclnerney, P. A. (2007). The experiences of mothers who were implementing Kangaroo Mother Care (KMC) at a Regional Hospital in KwaZulu-Natal. *Curationis, 30*(3), 62-67.

Reid, T., & Bramwell, R. (2003). Using the Parental Stressor Scale: NICU with a British sample of mothers of moderate risk preterm infants. *Journal of reproductive and infant psychology, 21*(4), 279-291.

Renfrew, M. J., Dyson, L., McCormick, F., Misso, K., Stenhouse, E., King, S. E., & Williams, A. F. (2010). Breastfeeding promotion for infants in neonatal units: a systematic review. *Child: care, health and development, 36*(2), 165-178.

Revenson, T., & Lepore, S. (2012). Coping in social context. In A. Baum, T. Revenson, & J. Singer (Eds.), *Handbook of Health Psychology* (Second ed., pp. 193-218). New York: Psychology Press.

Reyna, B. A., Pickler, R. H., & Thompson, A. (2006). A descriptive study of mothers' experiences feeding their preterm infants after discharge. *Advances in neonatal care: official journal of the National Association of Neonatal Nurses, 6*(6), 333.

Rini, C. K., Dunkel-Schetter, C., Wadhwa, P. D., & Sandman, C. A. (1999). Psychological adaptation and birth outcomes: the role of personal resources, stress, and sociocultural context in pregnancy. *Health Psychology, 18*(4), 333-345.

Robison, L. D. (2003). An organizational guide for an effective developmental program in the NICU. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 32*(3), 379-386.

Rogers, K. H., Luton, R., Biggs, H., Biggs, R., Blignaut, S., Choles, A. G., . . . Tangwe, P. (2013). Fostering Complexity Thinking in Action Research for Change in Social-Ecological Systems. *Ecology and Society, 18*(2), 31.

Roller, C. (2005). Getting to know you: Mothers' experiences of kangaroo care. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 34*(2), 210-217.

Romero, R., Dey, S. K., & Fisher, S. J. (2014). Preterm labor: one syndrome, many causes. *Science, 345*(6198), 760-765.

Romero, R., Espinoza, J., Kusanovic, J. P., Gotsch, F., Hassan, S., Erez, O., & ... & Mazor, M. (2006). The preterm parturition syndrome. *BJOG: An International Journal of Obstetrics & Gynaecology, 113*(S3), 17-42.

Rosa, E. M., & Tudge, J. (2013, December). Urie Bronfenbrenner's Theory of Human Development: Its Evolution From Ecology to Bioecology. *Journal of Family Theory & Review, 5*, 243-258.

Rossman, B., Greene, M. M., & Meier, P. P. (2015). The role of peer support in the development of maternal identity for "NICU moms". *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 44*(1), 3-16.

Rothman, J., & Thomas, E. J. (1994). An Integrative Perspective on Intervention Research. In J. Rothman, & E. J. Thomas, *Intervention Research: Design and Development for Human Service* (pp. 3-23). New York: Routledge.

Rubin, A., & Babbie, E. (2010). *Essential research methods for social workers* (2nd ed.). Belmont: Cengage Learning.

Rubin, R. (1967). Attainment of the maternal role. Part 1: Processes. *Nursing Research, 16*, 237-245.

Rubin, R. (1984). *Maternal identity and maternal experience.* New York: Springer.

Rusk, R., & Waters, L. E. (2013). Tracing the size, reach, impact, and breadth of positive psychology. *The Juornal of Positive Psychology, 8*(3), 207-221.

Ryan, R. M., & Deci, E. L. (2001). On Happiness and Human Potentials: A Review of Research on Hedonic and Eudaimonic Well-Being. *Annual Review of Psychology, 52*, 141-166.

Ryff, C. D. (1989). Beyond Ponce de Leon and life satisfaction: New direction in quest of successful aging. *International Journal of Behavioral Development, 12*, 35-55.

Ryff, C. D. (1995). Psychological well-being in adult life. *Current directions in psychological science, 4*(4), 99-104.

Ryff, C. D. (2013). Psychological well-being revisited: Advances in the science and practice of eudaimonia. *Psychotherapy and psychosomatics, 83*(1), 10-28.

Sankey, J. J., & Brennan, S. (2001). Living with difference: Caring for a premature baby at home. *Collegian, 8*(2), 10-18.

Saunders, R. P., Abraham, M. R., Crosby, M. J., Thomas, K., & Edwards, W. H. (2003). Evaluation and development of potentially better practices for improving family-centered care in neonatal intensive care units. *Pediatrics, 111(Supplement E1)*, e437-e449.

Save the Children. (2012). *Time to Focus on 84 000 Preterm Births in South Africa*. Retrieved from NGO Pulse: http://www.ngopulse.org/press-release/time-focus-84-000-preterm-births-south-africa

Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., & Ayers, S. (2013). Parents' experiences and satisfaction with care during the birth of their very preterm baby: a qualitative study. *BJOG: An International Journal of Obstetrics & Gynaecology*. doi:10.1111/1471-0528.12104

Sawyer, L. M. (1999). Engaged mothering: The transition to motherhood for a group of African Amrican women. *Journal of Transcultural Nursing, 10*, 14-21.

Scherer, S., Urech, C., Hösli, I., Tschudin, S., Gaab, J., Berger, T., & Alder, J. (2014). Internet-based stress management for women with preterm labour-a case-based experience. *Archives of Womens Mental Health, 17*, 593-600.

Sciscione, A. C. (2010). Maternal activity restriction and the prevention of preterm birth. *American journal of obstetrics and gynecology, 202*(3), 232-e1.

Seligman, M. (2002). *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment.* New York: Free Press.

Seligman, M. (2011). *Flourish: A visionary new understanding of happiness and well-being.* New York: Simon & Schuster.

Seligman, M. E. (2002). Positive Psychology, Positive Prevention and Positive Therapy. In C. Snyder, & S. Lopez (Eds.), *Handbook of Positive Psychology* (pp. 3-9). New York: Oxford University Press.

Seligman, M. E. (2011). *Learned optimism: How to change your mind and your life.* New York: Vintage Books.

Seligman, M., & Csikszentmihalyi, M. (2000). Positive Psychology: An Introduction. *American Psychologist, 55*(1), 5-14.

Sellick, K., Chia, P., & Gan, S. (2006). The attitudes and practices of neonatal nurses in the use of kangaroo care. *Australian Journal of Advanced Nursing, 23*(4), 20-27.

Seravalli, L., Patterson, F., & Nelson, D. B. (2014). Role of Perceived Stress in the Occurrence of Preterm Labor and Preterm Birth Among Urban Women. *Journal of Midwifery & Women's Health, 59*(4), 374-379.

Sharma, A. A., Jen, R., Butler, A., & Lavoie, P. M. (2012). The developing human preterm neonatal immune system: a case for more research in this area. *Clinical Immunology, 145*(1), 61-68.

Shaw, R. J., Bernard, R. S., DeBlois, T., Ikuta, L. M., Ginzburg, K., & Koopman, C. (2009). The Relationship Between Acute Stress Disorder and Posttraumatic Stress Disorder in the Neonatal Intensive Care Unit. *Psychosomatics, 50*, 131-137.

Shaw, R. J., Deblois, T., Ikuta, L., Ginzburg, K., Fleisher, B., & Koopman, C. (2006). Acute stress disorder among parents of infants in the neonatal intensive care nursery. *Psychosomatics, 47*(3), 206-212.

Shaw, R. J., St John, N., Lilo, E. A., Jo, B., Benitz, W., Stevenson, D. K., & Horwitz, S. M. (2013). Prevention of traumatic stress in mothers with preterm infants: a randomized controlled trial. *Pediatrics, 132*(4), e886-e894.

Sheldon, K., & King, L. (2001). Why positive psychology is necessary. *American Psychologist, 56*, 216-217.

Shields, L., Young, J., & McCann, D. (2008). The needs of parents of hospitalized children in Australia. *Journal of Child Health Care, 12*(1), 60-75.

Shin, H., & White-Traut, R. (2007). The conceptual structure of transition to motherhood in the neonatal intensive care unit. *Journal of advanced nursing, 58*(1), 90-98.

Shumway, J., O'campo, P., Gielen, A., Witter, F. R., Khouzami, A. N., & Blakemore, K. J. (1999). Preterm labor, placental abruption, and premature rupture of membranes in relation to maternal violence or verbal abuse. *Journal of Maternal-Fetal and Neonatal Medicine, 8*(3), 76-80.

Simhan, H. N., Iams, J. D., & Romero, R. (2012). Preterm Birth. In S. G. Gabbe, *Obstetrics: normal and problem pregnancies* (pp. 627-658). Elsevier Health Sciences.

Siminovitch, D. E., & Van Eron, A. M. (2006). The Pragmatics of Magic. *OD PRACTITIONER, 38*(1), 50-55.

Simmons, B., & Nelson, D. (2007). Eustress at Work: Extending the Holistic Stress Model. In D. Nelson, & C. Cooper (Eds.), *Positive Organizational Behavior* (pp. 40-53). London: Sage.

Simmons, H. A., & Goldberg, L. S. (2011). 'High-risk'pregnancy after perinatal loss: understanding the label. *Midwifery, 27*(4), 452-457.

Sin, N. L., & Lyubomirsky, S. (2009). Enhancing Well-Being and Alleviating Depressive Synptoms With Positive Psychology Interventions: A Practice-Friendly Meta-Analysis. *Journal of Clinical Psychology: In Session, 65*(5), 467-487.

Singer, L. T., Fulton, S., Davillier, M., Koshy, D., Salvator, A., & Baley, J. E. (2003). Effects of infant risk status and maternal psychological distress on maternal-infant interactions during the first year of life. *Journal of Developmental and Behavioral Pediatrics, 24*, 233-241.

Singer, L. T., Salvator, A., Guo, S., Collin, M., Lilien, L., & Baley, J. (1999). Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant. *Jama, 281*(9), 799-805.

Singer, L., Fulton, S., Kirchner, H., Eisengart, S., Lewis, B., Short, E., . . . Baley, J. (2007). Parenting very low birth weight children at school age: maternal stress and coping. *The Journal of pediatrics, 151*(5), 463-469.

Skene, C., Gerrish, K., Price, F., Pilling, E., & Bayliss, P. (2016). Developing family-centred care in a neonatal intensive care unit: an action research study protocol. *Journal of advanced nursing, 72*(3), 658-668.

Slade, M. (2010). Mental illness and well-being: the central importance of positive psychology and recovery approaches. *BMC Heath Services Research, 10*(26).

Sluckin, A. (1993). 'My baby doesn't need me': understanding bonding failure. *Health visitor, 66*(11), 409-412.

Smith, G. C., Gutovich, J., Smyser, C., Pineda, R., Newnham, C., Tjoeng, T. H., . . . Inder, T. (2011). Neonatal intensive care unit stress is associated with brain development in preterm infants. *Annals of neurology, 70*(4), 541-549.

Smith, V. C., SteelFisher, G. K., Salhi, C., & Shen, L. Y. (2012). Coping with the neonatal intensive care unit experience: parents' strategies and views of staff support. *The Journal of perinatal & neonatal nursing, 26*(4), 343-352.

Snyder, C. R., Sympson, S. C., Ybasco, F. C., Borders, T. F., Babyak, M. A., & Higgins, R. L. (1996). Development and validation of the State Hope Scale. *Journal of personality and social psychology, 70*(2), 321.

Solomons, N., & Rosant, C. (2012). Knowledge and attitudes of nursing staff and mothers towards kangaroo mother care in the eastern sub-district of Cape Town. *South African Journal of Clinical Nutrition, 25*(1), 33-39.

Spear, M. L., Leef, K., Epps, S., & Locke, R. (2002). Family reactions during infants' hospitalization in the neonatal intensive care unit. *American journal of perinatology, 19*(4), 205-213.

Spielberger, C. D. (1983). *Manual for the State-Trait Anxiety Inventory.* Palo Alto, California: Consulting Psychologists Press, Inc.

Spielberger, C. D. (1983). *State-Trait Anxiety Inventory for Adults: Manual and Sample.* Mind Garden.

Spinelli, M., Frigerio, A., Montali, L., Fasolo, M., Spada, M. S., & Mangili, G. (2016). 'I still have difficulties feeling like a mother': The transition to motherhood of preterm infants mothers. *Psychology & Health, 31*(2), 184-204.

Spinelli, M., Poehlmann, J., & Bolt, D. (2013). Predictors of parenting stress trajectories in premature infant–mother dyads. *Journal of Family Psychology, 27*(6), 873.

Spini, D., Hanappi, D., Bernardi, L., Oris, M., & Bickel, J. F. (2013). Vulnerability across the life course: A theoretical framework and research directions. *LIVES Working Papers, 27*, 1-35.

Spong, C. Y., Mercer, B. M., D'Alton, M., Kilpatrick, S., Blackwell, S., & Saade, G. (2011). Timing of indicated late-preterm and early-term birth. *Obstetrics and gynecology, 118*(2), 323.

Stacey, S., Osborn, M., & Salkovskis, P. (2015). Life is a rollercoaster… What helps parents cope with the Neonatal Intensive Care Unit (NICU)? *Journal of Neonatal Nursing, 21*, 136-141.

Stahl, K., & Hundley, V. (2003). Risk and risk assessment in pregnancy - do we scare because we care? *Midwifery, 19*, 298-309.

Steen, M., Downe, S., Bamford, N., & Edozien, L. (2012). Not-patient and not-visitor: A metasynthesis fathers' encounters with pregnancy, birth and maternity care. *Midwifery, 28*, 422-431.

Steger, M. F., Shin, J. Y., Shim, Y., & Fitch-Martin, A. (2013). Is meaning in life a flagship indicator of well-being? In A. Waterman (Ed.), *The best within us: Positive psychology perspectives on eudaimonia* (pp. 159-182). Washington DC: American psychological Association.

Stephens, B. E., & Vohr, B. R. (2009). Neurodevelopmental outcome of the premature infant. *Pediatric Clinics of North America, 56*, 631-646.

Stojanovich, L. (2010). Stress and autoimmunity. *Autoimmunity reviews, 9*(5), A271-A276.

Strümpfer, D. J. (1995, September). The origins of health and strength: from 'salutogenesis' to 'fortigenesis'. *South African Journal of Psychology, 25*(3), 81-89.

Strümpfer, D. J. (2006). The Strengths Perspective: Fortigenesis in Adult Life. *Social Indicators Research, 77*, 11-36.

Strümpfer, D. J. (2013). Towards Fortigenesis and Fortology. In M. P. Wissing (Ed.), *Well-Being Research in South Africa* (pp. 7-37). London: Springer.

Strunk, T., Currie, A., Richmond, P., Simmer, K., & Burgner, D. (2011). Innate immunity in human newborn infants: prematurity means more than immaturity. *The Journal of Maternal-Fetal & Neonatal Medicine, 24*(1), 25-31.

Strydom, H. (2011). Ethical aspects of research in the social siences and human service professions. In A. De Vos, H. Strydom, C. Fouche, & C. Delport (Eds.), *Researchar grass roots. For the soical sciences and human service professions* (4th ed., pp. 113-129). Pretoria: Van Schaik.

Strydom, H., Steyn, M., & Strydom, C. (2007). An adapted intervention research model: Suggestions for research and practice. *Social Work/Maatskaplike Werk, 43*(4), 329-342.

Sullivan, J. R. (1999). Development of father-infant attachment in fathers of preterm infants. *Neonatal network: NN, 18*(7), 33-39.

Sweet, L. (2006). Breastfeeding a preterm infant and the objectification of breastmilk. *Breastfeeding Review, 14*(1), 5-13.

Temane, Q. M., & Wissing, M. P. (2006). The role of spirituality as a mediator for psychological well-being across different contexts. *South African journal of psychology, 36*(3), 582-597.

Thomas, E. (1994). Evaluation, Advanced Development, and the Unilateral Family Therapy Experiment. In J. Rothman, & E. J. Thomas (Eds.), *Intervention research: design and development for the human service* (pp. 267-295). New York: Routledge.

Thomas, E. (2013). Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. *Breastfeeding Review, 21*(2), 54-56.

Thomas, E. J., & Rothman, J. (1994). An Integrative Perspective on Intervention Research. In J. Rothman, & E. J. Thomas (Eds.), *Intervention Research: Design and Development for Human Service* (pp. 3-23). New York: The Haworth Press.

Thornburg, P. (2002). “Waiting” As Experienced By Women Hospitalized During The Antepartum Period. *MCN: The American Journal of Maternal/Child Nursing, 27*(4), 245-248.

Tomlinson, M., O'Connor, M. J., Le Roux, I. M., Stewart, J., Mbewu, N., Harwood, J., & Rotheram-Borus, M. J. (2014). Multiple risk factors during pregnancy in South Africa: the need for a horizontal approach to perinatal care. *Prevention Science, 15*(3), 277-282.

Tooten, A., Hoffenkamp, H. N., Hall, R. A., Braeken, J., Vingerhoets, J. J., & van Bakel, H. J. (2013, September). Parental Perceptions and /experiences after Childbirth: A Comparison between Mothers and Fathers of Term and Preterm Infants. *Birth: Issues in Perinatal Care, 40*(3), 164-170.

Torricelli, M., Voltolini, C., De Bonis, M., Velluci, F. L., Conti, N., Severi, F. M., & Petraglia, F. (2012). The identification of high risk pregnancy: a new challenge in obstetrics. *The Journal of Maternal-Fetal and Neonatal Medicine, 25*(S1), 2-5.

Trajkovski, S., Schmied, V., Vickers, M., & Jackson, D. (2015). Using appreciative inquiry to bring neonatal nurses and parents together to enhance family-centred care A collaborative workshop. *Journal of Child Health Care, 19*(2), 239-253.

Tucker, J., & McGuire, W. (2005). Epidemiology of preterm birth. In W. McGuire, & P. W. Fowlie (Eds.), *ABC of Preterm Birth* (pp. 1-4). Massachusetts: Blackwell.

Tudehope, D. I. (2013). Human milk and the nutritional needs of preterm infants. *The Journal of pediatrics, 162*(3), S17-S25.

Turan, T., Başbakkal, Z., & Özbek, Ş. (2008). Effect of nursing interventions on stressors of parents of premature infants in neonatal intensive care unit. *Journal of clinical nursing, 17*(21), 2856-2866.

Turnbull (Ed.). (2010). *Oxford Advanced Learner's Dictionary of Current English* (Eighth ed.). Oxford: Oxford University Press.

Turnbull, D. A., Wilkinson, C., Gerard, K., Shanahan, M., Ryan, P., Griffith, E. C., . . . Stamp, G. E. (2004). Clinical, psychosocial, and economic effects of antenatal day care for three medical complications of pregnancy: a randomised controlled trial of 395 women. *The Lancet, 363*(9415), 1104-1109.

Turner, J. (2014). Metaphors and therapeutic encounters in mental health nursing. *Mental Health Nursing (Online), 34*(3), 16.

UNICEF; WHO; The World Bank; UN Population Division. (Report 2014). *Levels and Trends in Child Mortality*. Retrieved from http://www.who.int/maternal_child_adolescent/epidemiology/profiles/neonatal_child/zaf.pdf

University of Pennsylvania. (2007). *Frequently Asked Questions*. Retrieved from Positive Psychology Center: www.positive psychology.org/faqs.htm

Uvnäs-Moberg, K., & Eriksson, M. (1996). Breastfeeding: physiological, endocrine and behavioural adaptations caused by oxytocin and local neurogenic activity in the nipple and mammary gland. *Acta Paediatrica, 85*(5), 525-530.

Van der Merwe, M. (2005). A solution-building metaphorical concept for direct social work with children: An exploratory study. *Social Work/Maatskaplike Werk, 41*(1), 39-53.

Van Riper, M. (2001). Family-provider relationships and well-being in families with preterm infants in the NICU. *Heart & Lung, 30*(1), 74-84.

VandenBerg, K. A. (1993). Basic competencies to begin developmental care in the intensive care nursery. *Infants & Young Children, 6*(2), 52-59.

Vanderbilt, D., Bushley, T., Young, R., & Frank, D. A. (2009). Acute posttraumatic stress symptoms among urban mothers with newborns in the neonatal intensive care unit: a preliminary study. *Journal of Developmental & Behavioral Pediatrics, 30*(1), 50-56.

Vazquez, V., & Cong, X. (2014). Parenting the NICU infant: A meta-ethnographic synthesis. *International Journal of Nursing Sciences, 1*(3), 281-290.

Velaphi, S., & Rhoda, N. (2012, August). Reducing neonatal deaths in South Africa - are we there yet, and what can be done? *SA Journal of Child Health, 6*(3), 67-71.

Verwey, M., Jooste, K., & Arries, E. (2008). Experiences of parents during the hospitalisation of their child in a private paediatric unit. *Curationis, 31*(2), 30-42.

Vila Vda, S., & Rossi, L. A. (2002). Cultural meaning of humanized care at intensive care units: Lots of words, little action. *Revista Latino-Americana de Enfermagem, 10*(2), 137-144.

Voltolini, C., Torricelli, M., Conti, N., Vellucci, F. L., Severi, F. M., & Petraglia, F. (2013). Understanding Spontaneous Preterm Birth From Underlying Mechanisms to Predictive and Preventive Interventions. *Reproductive sciences, 20*(11), 1274-1292.

Wagner, C. (2012). Introducing social research in a global context. In C. Wagner, B. Kawulich, & M. Garner (Eds.), *Doing social research: A global context* (pp. 2-11). New York: McGraw-Hill.

Walker, L. O., Crain, H., & Thompson, E. (1986). Mothering behavior and maternal role attainment during the postpartum period. *Nursing Research, 35*, 352-355.

Walker, S. B. (1997). Neonatal nurses' views on the barriers to parenting in the intensive care nursery - a pilot study. *Australian Critical Care, 10*(1), 13-20.

Walter, K. H., Horsey, K. J., Palmieri, P. A., & Hobfoll, S. E. (2010). The role of protective self-cognitions in the relationship between childhood trauma and later resource loss. *Journal of traumatic stress, 23*(2), 264-273.

Wand, T. (2010). Mental health nursing from a solution focused perspective. *International Journal of Mental Health Nursing, 19*(3), 210-219.

Wand, T. (2013). Positioning mental health nursing practice within a positive health paradigm. *International journal of mental health nursing, 22*(2), 116-124.

Waterman, A. S. (1993). Two conceptions of happiness: contrasts of personal expressiveness (eudaimonia) and hedonic enjoyment. *Journal of personality and social psychology, 64*, 678-691.

Weaver, V. (2014, April). Neonatal Positioning. Retrieved from https://www.networks.nhs.uk/nhs...and.../NeonatalPositioningpresentation1.pdf

Weidner, K., Bittner, A., Junge-Hoffmeister, J., Zimmermann, K., Siedentopf, F., Richter, J., . . . Stöbel-Richter, Y. (2010). A psychosomatic intervention in pregnant in-patient women with prenatal somatic risks. *Journal of Psychosomatic Obstetrics & Gynecology, 31*(3), 188-198.

Weiss, M. E., Ryan, P., & Lokken, L. (2006). Validity and reliability of the perceived readiness for discharge after birth scale. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 35*(1), 34-45.

Weiss, M. E., Saks, N. P., & Harris, S. (2002). Resolving the uncertainty of preterm symptoms: Women's experiences with the onset of preterm labor. *Journla of Obstetric, Gynecologic, and Neonatal Nursing, 31*, 66-76.

Wells, A. (1988). Sef-esteem and optimal experience. In M. Csikszentmihalyi, & I. Csikszentmihalyi (Eds.), *Optimal experience* (pp. 327-341). Cambridge: Cambridge University Press.

Wenzel, A., & Stuart, S. C. (2011). *Anxiety in childbearing women: Diagnosis and treatment.* American Psychological Association.

Westerhof, G. J., & Keyes, C. L. (2010). Mental Illness and Mental Health: The Two Continua Model Across the Lifespan. *Journal of Adult Development, 17*, 110-119.

Wigert, H., Johansson, R., Berg, M., & Hellstrom, A. L. (2006). Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Science, 20*, 35-41.

Wildner, K. (2012). Kangaroo care. *Midwifery today with international midwife, 101*, 24-28.

Williams, M. B., & Poijula, S. (2016). *The PTSD workbook: Simple, effective techniques for overcoming traumatic stress symptoms* (Third ed.). Oakland: New Harbinger Publications.

Wissing, M. (2014). A path towards flourishing. In M. Wissing, J. Potgieter, T. Guse, T. Khumalo, & L. Nel (Eds.), *Toward flourishing. Contextualising positive psychology* (pp. 3-15). Pretoria: Van Schaik.

Wissing, M. P., & van Eeden, C. (1997). Psychological well-being: A fortigenic conceptualization and empirical clarification. *Annual Congress of the Psychological Society of South Africa.* Durban, South Africa.

Wissing, M. P., & van Eeden, C. (2002). Empirical clarification of the nature of psychological well-being. *South African Journal of Psychology, 32*, 32-44.

Wissing, M., & van Eeden, C. (2014). Harmonising perspectives on well-being. In M. Wissing, J. Potgieter, T. Guse, T. Khumalo, & L. Nel (Eds.), *Toward flourishing. Contextualising positive psychology* (pp. 77-112). Pretoria: Van Schaik.

Woldt, A. L., & Toman, S. M. (Eds.). (2005). *Gestalt therapy: History, theory, and practice.* California: Sage Publications.

Wong, D. L., Hockenberry, M. J., Wilson, D., Winkelstein, M. L., & Kline, N. E. (2003). *Wong's nursing care of infants and children.* St Louis MO: Mosby.

Wood, A., Maltby, J., Gillett, R., Linley, P., & Joseph, S. (2008). The role of gratitude in the development of social support, stress, and depression : two longitudinal studies. *Journal of Research in Personality, 42*(4), 854-871.

Woodward, L. J., Bora, S., Clark, C. A., Montgomery-Hönger, A., Pritchard, V. E., Spencer, C., & Austin, N. C. (2014). Very preterm birth: maternal experiences of the neonatal intensive care environment. *Journal of Perinatology, 34*(7), 555-561.

World Health Organization. (2004). *Promoting mental health: Concepts, emerging evidence, practice: Summary Report.* World Health Organization , Department of Mental Health and Substance Abuse. Geneva: World Health Organization.

World Health Organization. (2012). *Born too soon: the global action report on preterm birth.*

World Health Organization. (2012, November). Preterm birth. Retrieved from www.who.int/mediacentre/factsheets/fs363/en/#

World Health Organization, W. (2003). *Kangaroo mother care: a practical guide.* Geneva.

Yaari, M., Millo, I., Harel, A., Friedlander, E., Bar-Oz, B., Eventov-Friedman, S., & ...Yirmiya, N. (2015). Predicting Maternal Resolution of Preterm Birth at One Month Corrected Age. *Infancy, 20*(5), 507-522.

Yali, A. M., & Lobel, M. (2002). Stress-resistance resources and coping in pregnancy. *Anxiety, Stress, and Coping, 15*, 289-309.

Zabielski, M. T. (1994). Recognition of maternal identity in preterm and fullterm mothers. *Maternal-Child Nursing Journal, 22*, 2-35.

Zelkowitz, P., Feeley, N., Shrier, I., Stremler, R., Westreich, R., Dunkley, D., . . . Papageorgiou, A. (2008). The Cues and Care Trial: A randomized controlled trial of an intervention to reduce maternal anxiety and improve developmental outcomes in very low birthweight infants. *BMC Pediatrics, 38*(8).

Addenda

Addendum A

Permission from Gatekeepers

RESEARCH OPERATIONAL COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2014-0015

Mrs A Gibson

E mail: alisongibson.psych@gmail.com

Dear Mrs Gibson

RE: SUPPORT OF THE PARENTS OF VERY LOW BIRTHWEIGHT INFANTS IN A NEONATAL INTENSIVE CARE UNIT

The above-mentioned research was reviewed by the Research Operational Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at Private Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information with regards to Company will be treated as confidential.

iii) Company's name will not be mentioned without written consent from the Committee.

iv) All legal requirements with regards to patient rights and confidentiality will be complied with.

v) Insurance will be provided and maintained for the duration of the research. This cover provided to the researcher must also protect both the staff and the hospital facility from potential liability

vi) In accordance with MCC approval, that medicine will be administered by or under direction of the authorised Trialist

vii) The research will be conducted in compliance with the GUIDELINES FOR GOOD PRACTICE IN THE CONDUCT OF CLINICAL TRIALS IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2000)

viii) Company must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.

ix) A copy of the research report will be provided to Company once it is finally approved by the tertiary institution, or once complete.

x) Company has the right to implement any Best Practice recommendations from the research.

xi) Company reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/Netcare or should the researcher not comply with the conditions of approval.

xii) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER.

We wish you success in your research.

Yours faithfully

Dr CW Fölscher
Full member: Research Operational Committee evaluating research applications as per Company Policy

Shannon Nell
Chairperson: Research Operational Committee
Date: 8/4/2014

This letter has been anonymised to ensure confidentiality in the research report.
The original letter is available with author of research

25 April 2012

Ms A Gibson
P.O. Box 12257
CLUBVIEW
0014

Dear Alison

PERMISSION TO CONDUCT RESEARCH AT [redacted]

Your research proposal entitled "*Support programme for the parents of very low birthweight infants in a neonatal intensive care unit*" refers.

It is in order for you to conduct your research at [redacted] and I wish you success with this project.

Yours sincerely

Estelle Jordaan
ESTELLE JORDAAN
Nursing Executive

[redacted]

Addendum B

Pamphlet requesting VP assistance

Dear Parent

Did you have a premmie in a NICU?



If so, please help!

I am a doctoral student completing my PhD in Psychology and am looking for parents who are willing to be interviewed by myself regarding their experiences of having their baby in a NICU.

I myself also had a premmie who was in the NICU for 4 months and am now designing a support programme for parents with infants in a NICU.

The interview is voluntary and all information will be kept confidential.

If you are interested or would like some more info, please feel free to contact me at

082 948 2544

Alison Gibson



Thank-You!

Addendum C

Information letter for VP

Dear Parent

I, Alison Gibson, the undersigned, am an Educational Psychologist and a PhD student at North-West University (Potchefstroom campus). In fulfillment of the requirements for the doctoral degree, I have to undertake a research project and have decided to focus on developing a **"Support Programme for the Parents of Very Low Birthweight Infants in a Neonatal Intensive Care Unit"**.

In view of the fact, that you have already been in this situation of having an infant in a Neonatal Intensive Care Unit (NICU), I kindly would like to make a request to you to participate in the study. Participation in the research study is, however completely voluntary.

This research project originated as a result of having my own child admitted to a NICU for approximately four months. Internationally, there is widespread use of intervention programmes to help parents cope at this time; however, according to my brief research at hospitals and my own knowledge, there does not appear to be any formal support programmes in use in South Africa.

The information gathered will assist in the development of the support programme and will be published in a scientific journal. It is hoped that the support programme will facilitate constructive coping in parents who have an infant of low birthweight admitted to a NICU in the future.

Should you agree to participate, you will be requested to participate in a face-to-face interview that will be conducted at a venue and time to be determined and which will be convenient to you. It is estimated that the interview will take approximately 2 hours. Questions in the interview will pertain to your personal experiences and needs with having a pre-term infant admitted to a NICU. I will need to interview both parents together regarding your experiences. If necessary, an individual interview with one parent may need to be organized subsequently. Possible risks related to inclusion in this research

may include feeling uncomfortable when having to recall memories of the birth and admission of your infant into a NICU.

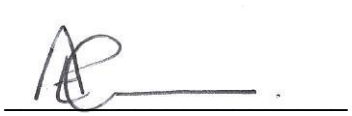
Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of not using your names when referring to you in the research report. I will keep all information locked and only I will have access to it. Interviews will be audio- and/or video recorded on tape and only I will have access to the tapes. When the research report is completed and all my examinations finished, all the recordings will be kept for five years in a special locked safe at the Centre for Child, Youth and Family Studies.

Should you agree to participate in this study, you are not waiving any legal claims, rights or remedies. You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as research participants, please contact Dr. Mariette van der Merwe, my study supervisor, at the Centre for Child, Youth and Family studies (082 9646697).

If you are interested in participating in the study, or need some more information please contact me. You will be requested to give your written consent on a form which will be provided to you, before continuation of participation in this study.

Your participation will be highly appreciated!

Kind regards



Alison Gibson (Researcher)

Contact details: Cell: 082 9482544

E-mail: alisongibson.psych@gmail.com

Addendum D

Consent form VP

CONSENT TO PARTICIPATE IN RESEARCH

Veteran Parents

SUPPORT PROGRAMME FOR PARENTS WITH VERY LOW BIRTHWEIGHT INFANTS IN A NEONATAL INTENSIVE CARE UNIT

You are asked to participate in a research study conducted by Alison Gibson, a qualified educational psychologist, who is currently completing her doctorate studies through North-West University. The results of the study will contribute to the finalization of a thesis. You were selected as possible participants in this study because you are parents of a very low birthweight (VLBW) pre-term infant.

1. **PURPOSE OF THE STUDY**

To develop a support programme to help parents cope with the birth of a VLBW pre-term infant that has been admitted to a neonatal intensive care unit (NICU).

2. **PROCEDURES**

If you volunteer to participate in this study, I would like to conduct an interview with both parents. Questions in the interview will pertain to your personal experiences and needs with having a very low birthweight pre-term infant admitted to a NICU.

3. **POTENTIAL RISKS AND DISCOMFORTS**

I will need to interview both parents regarding your experiences. Possible risks include feeling uncomfortable when having to recall memories of the birth and admission of your infant into a NICU.

4. **POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY**

The support programme will be beneficial to future parents who have a preterm infant that is of a very low birthweight and admitted to a NICU.

If necessary, Alison Gibson will make provision to provide follow-up intervention with you.

5. **PAYMENT FOR PARTICIPATION**

You will not receive any payment for participation in the study.

6. **CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

Confidentiality will be maintained by means of not using your names when referring to you in the research report. I will keep all information locked and only I will have access to it. Interviews will be audio recorded on tape and only I will have access to the tapes. When the research report is completed and all my examinations finished, the tape recordings will be destroyed.

7. **PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact me, Alison Gibson on 0829482544 or my study supervisor, Dr Mariette van der Merwe on 0829646697.

9. **RIGHTS OF RESEARCH PARTICIPANTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as research participants, contact Dr. Mariette van der Merwe at the Centre for Child, Youth and Family studies (0829646697).

SIGNATURE OF RESEARCH PARTICIPANTS

The information above was described to us by Alison Gibson in English and we are in command of this language. We were given the opportunity to ask questions and these questions were answered to our satisfaction.

We, _____ (full name of participant) and
_____ (full name of spouse) hereby consent to voluntarily participate in this study. We have been given a copy of this form.

_____ _____

SIGNATURE OF PARTICIPANTS

_____

DATE

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ (full name of participant) and _____ (full name of spouse). They were encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

_____ _____

Signature of Investigator Date

Addendum F

PSS: NICU

PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT

We are interested in knowing more about the stresses experienced by parents when a premature is sick and hospitalized in an neonatal intensive care unit (NICU). We would like to know about your experience as a parent whose child is presently in the NICU.

This questionnaire lists various experiences other parents have reported as stressful when their baby was in the NICU. We would like you to indicate how stressful each item listed below has been for you. **By stressful, we mean that the experience has caused you to feel anxious, upset, or tense.** On the questionnaire, circle the single number that best expresses how stressful each experience has been for you. The numbers indicate the following levels of stress:

1 = Not at all stressful the experience did not cause you to feel upset, tense, or anxious
2 = A little stressful
3 = Moderately stressful
4 = Very stressful
5 = Extremely stressful

If you have not experienced an item, please circle NA "not applicable"

Now let's take an item for an example: **The bright lights in the NICU.**

If for example you feel that the bright lights in the neonatal intensive care unit were extremely stressful to you, you would circle the number 5 below:
NA 1 2 3 4 (5)

If you feel that the lights were not stressful at all, you would circle the number 1 below:
NA (1) 2 3 4 5

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in an NICU. We are interested in knowing about your view of how stressful these **SIGHTS AND SOUNDS** are for you. Circle the number that best represents your level of stress. If you did not see or hear the item, circle the NA meaning "Not applicable."

1.	The presence of monitors and equipment	NA 1 2 3 4 5
2.	The constant noises of monitors and equipment	NA 1 2 3 4 5
3.	The sudden noises of monitor alarms	NA 1 2 3 4 5
4.	The other sick babies in the room	NA 1 2 3 4 5
5.	The large number of people working in the unit	NA 1 2 3 4 5

Below is a list of items that might describe the way your **BABY LOOKS AND BEHAVES** while you are visiting in the NICU as well as some of the **TREATMENTS** that you have seen done to the baby.

Not all babies have these experiences or look this way, so circle the NA, if you have not experienced or seen the listed item. If the item reflects something that you have experienced, then indicate how much the experience was stressful or upsetting to you by circling the appropriate number.

1.	Tubes and equipment on or near my baby	NA 1 2 3 4 5
2.	Bruises, cuts or incisions on my baby	NA 1 2 3 4 5
3.	The unusual color of my baby (for example looking pale or yellow jaundiced)	NA 1 2 3 4 5
4.	My baby's unusual or abnormal breathing patterns	NA 1 2 3 4 5
5.	The small size of my baby	NA 1 2 3 4 5
6.	The wrinkled appearance of my baby	NA 1 2 3 4 5
7.	Having a machine (respirator) breathe for my baby	NA 1 2 3 4 5
8.	Seeing needles and tubes put in my baby	NA 1 2 3 4 5
9.	My baby being fed by an intravenous line or tube	NA 1 2 3 4 5
10.	When my baby seemed to be in pain	NA 1 2 3 4 5
11.	When my baby looked sad	NA 1 2 3 4 5
12.	The limp and weak appearance of my baby	NA 1 2 3 4 5
13.	Jerky or restless movements of my baby	NA 1 2 3 4 5
14.	My baby not being able to cry like other babies	NA 1 2 3 4 5

The last area we want to ask you about is how you feel about your own **RELATIONSHIP** with the baby and your **PARENTAL ROLE**. If you have experienced the following situations or feelings, indicate how stressful you have been by them by circling the appropriate number. Again, circle NA if you did not experience the item.

1.	Being separated from my baby	NA 1 2 3 4 5
2.	Not feeding my baby myself	NA 1 2 3 4 5

3.	Not being able to care for my baby myself (for example, diapering, bathing)	NA 1 2 3 4 5
4.	Not being able to hold my baby when I want	NA 1 2 3 4 5
5.	Feeling helpless and unable to protect my baby from pain and painful procedures	NA 1 2 3 4 5
6.	Feeling helpless about how to help my baby during this time	NA 1 2 3 4 5
7.	Not having time alone with my baby	NA 1 2 3 4 5

Thank you for your help.

Feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit?

c Margaret S. Miles, RN, PhD 1987, 2004, 2011

Addendum G

Examples of VP transcriptions and coding

VP 1

INTERVIEWER: in a nutshell, how would you say you experienced the birth of them.	
PARTICIPANT: it was horrible, you mean the actual day everything happened.	Birth Experience: Negative feelings
INTERVIEWER: ok you can start with the actual leading up to it, and um what basically caused them to be born early.	
PARTICIPANT: Ok	
INTERVIEWER: if you can explain that to me	
PARTICIPANT: I shouldn't be eating	
INTERVIEWER: its fine	
PARTICIPANT: um ja [yes] um, ja [yes], I was due in May.	Before Birth: High risk preg
INTERVIEWER: ok	
PARTICIPANT: in January I started with problems, I had a bladder infection, so my doctor stopped me from driving, which caused chaos with my job. They forced me to take early maternity leave.	
INTERVIEWER: ja [yes]	Before Birth: Stress
PARTICIPANT: so I had a huge fight with them, got a lawyer involved which didn't help my stress levels at all because I would have then finished my maternity leave when they were born. I would have had to take four months unpaid leave so, and by law they are supposed to accommodate you with a job that does not include driving just until you have had the kids, then you can take your leave, so I had a huge argument, big fights with them. Then I was admitted into hospital again with bleeding.	Before Birth: High risk preg
INTERVIEWER: bleeding, when were you bleeding	
PARTICIPANT: that was in February.	
INTERVIEWER: ok	Before Birth: Problematic preg
PARTICIPANT: late January, February. Then I was in hospital for three weeks.	
INTERVIEWER: shoo	Before Birth: Bedrest
PARTICIPANT: then I came home and I was on bedrest from the end of February, like the last week of Feb until the 17 March when this happened.	
INTERVIEWER: when they were born	
PARTICIPANT: ja [yes]	
INTERVIEWER: ok	
PARTICIPANT: so from the beginning of January there was just chaos.	Before Birth: Stress
INTERVIEWER: and stress	
PARTICIPANT: from like nineteen weeks	
INTERVIEWER: shoo	
PARTICIPANT: drama	
INTERVIEWER: ok	Before Birth: Haste
PARTICIPANT: then my water broke at three o'clock in the morning, rushed to hospital, the nurse	
INTERVIEWER: so you were at home then	
PARTICIPANT: yes we were at home, ja, ja, [yes,yes] my husband was here luckily, um, I didn't know what was going on, I did not think it was my water because I did not have contractions.	Before Birth: Confusion
INTERVIEWER: ok	Before Birth: Haste
PARTICIPANT: so we rushed me off, the nurse did that test with that long earbud and if it's yellow it's not amniotic fluid and if it is black	
INTERVIEWER: I don't know the whole tooti [process]	Before Birth: Medical procedures
PARTICIPANT: they test your cervix with this long like earbud and if it goes black you leaking amniotic fluid but she didn't tell me that but I knew, so she pulled it out and it was black, and I just went hysterical. So they booked me in and they just elevated my bed because they, the doctor thought that if he	Before Birth: Negative feelings

keeps me elevated and I don't get up even to go to the bathroom. I didn't know but your membrane of the sack can actually kind of repair itself and you generate more water. INTERVIEWER: I did not know that either PARTICIPANT: ja [yes], so that's what he was aiming to do, so just keep me, even for a month, so if I just lie in bed and I don't move for a month. That's what he wanted to do. So everything was going fine until I was in the book-in area. They needed to move to the labour ward or the maternity ward so they had to move me out of the bed. So they tried to move me as stable as possible, but the minute they moved me it just came gushing out again. Then they put the monitors on me and I did not have any contractions but I had this like stabbing pain in my back, so I asked my Mom to call the nurse to tell the doctor I need a painkiller or something. So they said no that was weird so they just checked to see if I was dilating and I was 4 cm's dilated already but no contractions INTERVIEWER: mm, mm PARTICIPANT: and then the week before I'd been at the doctor and we thought they were 1.5 and 1.6 which would have been a lot better INTERVIEWER: mm, mm, what were they PARTICIPANT: 1.1 and 1.2 INTERVIEWER: ja [yes] PARTICIPANT: ja [yes], that was at two o clock that they saw that I was dilated, so they booked a theatre for six. So obviously you hysterical. INTERVIEWER: ja [yes] PARTICIPANT: I had nothing on me, the baby clothes were too big because you don't realize that you are not going to need clothes, you know, for the first month.	Before Birth: Vulnerability Before Birth: Immobility Before Birth: Pain Before Birth: Abnormal birth experience Before Birth: Negative feelings Before Birth: Emotion focused coping Before Birth: Unpreparedness Incident: Lack of knowledge of pre-term issues

VP 5

PARTICIPANT: then coming home was appalling, I was very protective of them when I came home. They are small and prone to infection and the one was in hospital for so long because he kept on getting infections. I didn't want lots of people holding them and breathing in their faces and I said to them here is the sterilizer bottle, wash your hands and all that kind of thing and they would think you are paranoid. But you know what I have just been though, do you have any concept of what my boy screamed at me for ten months. They screamed for ten months, that's all they did. Everyone was like don't worry, things will be fine, don't worry at six weeks it will be fine, don't worry after three months it will all be fine, it will all be over but they have no concept of certainly of what it's like to have twins and certainly what it's like to have premature babies that are underdeveloped. INTERVIEWER: and prone to illness PARTICIPANT: coming home it actually almost got worse cause now they supposedly fattened up a bit, they look a bit better, people were shocked at the size, people are not used to two and a half kg. babies these days. They lost quite a bit of weight before putting on. Some people were just very blasé and not understanding. I lost communication with them, I just could not be bothered. INTERVIEWER: ja, why bother PARTICIPANT: I didn't have time to start with anyway. Everyone thinks that their pregnancies are the worst or the best but they don't consider what that situation might be like. INTERVIEWER: ja, no, look you know they won't understand, they've never been in the situation. PARTICIPANT: they just don't get it. They also don't understand why I went to Pretoria to have my babies. I got a lot of flack [ridicule] for going to Pretoria to have my babies.	Home: Difficult Home: Infant different Home: Abnormal routines Home: Misunderstanding from others Home: Infant different Home: Misunderstanding from others

INTERVIEWER: Is it PARTICIPANT: If it had had them here they would have died. Our local hospital has one bed. There is no way they would have survived. They've got no resuscitation and I have had a stroke. I know what emergency situations are like.	

Addendum H

Consent forms for nursing professionals

CONSENT TO PARTICIPATE IN RESEARCH

Nursing Professionals

SUPPORT PROGRAMME FOR PARENTS WITH PRETERM INFANT(S) IN A NEONATAL INTENSIVE CARE UNIT

You are asked to participate in a research study conducted by Alison Gibson, a qualified educational psychologist, who is currently completing her doctorate studies through North-West University. The results of the study will contribute to the finalization of an article in a scientific journal. You were selected as a possible participant in this study because you as a nursing professional can provide valuable information regarding parents' experiences of having a pre-term infant.

1. PURPOSE OF THE STUDY

To develop a support programme to help parents cope with the birth of a pre-term infant that has been admitted to a neonatal intensive care unit (NICU).

2. PROCEDURES

If you volunteer to participate in this study, I would ask you to complete a questionnaire to help me gain insight on parental needs and offer suggestions on the content of a support programme.

3. POTENTIAL RISKS AND DISCOMFORTS

You will have to complete the questionnaire and return it within ONE week.

4. POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

The support programme will be beneficial to future parents who have a preterm infant that has been admitted to a NICU.

5. PAYMENT FOR PARTICIPATION

You will not receive any payment for participation in the study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

Confidentiality will be maintained by means of not using your names in the research report. I will keep all information locked and only I will have access to it. When the research report is completed and all my examinations finished, the questionnaires will be locked away at the Centre for Child, Youth and Family Studies.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact me, Alison Gibson on 0829482544 or my study supervisor, Dr Mariette van der Merwe on 0829646697.

9. RIGHTS OF THE RESEARCH PARTICIPANT

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as research participants, contact Dr. Mariette van der Merwe at the Centre for Child, Youth and Family Studies (0829646697).

SIGNATURE OF FOCUS GROUP RESEARCH PARTICIPANT

The information above was described to me by Alison Gibson in English and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I, _____ (full name of participant) hereby consent to voluntarily participate in this study. I have been given a copy of this form.

_____ _____

SIGNATURE OF PARTICIPANT DATE

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ (full name of participant). He/she was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

_____ _____

Signature of Investigator Date

Addendum I

Self-developed questionnaire for use with nursing professionals

Nursing Professionals Questionnaire [*Shortened*]

Please provide the following details. All personal particulars will remain confidential.

Name	
Age	
Gender	Male Female (please circle)
Home Language	
Qualification	
Experience in NICU (years)	
Primary responsibilities in NICU	
Experience in nursing overall (years)	
Approximate working hours (per week)	

Please complete the following questions.

I value your opinion and **thank you** for taking the time to complete the questionnaire for me!

1. How do you see your role in the NICU? (please explain)

……
……
……

2. What do you think the parent's role is when having an infant in the NICU?

……
……
……

3. What do you expect from the parents when they have an infant(s) in the NICU?

……
……
……

4. What, according to you, are the needs of parents?

……
……
……

5. Please indicate which of the above needs you are able to satisfy and which you are unable to meet due to various circumstances. Please explain the reasons for not being able to meet certain needs for example time constraints, lack of training, staff shortages etc.

……
……
……

6. Explain your communication with the parents. Please include any problems that are experienced by you or on the part of the parents.

……
……
……

7. Describe the relationship you have generally with the parents.

……
……
……

8. What do you understand under the term “Family-centered care?”

……
……
……
……

9. Do you think family-centered care is necessary in the NICU? If you answered yes, please explain what you think the benefits are.

……
……
……

10. Have you received any specific training or education on family-centered care?

……
……
……

11. What do you believe should be included in a support programme for parents? Please describe the content at the following different stages:

- Before birth:

……
……

- Just after birth

……
……

- First visit to NICU

……

……

- First few days at NICU

……

……

- During stay at NICU

……

……

- Before discharge

……

……

- At home

……

……

Thank-You again for taking the time to complete the questionnaire!

Alison Gibson

Addendum J

Information letter for NICU parents

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOMKAMPUS

Centre for Child, Youth and Family Studies
Corner of East and College Street
Wellington
7655

Tel: 021 8643593
Fax: 021 8642654

Dear Parent

I, Alison Gibson, the undersigned, am an Educational Psychologist and a PhD student at North-West University (Potchefstroom Campus). In fulfillment of the requirements for a PhD in Psychology, I have to undertake a research project and have decided to focus on developing a **"Family Centered Support Programme for the Parents of Preterm Infants in a Neonatal Intensive Care Unit"**.

In view of the fact, that you currently have an infant in a Neonatal Intensive Care Unit (NICU), I kindly would like to make a request to you to participate in the study. Participation in the research study is, however completely voluntary.

This research project originated as a result of having my own child admitted to a NICU for approximately four months. Internationally, there is widespread use of intervention programmes to help parents cope at this time; however, according to my brief research at hospitals and my own knowledge, there does not appear to be any formal support programmes in use in South Africa.

The information gathered from you and your participation is aimed at facilitating constructive coping in yourself and future parents who have a preterm infant admitted to a NICU.

Should you agree to participate, you will be requested to participate in the following: 1) a face-to-face interview; 2) complete two questionnaires; 3) participate in the support programme and lastly, 4) participate in a follow-up interview and complete the two questionnaires again.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of not using your names when referring to you in the research report. I will keep all information locked and only I will have access to it. Interviews and the support sessions will be audio recorded and only I will have access to the tapes. When the research report is completed and all my examinations finished, all the recordings will be kept for five years in a special locked safe at the Centre for Child, Youth and Family Studies.

Should you agree to participate in this study, you are not waiving any legal claims, rights or remedies. You may withdraw your consent at any time and discontinue participation without penalty. If you have questions regarding your rights as research participants, please contact Dr. Mariette van der Merwe, my study supervisor, at the Centre for Child, Youth and Family studies (082 9646697).

If you are interested in participating in the study, or need some more information please contact me. You will be requested to give your written consent on a form which will be provided to you, before continuation of participation in this study.

Your participation will be highly appreciated!

Kind regards



Alison Gibson (Researcher)

Contact details: Cell: 082 9482544 /E-mail: alisongibson.psych@gmail.com

Addendum K

Consent form for NICU parents

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOMKAMPUS

Centre for Child, Youth and Family Studies
Corner of East and College Street
Wellington
7655

Tel: 021 8643593
Fax: 021 8642654

CONSENT TO PARTICIPATE IN RESEARCH

A FAMILY CENTERED SUPPORT PROGRAMME FOR PARENTS OF PRETERM INFANTS IN A NEONATAL INTENSIVE CARE UNIT

You are asked to participate in a research study conducted by Alison Gibson, a qualified educational psychologist and a PhD student at North-West University (Potchefstroom campus). The School of Psychosocial Behavioral Sciences (subject group Psychology), Faculty of Health Sciences, Potchefstroom Campus, North-West University as well as the NWU Human Research (Ethics) Committee have given permission to me to conduct this research under project NWU-00060-12-A1. The results of the study will contribute to the finalization of a thesis. You were selected as possible participants in this study because you are parents of a preterm infant(s).

1. PURPOSE OF THE STUDY

To develop a family centered support programme to help parents cope with the birth of a preterm baby that has been admitted to a neonatal intensive care unit (NICU).

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

a) Both parents (if possible) be interviewed regarding the time leading up to the early birth of your baby.

b) Both parents complete two questionnaires. One relating to stress and another relating to anxiety.

c) Mother and father (if possible) will be educated and supported in a few sessions. Information will be provided regarding the following topics (for instance):

- ❖ Understanding reason for equipment commonly used in the NICU
- ❖ Development
- ❖ Understanding your baby
- ❖ Positive touch
- ❖ Sleep and awake states
- ❖ Positioning
- ❖ Kangaroo mother and father care etc.

Scheduling of the sessions will be dependent on the nature of your infants' health status. During the sessions, I, Alison Gibson may take notes and I will audio record the session.

d) Both parents (if possible) complete another questionnaire after the programme has been completed and then I, Alison Gibson will conduct an interview with both of you to gain feedback from you about the effectiveness and problems/limitations regarding the programme.

It will be necessary for Alison to have consent to have access to your baby's medical records and be allowed to speak to the doctor(s) dealing with your infant so as to structure and include the necessary information for the support programme. In this way the support programme will be specifically **individualised to your baby**.

3. POTENTIAL RISKS AND DISCOMFORTS

If one of you, or both parents feel at any time uncomfortable or have any questions, I will be available to discuss these issues. You may also be referred to other professionals.

4. POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

The support programme will be beneficial to you, the parents, to help you cope with the birth and care of your preterm infant and other parents who have a preterm infant in the future.

5. PAYMENT FOR PARTICIPATION

You will not receive any payment for participation in the study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you both will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of not using your names and using a number when referring to you both in the research report. I will keep all information locked and only I will have access to it. Sessions will be recorded on tape and only I will have access to the tapes. When the research report is completed and all my examinations finished, the tape recordings will be stored in a safe at the Centre for Child, Youth and Family Studies, North-West University, for a period of five years after which it will be destroyed.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact me, Alison Gibson on 0829482544 or my study supervisor, Dr Mariette van der Merwe on 0829646697.

9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as research participants, contact Dr. Mariette van der Merwe at the Centre for Child, Youth and Family studies (0829646697).

SIGNATURE OF RESEARCH PARTICIPANTS

The information above was described to us by Alison Gibson in English and we are in command of this language. We were given the opportunity to ask questions and these questions were answered to our satisfaction.

We, _____ (full name of participant) and _____ (full name of spouse) hereby consent to voluntarily participate in this study. We have been given a copy of this form.

_____ _____

_____

DATE

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ (full name of participant) and _____ (full name of spouse). They were encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

_____ _____

Signature of Investigator Date

Addendum L

Biographical details questionnaire for NICU parents

PERSONAL PARTICULARS

MOTHER

Name & surname	
Married to father at birth of child?	Yes / No
Years married at birth of child	Approximately …… years
Age at birth of child	
Any qualifications?	
Occupation at time of birth of child	
Cell no	

FATHER

Name & surname	
Age at birth of child	
Any qualifications?	
Occupation at time of birth of child	
Cell no	

HISTORY

Have you had any previous miscarriages?	
If so, how many?	
Do you have any other children? Names and ages?	

PRETERM INFANT

Name	
Gender (please circle)	MALE / FEMALE
Type of birth	VAGINAL / CESAREAN
Apgar score	First score: Second score:

Date of birth?	
Gestational age?	
How many days / weeks premature?	
Birth weight?	
How many days / weeks in NICU so far?	

MULTIPLE GESTATION PRETERM INFANT

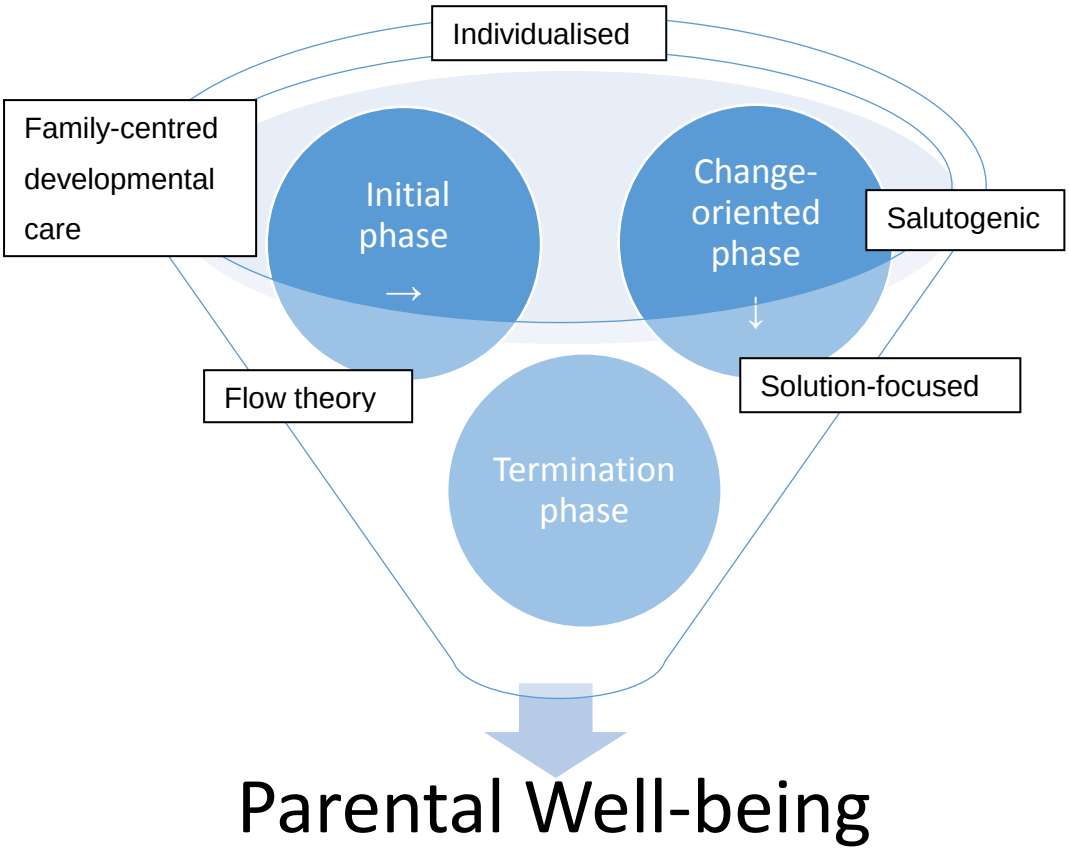
Name	
Gender (please circle)	MALE / FEMALE
Type of birth	VAGINAL / CESAREAN
Apgar score	First score: Second score:
Date of birth?	
Gestational age?	
How many days / weeks premature?	
Birth weight?	
How many days / weeks in NICU so far?	

Addendum M

Outline of support intervention

The helping process in the support intervention involved three major phases, namely: (1) an initial phase of exploration, engagement, assessment and planning; (2) a change-oriented phase of implementation and goal attainment; and lastly (3) a termination phase (Hepworth et al., 2013).

The three phases took place within a climate of salutogenesis, fortigenesis and family-centred developmental care. This climate aligns well with the statement of Goldberg (2007) that authentically listening to women, being open and non-judgemental, and valuing their experiences, contributes to establishing a trust relationship between the woman and health care professionals. The VP (parents who previously had infants in an NICU) gave reasons for the need for further support such as helping with the many questions parents have, help in understanding their feelings, catharsis, and sharing experiences with others who have understanding of the experience. The broad process is graphically presented in the following figure:



In the initial phase, processes of exploration and assessment were central. Clients' problems were explored by eliciting comprehensive data about the person(s), the problem, and environmental factors such as relevant aspects in the microsystem, but also in other relevant systems (medical aid health care policies). Exploring parents' problems helped "jump start" the helping process (Egan, 2013, p. 20) and as Sloan (as cited in Egan, 2013) indicates, self-disclosure is linked to psychological well-being. Further tasks in this phase included establishing rapport and enhancing motivation; formulating goals to be accomplished in alleviating problems and formulating a contract; making referrals if necessary; and formulating a multidimensional assessment of the problem, identifying systems that play a significant role in the difficulties, and identifying relevant resources that can be tapped or must be developed (Hepworth et al., 2013).

During the change-oriented phase of the support intervention, actions towards problem-solving and goal attainment were implemented. Intervention elements (tools and techniques) such as the provision of factual information regarding the NICU and the preterm infant; psycho-education; use of a metaphor; and awareness techniques were used. The following functional elements identified from the VP interviews and nursing questionnaires were used to help parents cope and thereby help promote well-being:

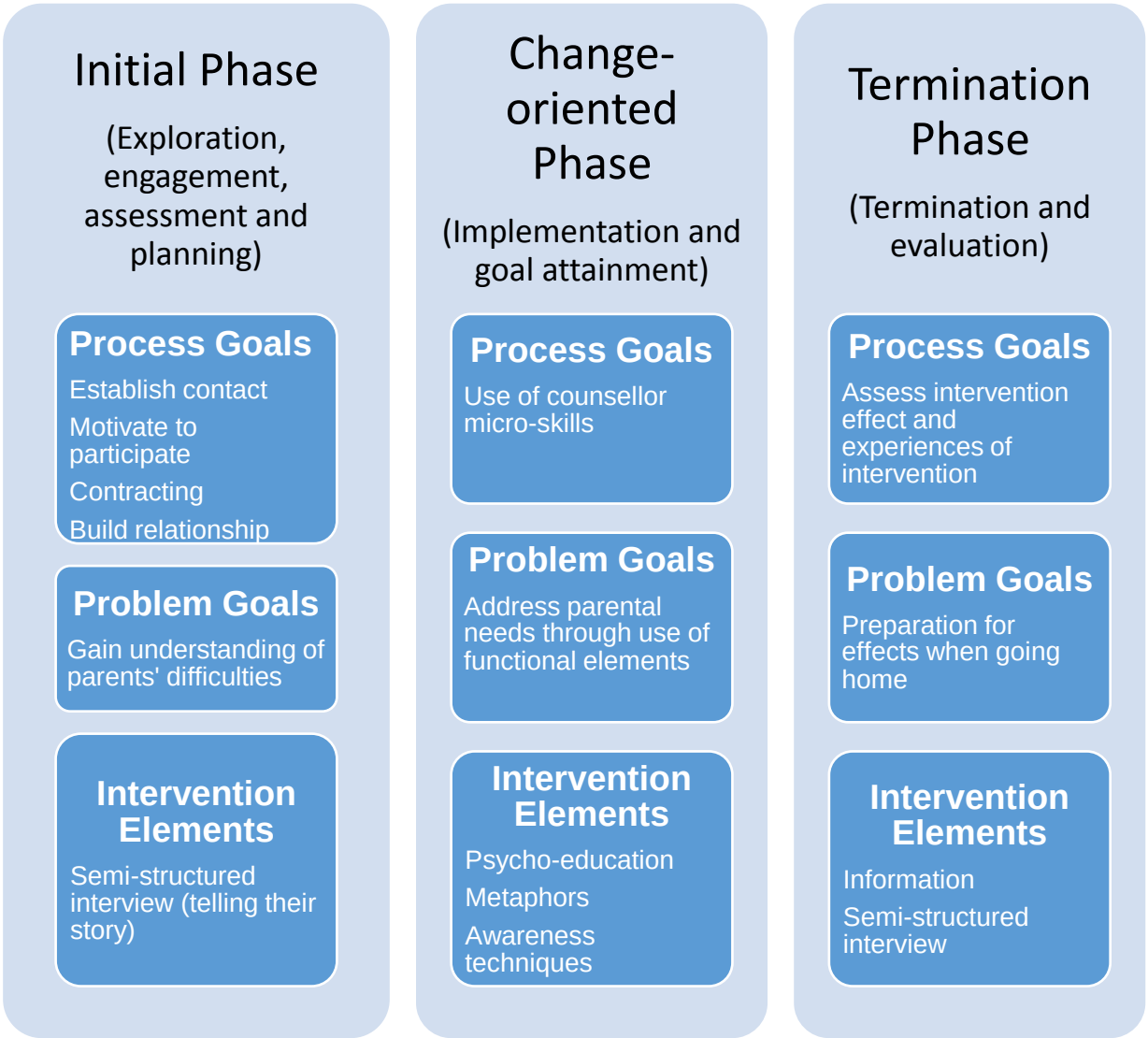
- Answering the parents questions, where possible;
- Factoring in time issues with setting up appointments as parents may be pressured to have available time for support;
- Providing information on machinery and equipment used;
- Explaining rules, routines and procedures of the NICU and the layout of the NICU;
- Interpreting confusing terminology used by the medical professionals;
- Reassuring parents that their infant is receiving good medical care;
- Providing education on infant growth and development;
- Providing information on infant behaviour;
- Encouraging active involvement of the parent with the infant.

Functional elements helped to improve parent's comprehensibility (Antonovsky, 1987), promote engagement and gain a sense of accomplishment (Seligman, 2011). Furthermore, the aim of using functional elements and intervention elements was to promote coping, reduce parental stress, decrease untoward responses such as parents moving into a state of languishing or even floundering (Keyes & Lopez, 2002), and foster well-being.

In the termination phase, information regarding going home with a preterm infant was discussed with the parents as the literature indicates that educational intervention provided to the mother before discharge increases knowledge, changes maternal behaviours and decreases maternal stress (Browne & Talmi, 2005). It has been shown that readiness for discharge is significantly

related to infant safety, parent satisfaction and physical, emotional, psychological and social well-being of the family (Weiss et al., 2006). Education and information provided at termination included information regarding expected emotional consequences for parents. With the education and information provided it was envisaged that parent's growth towards well-being will continue at home.

In summation, the outline of the intervention is summarised in the following figure:



Addendum N

Educational posters

A Preemie's Bill of Rights

by

READ MCCARTY | HAWAII MEDICAL



I DESERVE... to be understood and treated as the individual I am. I deserve to have my language of cues and signals understood by you, my caregiver. My grimaces, hand stretches, frowns and hiccups are as meaningful as any words, but delivered in the only language I know.



I DESERVE... your recognition that I may be completing many months of my physical and neurological development outside the protection of my mother's womb. Even as you give me the life sustaining care I so badly need, as much as possible I deserve to have the boundaries, quiet, warmth, gentle stimulation, dim lighting and fetal positioning I would have in my mother's womb.

I DESERVE... periods of uninterrupted quiet so I can use my energy to grow and not hopelessly trying to overcome excess light, noise and over stimulation.

I DESERVE... the warmth, tenderness and comfort of being held by my parents as soon as they feel comfortable and when my medical condition allows.

I DESERVE... the positive energy of love...your kind thoughts and words as you care for me...my father's soft touch... my mother's gentle words...a volunteer's quiet rocking. I deserve these things because in your heart you know their worth even though their absolute clinical value may never be proven.

I DESERVE... your understanding that what is normal and routine for you, as my caregiver, is abnormal and frightening for my mom and dad. So please answer kindly no matter how many times they ask the same question. They deserve your support and understanding and the support of other families as they go through the roller coaster experience of the NICU.



I DESERVE... your recognition that my parents are an integral part of my caregiving team and should be allowed and encouraged to the best of their ability to help care for me during my stay in your hospital.

I DESERVE... your understanding that part of your job is to help my family bond with me as we learn to trust each other in preparation for my homecoming.

I DESERVE... continuity of care from the NICU to my home... from my neonatologist to my primary care giver... so together my family and I can reach our full potential.

YOU DESERVE MY THANKS AND RECOGNITION I AM HERE BECAUSE OF YOU!

READ MCCARTY, FOUNDER OF HAWAII MEDICAL WAS THE FOUNDER AND FORMER CEO OF CHILDREN'S MEDICAL VENTURES, INC. BOTH COMPANIES ARE DEDICATED TO IMPROVING THE HEALTH CARE OF CHILDREN AND MAKING THE PRACTICE OF DEVELOPMENTALLY SUPPORTIVE/FAMILY CENTERED CARE THE STANDARD OF CARE IN THE NICU. THANKS TO OLIVA AND HER FAMILY. PLEASE FEEL FREE TO COPY AND SHARE.

Hawaii Medical
Innovating Medical Products for Kids

tel 1.800.596.1555 | 781.826.5565 fax 826.2544 web www.hawaiimedical.com

5110805A

FREQUENTLY ASKED QUESTIONS

1. How long will my baby have to stay in NICU before going home?
   This is one of the first questions most parents ask and one we cannot answer. If your baby was born prematurely, then work out how many weeks till he/she should have been born and that will give you a ROUGH estimate of the stay in NICU. Babies are discharged once all signs of infection are gone, they are feeding well and gaining weight and the problem for which they were admitted in the first place has been resolved.

2. What's the big deal with hand washing and restricting visitors in the NICU?
   Babies' immune systems are immature and not yet fully developed which means they are at a greater risk of developing an infection.

3. Why can't I breast/bottle feed my baby?
   The sucking reflex only starts to develop around 35 weeks so if your baby was born earlier, she will get tired and frustrated trying to suck which may even lead to nipple aversion (a situation where babies don't want anything put in their mouths) When your baby is ready, we will encourage her to nuzzle at your breast and may even feed her through the tube simultaneously so she associates the nipple with gradual filling of her tummy. If your baby was admitted for a reason other than prematurity, we will encourage breast/bottle feeding as soon as he/she is stable.

4. Why do you encourage the use of dummies/pacifiers in NICU?
   Non-nutritive sucking (sucking when there is no milk to swallow) is very important for the following reasons;
   It soothes and calms baby thus conserves energy
   It improves oral muscle tone and co-ordination which later aids the transfer to nutritive sucking on the breast/bottle.
   Helps tube fed babies keep the association between sucking and a full tummy.

5. Why does my baby need so many blood tests?
   Blood test are done to check many different things, most common of which are infection markers, anaemia, and respiratory and metabolic acidosis /alkalosis

6. Why does my baby need a drip?
   Premature or sick babies are unable to take enough fluids and nutrients orally so we often put up drips (intravenous therapy) to supplement their fluid intake. Sometimes we may give ITN/TPN (total parenteral nutrition) in the drip which is a meal in its simplest form and is directly absorbed into baby's blood stream without making his tummy do any work of digestion. We also use the drip to administer antibiotics or other medication that is better absorbed than if it was given via the tube or orally.

NICU equipment commonly used



Monitors:



Green line → Heart rate: Norm 120 to 160 beats/minute.

Blue line → Oxygen saturation: Level of oxygen in baby's blood. Normal when receiving oxygen (88-92%); When breathing on own (96% and above).

White/Yellow line → Respiratory rate: Normally: 40-60 breaths/minute.

Red → Blood pressure

Incubators



Open overhead crib / Warming table

Flat bed with heater which keeps baby warm.

Enough space and easy access to all tubes and wires.

Closed incubator



Warm and humidified environment.

Intravenous (IV) lines



Line inserted into vein to give baby fluids (sugar, electrolytes, medications etc.).

Usually placed on arm, leg, foot or scalp.

IV lines secured with splints if in arm or leg.

Broviac catheter is a central line placed in blood vessel leading directly to heart, inserted through a surgical procedure, when baby needs to receive fluids over a long period of time.

UAL (Umbilical arterial line): line inserted into umbilical artery to give baby fluids.

UVL (Umbilical venous line): line inserted into umbilical vein to give baby fluids.

CVP (Central venous line): line inserted into vein by the neck.

Respiratory Equipment

Many preemies have breathing problems as lungs mature relatively late in gestation. Your baby may attempt to breathe but every time he/she exhales the lungs collapse. This is very tiring for your baby so therefore there are a few devices to help your baby:

Oscillator

High frequency ventilator which keeps the lungs open with a constant pressure and gives hundreds of tiny puffs of oxygen each minute.



Tiny puffs do not appear as normal breathing but as a chest 'wiggle'.

Often used when baby not doing well on regular ventilator.



Ventilator



A machine which breathes for your baby.

Your baby will be intubated which means he/she will have a tube through the nose or mouth down into the windpipe.

CPAP (Continuous positive airway pressure)



Oxygen or normal air is provided to your baby.

Nasal prongs fit snuggly in the nostrils.

It provides a constant stream of air into the lungs preventing them from collapse each time he/she exhales.

Your baby breathes self but a little assistance is provided.

Neopuff



Equipment used to give baby oxygen while being moved from labour ward to NICU or while preparing other respiratory equipment.

Nasal Cannula



Flexible tube that fit into the nostrils of your baby to provide humidified oxygen.

Saturation probe



Little red light attached to baby's palm, foot or wrist which measures oxygen levels in the blood.

Indicates on the monitor (Blue line).

Bilirubin lights / Phototherapy



Blue / green or white lights used to break down bilirubin that naturally accumulates in baby's blood causing a yellowish colouring of the skin and eyes known as jaundice.

Eyes are covered to protect baby from the lights.

Feeding equipment

Naso/Oral-gastric tube (NG tube/ OGT)



Small tube inserted through baby's nose or mouth directly into the stomach.

Common Tests

Your baby will occasionally undergo tests to monitor his/her progress.

Ultrasound – Test that takes an ultrasound image of any organ by means of sound waves. Painless procedure.

X-Ray – Shows condition of lungs and position of any tubes or catheters. Painless.

Lab Tests:

Blood gasses – To check levels of oxygen, carbon dioxide and acids in the blood

Blood cultures – To check if baby has an infection

Electrolyte balance – To determine levels of salt and bicarbonates

Blood glucose levels – To determine blood sugar levels

Bilirubin level – To check for jaundice

Full blood count – To measure the level of different cells in the blood

Haematocrit – To check for anaemia (abnormally low level of oxygen carrying red blood cells).

Sources:

Lubbe, W. (2008). *Prematurity: Adjusting your dream.* Pretoria: Little Steps.

Madden, S. L. (2000). *The Preemie Parents' Companion.* Boston, Massacusetts: The Hardvard Common Press.

Understanding your baby

By interpreting your baby's reactions more accurately, you can adjust the way you do things to minimize any stress.

Normal preemie behaviours:

1. Your baby will sleep most of the time

< 30 – 32 weeks: Spend most time sleeping
May twitch with slight movements
Eyes move while closed
Not reach stage of quiet alert easily

32 weeks onwards: Can reach quiet alert state
Periods start short from 1 to 10 minutes eventually

2. Your baby is able to see and hear you

Hearing fairly well developed at 20 weeks gestation

They dislike loud noises

Prefer voices, especially mothers and rhythmic sounds such as singing

30 weeks: can see contrasts of light and dark, but cannot focus

Reactions to light delayed

35 weeks: Nearsighted, can see clearly at 8-12 inches from face
Likes human faces, bright colours and pattern in black and white

3. Your baby is extremely sensitive to sounds, lights, touch and movement

Become easily overwhelmed when exposed to too many forms of stimulation at once

4. Your baby communicates through physical reactions

Many do not cry until close to due date because it is extremely tiring

They show that they are stressed through changes in

- heart and breathing rates,
- become limp or stiff,
- become pale or flushed,
- grimace and hiccup.

Source:

Madden, S.L. (2000). *The Preemie Parents' Companion.* Boston, Massachusetts: The Harvard Common Press.

Understanding your baby

Happy



Breathing, heart rate and oxygen levels are steady

Skin tone is even and looks healthy

Arms and legs relaxed and tucked up into a flexed position

Face looks relaxed

Looks alert and interested when awake



Hands clasped together

May touch face or mouth with hands

Sucks on tongue, fist, finger or pacifier

Grasps your finger

Fingers gently curled into fists

(Most factors dependent on gestational development)



Stressed

Heart and breathing rates drop or increase

May have an apnea or bradycardia spell

Oxygen saturation levels decrease





Skin becomes mottled and pale

Suddenly becomes limp or stiff

May tremble, startle or move frantically

Looks worries, may grimace or look away

May arch back



Holds arms out stiffly, stretching out fingers

Holds hands up in front of face in a stop gesture

Cries, yawns or hiccups

May gag, spit or grunt

Source: Madden, S.L. (2000). *The Preemie Parents' Companion.* Boston, Massachusetts: The Harvard Common Press.

KANGAROO CARE



Kangaroo Care is a technique where the premature baby is placed in an upright position on its mother's bare chest allowing skin to skin contact. The baby's head is turned so that the ear is above the mother's heart.

Benefits of KMC for Babies:

- They fall into a deeper sleep and are more alert when awake
- Better breathing and fewer apnoea attacks
- Less fussing and crying thus better weight gain due to energy conservation
- A more stable temperature
- A more stable heart rate
- Better oxygenation levels
- More breast milk is produced
- Gestation specific milk is produced
- Breastfeeding starts more easily

Benefits of KMC for Parents:

- Parents become central to the caring team
- Parents are calmer and less stressed
- Mothers are less depressed
- Parents feel more empowered and confident in caring for baby
- Parents learn their babies cues and understand different behavioural signals
- Better bonding, attachment and interaction with baby
- Parents feel less guilt and start to heal emotionally
- Baby is seen as "normal "and less "abnormal" or "sick"





Positive Touch

To calm, stabilise and bond!

Containment hold





Cupping





Foot bracing





Finger grasp







Sleep and Awake States

(Source: Lubbe, W. (2008). *Prematurity: Adjusting your dream.* Pretoria: Little Steps)

Quiet Sleep → Active Sleep → Drowsiness → Quiet Awake → Active Awake → Crying

States reflect maturation of central nervous system (the complex of nerve tissues that controls the activities of the body. In humans, it comprises the brain and spinal cord).

They influence growth, development and learning.

States can be skipped due to immaturity of the CNS.

Are influenced by stimulation such as:

- Touch (stroking, fabric textures, pain),
- Sound (talking, monitor alarms, phones ringing),
- Handling (movement, picking up, changing nappy),
- Environment (light, sound, vibration, temperature).

Quiet Sleep (Deep sleep)



Eyes tightly shut

No eye or facial movement

Breathing regular and smooth

Occasional startles or sucking movements



Active Sleep (Light sleep, REM sleep)

Some body movement (minor twitches, stretching, sucking actions)

Eyes closed but with slow rolling movements (REM), fluttering and may open eyes briefly

Breathing irregular

Developmental Stages

Reciprocity Stage

> 36 weeks

Able to actively interact with parents

Depends less on machines but more on love and caretaking

Responds in very specific and predictable ways

Abel to recover from agitation using self-quieting behaviours

Parents must teach self-calming techniques







Source: Lubbe, W. (2008). *Prematurity: Adjusting your dream.* Pretoria: Little Steps.



Drowsiness

Increased movement with mild startles

Open and close eyes

When eyes open may stare and eyes appear dull with droopy eyelids

Breathing faster and shallower

Response to voices and noises delayed

Quiet Alert

Can focus attention

Little or on facial movements

Eyes wide open, bright and shiny

Breathing regular

Best time to feed, talk to, look at and to hold!



Active Alert



Eyes open but not as bright

Generalised body movements (thrusting arms and legs)

Movements smooth

No or decreased facial movements

Breathing irregular

Reacts to sensory stimuli in a delayed fashion

Increasingly irritable

Crying

Irregular breathing and a lot of generalised movement

Skin colour changes to darker red

Eyes either tightly closed or open with facial grimacing



Developmental Stages

Turning-in Stage

< 32 weeks

Often need breathing support

Physiologically unstable (heart rate, breathing, blood pressure)

Easily overwhelmed by stimuli

Unable to attain and maintain quiet-alert state

Baby appear to not like being touched

Suitable touch: Gentle but firm touch

Can hold hand or

Allow your baby to hold your finger (like umbilical cord, may pull away – needs to become accustomed to it)

Hand cuddling

Feels secure if provided with soft, firm and non-rigid boundaries

Not wake up a lot

Leave him/her to sleep

Talk to your baby when awake – the sound of your voice is calming









Source: Lubbe, W. (2008). *Prematurity: Adjusting your dream.* Preoria: Little Steps.

Developmental Stages

Coming-out Stage

32 - 35 weeks

Still in need of constant care

Able to maintain physiological stability (heart rate, breathing, blood pressure)

May breathe comfortably

Reacts to social interaction

When agitated, better to leave alone to recover

Able to display organised behavioural responses

Activities that you can do:

Take photographs to see progress
Change nappy
Identify stress and readiness cues to help your baby stay calm
Help with feedings and give your baby a pacifier
Ask when you can bath baby (if stable enough)
Talk softly using his/her name
Ask when you can start doing KMC



33 weeks

34 weeks





35 weeks

(Source: Lubbe, W. (2008) *Prematurity: Adjusting your dream.* Pretoria: Little Steps.)

Positioning

Decreased muscle tone and strength »

- Risk of postural problems after a long stay in the NICU
- Difficulty controlling movements.

Correct positioning » reduces probability of future postural problems.

Supportive positioning » enhances comfort and reduces stress.

Snug, secure foetal position

Flexed arms and legs

Knees and elbows tucked to midline

Curved spine

Head tucked forwards



'Frog' position

Gravity causes weak arms and legs to flop out to sides

Baby can feel unsafe and stressed

Can lead to abnormal tone and delay in motor development



Containment or Nesting

Limiting movement by giving baby something to push against to practice flexing muscles.

Decreases stress and promotes feelings of security.

Baby will always benefit from boundary at her head.

Can use rolled up blankets.

Lying on back / supine

Shoulders rounded forward and supported off mattress

Roll under shoulders **not** neck

Legs bent and together with foot support

Head in line with body

Hands to face



Lying on front / prone

Shoulders rounded and forward

Hands to face

Head in neutral position

Legs tucked under

Avoid hips in W or frog shape

Small roll under hips to tilt hips

Ensure hips below level of head



Baby must be **monitored** in the NICU!

Do **not** place baby on front when at **home** due to increased risk of SIDS!!!

Lying on side

Hand to face and mouth

Legs together

Head in neutral position in the midline

Shoulders and hips rounded forward

Feet supported against boundary

Back slightly rounded

Ears, shoulders and hips in straight line



Source:

Lubbe, W. (2008). *Prematurity: Adjusting your dream.* Pretoria: Little Steps.

Weaver, V. (n.d.). *Neonatal Positioning.* Retrieved from file:///C:/Users/Alison/Downloads/NeonatalPositioningpresentation1%20(5).pdf

Addendum O

Information notes regarding siblings

Preemie's and their Siblings

Even with the stress and demands of NICU it is important to find ways to explain what is happening to the other children at home to ensure they still feel loved and secure.

Common Reactions and possible solutions to help:

1. They will notice that you may be sad and are absent quite a bit. They may think they have caused the baby to be sick and do not want to share their parents, and may wish the baby was not born. This is very common in children aged between 2 -7 years of age.

Assure them that they did not cause baby to come early or to be unwell.

2. They may think they have said or done something that has made you upset

Let them know that you are sad because your new baby is so tiny and sick, assuring them it is not something they said or did.

3. Acting out is a common reaction. Changes in routine can be unsettling which causes child to feel out of control and insecure and acting out is a way to get attention.

Try to find someone the child knows well and likes, to provide extra attention. Organise special outings. Try to stick to their typical routine as much as possible. Inform their teachers if at school so they can provide additional support.

4. Some siblings may feel left out, lonely and insecure.

Assure your child that you love them just as much as before the new baby arrived. Ask the NICU if siblings can visit. Children who visit the NICU are more responsive to their mothers and to the new preemie than those who do not visit. You can also try get them involved in for example packing a bag for the hospital.

5. Feeling sick and complaining of tummy aches.

Try increasing attention, cuddles and kisses and inclusion in things where appropriate. Set aside special time for them.

6. Fear of catching preemie's sickness.

Assure them that they and you cannot get the baby's illness.

7. Wonder and worry who will care for them once the new baby comes home.

Show them and tell them how important they are to you and the family. Encourage them and find special ways of welcoming the new baby to the family. Show how proud you are of things they can do themselves that babies cannot. Help them make a brag book they can take to school, which could include the first cuddle etc.

8. Regressing (return to less mature behaviour)

Do not punish, scold, talk negatively or make a big deal of it. It is just a way of letting you know they need more love and attention. The regression should be temporary once they are feeling more secure.

Source: (Rose & Feldman, 1996)

Preemie's and their Siblings

What to tell siblings about a preemie who is dying

It is important to be honest with your child. You do not have to hide everything you are feeling from them because they will notice how upset you are.

It is important to explain why you are sad and that they are not the cause of this sadness.

You could explain that it is ok to be sad, and offer lots of hugs and support.

Do NOT use the following terms for death:

- "Baby just went to sleep"
  Why? They will fear dying during naps and at night.
- " It was God's will" or "God took baby because they were so good or so special"
  Why? They may fear God will decide to take them too.
- "Baby went on a trip"
  Why? They will fear travel, for themselves or others.

Other Considerations:

Assure them they will not die. The baby died because he/she was so small but you are big.

Assure them they did not cause the baby to die.

You may want to help your child choose a good-bye gift, which may help them accept the baby's death. A scrap book can be made to remember the baby.

Explain that most people who go to hospital get better and are able to go home. Provide examples from your own and others experiences.

Source: (Rose & Feldman, 1996)

Addendum P

Information notes regarding grieving process

The Grieving Process

The first few days

In the first few days after losing your baby you will have a cope with immense grief and a mixture of emotions, as well as the physical aspects of losing a baby.

There will also be some practical things that you may need to take care. For example, considering if you should have a post mortem performed on your baby, and organizing the funeral. It's important to know that there are people who can support and advise you through all of this so please do not go through this alone.

Most women, will agree that the emotional pain is infinitely more difficult to bear than the physical discomfort. Remember that your hormone levels are rapidly changing after the birth, and mood swings and tears are normal after any delivery. Your breasts will fill with milk. Milk production can be suppressed by medication but many women decide not to take this. Breast engorgement can be painful, ask your doctor for advice.

The first few weeks

If you have suffered a stillbirth you will experience vaginal bleeding, possibly for several weeks after the birth, and you may have after-pains (like period pains). Again this is normal after any delivery, but can also be a constant physical reminder of your tragic loss. It is important to try to look after yourself physically after the birth. You may not feel like eating or drinking but you need to do so. It is important to get your general physical health back to normal – you will be able to cope with the emotional aspects better if you are physically stronger. Try to get a bit of exercise, perhaps a walk in the fresh air. Many women felt it was very difficult to leave the house but if you can you will probably feel better.

The longer term

After any bereavement, loss of appetite and weight loss is not unusual, however, if it is excessive do talk to your GP. It may take you longer to recover from the birth than would be expected. You may be prone to lots of viral infections such as colds. You may feel physically exhausted. Sleep may be difficult for a while. Make sure you attend your six weeks-post -natal check.

Often parents are frightened by the intensity of their physical experiences – you may feel, hear or see something you cannot explain. Talking things through with someone who has lost a baby themselves can be helpful - making you feel less isolated.

Finally, it is not an unusual phenomenon for bereaved parents, particularly mothers, to become obsessed with their own, their partners or their other children's health. Every symptom becomes blown out of proportion. Your own mortality comes to the fore - if a tiny baby can die, so can anyone. Again, this reaction usually fades with time – if it does not, talk to your doctor or a medical professional.

Parents and their feelings

Recognizing your baby as a real person is important. Take time to create memories and acknowledge your baby's existence in the world. The grieving process takes much longer than we, as a society, anticipate. Anger and fury towards the hospital, family and friends is also very common.

Mothers

Many mothers said after losing their baby they could not think straight and felt unable to make decisions. Very powerful maternal urges were common. Some were frightened by the intensity of these feelings. For example, some mothers wanted to dig up their babies bodies from the graves to cuddle them. Some women felt they could not face going out, and dreaded having to explain to an acquaintance where their baby was.

As the grieving process goes on your emotions may change dramatically day to day or even hour to hour. Many experience a feeling of failure – how could they have let a tiny baby die? Many mothers cannot face the idea of seeing others' babies and experience intense jealousy of other mothers. Some felt brave enough to visit their antenatal group; this was often a distressing but a positive experience.

Other common emotions were guilt and self blame because their body had let them down, particularly as the grief became less raw. For example, mothers say that they felt that they had let their baby down when they started crying less. All these feelings are perfectly normal.

Most mothers felt that talking to other women who had also experienced still births or their baby dying as very helpful and reassured them that their feelings were normal, and sometimes made them feel less alone.

Fathers

Fathers are often forgotten. Men and women grieve differently and many men take on the protective roll in the family, supporting their wives or partners and not allowing time for their own grief. Even in today's society, some men find it difficult to express their emotions and feelings can get locked up. Some women take this as indifference to the loss of baby.

Many men need time and space to grieve. This may happen after the funeral if there is one, or possibly many weeks later. Fathers tend to take on the practicalities and keep themselves busy. However, do allow yourself time to grieve. "He didn't cry until the funeral and I felt very bitter about it. I felt he was not acknowledging our baby."

The effect on the family

Losing a baby will obviously affect the relationship between the two parents. Some couples find the tragedy brings them closer together; others are pulled apart and may find the loss puts a strain on their relationship.

The stress is better dealt with if you acknowledge the fact that everyone grieves in different ways – if there is a grave, some parents may want to visit it every day, others may want to go back to work, some cannot get out of bed, some may cry all the time, some will want to spend days researching into pregnancy problems to find an answer and so on. All grieving parents have "good" and "bad" days - try to be aware and support each other during "bad" days.

Many women find it difficult to understand their partner's lack of tears and visible distress – they feel the baby did not mean anything to them. Remember, a lack of expression of feelings does not equate to a lack of feelings. Conversely, some women are disturbed by the emotional outburst of their partners. They may never have seen them cry or sob uncontrollable before.

It is usually the father that goes back to work first. This is often a difficult time for both the father and mother. The mother may feel abandoned and may feel her partner has "moved on", and forgotten about the baby. The father may feel he cannot cope yet with the extra stress of work but has to go back. He may also resent the mothers time to continue the grieving process.

It is not unusual to have some sexual problems in the relationship in the first few months. Again everyone is different; one member of the couple may have strong desire to make love and show desire and comfort for the other one, who in turn may have no desire at all. Try to talk about how you feel. Bereavement is usually associated with a depressed feeling that often diminishes the libido for a while. It will return at different times for the couple.

Sex and pregnancy are inextricably linked. You may feel terrified at the thought of getting pregnant again; likewise sex may become very mechanical in the desire to become pregnant as soon as possible. Be aware of these possibilities, and be open and honest.

Sex after pregnancy, whatever the outcome, is different. A women's body changes and she will have to recover from the physical effects of the pregnancy and delivery. If problems in the relationship persist past the first few months and appear not to be resolving, be they sexual or otherwise, do seek help. Some couples find a few sessions with a professional counselor very helpful.

The effect on the children

"I was worried about constantly crying in front of my daughter. I was afraid for her to see me sad."

The loss of a baby will have an effect on everyone, including your existing children. In the first few weeks after the loss the practical involvement of a grandparent, aunt or close friend may be invaluable. Someone needs to keep the practical aspects of life under control, such as going shopping and cooking. Many friends will want to help, and will be glad to do something, so accept their help and ask if you need it.

What you tell your children again depends not only on their age but also on past experiences of death and any religious beliefs. Tell your child in very simple terms – if they want more details they will ask.

Children often mull facts over and ask questions many weeks later, often in seemingly random situations such as during dinner or in a shop. Answer them again honestly and openly. Do not be afraid to show your emotions, likewise let them cry.

Explaining the death of "it was nobody's fault" is very important. Most children at some stage will blame themselves for the death of their baby brother or sister. Again reassure them and explain what a wonderful brother or sister they are because they are thinking about the baby or helping you put flowers on the grave or however they can help you. Children sometimes hide their sadness to protect their parents. A recent study identified the three most important aids in dealing with children who have lost a sibling

- Recognize and acknowledge the child's grief
- Include the child in family rituals
- Keep the memory of the baby alive in the family.

Try to be as open and as honest about the situation as you can be. Children are often much more disturbed when they sense something is wrong but don't know what it is.

A special word for grandparents

As grandparents, you may often feel left out or excluded from the grief. This must obviously be a very difficult time for you - not only have you lost your grand child but you see your own child suffering.

The support to your son or daughter will be invaluable. Try to visit them in hospital and if their baby was still born, ask them if they are happy for you to see your grandchild. You may like to cuddle him and spend some time sharing him as a family. This will be invaluable later as you have a shared memory to treasure. You may be surprised about how things have changed over the years. We have learnt that it is best to acknowledge the existence of still born babies and baby's dying, and to help parents to spend time with their babies as well as creating memories by taking photographs or footprints.

Addendum Q

Personal reflections from researcher

In order to provide a thorough and valid reflection, it is of the opinion the researcher to ‘start at the beginning.’

To our delight, I found out that I was expecting our first child. Pregnancy proceeded as normal. It was actually good as I did not experience any morning sickness. After 7 months of smooth sailing, suddenly something felt wrong. I booked an appointment with the gynae as I was concerned. The secretary did not have space for me but said that I could come in and wait for the gynae. My husband joined me in the waiting room. While sitting there, I started to experience pains. Not realising it was labour, I brushed it off to Braxton Hicks pains. Eventually upon examination by the the gynae, it was confirmed that I was in preterm labour. I was rushed off to the hospital and administered various medications. This was the first shock. The medical staff were able to stop labour and I was able to return home for bedrest. I completed 2 weeks of frustrating bedrest when labour started again. We returned to the hospital and the gynae said that I was to deliver the next morning. My daughter was born via emergency c-section weighing 1.1 kg. I was not able to hold or see her as she was rushed out of the theatre to the NICU as she was not breathing. My husband followed her to the NICU. I was only able to see her for the first time the following morning. Upon entering the NICU, a second shock occurred. The equipment is overwhelming for the tiny little being lying on a warming table. Nursing staff were very supportive and explained use of some of the monitors. Rules of the unit were explained as well as what was needed for my daughter. Breastmilk was recommended and I had to start expressing as soon as possible. My husband had the task of buying all the necessary supplies (as well as a breast pump). Eventually life became one of spending the whole day at the hospital. However, everyday was uncertain as our daughter’s health changed in a minute, at times. Many medical procedures were undertaken which we did not understand. It also raised concerns in us regarding pain. Going home in the evening was difficult as we were worried if she would survive the evening.

Other parents and their infant(s) would be admitted and eventually go home. We were not. After a while, I became very despondent and depressed. The nursing staff recommended I see the hospital counsellor as they were concerned about me. I willingly went to see the counsellor, however I was disappointed as she had no idea of what the NICU is about and the experiences we were going though. After 4 months of spending every day in the NICU, we came home with our infant. Due to my experience of a lack of support from the counsellor and some nurses, I was motivated to design an intervention to support parents in a similar situation.

The empirical research commenced with interviewing veteran parents of their experiences. I was pleasantly surprised that my experiences, thoughts and emotions were not unique. During the interview, VP wanted to know of my experiences. I believe that as I briefly mentioned certain experiences with my daughter in the NICU, parents were able to open up about their own experiences. A second form of confirmation and validation of my feelings and experiences came from completing a literature study.

The second phase of the empirical research involved obtaining information from the nurses. The questionnaire was given to the unit managers to give to every nurse working in the unit. I received some questionnaires soon after giving them out but was forced to keep asking the unit managers to request the nurses to return their questionnaires. Not all questionnaires were returned but I believed that 23 would be sufficient.

In the last phase of empirical research, I conducted a support intervention with parents who presently had their infants in a NICU. One of my first impressions was the collaboration with the nursing staff and doctors. In one NICU, I felt very much like an outsider. In the other two NICU's, the nurses welcomed me to see the parents. In one of these two NICU's, one doctor would even request that I see some of her client parents. It is seen that the relationship between myself and the medical personnel can either help or hinder the support intervention.

I completed a book of my reflections of the support sessions in the pilot study. Notes were taken regarding dates of appointments, content of support and my personal reflections. Initially I was very excited to start with the pilot study. Unit managers were positive and happy for me to see parents. After a few requests, I realised that not every parent is keen to see me - even though the unit managers believe the parent needs the support. As this research study was conducted with human beings, some challenges and frustrations arose as parents get sick, miss appointments and do not return forms.

The initial interviews were interesting. Various factors may lead to preterm birth and NICU admission. The distress was clearly observed in the mothers, and fathers who were present for the initial interview showed concern for their spouse.

With the support sessions, I enjoyed imparting knowledge and information to the parents as they showed interest and appreciation for the content. It is seen that the support intervention needs to be individualised as some mothers may still be very emotional, which I felt needed to be processed before conducting education. As can be expected each infant progressed differently and affected parents differently.

With regards to the support offered, I got the impression that all the mothers appreciated what we discussed except one mother who was very quiet and introverted. This caused me to wonder if I

was helping her. It was observed that KMC helps mothers and fathers immensely as they can start to feel a bond with their infant. Breastfeeding was promoted by the medical staff and mothers were keen to breastfeed.

I experienced a pang of jealousy and had to bracket my feelings regarding undertaking KMC and breastfeeding as, due to the weakness of my daughter, I was not able to breastfeed. I was also only able to do KMC once. However, at the time, KMC was not the norm. I believe with more knowledge, insight is gained.

Overall, I feel that the support intervention was useful for all of the parents but is still a work in progress with regard to the psychosocial support component. It is also necessary for NICU's to 'buy in' to the idea of having a support process in the NICU. I observed that family-centred developmental care is also a work in progress for the NICU's.

Addendum R
Article for publishing purposes

For the journal: Families in Society

Author guidelines available: www.allinace1.org/fis/submissions

Risk and Protective Factors for Parents with Infants in the Neonatal Intensive Care Unit

Abstract

The birth and necessary hospitalisation of a preterm infant is described as an acutely stressful event for parents. This qualitative study utilized semi-structured interviews to determine parents' experiences of having their preterm infant hospitalized in a neonatal intensive care unit (NICU). A thematic analysis of the parents' experiences was conducted. Results indicate that there are various risk and protective factors in the NICU shaping parental experience, namely: the context of the NICU; the appearance and health status of preterm infant; relationships and social support; information, education and communication needs; and matters relating to the mother specifically. To alleviate negative experiences, support in a format that is family centered is recommended which has implications for policy development in South African hospitals.

Introduction

Preterm birth, defined as birth before 37 weeks gestation, is increasing worldwide. According to the Global Action Report on Preterm Birth, "Born Too Soon," 15 million babies are born prematurely every year around the world (World Health Organisation, 2012). In South Africa (SA), more than 8% of babies are born preterm (Save the Children, 2012). However, these statistics may not be a true reflection of actual numbers of preterm births in SA to date, as registration data collected by the

Department of Home Affairs which is published by Statistics SA has a two-year delay. In addition, registration is often incomplete because of under-reporting and delayed registrations (Velaphi & Rhoda, 2012). Due to advances in technology, greater numbers of these preterm infants survive (Melnyk, et al., 2006; Zelkowitz P. F., 2008) resulting in the use of specialist neonatal intensive care rising year after year (Afrasiabi, Mohagheghi, Kalani, Mohades, & Farahani, the Effect of High Risk Pregnancy on Duration of Neonatal Stay in Neonatal Intensive Care Unit, 2014; Stacey, Osborn, & Salkovskis, 2015).

Effects of preterm birth on parents

Preterm birth has many consequences for parents. First of all, the parents are not prepared emotionally for the birth and admission of their infant into an NICU. Emotional effects include, among others, parental stress, anxiety (Busse, Stromgren, Thorngate, & Thomas, Parents' responses to stress in the neonatal intensive care unit, 2013; Kaaresen, Rønning, Ulvund, & Dahl, 2006), guilt, and depression (Hagan, Evans, & Pope, 2004; Kersting, et al., Maternal posttraumatic stress response after the birth of a very low-birth-weight infant., 2004; Perun, Maternality of Women in the Postpartum Period, 2013). Symptoms of post-traumatic stress disorder (PTSD) as well as postpartum depression (PPD) have been identified as emotional consequences (Busse et al., 2013; Friedman, et al., 2013). Family disruption, strain on relationships, alterations in self-esteem, and deterioration in the physical and mental health of the parents are also evident (Lasiuk, Comeau, & Newburn-Cook, 2013). Significantly higher rates of PTSD, depression, and anxiety disorders are found among parents with infants in the NICU than among parents of full-term healthy infants (Friedman, et al., 2013; Novotney, 2013). Parents are reported to experience distress, anxiety, and symptoms of post-traumatic stress or complaints for several years after the preterm birth (Busse et al., 2013; Fowlie & McHaffie, 2004; Jotzo & Poets, 2005).

Additional problems related to the birth of a preterm infant involve parenting. While the infant is in the NICU, loss of the expected and desired parental role is cited as one of the greatest sources of stress for parents (Al Maghaireh, Abdullah, Chan, Piaw, & Al Kawafha, 2016; Woodward, et al., 2014). Barriers to parenting are defined as anything that prevents parents handling, interacting with or providing care for their infant such as the physical NICU environment (Leonard & Mayers, 2008) as well as poor communication between the nursing staff and parents (Bry, et al., 2016; Busse et al., 2013). Vazquez and Cong (2014) state that the prevention of contact, lack of close proximity to their infant, and a delay in the attainment of the parental role causes parental depression, anxiety, fear, anger, and frustration.

According to Lasiuk et al. (2013, p. S13), parental expectations are "shattered" by the "traumatic" event of a preterm birth. This trauma is related to the prolonged uncertainty, lack of control, modifications in one's meaning systems, and, as stated, alterations in parental role expectations. The postponement of parenting can result in extended periods of emotional and psychological distress. It has been noted that the effects of the NICU experience may continue beyond the acute admission and influence subsequent family functioning and parental mental health (Pinelli, et al., 2008). Thus, to alleviate the possibility of negative family functioning and poor parental mental health, exploring parental experiences provides important foundational knowledge (Rothman & Thomas, 1994) necessary for determining the need for support.

Research Question

What are the experiences of veteran parents regarding having a preterm infant hospitalised in an NICU, and is there a need for a support intervention?

Methodology

In this section, the sample used as well as data generation and analysis is discussed.

Sample

Veteran parents (VP) are parents of preterm infants previously admitted to an NICU. Non-probability sampling and specifically purposive sampling (Lombard, 2016; Maree & Pietersen, 2016) were used to find a sample of VP. Inclusion criteria for VP were any parents of preterm infant(s) that were hospitalised in an NICU within the last six years. The first author was sensitive to the fact that the particular gestational age and birthweight of the infant could influence the experience, however, the focus of the study was on general parental experiences and not experiences related to a particular gestational age and/or birthweight. Six mothers and two fathers were included in the semi-structured interviews. Reasons given for the absence of fathers were work commitments. Despite the fact that only six mothers and two fathers were interviewed, thick description (Braun & Clarke, 2013) was reached with these parents. The demographic details of each of the six families and infants are available in Table 1.

Data generation

To get VP involved in the study, pamphlets were left at gynaecologists' and paediatricians' consulting rooms with the doctor's consent. VP were requested to contact the researcher for further details. Information was e-mailed to interested parents who could indicate via e-mail or telephone if they were interested in being interviewed. The time and place for the interviews were selected by the parents. Data was collected from VP by using semi-structured interviews. Questions asked in the semi-structured interview included: How did you experience the preterm birth of ***? Did you feel you were supported during those times? If so, who supported you and helped you cope? How did you cope when you were at home? When you think back on the experience, what is your overall feeling now? Do you think you would have benefitted from a support programme? What do you think should be included in a support programme?

Data analysis

The interviews were tape recorded and transcribed verbatim. Thereafter, a qualitative, thematic analysis was conducted following the six phase guide of Braun and Clarke (2013) which includes the following phases: gaining familiarity with data; generating initial codes; searching for; reviewing; defining; and naming themes. Although the six phase guide is presented as a linear, step-by-step procedure, analysis was done manually and iteratively. A data-driven inductive approach (Braun & Clarke, 2013) was followed where analysis was a process of coding the data without trying to fit them into a pre-existing coding frame. A social constructivism approach was adhered to as it accepts personal experiences as valid knowledge and realizes parents' realities are constructed in social interaction (Conrad & Barker, 2010; Du-Preez & Eskell-Blokland, 2012)

Findings

The parental experiences relating to the NICU can be regarded as being diverse since there are factors that put parent's well-being at risk and other additional factors that may be more protective of the parent's well-being. These risk or protective experiences of parents can be divided into five different areas of focus, namely: the context of the NICU; the appearance and health status of the preterm infant; relationships; information, education and communication needs; and matters relating to the mother specifically. These factors with each of their risk and protective components can be seen in Table 2.

Context of the NICU

The NICU is described by parents (VP 1, 2, 5) as almost being an **'alien' environment** (Conn & Discenza, 2009; Lasiuk et al., 2013): "*It's like a whole other world in there that no one else knows about"* (VP 1). In addition, in this 'alien world', another language is spoken: "*The terminology is not something I can comprehend"* (VP 5).

A sense of **confinement** in this strange and alien 'world' was experienced as mothers (VP 1, 2, 3, 4, 6) spent entire days at the hospital. Reasons for such confinement may include having to breastfeed every two hours (VP 2), to express breastmilk regularly and to be with their infant. In the study of Lasiuk et al. (2013), the parents only concern was their infant's survival, leading to vigilance and a strong desire to stay with their infant and thus they would spend long hours at the NICU, sometimes at the cost of their own well-being. In addition, in the first few weeks after birth, mothers are forced to rely on others for transport as they are not allowed to drive which further aggravates the sense of confinement.

All hospitals and NICUs follow certain **procedures** and protocols to allow for smooth running. Procedures in the NICU include shift changes, special storage and use of expressed breastmilk, day-passes, and hand cleaning routines before entry. In this study, some of these procedures acted as either risk or protective factors, based on parental perceptions. For example, routines such as staff lunch and tea-times caused irritation for one mother: "*lunch and tea time drives me insane. All of them go and have lunch and teatime at the same time. I had to look after five babies. I put dummies in their mouths, I sshh'ed this one, I had to call them on a few occasions because the babies were hysterical and I don't want to touch them"* (VP 1). A father (VP 2) described the **cleaning procedures** on entry as being a positive element of care in the NICU. It is evident that each NICU develops a 'culture' derived from the collective behaviours of the staff (Lefton, 2014) which will have an effect on parental experiences.

The preterm infant

Risk and protective factors relating to the infant include appearance, the roller coaster of health, parental role alteration, fearing death, and kangaroo mother care (KMC). Mothers are *"emotional"* (VP 1) when seeing their infant for the first time. The size and **appearance** of the infant cause intense emotions: "*I was a bit afraid of him at first because he was so small and his nose was skew*"

(VP 4); "*nothing prepares you…and you can see all the blood vessels and the bones. Agh, they look like little skeletons"* (VP 1). For some mothers the appearance can be a positive experience: "*My baby was fine, was pink, not blue and he cried immediately and everybody was happy and so I was relieved"* (VP 6). In the study of Meijssen et al. (2011), half of the mothers (50%) in their study described negative emotions about the first time they saw their infant, such as fear about the size of the infant and the infant's medical condition and feelings of alienation. Of this 50%, 31% felt that the infant was not theirs as they could not relate to them. The appearance of the infant, coupled with the supportive technology surrounding the infant in the NICU represent a source of worry for mothers making them feel disconnected from their infant (Spinelli et al., 2016).

Due to the preterm infant's **unstable health**, parents may experience high levels of uncertainty (Lasiuk et al., 2013). In addition, a common characteristic of preterm infant's health is the unpredictability. This is often described as a roller coaster (Stacey et al., 2015). Four mothers (VP 1, 3, 4, 5) in this study expressed this phenomenon: *"you take three steps forward and two steps back, like they came off the jaundice lights and it was like yay, and then three days later they were back on the jaundice lights"* (VP 1); "*I was crying nearly every day when we went there because I was so afraid that there might be something wrong with him or he might be on oxygen or something like that"* (VP 4); and *"He was kind of doing forward steps and backward steps so it was quite difficult to understand where we are today…it was frustrating cos* [because] *I didn't know from one day to the next what was going to develop"* (VP 5).

A further risk factor to parental well-being is related to the **changed parental role**. Delayed parenthood is regarded as the greatest source of parental stress (Busse et al., 2013; Montirosso, Del Prete, Bellù, Tronick, & Borgatti, 2012).

The majority of parents (VP 1, 3, 4, 6) experienced some form of **fear relating to the survival** of their infant. These fears can start at the time of birth: *"in theatre, that was very emotional because*

you don't know if they going to live" (VP 1). These fears continue to exist in the NICU: *"I was picturing buying one of those baby little coffins"* (VP 1); *"I went through the motions that he is not going to make it. I was planning his funeral in my head. You know I thought* [my husband] *will have to, he will have to carry *** coffin to his grave, you know I was thinking of all of those things. It was actually very bad because while he was oscillated* [high frequency ventilator] *he will still desaturate too, so that was a terrible time for me"* (VP 3) and *"you don't even know what you want to ask because you don't even know what is going to happen, is he going to live?"* (VP 6).

Positive health appears to moderate parental well-being (Stacey et al., 2015). Two mothers (VP 1, 4) were positive when describing the health status of their infant: *"they did all the x-rays and they were fine. They didn't have any stomach issues, no lung issues, no liver issues, no brain bleeds. They had nothing wrong with them. They were just tiny"* (VP 1). However, when the preterm infant's health declines, parents experience severe emotional distress. This is shown in this response: "*He was only intubated in neonatal for the medicine for his lungs. Then he went onto CPAP* [Continuous Positive Airway] *for five days and then onto nasal cannula* [oxygen tube inserted into nose] *which is actually very good of him, but after two weeks he started desaturating a lot, but it was when they increased his milk intake, then his problems started. He* [the father] *didn't think they were going to make it"* (VP 3).

A protective factor of well-being was experienced by two mothers and a father (VP 4 mother and father, VP 6). **KMC** helped mothers feel involved in the care of their infant: *"The fact that you are just there, staring at him and not doing anything for him, for me at least I felt like I'm doing something...every day I would kangaroo him"* (VP 6). The literature reports many benefits of KMC for infants and parents, for example: KMC reduces procedural pain, promotes earlier infant sleep regulation, enhances bonding and attachment between the mother or father and infant, and reduces parental stress and depression (Nyqvist K. H., 2016).

Relationships

Relationships also include risk or protective factors. Risk factors for poor parental well-being include the insensitivity of nursing staff and a lack of support, bonding issues, and distress in the extended family. Protective factors include support from the nurses, other mothers in the unit, spousal support, and support from family.

Three mothers (VP 1, 3, 5) experienced a **lack of support** from the nurses: *"the emotional support of the mother is what is lacking when you get to the NICU. They support the child, but not the mother and I understand why they do that, but at the same time I think not doing that has more major repercussions than anything else because at the end of the day that child is going to be dependent on you and wherever you are that child is going to be at"* (VP 5). Two mothers (VP 2, 3) experienced an insensitivity from the nurses: *"It felt like a prick on the heart, when I overheard when they were changing shift…they give each other a report of how progress was with all the patients…I remember hearing one of the sisters telling, um, the new staff coming through to say *** is brain damaged, and I remember one of the nurses asking her, what do you mean, and I remember her saying no she was born with a dead brain. So I just felt, how could she say that?"* (VP 2).

A further risk factor for parental well-being is **distress in other family members**. Siblings and other family members can exacerbate parental stress: *"and she* [sibling] *would scream blue murder because she wanted to go up with me. She wanted to see her brothers and she's not allowed in there, so that was bad"* (VP 1); *"everyone else was terrified because an aunt of mine, she walked in, her reaction, she actually scared me. Because she was like oh my word, like she was, held my hand so tightly and I was thinking ok, is anything wrong?"* (VP 6). It is shown that grandparents also bear the emotional costs of the preterm birth (Lasiuk et al., 2013).

Bonding is a significant issue for mothers (VP 1, 3, 4, 5, 6) as they fear it cannot take place, firstly due to the separation at birth, and secondly due to the infant being in the NICU: *"it's difficult to bond*

obviously, you know when they are in ICU. You hold them a little bit but, it's not as much as you would at home" (VP 1); *"The concept of bonding with the baby is not there at all. They were like complete little aliens…You don't feel like you've had a child to start with, besides all the aches and pains, you know, because you haven't had any bonding with it"* (VP 5). The NICU contributes to impaired bonding, with its tubes, patches, noises, bright lights, incubators, and painful procedures that reduce the quality and quantity of cues and sensitivity to cues from the mother and infant (Browne & White, 2011). In addition, incubators are physical barriers to comforting touch and cause separation between the infants and parents (Kommers, Oei, Chen, Feijs, & Bambang Oetomo, 2015). Studies of KMC, have indicated that skin-to-skin care can improve a mother's bonding and her feeling of being needed and comfortable with her infant (Nyqvist, et al., Towards universal kangaroo mother care: recommendations and report from the first European conference and seventh international workshop on kangaroo mother care, 2010; Thomas E. , Kangaroo mother care to reduce morbidity and mortality in low birth-weight infants, 2013). The literature has confirmed that due to the preterm birth and long hospitalisations, fathers and mothers felt that it took a long time to feel a bond with their infant (Flacking, Wallin, & Ewald, Perinatal and socioeconomic determinants of breastfeeding duration in very preterm infants, 2007; Lindberg, Axelsson, & Öhrling, Adjusting to being a father to an infant born prematurely: experiences from Swedish fathers, 2008).

Protective factors in the NICU include parents receiving support from nurses, other mothers in the unit, the extended family and from partners (spouses). The majority of parents (VP 2, 3, 4, 5, 6) felt they received support from some of the **nursing staff** when they answered parents' questions and gave them information: *"He felt that he had support because at first they were telling us everything"* (VP 3); *"They were always there basically, very supportive, very willing, willing to answer questions"* (VP 6). Parents are exposed to other infants and parents in the unit. The presence of **other parents** in the unit can be a source of support or stress (Stacey et al., 2015). There is the possibility of further stress for some parents: *"the one day we came there, and every single day we came there,*

*that boy, his name was ***, every single day when we got there, there was something wrong with him. Today he's getting a blood transfusion, the next day his arm was swollen because of the drip. And then he was supposed to get eye surgery oh no, and it was terrible and I think that's what made everything 'dubbel so erg'* [made it twice as bad] " (VP 4).However, it is mostly seen that other mothers and parents can be a form of support: *"and there were other mothers there that I spoke to, and there were other mothers that were there with babies that were older than mine, and at least you were there with people that travelled the same road"* (VP 6). In the findings of the study conducted by Stacey et al. (2015), positive relationships with staff and other parents in the unit are key to parental coping in the context of preterm birth and admission to the NICU.

Spousal support is particularly a protective factor for mothers before birth, during the NICU stay and on returning home. During the stay at NICU, mothers (VP 1, 2, 3, 4, 6) indicated that their spouses were supportive. Some spouses were present in the unit itself: *"He was very supportive at the time so he would come and see us every single, almost every hour. So that was exhausting for him as well, I can imagine"* (VP 2); *"He was there all the time for me"* (VP 4). Other fathers helped at home: *"he supported me well because he was the one raising her* [sibling]" (VP 3).

A further protective factor is **support from the extended family**. During their infant's hospitalisation in the NICU parents (VP 1, 4, 6) received support from their extended family with sibling care and general emotional support: *"On weekends it was difficult because she* [sibling] *wasn't at school and we wanted to go spend time with the boys but then luckily my Mom and Dad and my in-laws are amazing. My in-laws live in *** and my parents live just down the road. And she actually sleeps out at them often"* (VP 1); *"both the families made a huge difference. Played a huge role. I don't think we would have made it without them"* (VP 4). One mother (VP 6) indicated that, although she felt supported, she also experienced difficulty relating to family being present: *"I have an aunt, my mom's sister who, 2 aunts actually who's here, they came in. I got their support quite often. My mom came in for a week – she lives in ***. I had everyone's support but it was very*

difficult to give them attention with the baby. I actually preferred it when they weren't there because they not allowed into the ward and it felt like a split between being with the child and your family." The literature indicates that the extended family can provide certain types of support: emotional support, advice and information, prayer, and instrumental help such as child care (Kavanaugh, Nantais-Smith, Savage, Schim, & Natarajan, Extended Family Support for Parents Faced with Life-Support Decisions for Extremely Premature Infants, 2014).

Needs for information, education and communication

The fourth focus area relating to the NICU relates to the parents' needs for information, education and communication. A significant risk factor for parents is a **lack of information**, guidance and education. Four parents (VP 1, 2, 4, 5) in this study experienced a need for more information. For example, some mothers felt that the staff did not prepare them for the sights and sounds of the NICU: *"It would have been nice if a nurse had come in with me and explained what this drip is for and said this pipe is for this and this is for that…No one explained what everything was"* (VP 1). Information regarding policies of the unit was also lacking: *"They don't tell you that before the time, they only jump on your head afterwards...so we were a bit scared at the beginning"* (VP 4). Furthermore, information regarding their infant was lacking: *"they should have a meeting with you, explain what his condition is, this is how things run here"* (VP 5). A significant consequence of the lack of information is misunderstanding: *"I think a lot of the trauma was related to that respect. You know, not understanding and being the type of personality I am, it was very difficult. With all these different breathing apparatus you don't know which is for which at which levels in the process. The little one was on three forms of respiration – I actually can't tell you cos* [because] *I didn't understand it all"* (VP 5). It is seen that the quality of the relationship with the nursing personnel is one of the factors that either facilitates or constrains parents coping (Bry, et al., 2016; Lasiuk et al., 2013).

In contrast, **information and education provision** to parents (VP 1, 2, 4, 6) contributes to parental well-being. For example, this mother appreciated information from the doctor: *"she would come to me and she would tell me that everything's fine with the breastmilk and he's doing fine, he's now on room air, and she'd come to me and she'd, ja* [yes], *just make me relax a little bit more"* (VP 4). Education is also important for mothers: *"they really taught me, I mean she was my first baby I did not know how to actually* [breastfeed]" (VP 2). Another mother explains: *"she* [the nurse] *said 'ok we going to bath them for the first time', so she told me what to bring, what time to be there. She said bring your camera, she was lovely. She helped me, she bathed them for the first time. That was lovely. She was the only one who really took an interest in explaining how to bath them"* (VP 1). Factors identified in the literature to satisfy parental needs involve: emotional support by friendly, flexible staff; parent-empowerment through parental involvement in care; a welcoming, calm environment, and parent education (Bry, et al., 2016; Cleveland, 2008; Stacey et al., 2015). A positive effect of information and education provision is seen by this mother's comment: *"They* [the grandparents] *had also never seen anything so small in their life, pipes and everything, but by then I could explain to them. This is the feeding tube, this is for this, this is for that, I could explain everything to them. So, then it was better and I had accepted it, so it wasn't so traumatic for me"* (VP 1). Education empowers parents and thus can be a positive element in developing well-being.

A further need related to information is during the discharge process. Three mothers (VP 1, 3, 5) were unhappy with the discharge process due to not being provided with information regarding possible illnesses to look out for (VP 1), information on medicines for their infant and themselves (VP 1, 5) as well as a course in CPR (VP 1). There was also no forewarning in terms of date and time of discharge, and thus sometimes no time to prepare logistically: *"with *** he was in for two weeks and everything was dire and frantic and all the rest and the next things they say ok you can take him home and we literally had to go and fetch him. We* [are] *living in a strange town, nothing at home, everything is at home, living in a B&B and suddenly here is your child"* (VP 5).

Matters relating specifically to the mother

The fifth area of focus is with regard to matters relating to the mother specifically. A risk factor affecting the mothers themselves was experiencing a sense of doing a **'juggling act'** (VP 1, 5, 6). Coping with all of the demands of visiting the infant, expressing breastmilk, doing KMC, self-care and balancing family life was stressful. An example of this is described by one mother: *"It was tiring because every now and then I would have to go home and see things are going fine at home and come back to the hospital cos* [because] *I got a baby there and* [have to] *be there to express* [breastmilk] *and make sure I am eating right, and it was just difficult juggling all of that"* (VP 6); *"a juggling scenario going up and down to the hospital, feeding this one, feeding that one"* (VP 5). A factor relating to the juggling act which may act as being protective to well-being was that some mothers (VP 1, 2, 6) **stayed at the hospital**: *"hospital gave me a flat within the premises so at least I was there full time, I wasn't at home, but it was tiring"* (VP 6); *"I had a choice of leaving her and coming home and going there on a regular base, but I chose not to, I was there until the last day"* (VP 2); and *"ja* [yes] *so for a week I actually lived at the hospital. It was actually easier"* (VP 1). This factor however, may exacerbate the sense of confinement.

It is mentioned that having a preterm infant, going through the hospitalisation process, **changes the self**: *"we are definitely affected by it"* (VP 4) and *"coming so close to losing a child. I think it really does change you forever. I don't think I will ever be the same person again"* (VP 1). Lasiuk et al. (2013) indicate that preterm birth disrupts parents' fundamental assumptions about their selves, the world, and their place in it.

Mothers (VP 1, 4, 5) **blame themselves** for the early birth: *"I thought I'd done something to cause them to come early, which I really think I did"* (VP 1); *"I felt like it was my fault because I couldn't keep him inside, so I'm the failure, that's what it felt like"* (VP 4); and *"everything was dire, because you know, you know you get to the point when you think, what have I done"* (VP 5). Parents (VP 2, 4)

do not want to have to go through the same experience again and wish ultimately for normality in their lives (VP 1, 4). The literature indicates that the stress of preterm birth is heightened by the feelings of guilt and inadequacy felt by mothers (Lasiuk et al., 2013).

Implications for Practice and Policy

Parents (VP 3, 4, 5) were traumatised by the incident and affected by it months later: *"it is still traumatic; if I think about it I still get emotional"* (VP 4 mother and father). It is vitally necessary to provide psycho-social support for parents during and after their infant has been hospitalised in an NICU. In addition, support can be offered regarding informing parents of the layout, rules, and procedures of the unit. Information on the general process should also be provided.

In the event that a preterm birth is predicted, parents should be taken on a tour of the NICU before the birth of the infant.

It would be beneficial if a counsellor were appointed into the NICU as a staff member to facilitate screening for depression, to offer support, and to provide referral where necessary. A counsellor can also act as an intermediary between the medical staff and parent, as well as 'interpret' any medical jargon used.

Due to a lack of understanding from others, parents feel isolated in their experiences: *"having a prem is such a lonely path, such a lonely path"* (VP 3). Peer counsellors, who have experienced preterm birth and hospitalisation themselves, would be a further positive intervention for parents. In addition, awareness needs to be developed in the community of the effects of preterm birth and hospitalisation.

Parents who have their infants hospitalised in an NICU need to have all their many questions answered. Provision must be made for parents to express and understand their feelings.

Further research is necessary to determine the impact on siblings and specifically practical problems related to siblings and strategies to help parents with sibling issues.

In sum, interventions developed and guided by the insights and experiences of NICU families will be positioned for the highest likelihood of success in meeting the emotional needs of parents during and after NICU hospitalisation (Gregory, 2015).

Limitations

Even though this study had a disproportion between mother and father participants, paternal feelings related to the NICU are of value. Further research into

Acknowledgements

The first author would like to thank the parents who participated in this study.

REFERENCES

Afrasiabi, N., Mohagheghi, P., Kalani, M., Mohades, G., & Farahani, Z. (2014, August). the Effect of High Risk Pregnancy on Duration of Neonatal Stay in Neonatal Intensive Care Unit. *Iranian Journal of Pediatrics, 24*(4), 423-428.

Al Maghaireh, D. A., Abdullah, K. L., Chan, C. M., Piaw, C. Y., & Al Kawafha, M. M. (2016). Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit. *Journal of clinical nursing, 25*, 2745-2756.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* Los Angeles: Sage.

Browne, J. V., & White, R. D. (2011). Foundations of developmental care. *Clinics in perinatology, 38*(4), xv-xvii.

Bry, K., Bry, M., Hentz, E., Karlsson, H. L., Kyllönen, H., Lundkvist, M., & Wigert, H. (2016). Communication skills training enhances nurses' ability to respond with empathy to parents' emotions in a neonatal intensive care unit. *Acta Paediatrica, 105*, 397-406.

Busse, M., Stromgren, K., Thorngate, L., & Thomas, K. A. (2013). Parents’ responses to stress in the neonatal intensive care unit. *Critical care nurse, 33*(4), 52-59.

Cleveland, L. M. (2008). Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 37*(6), 666-691.

Conn, N., & Discenza, D. (2009). *The Preemie Parent's Survival Guide to the NICU.* PreemieWorld, LLC.

Conrad, P., & Barker, K. K. (2010). The Social Construction of Ilnness: Key Insights and Policy Implications. *Journal of Health and Social Behavior, 51*, 567-579.

Du-Preez, E., & Eskell-Blokland, L. (2012). Social constructionism. In M. Visser, & A. Moleko (Eds.), *Community Psychology in South Africa* (2nd ed., pp. 41-53). Pretoria: Van Schaik.

Flacking, R., Wallin, L., & Ewald, U. (2007). Perinatal and socioeconomic determinants of breastfeeding duration in very preterm infants. *Acta Paediatrica, 96*(8), 1126-1130.

Fowlie, P. W., & McHaffie, H. (2004, Dec). ABC of preterm birth: Supporting parents in the neonatal unit. *BMJ: British Medical Journal, 329*(7478), 1336-1338.

Friedman, S., Kessler, A., Nagle Yang, S., Parsons, S., Friedman, H., & Martin, R. J. (2013). Delivering perinatal psychiatric services in the neonatal intensive care unit. *Acta Paediatrica, 102*(9), e392-e397.

Gregory, K. E. (2015). Strategies for Surviving and Thriving as Parents in the NICU. *The Journal of perinatal & neonatal nursing, 29*(4), 270-272.

Hagan, R., Evans, S., & Pope, S. (2004). Preventing postnatal depression in mothers of very preterm infants: A randomised controlled trial. *BJOG- An International Journal of Obstetrics and Gynaecology*, 111(7), 641-647.

Jotzo, M., & Poets, C. F. (2005). Helping Parents Cope With the Trauma of Premature Birth: An Evaluation of a Trauma-Preventive Psychological Intervention. *Pediatrics, 115*, 915-919.

Kaaresen, P. I., Rønning, J. A., Ulvund, S. E., & Dahl, L. B. (2006, July). A Randomized, Controlled Trial of the Effectiveness of an Early-Intervention Program in Reducing Parenting Stress After Preterm Birth. *Pediatrics, 118*(1), e9-e19.

Kavanaugh, K., Nantais-Smith, F. L., Savage, T., Schim, S. M., & Natarajan, G. (2014). Extended Family Support for Parents Faced with Life-Support Decisions for Extremely Premature Infants. *Neonatal Network, 33*(5), 255-262.

Kersting, A., Dorsch, M., Wesselman, U., Ludorff, K., Witthaut, J., & Ohrmann, P. (2004). Maternal posttraumatic stress response after the birth of a very low-birth-weight infant. *Journal of Psychosomatic Research*, 57(5), 473-476.

Kommers, D., Oei, G., Chen, W., Feijs, L., & Bambang Oetomo, S. (2015). Suboptimal bonding impairs hormonal, epigenetic and neuronal development in preterm infants, but these impairments can be reversed. *Acta Paediatrica*. doi:10.1111/apa.13254

Lasiuk, G. C., Comeau, T., & Newburn-Cook, C. (2013). Unexpected: an interpretive description of parental traumas' associated with preterm birth. *BMC Pregnancy and Childbirth, 13 (Suppl 1)*, S13. Retrieved from http://www.biomedcentral.com/1471-2393/13/S1/S13

Lefton, C. (2014). Nursing Perspectives: Transforming NICU Culture: The Power of Meaningful Recognition. *NeoReviews, 15*(6), e221-e224.

Leonard, A., & Mayers, P. (2008). Parents' lived experience of providing kangaroo care to their preterm infants. *Heath SA Gesondheid, 13*(4), 16-28.

Lindberg, B., Axelsson, K., & Öhrling, K. (2008). Adjusting to being a father to an infant born prematurely: experiences from Swedish fathers. *Scandinavian Journal of Caring Sciences, 22*(1), 79-85.

Lombard, K. (2016). Steekproefneming. In I. Lombard, C. Hartell, & K. Lombard (Eds.), *Navorsing. 'n Gids vir die beginnernavorser* (pp. 93-106). Pretoria: Van Schaik.

Maree, K., & Pietersen, J. (2016). Sampling. In K. Maree (Ed.), *First Steps in Research* (pp. 171-181). Pretoria: Van Schaik.

Meijssen, D., Wolf, M. J., van Bakel, H., Koldewijn, K., Kok, J., & van Baar, A. (2011). Maternal attachment representations after very preterm birth and the effect of early intervention. *Infant Behavior and Development, 34*(1), 72-80.

Melnyk, B. M., Feinstein, N. F., Alpert-Gillis, L., Fairbanks, E., Crean, H. F., Sinkin, R. A., & ... & Gross, S. J. (2006). Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics, 118*(5), e1414-e1427.

Montirosso, R., Del Prete, A., Bellù, R., Tronick, E., & Borgatti, R. (2012). Level of NICU quality of developmental care and neurobehavioral performance in very preterm infants. *Pediatrics, 129*(5), 1-9.

Novotney, A. (2013, July/August). *Supporting psychologists' youngest clients*. Retrieved from American Psychological Association: www.apa.org/monitor/2013/07-08/youngest-clients.aspx

Nyqvist, K. H. (2016). Given the benefits of Kangaroo mother care, why has its routine uptake been so slow? *Acta Paediatrica, 105*(4), 341-342.

Nyqvist, K. H., Anderson, G. C., Bergman, N., Cattaneo, A., Charpak, N., Davanzo, R., & ... & Pallás-Allonso, C. (2010). Towards universal kangaroo mother care: recommendations and report from the first European conference and seventh international workshop on kangaroo mother care. *Acta Paediatrica, 99*(6), 820-826.

Perun, M. B. (2013). Maternality of Women in the Postpartum Period. *Journal of Education Culture and Society, 1*, 95-105.

Pinelli, J., Saigal, S., Wu, Y., Cunningham, C., DiCenso, A., Steele, S., . . . Turner, S. (2008). Patterns of change in family functioning, resources, coping and parental depression in mothers and fathers of sick newborns over the first year of life. *Journal of Neonatal Nursing, 14*(5), 156-165.

Rothman, J., & Thomas, E. J. (1994). An Integrative Perspective on Intervention Research. In J. Rothman, & E. J. Thomas, *Intervention Research: Design and Development for Human Service* (pp. 3-23). New York: Routledge.

Save the Children. (2012, November 19). *Time to Focus on 84 000 Preterm Births in South Africa*. Retrieved from NGO Pulse: http://www.ngopulse.org/press-release/time-focus-84-000-preterm-births-south-africa

Spinelli, M., Frigerio, A., Montali, L., Fasolo, M., Spada, M. S., & Mangili, G. (2016). 'I still have difficulties feeling like a mother': The transition to motherhood of preterm infants mothers. *Psychology & Health, 31*(2), 184-204.

Stacey, S., Osborn, M., & Salkovskis, P. (2015). Life is a rollercoaster… What helps parents cope with the Neonatal Intensive Care Unit (NICU)? *Journal of Neonatal Nursing, 21*, 136-141.

Thomas, E. (2013). Kangaroo mother care to reduce morbidity and mortality in low birth-weight infants. *Breastfeeding Review, 21*(2), 54-56.

Vazquez, V., & Cong, X. (2014). Parenting the NICU infant: A meta-ethnographic synthesis. *International Journal of Nursing Sciences, 1*(3), 281-290.

Velaphi, S., & Rhoda, N. (2012, August). Reducing neonatal deaths in South Africa - are we there yet, and what can be done? *SA Journal of Child Health, 6*(3), 67-71.

Woodward, L. J., Bora, S., Clark, C. A., Montgomery-Hönger, A., Pritchard, V. E., Spencer, C., & Austin, N. C. (2014). Very preterm birth: maternal experiences of the neonatal intensive care environment. *Journal of Perinatology, 34*(7), 555-561.

World Health Organisation. (2012). *Born Too Soon: The Global Action Report on Preterm Birth.*

Zelkowitz, P. F. (2008). The Cues and Care Trial: A randomized controlled trial of an intervention to reduce maternal anxiety and improve developmental outcomes in very low birthweight infants. *BMC pediatrics, 8*(38), 1471-2431.

Table 1:

Demographic details of veteran parents and infants

Veteran parent	VP 1	VP 2	VP 3	VP 4	VP 5	VP 6
Mother's age	30	34	32	27	34	28
Father's age	34	38	50	27	34	39
Previous births	1	0	0	0	0	0
Previous loss / miscarriage	No	No	No	Yes	No	Yes
Parent interviewed	Mom	Mom & Dad	Mom	Mom & Dad	Mom	Mom
Multiple birth?	Yes	No	Yes	No	Yes	No
Infant's birthweight	1.2 kg 1.3 kg	2.1 kg	1.21 kg 970 g	1.22 kg	2.3 kg 1.9 kg	1.18 kg
Infant's gestational age (weeks)	30/52	36/52	29/52	31/52	34/52	27/52
Require breathing assistance	Yes	No	Yes	Yes	Yes	Yes
Length of hospitalisation for infant	59 days	13 days	69 days 154 days	39 days	14 days 35 days	69 days
Age of infant at time of interview approximate)	5 months	6 years 2 months	2 years 9 months	3 months	1 year 7 months	4 years 1 month

Table 2:

Risk and protective factors of the NICU

Theme	**Risk Factors**	**Protective Factors**
Context of NICU	• 'Alien' environment • Sense of confinement • Procedures	• Cleaning procedures
The preterm Infant	• Appearance • Unstable health • Changed parental role • Fear infant death	• Positive health • Kangaroo Mother Care (KMC)
Relationships	• Insensitivity of nursing staff and lack of support • Extended family distress • Bonding	• Nursing support • Other mothers in unit • Spousal support • Extended family support
Needs for information, education & communication	• Lack of information	• Education provision
Matters relating specifically to the mother	• Juggling act • Changes in self • Guilt	• Mom stay at hospital