

https://dspace.org/

Stress experienced by mothers of neonates in a private hospital NICU.

Buys, Lauren Mildred

2014-03-28
http://hdl.handle.net10539/14399

Downloaded from a DSpace repository. https://dspace.org/

STRESS EXPERIENCED BY MOTHERS OF NEONATES IN A PRIVATE HOSPITAL NICU

Lauren Mildred Buys

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Nursing

Johannesburg 2013

DECLARATION

I, Lauren Mildred Buys, declare that this research report is my own work. It is being submitted for the degree of Master of Science in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

.....

L. M. Buys.

4th September, 2013.

ABSTRACT

Mothers of neonates admitted to neonatal intensive care units appear to suffer stress which may be related to the illness and treatments the neonate is undergoing, separation from the neonate and social and relationship issues. Nursing professionals employed in the neonatal intensive care unit (NICU) need specific preparation in order to assist mothers to cope with the experience of their neonate being admitted to the NICU. Research is required in order to adequately describe the nature of the stress and whether it changes over a period of time and to provide nursing professionals with information relating to the subject of stress suffered by mothers in this situation.

A quantitative, longitudinal study of stress experienced by mothers of the neonate NICU patient was undertaken using the Neonatal Unit Parental Stress (NUPS) Scale (Reid, Bramwell, Booth & Weindling, 2007) (Reid et al., 2007). Mothers who met inclusion criteria were recruited to participate in the study. They were asked to complete the NUPS questionnaire at two time points. Correlations were examined between data obtained on the NUPS questionnaire and the mother and infant demographic data.

The results of this study have shown that mothers experience the greatest stress as a result of neonatal suffering and their inability to perform functions of the mother role as a result of separation from the neonate. These findings have been used to make recommendations for the preparation of nursing professionals who work in the NICU.

ACKNOWLEDGEMENTS

With thanks to Dr S. J. Armstrong (Supervisor) and Ms E. Chirwa (Statistician) for advice.

TABLE OF CONTENTS

	Page
DECLARATION	ii
ABSTRACT	iii
ACKNOWLEDGEMENTS	iv
TABLE OF CONTENTS	v
LIST OF FIGURES	ix
LIST OF TABLES	x
1.0 INTRODUCTION	1
1.1 Context of the study	1
1.2 Problem statement	4
1.3 Purpose of the study	4
1.4 Research questions	4
1.5 Objectives of the study	5
1.6 Methodology	5
1.6.1 Research strategy	5
1.6.2 Research methods	5
1.6.2.1 Population	5
1.6.2.2 Sample	5
1.6.2.3 Inclusion criteria	6
1.6.2.4 Exclusion criteria	6
1.6.2.5 Sample size	6
1.6.3 Data collection	6
1.6.3.1 Pilot study	7
1.7 Data analysis	8
1.7.1 Validity and reliability of the NUPS Scale	9
1.7.2 Validity and reliability related to the current study	10
1.8 Ethical considerations	10
1.9 Conclusion	12
2.0 LITERATURE REVIEW	13
2.1 Introduction	13
2.2 Literature survey	13
2.2.1 Measurement of parental stress	13
2.2.2 The experience of the father of the NICU patient	14
2.2.3 The NICU environment	15
2.2.4 Separation of the mother from her neonate	16
2.2.5 Neonatal suffering	18
2.2.6 The unique position of the nurse	19
2.2.7 Barriers to parent advocacy	21
2.2.8 Description of stress in relation to the current study	22
2.3 Conclusion	23

	Page
3.0 RESEARCH METHODOLOGY	24
3.1 Introduction	24
3.2 Problem statement	24
3.3 Purpose of the study	24
3.4 Research questions	24
3.5 Objectives of the study	25
3.6 Research strategy	25
3.6.1 Research methods	25
3.6.1.1 Population	25
3.6.1.2 Sample	25
3.6.1.3 Inclusion criteria	26
3.6.1.4 Exclusion criteria	26
3.6.1.5 Sample size	26
3.6.1.6 Pilot study	27
3.6.1.7 Data collection	27
3.6.1.8 Validity and reliability of the NUPS Scale as established by the original author	28
3.7 Methods used for data analysis for current study	30
3.7.1 Normality	30
3.7.2 Correlation	31
3.7.3 Difference	31
3.7.4 Reliability	31
3.8 Ethical considerations	32
3.9 Conclusion	32
4.0 DATA ANALYSIS	33
4.1 Introduction	33
4.2 Demographic data	33
4.2.1 Home language	33
4.2.2 Maternal age	34
4.2.3 Duration of pregnancy	34
4.2.4 Neonatal birth weight	35
4.2.5 Previous pregnancy	35
4.2.6 Number of live children	36
4.2.7 Previous admission of a neonate to NICU	36
4.3 Face validity of the instrument for the current study	37
4.3.1 Pilot study	37
4.4 Content validity and construct validity	38
4.5 Internal reliability	38
4.6 The NUPS questionnaire	40
4.7 Data analysis in relation to the research objectives for the study	40
4.7.1 First objective	40
4.7.1.1 The overall experience of NICU	40
4.7.1.2 Looks and Behaves factor	41
4.7.1.3 Relationship factor	42

	Page
4.7.1.4 Practical Hassles and Social Relationship Strain factor	44
4.7.1.5 Correlation between demographic characteristics of respondents and stress levels	45
4.7.2 Second objective	53
4.7.2.1 Differences in stress level between first and second time points	53
4.7.3 Third objective	54
4.7.3.1 Findings which are important when considering the preparation of NICU nurses	54
4.8 Conclusion	55
5.0 DISCUSSION	56
5.1 Recruiting participants to the study	56
5.2 Language of the respondents	57
5.3 Omitted items	57
5.4 The age of the respondents	58
5.5 Birth weight and gestational age	58
5.6 Previous pregnancy and number of live children	60
5.7 Previous admission of a neonate to NICU	60
5.8 Discussion in relation to the research objectives for the study	61
5.8.1 First objective	61
5.8.1.1 Looks and Behaves factor	61
5.8.1.2 Relationship factor	65
5.8.1.3 Practical Hassles and Social Relationship Strains factor	69
5.8.1.4 Correlation between scores on the NUPS Scale and demographic characteristics	70
5.8.2 Second objective	72
5.8.3 Third objective	73
5.8.3.1 Preparation of NICU nurses in relation to neonatal pain	74
5.8.3.2 Preparation of NICU nurses in relation to maternal/neonatal Relationship	75
5.9 Conclusion	77
6.0 CONCLUSION	78
6.1 Summary of causes of maternal stress	78
6.1.1 Looks and Behaves factor	78
6.1.2 Relationship factor	78
6.1.3 Practical Hassles and Social Relationship Strains factor	78
6.1.4 Correlations	78
6.2 Limitations	79
6.2.1 Second time point responses	79
6.2.2 The location of the NICU	79
6.2.3 Incidence of Caesarean section births	80
6.3 Recommendations for further research	81

Page

6.4 Conclusion 81

ANNEXURE A Information letter 82
ANNEXURE B Patient information 84
ANNEXURE C 3 Factor for analysis 85
ANNEXURE D The NUPS Scale 89
ANNEXURE E Permission from Dr T. Reid, original author of NUPS Scale 94
ANNEXURE F Ethics clearance certificate M120326 97
ANNEXURE G Permission to proceed with research 98
ANNEXURE H Approval of title letter 99
ANNEXURE I Change of title letter 100
ANNEXURE J Netcare Research committee – Approval of research 101

REFERENCES 103

LIST OF FIGURES

Figure		Page
4.1	Looks and Behaves	42
4.2	Relationship	43
4.3	Practical Hassles and Social Relationship Strains	45
4.4	Stress score contribution per age group	46
4.5	Stress score contribution per gestation period group	48
4.6	Stress score contribution per weight group	49
4.7	Stress score contribution per number of pregnancies	50
4.8	Stress score contribution per number of live children	51
4.9	Comparison of stress levels in mothers experiencing NICU admission for the first time as against those with previous experience of NICU admission	52

LIST OF TABLES

Table		Page
1.1	Cronbach's Alpha Coefficients for the current study	10
4.1	Frequency distribution – Home language	34
4.2	Maternal age	34
4.3	Duration of pregnancy	34
4.4	Birth weight	35
4.5	Cronbach's Alpha values for each subscale	39
4.6	Looks and Behaves factor – Highest scoring items	41
4.7	Relationship facor – Highest scoring items	43
4.8	Practical Hassles and Social Relationship Strains factor – Highest scoring Items	44
4.9	Correlation between Maternal Age and Subscales	47

CHAPTER 1

1. INTRODUCTION

1.1 Context of the study

When neonates, no matter how early or late in gestation are admitted to a neonatal intensive care or high care unit, the mother and neonate are separated. What started off as an enduring bond which developed from the beginning of pregnancy is put under strain as the neonate is removed from the mother's bedside, possibly at delivery and cared for in a location to some extent distant from the mother. This leads to many different stressors impacting on the mother, her partner and perhaps her immediate family.

The context of the study is a private hospital neonatal intensive care unit (NICU) which is comprised of 35 beds. The level of care provided in this NICU corresponds to that provided at the two Tertiary 3 (Central Referral Hospitals) in Gauteng, which is the capacity to provide neonatal ventilation and neonatal surgery.

Within the public sector, Central Referral Hospitals provide a very high level of clinical specialization and treatment that would typically be of high cost and low volume (Cullinan, 2006). Neonatal care in South Africa is provided within both the private and public sector with significant differences in resources, in relation to population served, between the two sectors. The adequacy of these resources in relation to demand determines, to a large extent, the access of patients to specialized medical care (Anecdotal, Prof D. Ballot, 8th August 2013).

Previously, due to a shortage of resources in the public sector, a cut off weight of 1 000 g has been used to determine access to NICU care, where infants below 1 000 g were not offered ventilatory support. It has subsequently been recommended that the cut off should be 900 g and 26-27 weeks of gestational age (Velaphi, Mokhachane, Mphahlele, Beckh-Arnold, Kuwanda & Cooper, 2005). A subsequent study stated the survival rate of Very Low Birth Weight (VLBW) infants to be 70,5%, which was comparable to that of the study by Velaphi et al., and this was thought to be due to the fact that the hospitals where the studies were carried out were part of the same academic complex, using the same criteria for resuscitation and ventilation (Ballot, Chirwa & Cooper, 2010). The survival figure of 70,5% compared well with global results for VLBW infants. However, it was found that survival figures for Extremely Low Birth Weight (ELBW) infants was low in the public sector and required improvement. This was possibly due to neonates below the cut off weight not being offered ventilatory support. Subsequently, the birth weight cut off for ventilatory assistance has been lowered to 900 g in the public sector Tertiary 3 hospitals, with preterm neonates weighing 750 g or more being offered treatment with surfactant and Nasal Continuous Positive Airways Pressure or non-invasive Synchronised Intermittent Positive Airways Pressure (Anecdotal,Prof D. Ballot, 7th February 2013).

The private hospital NICU, where the research was conducted, is situated in Gauteng and provides medical and nursing care to patients who are covered by medical insurance or have sufficient funds to cover costs. This restricts access to the unit to a population which has medical insurance or adequate funds to cover costs, which can be extremely high.

Within the private sector, neonates as young as 23 to 25 weeks gestational age and weighing as little as 400 - 500 g may be resuscitated and ventilated. Long hospital stays result, with multiple complications, and many frustrations for the parents (Partridge, Martinez, Nishida, Boo, Tan, Yeung, Lu & Yu, 2005a) as well as financial strain. Although the private sector hospitals exist independently of public sector institutions, one should view the private sector hospitals as part of a broader societal context, and a view has been expressed that the same constraints should be applied to both sectors in the interests of addressing disparities in health care access of citizens (Partridge, Ranchod, Ballot, Martinez, Cory & Davies, 2005b).

The number of admissions to the private NICU ranges from 40 to 60 per month and the total number of admissions for the year 2012 was 618. The patient profile consists of premature neonates, being 61% of the total number, and the remainder being made up of term neonates with complications, neonates suffering from congenital abnormalities and newborns with surgical conditions from outlying hospitals. Neonates with cardiac abnormalities are provided with care for stabilization and then transferred to a facility specializing in cardiac care.

The parents of the neonates in this unit appear to experience stress, the nature of which has not been explored in the South African private hospital context. Aspects of neonatal intensive care are covered in the Advanced Midwifery course, and a few Neonatal Certificate courses that exist. These courses focus on the practical aspects of nursing the neonate, while psychosocial aspects affecting mother and neonate receive less attention. The emotional needs of the parents and the neonate are often neglected in the pressure of work. In addition to this, staffing of the NICU is

often less than adequate. Enrolled nurses make up 40% to 60% of the nursing complement and they lack the specific preparation for nursing neonates in NICU.

The population of patients and, their parents in NICU have special and individualized needs and meeting these needs requires specialized preparation.

1.2 Problem statement

Anecdotal evidence shows that nurses are ill-equipped to manage the stress of mothers with neonates in NICU. Information is needed about the nature of this stress in order to better prepare nurses in the NICU to assist mothers in coping with stress and to develop strong attachment and caring behaviors in relation to their neonates.

1.3 Purpose of the study

The purpose of the study is to describe the level and source of stress experienced by mothers of neonates in the NICU in terms of the Neonatal Unit Parental Stress (NUPS) Scale, and to obtain information that could be used to empower nurses to assist mothers to cope with stress.

1.4 Research questions

1.4.1 What is the source and level of stress experienced by mothers of neonates admitted to a private hospital NICU in terms of the NUPS Scale?

1.4.2 Does the stress experienced by these mothers change over a period of two weeks and in what way?

1.4.3 What preparation would empower NICU nurses to assist mothers to cope with this stress?

1.5 Objectives of the study

1.5.1 To explore and describe the level and source of stress experienced by mothers of neonates in the NICU using the NUPS Scale.

1.5.2 To explore and describe whether change occurs in the level and source of stress over a two week period by comparing level and source of stress experienced by mothers at 2 – 4 days and 10 – 14 days in the neonate's life.

1.5.3 To make recommendations for preparation of NICU nurses to enable them to assist mothers effectively in coping with stress associated with the neonate's admission.

1.6. Methodology

1.6.1 Research strategy

The study has a quantitative longitudinal design, using a survey tool, viz. the NUPS Scale.

1.6.2 Research methods

1.6.2.1 Population

The population consists of mothers of all neonates admitted to the private hospital NICU's in Johannesburg.

1.6.2.2 Sample

The particular private hospital, chosen for this study, has one of the largest NICU's in Johannesburg, which admits neonates with surgical conditions from outlying hospitals as well as catering to inborn neonates. The private sector has been chosen for the study because infants as young as 23 to 25 weeks gestational age and a weight of 400g to 500g are treated actively, whereas in the public sector there is a weight and gestational age cut off for treatment.

The mothers of all neonated admitted to this NICU are included in the sample during the period of the study

1.6.2.3 Inclusion criteria

- Mothers of all neonates admitted to the NICU, where the mother is well enough to visit the neonate in the NICU.
- Mothers who are able to read and understand English.
- Mothers who are 18 years of age or older (In terms of the Children's Act 38 of 2005, Section 17, the age at which a person reaches majority).
- Mothers who meet the above criteria and agree to participate in the study.

1.6.2.4 Exclusion criteria

- Mothers of neonates who are diagnosed with a terminal condition.

1.6.2.5 Sample size

The sample size calculator, Raosoft (http://www.raosoft.com/samplesize.html) was used to estimate the sample size needed.

A sample size of 148 respondents was aimed for. Data collection was planned for 5 months. The sample size of 148 provides a confidence interval of 95%, $p < 0,05$. The margin of error is 4,91 %.

1.6.3 Data collection

The NUPS Scale was developed from reviewing the literature, individual and focus group discussion with volunteer parents who currently had a neonate in NICU and from insights from

members of the multidisciplinary team of staff in the NICU (Reid, 2005, Reid, Bramwell, Booth & Weindling, 2007). The NUPS Scale is a self report scale, consisting of 48 items made up of Likert scales (Reid, 2005). The scale was presented to respondents as 4 subscales – "**Sights and sounds", "Looks and behaves and treatments", "Relationship with infant" and "Practical hassles and social relationship strains" (Annexure D).**

Data relating to the mother such as age, home language, parity and gravidity, and previous experience of neonate admission to NICU were recorded. Data relating to the neonate such as gestational age and birth weight were recorded (Annexure B). The neonatal characteristics of gestational age and birth weight reflect indirectly neonatal morbidity, and this may impact on maternal experience.

The respondents were asked to complete the questionnaire within 2 to 4 days after delivery and again at 10 to 14 days after delivery. The data collected on the questionnaire is interval in nature.

1.6.3.1 Pilot study

The term pilot study is defined as "A small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate" by Bless, Higson-Smith and Kajee (*in* de Vos, Strydom, Fouche & Delport, 2011:237).

A pilot study was undertaken in order to assess the appropriateness of the data collection instrument and procedure, the clarity of the instrument, time taken to complete, and the face

validity. Respondents for the pilot study consisted of five mothers from the eligible population as well as a group of 5 NICU employed Registered Nurses. The Registered Nurses provided input regarding the feasibility of administering the questionnaire and its appropriateness in terms of questions asked and time administered.

1.7. Data analysis

The StatSoft Statistica Program, Version 11, was used for data analysis after consultation with a statistician.

Descriptive statistics were used to summarize neonatal and maternal characteristics including measures of central tendency and dispersion (mean and standard deviation).

The data obtained from the completed NUPS Scale were described by means of descriptive statistics (means and standard deviations) for each subscale at two time points.

Maternal and infant characteristics were correlated with maternal stress levels using Spearman's Rho and Pearson's r statistics.

The data on the subscales at the two time points were compared by means of the Wilcoxon Test for paired samples, as per consultation with the statistician. The level of significance was set at $p< 0,05$.

The data from respondents who did not complete the questionnaire at the second time point were used for descriptive purposes only and not subjected to the Wilcoxon Test.

1.7.1 Validity and reliability of the NUPS Scale

The validity of the NUPS scale was established by Reid as part of a Doctoral thesis (Reid, 2005, Reid et al., 2007).

Content and face validity were achieved (Reid et al., 2007) by generating the items from a study of existing literature, interviews with mothers and fathers of neonate NICU patients, and discussions with nurses, psychologists and medical staff. In addition, a pilot study was carried out to further refine the items on the questionnaire.

Construct validity was shown using the following two processes (Reid et al., 2007):

- Exploratory and confirmatory factor analysis of the data originally obtained using the instrument, showed that the items in the NUPS scale loaded onto three factors. The first related to illness and suffering of the neonate, the second related to the relationship of the mother with the neonate and the third to social and practical issues.
- The responses of parents to items on the NUPS scale were compared with their responses on the Hospital Anxiety and Depression Scale (HADS) and the McMaster Family Assessment Device (FAD-GF). The HADS measures symptoms of anxiety and depression and the FAD-GF measures perceived family/social support. These instruments were used because of their established validity and reliability. The responses on the NUPS scale correlated well with those on the HADS and the FAD-GF.

Cronbach's Alpha values for the NUPS scale as a whole and for the individual subscales were consistently high (above 0,8) (Reid et al., 2007), demonstrating internal reliability.

1.7.2 Validity and reliability related to the current study

Face validity was assessed using a pilot study, as described above.

The internal reliability of the scale in this specific context was examined using the Cronbach's Alpha Coefficient, and values of more than 0,80 were obtained. Cronbach's Alpha Coefficient is considered to be an indication of reliability of the scale when values are greater than 0,80 (Burns and Grove, 2005), and between 0,8 – 0,9 (Pallant, 2010). Cronbach's Alpha values greater than 0,80 are considered to indicate reliability for the purposes of this study.

Table 1.1 Cronbach's Alpha Coefficients for the current study

Subscale	**Cronbach's Alpha**
Looks and Behaves:	0,920
Relationship:	0,893
Practical Hassles and Social Relationship Strains:	0,862

1.8 Ethical considerations

Consent was sought from mothers who met eligibility criteria to participate in the study. This process was managed with great sensitivity as the mothers and neonates were extremely vulnerable at the time that the consent was sought. The mother in the NICU environment is considered to be vulnerable as she is dealing with her subjectively perceived stressors at this time, as well as the potentially overwhelming reality of the situation. Additionally, the mother may feel that if she does not consent, the neonate's care may be prejudiced in some way, despite the professional nurse's role of advocacy for the patient. This factor threatens the voluntariness of participation.

Golec et al., have suggested a process related to recruitment to studies carried out in NICU which promotes respect for parental autonomy and is as follows (Golec, Gibbins, Dunn & Hebert, 2004). The mother/neonate should meet the eligibility criteria.

- Minimize information overload: At time of admission, parents are faced with a vast array of new information. As a family unit they require time to process this information and part of providing family centered care is being sensitive to this requirement. Research solicitation should be carried out in an empathic, sensitive and culturally acceptable manner, guided by parental receptiveness.
- 'Informed consent' is synonymous with 'understanding consent' where the parent is given the time to think about the information and to deliberate on the decision. As part of family centered care, the mother should be given time to consult with her partner in the decision making process.

In keeping with the above suggestions, the mothers were approached by the researcher at or soon after 24 hours of the neonate's admission, at the time of a visit to the NICU. At this time they were given the information letter related to the study (Annexure A) as well as the yellow and pink questionnaires (Annexure D). A verbal explanation about the reasons for performing the research and how to complete the questionnaire was given. The yellow and pink questionnaires were numbered randomly in pairs and were anonymous.

Provision for maintaining confidentiality, as well as how to return the questionnaire were explained. The questionnaires were returned, completed or uncompleted in the provided envelope, into a box marked QUESTIONNAIRES at the NICU entrance. A notice was placed in

a visible location near to the collection box reminding mothers who were part of the study to complete the questionnaire at the second time point.

In order to protect the respondents' confidentiality, there was no separate consent form. Completion of the questionnaire and depositing it in the box implied consent.
The researcher was employed in the NICU in a clinical capacity and it was considered to be important that the researcher did not know who had agreed to participate in the study. This was to prevent any element of coercion and to protect the voluntariness of participation. Parent and neonate confidentiality was respected, in that no identifying data was disclosed in the study.

A social worker who functions as an NICU counselor was available daily and free of charge to all parents in the NICU for emotional support. The parents were given an information letter containing the telephone numbers of both the counselor and the researcher.

Permission was requested, in writing, from the private hospital management and hospital group ethics committee to carry out the research within the NICU of the private hospital.
Permission from the University of the Witwatersrand Ethics Committee was sought to carry out the study. The above mentioned permissions were granted.

1.9 Conclusion

The introductory chapter has outlined the context, purpose, methods and data analysis of the study.

CHAPTER 2

2. LITERATURE REVIEW

2.1 Introduction

The literature survey was performed, searching for original studies focusing on maternal stress experienced during the neonate's admission to NICU. Reviews, a meta-analysis and meta-synthesis have been included and provide valuable insights to the experiences of mothers in the NICU. A brief description of stress is given, for the purposes of this study.

2.2 Literature survey

2.2.1 Measurement of parental stress

The literature study was commenced with two quantitative studies, where parental stress was measured using instruments with established validity and reliability. In the first of these, two random samples of parents (NICU and non-NICU parents) were studied using the *Dyadic Adjustment Scale, Edinburgh Postnatal Depression Scale, Hospital Anxiety and Depression Rating Scale* and *Social Adjustment Scale* (Carter, Mulder, Bartram & Darlow, 2005). The NICU group showed more anxiety on the Hospital Anxiety and Depression Rating Scale in both mothers and fathers than the non-NICU group (the control group). The second study measured parent symptoms against symptoms of Acute Stress Disorder and correlated scores with those obtained on the Parental Stress Scale:Neonatal Intensive Care Unit (PSS:NICU) developed by Margaret Shandor Miles (Miles, Funk & Carlson, 1993, Shaw, Deblois, Ikuta, Ginzburg, Fleisher & Koopman, 2006). This study showed that the severity of Acute Stress Disorder was greater among mothers than fathers and was positively correlated to the scores relating to "Parental Role Alteration", Infant behavior and Appearance", and "Sights and Sounds of NICU" obtained on the

PSS:NICU instrument. In families where there was a great degree of family cohesion and expressiveness, less stress was experienced with admission of the neonate to NICU. The significance of these two studies is that stress in mothers of neonates in NICU was measured quantitatively on recognized instruments and the development of Acute Stress Disorder was shown to correlate positively with stress measured on the PSS:NICU.

The studies accessed for this review were mostly qualitative, as it was thought that the qualitative studies may demonstrate the subtle nuances of maternal emotional experience in relation to the neonate's admission to NICU to a greater extent than did the quantitative studies. Common themes emerged and they are as follows.

2.2.2 The experience of the father of the Neonatal Intensive Care Unit (NICU) patient

Three of the studies focus on the father of the neonate in NICU and the experience of the father is subtly different from that of the mother, viz. the pressure of work, being the care taker of the family, being the protector of the family and feelings of lack of control (Arockiasamy, Holsti & Albersheim, 2008, Mackley, Locke, Spear & Joseph, 2010, Hollywood & Hollywood, 2011). Fathers seem more likely to discount the severity of the problem, minimize their own emotional response and provide support for their spouse during the infant's admission. Fathers tend to make instrumental moves to address aspects of the crisis in order to make it more manageable. Mothers are more likely to experience greater levels of distress because of their greater level of psychological involvement with the infant (Shaw et al., 2006, Carter et al., 2005). Fathers experienced anxiety related to neonate's admission to NICU, not to the prematurity itself, whereas both parents experienced depressive symptoms relating to the preterm birth of their

infant. Altered parental role was the source of greatest stress for both parents (Carter et al., 2005).

2.2.3 The NICU environment

The experience of being overwhelmed by the sights and sounds of NICU seems to be a common thread (Gavey, 2007, Aagaard and Hall, 2008, Hollywood and Hollywood, 2011). Aspects of the environment such as the level of activity among the staff, staff expertise, machines, lights, the noise of alarms and the appearance of the neonate itself are described as overwhelming, producing feelings of alienation and of being an outsider (Aagaard and Hall, 2008, Gavey, 2007).

Initially the mother sees the unfamiliar and intimidating environment in the foreground, detracting from focusing on her infant (Heermann, Wilson & Wilhelm, 2005). As she becomes more engaged with her infant, she sees the infant first and the environment becomes background, constantly there but not intrusive. As the parents begin to interact with the infant, the lack of privacy means that the illness of the neonate as well as the care practices of the parents and their interactions become the property of the unit staff and other parents.

The noise of alarms was described as terrifying because of possible deterioration in the neonate's condition (Reid, 2000). It is interesting to note that parents of neonates admitted to a special care nursery experienced stress, whether or not the infant was considered to be critically ill, and this confirms the impression that the special care nursery is a stress provoking environment (Lau and Morse, 2003, Reid, 2000)

2.2.4 Separation of the mother from her neonate

The theme of grief, loss and anxiety because of separation from the neonate was evident throughout, where the mothers expressed feelings of being unnecessary, an outsider, and having to make a positive effort to re-establish the connection with the neonate (Gavey 2007, Orapiriyakul, Jirapaet & Rodcumdee, 2007). The fear that the infant may not survive (Reid, 2000), as well as lack of access to information regarding diagnosis and prognosis led to feelings of alienation and lack of control .

The mother-infant dyad is the focus of studies relating to the attainment of the maternal role and the consequent formation of maternal identity. Rubin described the interaction between the mother and fetus during the pregnancy as resulting in a cognitive process in which the mother constantly redefines her self-concept in order to fully internalize the role of mother (Rubin, 1967a, Rubin, 1967b, Koniak-Griffin, 1993). This process continues after the birth of the infant, as the mother takes on the role behaviors and functions of mother, demonstrating maternal role attainment, and this culminates in the formation of maternal identity (Koniak-Griffin, 1993, Mercer, 2004, Mercer, 2006). Maternal role attainment is characterized by the mother experiencing a sense of confidence and competence in her role as the mother. Reid similarly described the development of maternal identity as being part of a process that extends from the onset of gestation into the postnatal period (Reid, 2000). In the case of preterm birth, or an ill neonate admitted to NICU, this process is disrupted by the many stressors present in NICU and the necessity for clinical procedures to care for the neonate, necessitating the separation of the mother from the neonate, thereby delaying the formation of maternal identity (Koniak-Griffin, 1993, Reid, 2000, Mercer, 2004).

Mercer has described the process of becoming a mother as consisting of four stages (Mercer, 2006): 1) Commitment to and preparation for the infant during the pregnancy, 2) Learning to care for the infant and increasing attachment to the infant, learning infant behavioral cues, recovery from the physiological process of the birth, 3) Moving towards a "new normal", and 4) completion of the formation of maternal identity at around 4 months of infant age. It is seen therefore that maternal attachment to the neonate is closely related to the formation of maternal identity. Factors which impacted negatively on development of maternal attachment were physical and emotional isolation from the neonate as well as the unfulfilled need to see, hold and touch the neonate (Reid 2000, Mercer 2004, Obeidat, Bond & Callister, 2009). Mothers expressed feelings of being a stranger with no connection to the neonate and not feeling like the parent of the fragile, tiny infant (Gavey, 2007, Heermann et al., 2005, Reid, 2000). Mothers expressed concern that their neonates didn't recognize them, and also a resentment of the nurses who were caring for the neonate (Reid, 2000). Mothers felt split between home and the hospital and the most common worry was that there would be deterioration in the neonate's condition.

The mother-infant relationship which was established during the pregnancy is changed with the birth and mothers experienced a wide range of emotions such as previously described alienation, grief, despair, anger, happiness and joy. Mothers were described as craving to hold their baby, which was often not possible, and committing themselves to remain by the bedside and seek information (Schenk and Kelley, 2010).

Separation of the mother and neonate due to admission of the neonate has been reported to result in a reduction of maternal affiliative behavior such as touch and caring behavior towards the

neonate with long term effects on neonate psychosocial development (Phillips and Tooley, 2005).

Parents tended to discourage each other from becoming involved with the neonate, as a protective mechanism, and possible negative effects were seen on the marital relationship due to communication difficulties.

2.2.5 Neonatal suffering

Neonatal suffering and feeling helpless in not knowing how to help or protect the baby as well as alteration of parental role was described as the worst part of the NICU experience by mothers in a retrospective study by Wereszak, Miles and Holditch-Davis (*in* Franck, Cox, Allen & Winter, 2004). Parents described feelings of helplessness and an inability to protect the infant from pain (Obeidat et al., 2009). Parents had strong feelings of anger towards doctors and nurses performing invasive and painful procedures and avoided showing any reaction for fear of reprisal against the vulnerable infant (Padden and Glenn, 1997, Reid, 2000). The inability to protect the neonate from pain, as well as alteration in parental role and not being able to help care for the neonate, were the greatest contributors towards development of symptoms of Acute Stress Disorder (Shaw et al., 2006).

Parents were worried about the effects of pain on their infants, and were worried about long term effects of pain (Franck et al., 2004). The level of distress parents experienced was directly related to their estimate of the infant's worst pain experienced and the degree of satisfaction with information on pain and pain relief that they received. Parents expected a high degree of pain

relief for their infants and required information about how to participate in the infant's pain care. They desired involvement in the infant's care.

2.2.6 The unique position of the nurse

The feeling of requiring the nurse's permission to touch the neonate and of having to re-assert the position of "being the mama" was reported in one study and the necessity of extending connections in order to cope with the demands of being the mother of a neonate in the NICU (Schenk and Kelley, 2010). Extending connections refers to "connectedness" or becoming connected by forming relationships with others such as nurses, doctors, family members to facilitate learning a mothering role. Feelings of jealousy of the nurse being able to touch and handle baby and of being unwelcome at the baby's bedside because of the nursing staff attitudes were described (Padden and Glenn, 1997, Schenk and Kelley, 2010).

Nurses are in a unique position to help parents cope with their stress responses after admission of their infant to NICU as shown in two studies in particular (Fenwick, Barclay & Schmied, 2001, Ranchod, Ballot, Martinez, Cory, Davies & Partridge, 2004). In her study, Fenwick showed that nurses could facilitate formation of maternal attachment to the neonate through a process of "chatting" which involves the nurse and mother sharing equally. The mother becomes an equal partner in the interaction and the nurse relinquishes her power in the therapeutic situation. Through "chatting" the nurse helps the mother to learn her maternal role and facilitates the development of maternal attachment to the neonate. The nurse shares her knowledge and enters the mother's world. The ability of the nurse to form relationships with parents through "chatting" is considered to be a powerful clinical tool in facilitating mothering in the NICU.

Ranchod et al. reported that parents found nurses more helpful when talking about their neonate's condition and treatments than were physicians (Ranchod et al., 2004).

Nursing actions can facilitate development of maternal infant attachment and reduce the stress and loss of control experienced by the parents by focusing on family centered, developmentally supportive nursing care (Als, Gilkerson, Duffy, McAnulty, Buehler, van Blickman & Jones, 2003, Heerman et al., 2005, Obeidat et al., 2009). One of the central tenets of family centered care is that parents are viewed as primary advocates for the neonate and partners in care and that nurses and parents work together to provide care to the neonate

Developmentally supportive care is that which enhances the physical and neurological development of the premature infant and engages the parents in the provision of this care (Als et al., 2003). Developmentally supportive care is individualized to suit the needs of each particular neonate and involves the parents as primary advocates for the well being of the neonate. The parent-neonate relationship is regarded as the primary relationship for the neonate. A study of individualized neuro-developmental care showed a reduction of family stress and increased understanding of the infant with greater involvement of the parent in neonatal care. However, there have been variable conclusions regarding outcomes such as incidence of Chronic Lung Disease and Necrotising Enterocolitis and there has been limited evidence of improvement in long term behavior, cognition and movement at 5 years of corrected age (Symington & Pinelli, 2006).

When parents were involved in neonatal care and well integrated into the NICU, they felt more satisfied and confident in their roles as parents. Nurses showed mothers ways of relating to the neonate and parents moved from an experience of “their baby” to “my baby” as they became more involved in the care of the neonate (Heermann et al., 2005). This requires a therapeutic relationship between members of the care team and the parents, emotional support for the parents and sharing information with them (Obeidat et al., 2009, Heermann et al., 2005). However, most nurses are not ready to have parents in a partnership role and mothers moving towards advocacy may encounter resistance from the nurses involved in neonatal care (Heermann et al., 2005). The nurse needs to have an understanding of parents’ experience in order to meet their needs (Obeidat et al., 2009).

The mother’s and family’s role in patient outcome is critical and, in order to promote maternal involvement in care, the nurse’s role changes to that of coaching and supporting parents, and requires that the nurse relinquishes power in this situation (Heermann et al., 2005).

2.2.7 Barriers to parent advocacy

The importance of the parents’ role of advocacy for their infants was shown in a study within the public sector hospital of Gauteng, where parents who were interviewed expressed a desire for more involvement in decision making regarding their infant’s treatment and that they experienced nurses as more helpful in discussing their infant’s condition than the attending physicians (Ranchod et al., 2004). Parents played a passive role in relation to life support decisions. Ethnic, religious and language differences among the South African population groups can impact on communication, and this again highlighted the important position of the nurse and her relationship with the parents.

The question of parents advocating for their infants was addressed in a subsequent or almost concurrent study of attitudes of physicians to parent participation in decision making and it was found that in South Africa, parents' wishes were considered less relevant to resuscitation decisions than in developed countries such as the United States of America and Australia and, aspects of decision making not considered important by the physician (for example religion) were not discussed (Partridge et al., 2005b). A general desire for a greater role in advocacy for the infant was shown by Partridge et al., in an international study. Conversely in countries with a high degree of medical paternalism (viz. Japan) parents were less likely to expect to have a voice in the care of their infants (Partridge et al., 2005a).

2.2.8 Description of stress in relation to current study

For the purposes of this study, stress is defined as a reaction to the environment where there is a perceived or actual loss of resources, or failure to gain resources after investment of resources, as described in Hobfoll's Conservation of Resources model (Hobfoll, 1989), as well as by Lazarus (Lazarus, 1991). It should be noted that the perceived or actual loss of resources constitutes both a subjective and objective evaluation of the situation. The way in which an individual identifies a situation as stressful depends on the person's appraisal of the stressor, and whether or not the demands of the situation exceed the resources available to the individual. The reaction to the stressor is unique to the individual, dependent on the coping processes available, and the individual's subjective assessment of the situation as well as the objective reality. There is therefore an emotional and cognitive component to coping, in that the emotional response to a stressor is accompanied with a cognitive response during which the individual evaluates the available resources and the desired objectives. In the development of the NUPS Scale, stress was described as resulting from threatening situations that challenge the person's existing

resources and nurses in the NICU were seen as part of resources available to the parents (Reid, 2005:77).

2.3 Conclusion

Stress in parents of neonates admitted to NICU has been measured quantitatively using instruments such as the *Hospital Anxiety and Depression Rating Scale* , *Acute Stress Disorder* measures and the *Parental Stress Scale:NICU*. Numerous qualitative studies have been undertaken. These studies show important causes of parent stress to be separation from the neonate, suffering of the neonate, delayed maternal role attainment and delayed achievement of maternal identity.

Stress is viewed against the available resources for adaptation, where the individual appraises the stress stimulus both subjectively and objectively in relation to available internal and external resources. In the NICU, the nursing professional has an important role in support of the mother, as a significant component of the mother's resources.

CHAPTER 3

3. RESEARCH METHODOLOGY

3.1 Introduction

The problem statement, purpose of the study as well as research questions and objectives of the study are stated. The instrument, established reliability and validity, and data collection is described. An outline is given of data analysis methods used.

3.2 Problem statement

Anecdotal evidence shows that nurses are ill-equipped to manage the stress of mothers with neonates in NICU. Information is needed about the nature of this stress in order to better prepare nurses in the NICU to assist mothers in coping with stress and to develop strong attachment and caring behaviors in relation to their neonates.

3.3 Purpose of the study

The purpose of the study is to describe the level and source of stress experienced by mothers of neonates in the NICU in terms of the NUPS Scale, and to obtain information that could be used to empower nurses to assist mothers to cope with stress.

3.4 Research questions

3.4.1 What is the source and level of stress experienced by mothers of premature neonates admitted to a private hospital NICU in terms of the NUPS Scale?

3.4.2 Does the stress experienced by these mothers change over a period of two weeks and in what way?

3.4.3 What preparation would empower NICU nurses to assist mothers to cope with this stress?

3.5 Objectives of the study

3.5.1 To explore and describe the level and source of stress experienced by mothers of neonates in the NICU using the NUPS Scale.

3.5.2 To explore and describe whether change occurs in the level and source of stress over a two week period by comparing level and source of stress experienced by mothers at 2 – 4 days and 10 – 14 days of the neonatal age.

3.5.3 To make recommendations for preparation of NICU nurses to enable them to assist mothers effectively in coping with stress associated with the neonate's admission.

3.6 Research strategy

The study has a quantitative longitudinal design, using the survey tool, the NUPS Scale.

3.6.1 Research methods

3.6.1.1 Population

The population consists of all the mothers who had neonates admitted to the private hospital NICU's in Johannesburg.

3.6.1.2 Sample

The particular private hospital, chosen for this study, has one of the largest NICU's in Johannesburg, which admits neonates with surgical conditions from outlying hospitals as well as catering to inborn neonates. The private sector has been chosen for the study because infants as young as 23 to 25 weeks gestational age and a weight of 400g to 500g are treated actively, whereas in the public sector there is a weight and gestational age cut off for treatment.

The mothers of all infants admitted to this NICU were included in the sample during the period of the study.

3.6.1.3 Inclusion criteria

- Mothers of all neonates admitted to the NICU, where the mother is well enough to visit the neonate in the NICU.
- Mothers who are able to read and understand English.
- Mothers who are 18 years of age or older (In terms of the Children's Act 38 of 2005, Section 17, the age at which a person reaches majority).
- Mothers who meet the above criteria and agree to participate in the study.

3.6.1.4 Exclusion criteria

- Mothers of neonates who are diagnosed with a terminal condition.

3.6.1.5 Sample size

One hundred and seventy six (176) mothers were recruited to the study between 29th July 2012 and 20th December 2012. Mothers of infants who were more than 4 days old at the time of admission (14 in number) were excluded as the questionnaire was designed for use by the fourth day of age. Four (4) mothers who were less than 18 years of age were excluded as well as one mother who was blind. Ten (10) neonates were discharged from the NICU before their mothers were recruited. Three (3) mothers were excluded due to severe abnormalities in the neonate, and five (5) mothers excluded due to severe maternal illness.

Ninety five (95) mothers returned the questionnaire at the first time point and twenty two (22) mothers returned the questionnaire at the second time point. Of the five mothers who comprised

the pilot study, five (5) questionnaires were returned at the first time point and three (3) at the second time point.

3.6.1.6 Pilot study

The instrument was piloted using five eligible mothers and five registered nurses employed in the NICU. The objectives of the pilot study were to ascertain the face validity of the instrument, the feasibility of recruiting mothers to complete the questionnaire and the time taken to complete the questionnaire. The mothers and staff members were aware that their responses were part of a pilot study and they were invited to comment on any aspect of the questionnaire.

3.6.1.7 Data collection

Data collection was performed using the Neonatal Unit Parental Stress (NUPS) Scale (Annexure D).

The NUPS Scale is a self report scale, consisting of 48 items made up of Likert scales (Reid, 2005). The scale was presented to parents consisting of four subscales – "**Sights and sounds", "Looks and behaves and treatments", "Relationship with infant" and "Practical hassles and social relationship strains".**

A short questionnaire was attached to the NUPS Scale requesting data relating to the mother such as age, home language, parity and gravidity, and previous experience of neonate admission to NICU, as well as information relating to the neonate such as gestational age and birth weight (Annexure B). The neonatal characteristics of gestational age and birth weight reflect indirectly neonatal morbidity, and this impacts on maternal experience.

The mothers were approached once by the researcher around twenty four hours to forty eight hours after delivery. Mothers were recruited in the NICU, and therefore had to have recovered from the delivery sufficiently to visit in the NICU. The completed questionnaires were placed by the mothers in a marked box near the entrance of the NICU and a reminder in the form of a poster for mothers who had made the decision to participate was placed at the entrance door of the NICU. The questionnaires were completed anonymously.

The respondents were asked to complete the questionnaire within 2 to 4 days after delivery and again at 10 to 14 days after delivery. The data collected on the NUPS Scale is interval in nature.

3.6.1.8 Validity and reliability of the NUPS Scale as established by the original author

The NUPS Scale was developed by the original author, as part of a doctoral thesis, subsequent to a literature search, individual interviews with parents, focus group discussions with parents and discussions with a multidisciplinary team of NICU nurses, psychologists and medical staff of the NICU (Reid et al., 2007). This process helped to ensure content validity and face validity. Content validity is defined as the "extent to which the method of measurement measures all major elements relevant to the construct being measured" (Burns and Grove, 2005:732). Face validity is established if the instrument appears to measure the content of the study (Burns and Grove, 2005). In addition, a pilot study was carried out to further refine the items on the questionnaire (Reid et al., 2007).

Construct validity was determined using exploratory and confirmatory factor analysis (Reid et al., 2007). An instrument that has the quality of construct validity, is one that measures the construct it purports to measure (Burns and Grove, 2005).

Exploratory and confirmatory factor analysis of the data originally obtained using the instrument, showed that the items in the NUPS scale loaded onto three factors (Reid et al., 2007). The first related to illness and suffering of the neonate, the second related to the relationship of the mother with the neonate and the third to social and practical issues.

The responses of parents to items on the NUPS scale were compared with their responses on the Hospital Anxiety and Depression Scale (HADS) and the McMaster Family Assessment Device (FAD-GF). The HADS measures symptoms of anxiety and depression and the FAD-GF measures perceived family/social support. These instruments were used because of their established validity and reliability. The responses on the NUPS scale correlated well with those on the HADS and the FAD-GF.

The instrument, in its original form, consisted of four subscales (Reid, 2005): **Sights and Sounds, Looks and Behaves, Relationship, Practical Hassles and Social Relationship Strains (**Annexure D**).** Exploratory and confirmatory factor analysis demonstrated that all items loaded onto three distinct factors. These factors are represented in three subscale groupings, namely, items related to the illness of the infant (**Looks and Behaves**), establishing a relationship with the infant (**Relationship**), and the social/practical aspects (**Practical Hassles and Social Relationship Strains**) (Annexure C). The clinical environment items, originally the Sights and Sounds subscale, loaded onto the Looks and Behaves factor (Item 1.1, 1.2 and 1.3) and the Practical Hassles and Social Relationship Strains factor (Items 1.4 and 1.5). Items 3.5, 3.6 and 3.9 from the Relationship subscale loaded onto the Looks and Behaves factor. Item 3.15

from the Relationship subscale loaded onto the Practical Hassles and Social Relationship Strains factor. Item 4.15 from Practical Hassles and Social Relationship Strains loaded onto the Relationship factor (Reid et al., 2007). These three subscale groupings have been used in the analysis of data obtained for the current study.

There are two aspects to internal reliability. The first is that the measurement is free from random error and the second is that the elements of the instrument demonstrate internal consistency. The quality of internal consistency means that all items of the instrument measure aspects of a construct that belong together (Pallant, 2010). Linked to the concept of internal consistency is that of unidimensionality of the items, and reliability is based on the assumption of unidimensionality (Tavakol and Dennick, 2011). Unidimensionality was established by means of Exploratory Factor Analysis and Confirmatory Factor Analysis, as described above. The Cronbach's Alpha was calculated for the entire scale and the subscales separately and the values were consistently high (above 0,8) indicating good internal reliability (Reid et al., 2007). Internal consistency and reliability of the instrument for the original study were thus established.

3.7 Methods used for data analysis for current study

Data were loaded onto an Excel spreadsheet and then imported into the Statsoft Statistica Version 11 statistical programme. Data were analysed after consultation with a statistician.

3.7.1 Normality

The Shapiro-Wilk test of normality was used to assess the normality of the distribution of the data, and a non-significant result ($p>0,05$) indicates normality (Pallant, 2010). This was

necessary to determine which statistical test to use (either parametric or non-parametric) when correlating demographic data with stress levels on the instrument.

3.7.2 Correlation

When the data met the requirements for normality, Pearson's r was used to determine correlation. When the data did not meet the requirements for normality, Spearman's rho was used to determine correlation (Pallant, 2010, StatSoft, 2013).

3.7.3 Difference

The Wilcoxon test for matched pairs was used to compare the data for the respondents at the two time points. The Wilcoxon test was chosen as it is suitable for small samples (approximately 20 subjects), where the data comes from the same subjects at two different time points (matched pairs) and where the distribution of the data is not known (Pallant, 2010, StatSoft, 2013).

3.7.4 Reliability

Reliability of the instrument for the current study was measured using the Cronbach's Alpha coefficient. Reliability in the instrument is a measure of the internal consistency or the extent to which the items measure aspects of the construct under study (Pallant, 2010). A value of zero for the Cronbach's alpha would mean that the items measured completely unrelated aspects, and a value of one would mean that the items measured the same aspect, rendering most of the items unnecessary (Pallant, 2010, Tavakol and Dennick, 2011). An acceptable level of reliability is considered to be a Cronbach's Alpha of 0,8 – 0,9, indicating a reliable instrument (Pallant, 2010). Reliability is a necessary pre-requisite for validity (de Vos et al., 2011).

3.8 Ethical considerations

Only mothers who met the inclusion criteria of the study were invited to participate. This was done by the researcher, who approached eligible mothers when they came to the unit to visit their infants, most often on the day after the delivery of the infant.

Anonymity of the respondents was preserved in that the respondent's name did not appear on the questionnaire and there was no separate consent sheet. Consent was implied if the mother completed the questionnaire and submitted it into the collection box. Questionnaires were marked with a randomly allocated number in order to match questionnaires at the first and second time point for each respondent. The numbers were not linked in any way with the names of the infants whose mothers were recruited to the study.

The availability of the unit counselor was pointed out to the mothers who received the questionnaire as well as her telephone number, which was included in the introductory letter (Annexure A).

Home language of the respondents was recorded on the data sheet, in order to describe the demographics of the sample.

3.9 Conclusion

The research methodology has been described. An outline has been given of the proposed data analysis.

CHAPTER 4

4. DATA ANALYSIS

4.1 Introduction

The demographic data of the sample recruited to the study are described. Descriptive statistics are used to describe data obtained in response to the NUPS Scale. Inferential statistics are used to establish correlation between demographic data and stress levels in the mothers, and to determine if a difference exists between data obtained at the two time points. The data are examined in relation to the objectives of the study.

4.2 Demographic data

Ninety five (95) mothers completed and returned the questionnaire at the first time point and twenty two (22) mothers completed and returned the questionnaire at the second time point. There are therefore data for 22 respondents at both first and second time points and for a further 73 respondents at just the first time point. At the second time point, as at the first time point, there were mothers who omitted to answer certain items, so the sample size for some items may be less than 22.

4.2.1 Home language

Home language of the respondents as provided on the demographic data questionnaire was English (53%), Isizulu (11%), Sesotho (8%) and Setswana (6%). The remaining 19% was made up of a mixture of home languages (Afrikaans, Northern Sotho, Tshivenda, Tsonga, Sepedi, Igbo and Xhosa). Out of the total of 95 mothers responding, 3 mothers (3%) omitted to give their home language. (Percentages have been rounded off).

Table 4.1 Frequency distribution – Home language

Language	English	Isizulu	Sotho	Tswana	Tshivenda	Tsonga	Xhosa	Afrikaans	Ibo	Pedi	Northern Sotho	Omitted
Frequency	50	10	8	6	4	4	3	2	2	2	1	3

4.2.2 Maternal age

The mean of mother's age was 31,12 years (Standard Deviation SD 6.415). The minimum age was 19 years and the maximum 54 years. Four (4) mothers omitted to give their ages.

Table 4.2 Maternal age

Mean	**31,12 years**
Standard Deviation	**6,415**
Maximum	**54 years**
Minimum	**19 years**

4.2.3 Duration of pregnancy

The mean of the duration of pregnancy was 34,81 weeks, (SD 3,465). The minimum duration was 26 weeks and the maximum was 40 weeks. The largest group of infants was born at 34 weeks gestation (17%), and then the next group at 35 weeks (16%). More than half (56%) of infants whose mothers agreed to take part in the study were born at 35 weeks or less gestation. (Percentages have been rounded off).

Table 4.3 Duration of pregnancy

Mean	**34,81 weeks**
Standard Deviation	**3,465**
Maximum	**40 weeks**
Minimum	**26 weeks**

An interesting increase in number of births is seen at 38 weeks gestation and this may be due to the fact that Caesarean section proportion in this hospital is high and this may be planned for 38 weeks most frequently.

4.2.4 Neonatal birth weight

Neonatal birth weight ranged from 585 g to 4100 g with a mean of 2329,91g (SD 776,70). Infant birth weights for multiple pregnancies have been included in this calculation and, being lower generally, the results are slightly negatively skewed (skewness value being -0,209). The smallest infant was one which weighed 585g.

Table 4.4 Birth weight

Mean	**2 329,91 g**
Standard Deviation	**776,70**
Maximum	**4 100 g**
Minimum	**585 g**
Skewness Value	**-0,209 g**

4.2.5 Previous pregnancy

For almost half (46%) of mothers, the current pregnancy was the first, and 32% of mothers reported that the current pregnancy had been their second. Of the remainder, 13% reported the current pregnancy as their third, 6% as the fourth pregnancy and 1% the fifth and sixth pregnancy. Two mothers (2%) omitted to state their parity and gravidity. (Percentages have been rounded off).

4.2.6 Number of live children

There were 46% of mothers who reported having 1 live child and 33% having 2 live children. The percentage of mothers who had three, four and five live children were respectively 13%, 3% and 2%. (The percentages have been rounded off). This was taken to mean live children including the one that was currently admitted to the NICU. The questionnaire was worded in such a way that it did not specify live children from previous pregnancies, but live children in existence at the present time.

One mother stated that she had no live children and this may have been the mother of a neonate who died unexpectedly after the mother was recruited to the study. There is no way to determine if this is the case because of the confidentiality of mothers who decided to be part of the study and return completed questionnaires.

Two mothers omitted to state whether or not they had any live children.

4.2.7 Previous admission of an infant to NICU

Only 14% of mothers reported having had a neonate admitted to NICU previously. The majority of mothers (84%) had not had an experience of neonatal admission to NICU in the past. Two mothers, comprising 2% of the sample, omitted to answer the question related to previous admission. (Percentages have been rounded off).

4.3 Face validity of the instrument for the current study

The face validity of the instrument for the context of this study was evaluated by means of the pilot study. Factors that may have affected the face validity of the instrument are the numerous languages spoken by the different cultural groups in South Africa and the fact that the language of the instrument is English.

4.3.1 Pilot study

The original form of the instrument, consisting of the four subscales, was used for the current study, and therefore the pilot study.

The term pilot study is defined as "A small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate" by Bless, Higson-Smith and Kajee (*in* de Vos et al., 2011:237). A pilot study was undertaken in order to assess the appropriateness of the data collection instrument and procedure, the clarity of the instrument, time taken to complete, and the face validity of the instrument in the South African context.

The instrument was piloted using the first five mothers from the eligible population as well as a group of 5 NICU employed Registered Nurses. The mothers reported no difficulties in completing the questionnaires and stated that they had understood the questions. There appeared to be a range of responses to the questions asked. The questionnaire took approximately ten minutes to complete. Three questionnaires were returned at the second time point, indicating feasibility of administering the questionnaire at the second time point.

In the second part of the pilot study, registered nurses employed in NICU were asked to study the questionnaire and comment. Comment sheets were issued for them to complete. Three of the staff members commented that the questionnaire was easy to understand and complete and the questions relevant. The two remaining staff members felt that a section should be included in the questionnaire relating to staff communication with the parents. No additions were made to the questionnaire since, in the initial formulation of the questionnaire, it was found that a staff communication scale was more appropriately administered as a separate questionnaire (Reid, 2005), and permission (Annexure E) had been granted to use the validated items in the original questionnaire.

4.4 Content validity and construct validity

Content validity, construct validity and reliability of the items on the instrument have been established by Reid (Reid 2005), as described previously in the Methodology chapter (**3.6.1.8 Validity and reliability of the NUPS Scale as established by the original author**).

4.5 Internal reliability

The data from the items on the completed questionnaires were loaded onto an Excel spreadsheet and arranged within the three factors as established by Reid (2005). The data were then imported into the Statsoft Statistica Version 11 program. Cronbach's Alpha values were calculated for the three separate factors and the following values were obtained:

Table 4.5: Cronbach's Alpha values for each subscale

Subscale	**Cronbach's Alpha**
Looks and Behaves:	0,920
Relationship:	0,893
Practical Hassles and Social Relationship Strains:	0,862

Cases with missing data on the variable in question were deleted by means of Case wise Deletion for these calculations.

The Cronbach's Alpha for the entire scale was 0,935, achieved by Mean Substitution for missing data, and therefore the reliability for the three separate factors as described above is taken to be the more accurate statistic. The instrument is therefore taken to have good internal reliability across the three factors for the data obtained from respondents to the current study.

Case wise deletion means that only cases with complete data are included in the analysis. Therefore, cases with missing data would be excluded from analysis of the reliability (Cronbach's alpha) of the subscale. When mean substitution is applied to the analysis, the mean for the variable in question is substituted where data is missing. This results in a situation where there is artificial uniformity of the data. Case wise deletion produces a more valid result in that the statistic is based on actual data, and not the mean (StatSoft, 2013).

Cronbach's Alpha Coefficient is considered to be an indication of reliability of the scale when values are greater than 0,80 (Burns and Grove, 2005), and between 0,80 – 0,90 (Pallant, 2010). Cronbach's Alpha values greater than 0,80 indicate reliability for the purposes of this study.

4.6 The NUPS questionnaire

The NUPS questionnaire was given to all mothers who were recruited to the study (176 in number) and was returned at the first time point by 95 mothers (54% return rate) and, at the second time point, by 22 mothers.

The questionnaire consisted of 48 items which were rated by the respondents in terms of how much stress they experienced in relation to the items on a scale from 1 to 5. The level of stress allocated to the numerical scores, were as follows:

1 = Not at all 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, the experience upset you and caused a lot of anxiety.

If the item was not experienced at all, a Not Applicable (N/A) column was provided. A Not Applicable answer to an item or an omitted item scored zero.

4.7 Data analysis in relation to the research objectives for the study

4.7.1 First objective: *To explore and describe the level and source of stress experienced by mothers of neonates in the NICU using the NUPS Scale.*

4.7.1.1 The overall experience of NICU

The overall experience of having an infant in NICU was rated as Moderately to Extremely Stressful (score 3 – 5) by approximately 90% of mothers. Little to No Stress, (score 1 – 2) was reported by 10% of mothers. The mean of the stress scores was 3.988 (SD1,06).

4.7.1.2 Looks and Behaves factor

The item having the lowest number of responses in this factor was item 2.4 (The small size of my baby) with 70 responses. The items having the greatest number of responses within this factor were items 1.3 (The sudden noises of monitor alarms), 3.6 (Feeling helpless about how to help my baby during this time) and item 3.9 (Feeling worried about how my baby will grow and develop). These three items each had 90 responses.

The item scoring the highest in terms of stress level was item 3.5 (Feeling helpless and unable to protect my baby from pain and painful procedures) with a mean of 4,411 (standard deviation SD 0,993). The second highest scoring item was item 3.6 (Feeling helpless about how to help my baby during this time) with a mean of 4,366 (SD 0,999), and the third highest scoring item was item 2.70 (When my baby seemed to be in pain) with a mean of 4,294 (SD 1,125). The item scoring the lowest in terms of stress level was item 1.1 (The presence of monitors and equipment) with a mean of 2,766 (SD 1,382). See Table 4.6.

The mean score of all the items making up the Looks and Behaves factor was 3.610 (SD 0,885).

Table 4.6 Looks and Behaves factor – Highest scoring items.

Item No.	Item	Mean	SD
3.5	Feeling helpless and unable to protect my baby from pain and painful procedures.	4,411	0,993
3.6	Feeling helpless about how to help my baby during this time.	4,366	0,999
2.7	When my baby seemed to be in pain.	4,294	1,125

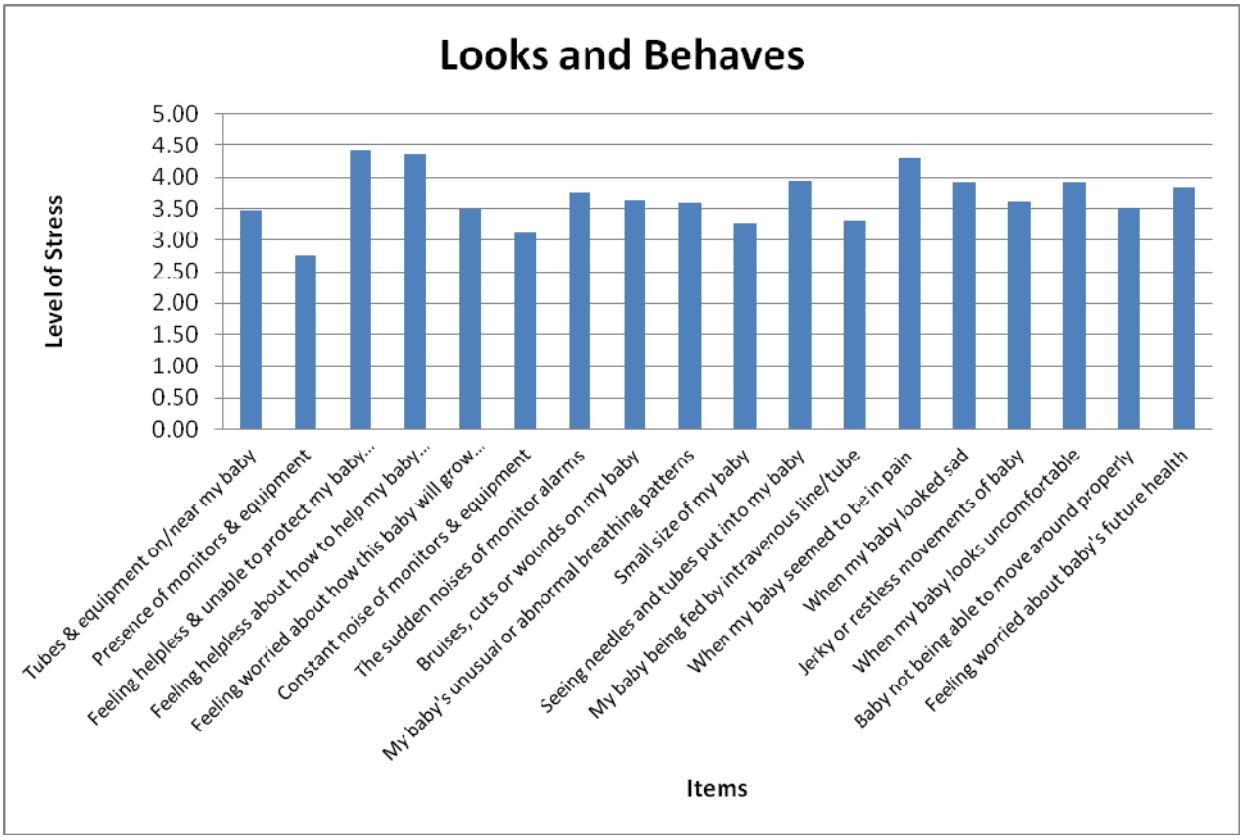

Figure 4.1: Looks and Behaves

4.7.1.3 Relationship factor

The number of responses to items within this factor ranged between 36 to 95, item 3.14 (Resenting my baby for causing upheaval in my everyday life) having the lowest number of responses, and item 3.1 (Being separated from my baby) having the highest number of responses.

The item which scored the highest in terms of stress level was item 3.1 (Being separated from my baby) with a mean of 4,378 (SD 1,063). The second highest scoring item was item 3,4 (Not being able to hold my baby when I want) with a mean of 4,34 (SD 1,097). The third highest scoring item was item 3.16, (Feeling worried about going home without my baby), mean 4,280

(SD 1,033), and the fourth highest scoring item was item 3.2 (Not feeding my baby myself), mean 4,172 (SD 1,069). The lowest scoring item in terms of stress level was item 3.14 (Resenting my baby for causing upheaval in my everyday life), mean 1,888 (SD 1,449).

Table 4.7: Relationship Factor – Highest scoring items.

Item No.	Item	Mean	SD
3.1	Being separated from my baby.	4,378	1,063
3,4	Not being able to hold my baby when I want.	4,34	1,097
3,16	Feeling worried about going home without my baby.	4,28	1,033
3,2	Not feeding my baby myself.	4,172	1,069

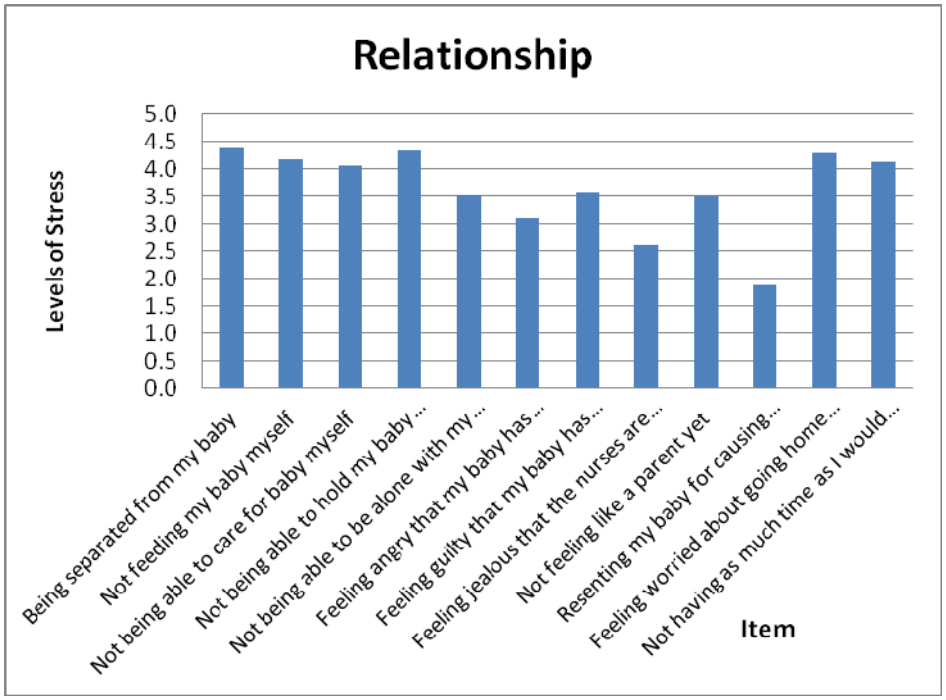

Figure 4.2: Relationship

4.7.1.4 Practical Hassles and Social Relationship Strain factor

The number of responses to items within this factor ranged between 40 to 86. Item number 4.14 (Feeling worried about how my other children will feel about this baby) had the lowest number of responses and item 1.4 (The other sick babies in the room) had the highest number of responses.

The highest scoring item in this factor, in terms of stress experienced was Item 4.1 (Having to keep cheerful when I don't feel like it), mean 3,272 (SD 1,191). The second highest scoring was Item 4.3 (Feeling that no-one knows how I feel), mean 3,094 (SD 1,517), and the third highest scoring item was Item 4.2 (Not having enough time to do everything), mean 3,064 (SD 1,272). The lowest scoring item in this factor was 1.5 (The lack of space around my baby's cot), mean 2,329 (SD 1,338).

Table 4.8: Practical Hassles and Social Relationship Strains Factor – Highest scoring items.

Item	Item	Mean	SD
4.1	Having to keep cheerful when I don't feel like it.	3,272	1,191
4.3	Feeling that no-one knows how I feel.	3,094	1.517
4.2	Not having enough time to do everything.	3.064	1.272

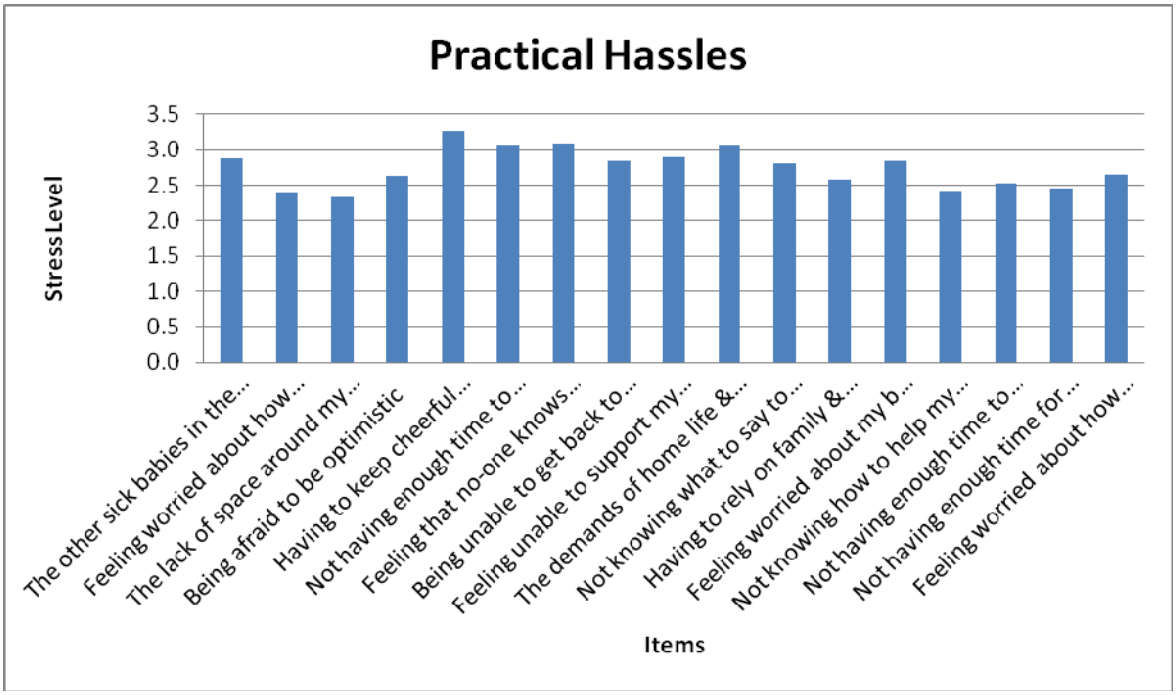

Figure 4.3: Practical Hassles and Social Relationship Strains

4.7.1.5 Correlation between demographic characteristics of respondents and stress levels experienced

4.7.1.5.1 Maternal Age

Initially, using an Excel spreadsheet, the maternal ages were divided into 5 year strata. The total stress score and an average stress score within each group was calculated. These figures were converted to percentages so that the total stress score of all the mothers combined was 100%, and the stress contribution in terms of a percentage of the whole for each age group was calculated.

It appeared that mothers below the age of twenty one years were the most stressed, scoring 17,82% of the total stress scored in all age groups. Stress contribution as a percentage gradually decreased as age increased, with the exception of the 41-45 year age group, which again showed

an increase in stress level. However, there was only one mother in this age group, and therefore this is not considered to be a meaningful observation.

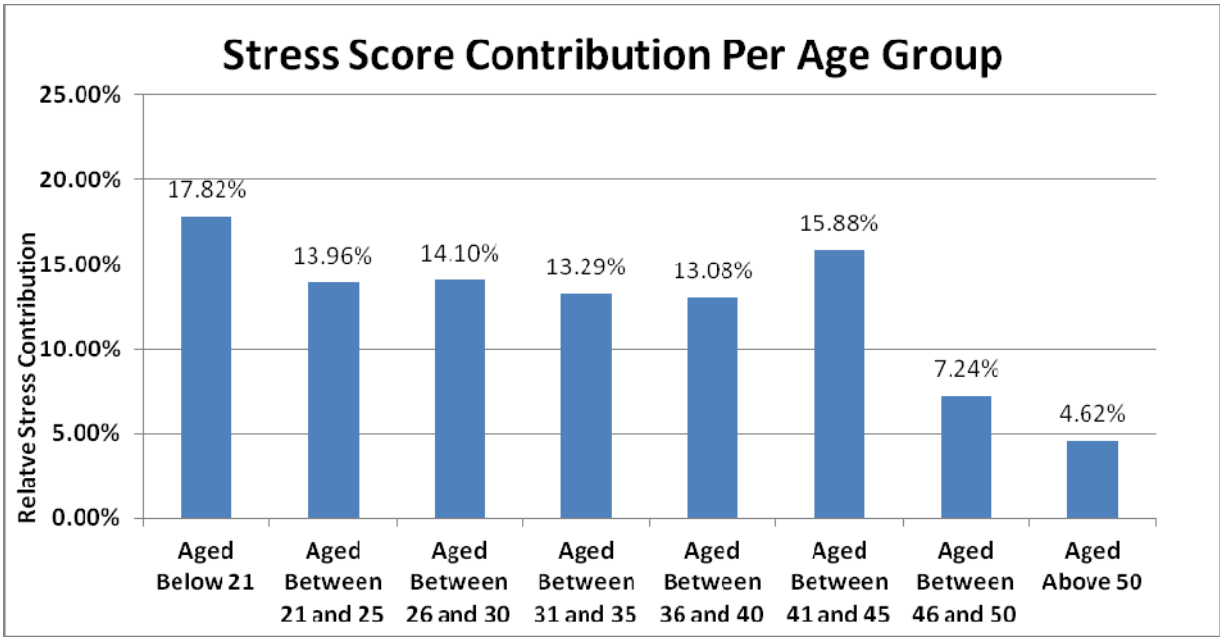

Figure 4.4: Stress score contribution per age group.

Correlation between maternal age and stress scores within the three factor subscales was then calculated using the Statistica program, and this showed significant negative correlations between the items in the Looks and Behaves subscale and maternal age and the Relationship subscale and maternal age. There was no significant correlation between the Practical Hassles subscale and maternal age.

Table 4.9 Correlation between Maternal Age and Subscales

Subscale	Pearson's r	P value	Significance
Looks and Behaves/Maternal age	-0,3477	0,001	p<0,05.
Relationship/Maternal age	-0,2847	0,006	p<0,05.

The mother's age data followed a normal curve, as indicated by the Shapiro-Wilk W test of normality (Shapiro-Wilk W = 0,97663, p = 0,10079) and, therefore, the Pearson's r correlation coefficient was used.

There was no significant correlation between the overall stress level and maternal age. The overall stress level refers to the last item in the questionnaire: Indicate how stressful in general the experience of having your baby hospitalized in the NICU has been for you.

4.7.1.5.2 Gestational age

A histogram showing relative stress contribution per gestational age did not reveal any correlation and a Spearman's Rho was calculated between gestational age and Looks and Behaves, Relationship and Practical Hassles factor subscales. This did not reveal any significant correlations. Spearman's Rho was used since the data for gestational age did not fit a normal distribution (as shown by the Shapiro-Wilk W, 0,93264, p = 0,00036), which therefore necessitated using a non-parametric statistic (Pallant, 2010, StatSoft, 2013).

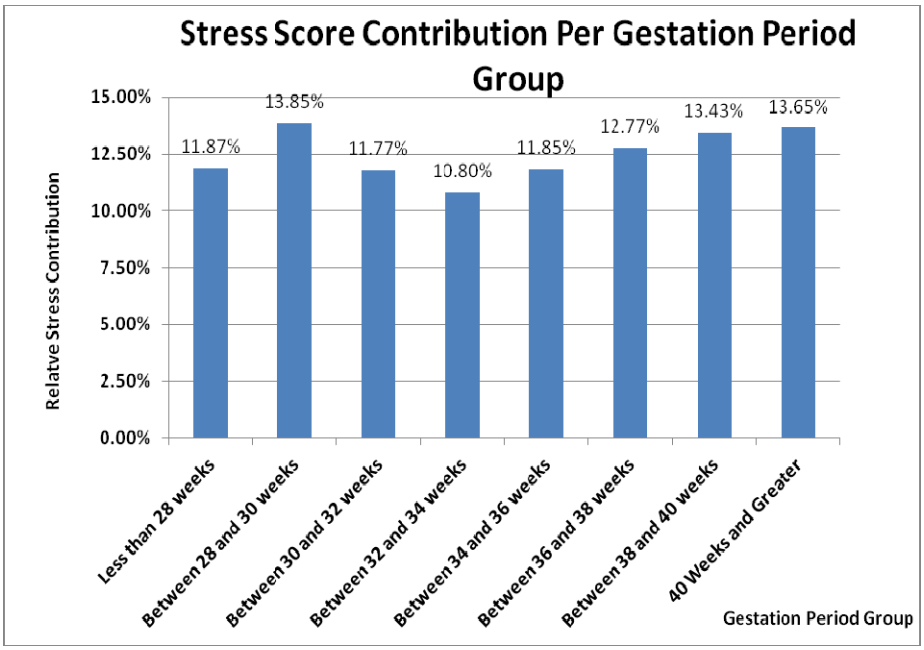

Figure 4.5: Stress score contribution per gestation period group.

No significant correlation was seen between overall stress level (the last item in the questionnaire) and gestational age.

4.7.1.5.3 Infant birth weight

A histogram showing stress score contribution against infant birth weight did not appear to show any relationship between the two.

Pearson's r was calculated between infant birth weight and data from the three factor subscales and these values did not reveal any significant correlations. The data for birth weight followed a normal distribution as shown by the Shapiro-Wilk W, (0,98665, p = 0,47566), hence the use of the Pearson's r.

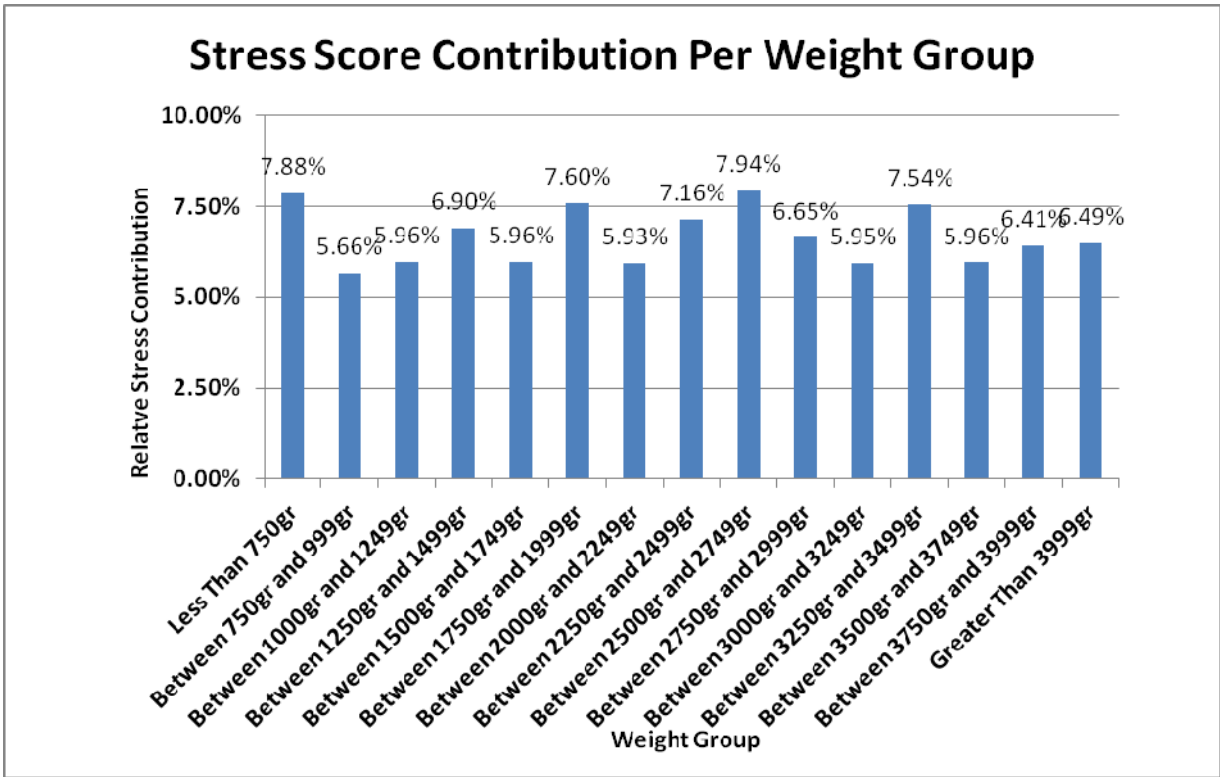

Figure 4.6: Stress score contribution per weight group.

Pearson's r calculation showed a significant positive correlation between overall stress level (the last item on the questionnaire) and birth weight, (r = 0,2303, p = 0,035). This indicates that as birth weight increases, overall stress level increases.

4.7.1.5.4 Number of pregnancies

A histogram showing Stress Score Contribution per Number of Pregnancies showed a slight increase in stress score contribution as number of pregnancy increased. Scatter plots showing the three factor subscales in relation to number of pregnancy, supported the impression that there may be correlation between the number of pregnancies and Relationship and Practical Hassles subscale. However, when the Spearman's Rho was calculated, there was no significant correlation between the number of pregnancy and the three factor subscales. The Spearman's

Rho was used since the number of pregnancy variable did not show a normal distribution (Shapiro-Wilk W 0,78106, p = 0,00).

No significant correlation was seen between overall stress level and number of pregnancies.

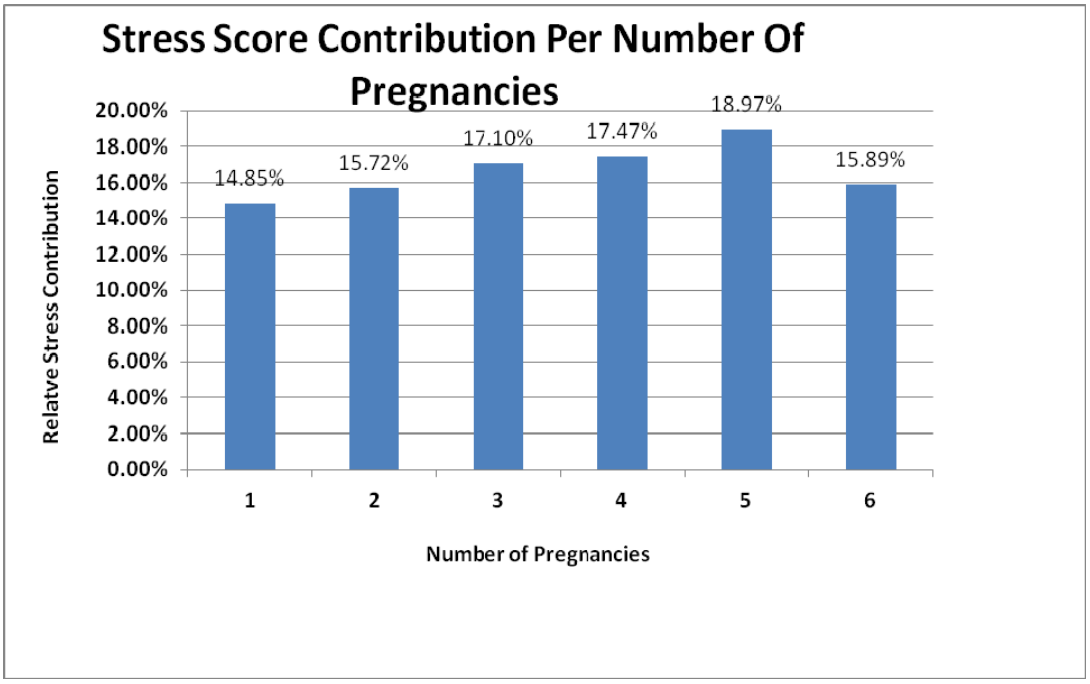

Figure 4.7: Stress score contribution per number of pregnancies.

4.7.1.5.5 Number of live children

A histogram of relative stress contribution per number of live children, showed a decrease in stress experienced as number of live children increases, especially between two and three live children.

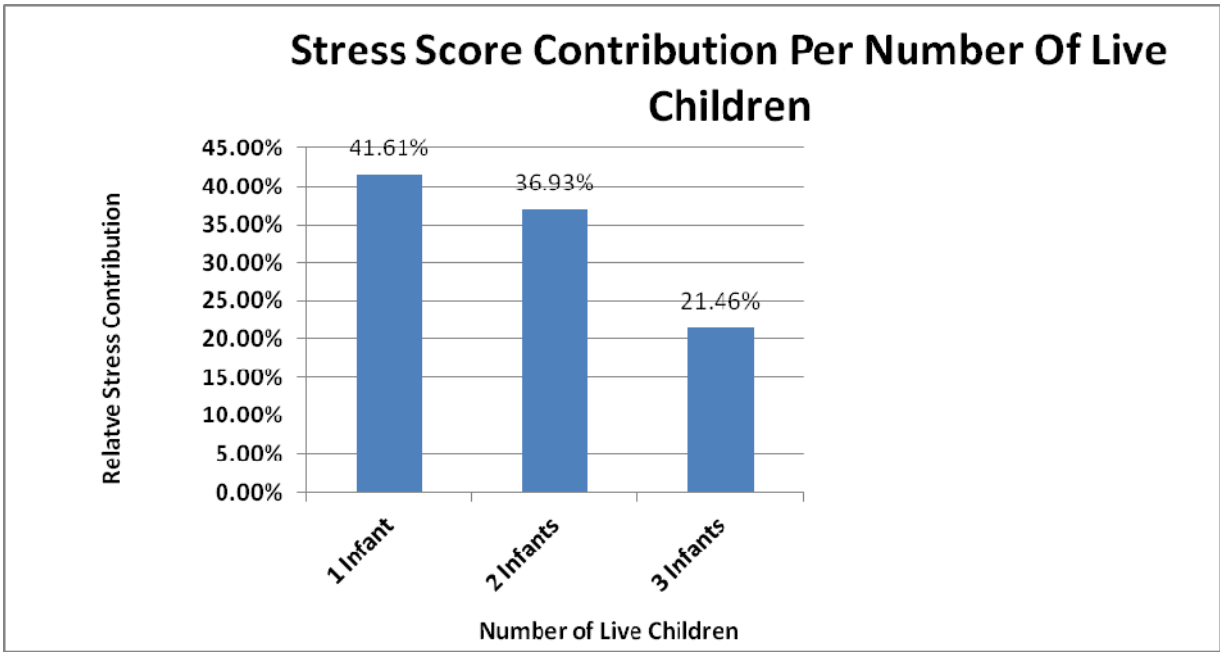

Figure 4.8: Stress score contribution per number of live children.

However, this was not shown to be statistically significant. The data for number of live children did not follow a normal distribution (Shapiro-Wilk W 0,80022, p = 0,000) and therefore Spearman's Rho was calculated for number of live children and the three factor subscales. No significant correlations were seen.

No significant correlation was seen between overall stress level and number of live children.

4.7.1.5.6 Previous infant admission to NICU

The data for those mothers who had previous experience of admission to NICU was separated from that of mothers who had no previous experience of admission to NICU. There were 13 mothers who had previously had an infant in NICU and 82 who had not been exposed to this experience. Averages for the data on each of the three factor subscales were calculated using the Excel program and then these data were compared by means of a bar chart.

Stress levels in the Looks and Behaves factor subscale appeared to be slightly higher for those mothers having the first experience of NICU than for those who had previously experienced admission of an infant to NICU. Both groups appeared to experience almost equal stress in the Relationship subscale. In the Practical Hassles subscale those mothers who had previous experience of NICU appeared to experience more stress than those experiencing NICU for the first time. The overall experience was equally stressful for both groups of mothers. The Practical Hassles subscale seemed to reflect less stress experienced in both groups than the Looks and Behaves and Relationship subscales.

Due to the small number of respondents who had previous experience of admission of a neonate to NICU, it was not possible to use inferential statistics to determine correlations in this group.

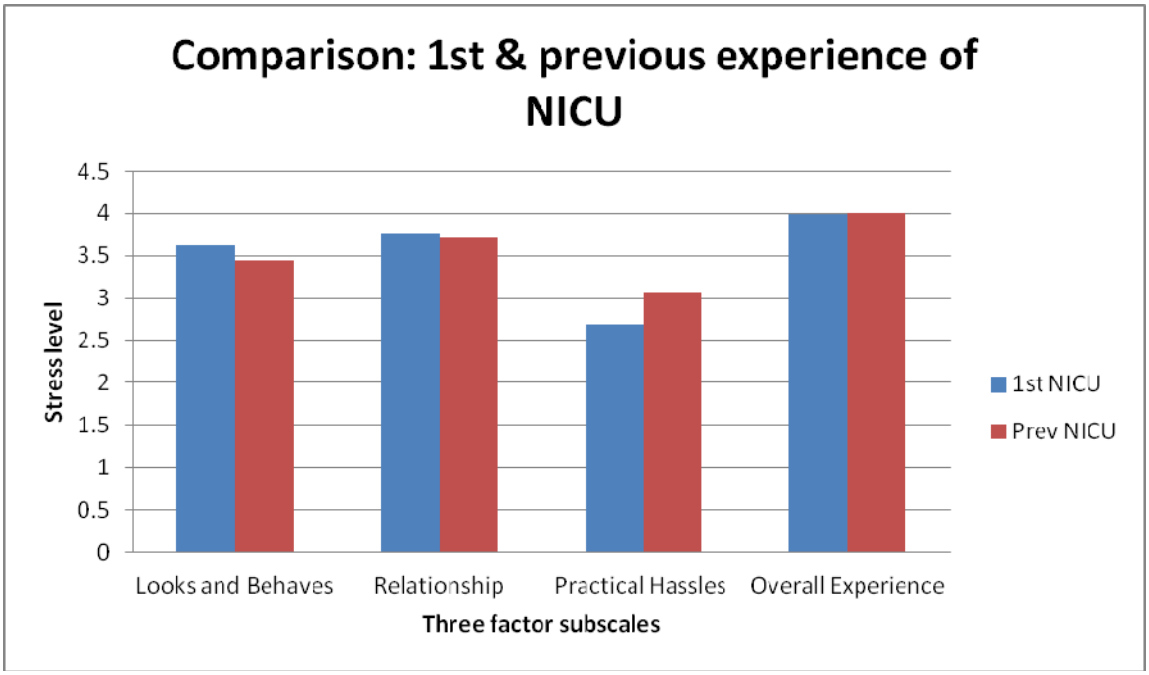

Figure 4.9: Comparison of stress levels in mothers experiencing NICU admission for the first time as against those with previous experience of NICU admission.

4.7.2 Second objective: *To explore and describe whether change occurs in the level and source of stress over a two week period by comparing level and source of stress experienced by mothers at 2 – 4 days and 10 – 14 days of the neonatal age*.

4.7.2.1 Differences in stress levels between first and second time point

Using the number that was randomly allocated to each respondent, the questionnaires from the first and second time points were matched. Twenty two pairs of questionnaires completed at both time points were available for analysis.

The data were arranged within the three factors, and then the average in each factor subscale was calculated for each respondent. This was done for both time points. The data for each subscale for the first and second time points were plotted in box and whisker plots and the median and inter-quartile ranges examined. There was very little difference between the medians and inter-quartile ranges for the two time points on the three subscales. The ranges for the data at the two time points were also very similar. It appeared from this examination that there was no difference in the data between the first and second time points for the twenty two respondents.

The Wilcoxon test for matched pairs was used to compare the data for the 22 respondents at the two time points. Each factor subscale was examined separately. The initial impression was confirmed since the Wilcoxon test did not reveal any significant differences between the data at the two time points for the 22 respondents.

There is a possibility that the failure to detect a difference between stress experienced at the first and second time points represents a Type II error, that is, failing to reject the null hypothesis (the hypothesis that no difference exists between the groups). It is possible that there may be a difference in the stress levels experienced at the two time points, which is not detected because of the small sample size.

4.7.3 Third Objective: *To make recommendations for preparation of NICU nurses to enable them to assist mothers effectively in coping with stress associated with the neonate's admission.*

Recommendations for preparation of NICU nurses to enable them to assist mothers to cope with stress associated with the neonate's admission to NICU can be made considering the findings from the above data analysis.

4.7.3.1 Findings which are important when considering the preparation of NICU nurses

From the descriptive and inferential analysis of the data, it appears that the following facets of the experience of mothers are important causes of maternal stress:

Descriptive Statistics - Looks and Behaves Factor

- Infant pain and discomfort.
- Feelings of powerlessness to help the infant in this situation.
- Factors which indicate a level of illness in the infant, such as sudden activation of monitor alarms.

Descriptive Statistics - Relationship Factor

- Separation of the infant and mother.

- Factors which prevent the mother from functioning in the maternal role (not being able to hold the infant, not feeding the infant herself.

Descriptive Statistics - Looks and Behaves, Relationship and Practical Hassles Factor

- Although mothers experience stress as shown by the three factor subscales, more stress is demonstrated in the **Relationship** and **Looks and Behaves** subscales than is shown in the **Practical Hassles** subscale.

Inferential Statistics - Correlations

- Maternal age is negatively correlated with the level of stress experienced.
- Overall level of stress experienced is positively correlated with infant birth weight. However, when considering the three individual factor subscales, there is no significant correlation with infant characteristics. Therefore, on the three subscales, the experience appears to be stressful regardless of infant characteristics such as gestational age and birth weight.

The above factors have been considered important in the preparation of NICU nurses and will be covered more fully in the following chapter.

4.8 Conclusion

The data available after data collection have been analysed using the Statsoft Statistica Version 11 program. The Research Objectives have been used to guide data analysis.

CHAPTER 5

5. DISCUSSION

5.1 Recruiting participants to the study

The participants were recruited to the study with consideration for the mothers' condition of emotional and physical vulnerability, in that mothers were approached after 24 hours of their infant's delivery. In the event of severe illness of the neonate or severe congenital abnormality of the neonate the mother was excluded from the study. The researcher presented the study to the mother on one occasion only and handed her the questionnaire, leaving her to make her decision regarding participation. In this way coercion to participate was avoided. If the father was with the mother at the time of the invitation to participate, he was included in the conversation relating to giving information to the mother, but it was stressed that the questionnaire was to be completed by the mother. The mother's attention was drawn to the fact that the NICU counselor was available should she be needed and that the telephone number of the counselor and researcher were contained in the information letter given with the questionnaire. This was the final contact between the researcher and the mother regarding the participation in the study. A poster was placed near the exit door and collection box reminding mothers to complete the questionnaire at the second time point.

The average length of stay for all neonates whose mothers were recruited to the study was 20,085 days. Of the 176 mothers who were recruited to the study, 95 mothers agreed to participate (54%) and submitted a questionnaire at the first time point. Given the average length of stay of infants, it was felt that the response at the second time point of only 22 mothers was disappointing (23% of the total number of participants). Perhaps an administered questionnaire

with an independent researcher administering the questionnaire, with parents in an interview situation, would have secured a larger first and second time point response. The small number of second time point responses has lessened the power to detect differences between the two time points in the statistical calculations.

5.2 Language of the respondents

One of the inclusion criteria for recruitment to the study was the ability to read and understand English. Just over half of the respondents gave their home language as English (53%). The second largest language group was Isizulu (11%), with the remainder being made up of a variety of African languages.

5.3 Omitted items

There were some items on the questionnaire that were omitted by respondents such as:

Q3.14 Resenting my baby for causing upheaval in my life – 36 responses.

Q4.14 Feeling worried about how my other children will feel about this baby – 40 responses.

These two questions represent the lowest number of responses, there being a varied number of responses to the items.

The reasons for the omissions are not known. Respondents may have omitted an item because they considered the information too personal, for example feeling guilty about resenting the infant may have led them to omit the answer. However, this is speculation as there is no evidence for this in the data.

The current pregnancy was stated as being the first for 46% of the respondents and this appears to be the reason for only 40 responses to Q4.14 (Feeling worried about how my other children will feel about this baby), since 46% of the respondents did not have other children. (Percentages have been rounded off).

5.4 The age of the respondents

The mean of mother's age was 31,12 years with a standard deviation of 6,415. The minimum age was 19 years and the maximum 54 years. It is interesting to note that the hospital where the NICU is located has an infertility treatment facility and the 54 year old mother may have become pregnant as a result of infertility treatment. The location of the infertility treatment facility in the hospital results in many multiple pregnancies, some of the neonates being admitted to the NICU. It is not known how many of the pregnancies, multiple or singleton were the result of infertility treatment.

5.5 Birth weight and gestational age

Infant birth weight ranged from 585 g to 4100 g with a mean of 2329,91g (SD 776,70). The mean of the duration of pregnancy was 34,81 weeks with a standard deviation of 3,465 weeks. It is interesting to note that the mean birth weight is just under the 50th centile of birth weight for the mean gestational age. The neonates are, on average, appropriate in weight for gestational age, which possibly reflects the fact that the mothers are from a population whose standard of living includes medical insurance (in order to be able to afford to be in a private hospital) and antenatal care.

The median value for gestational age is 35 weeks. Despite the fact that half of all infants in the study were born before 35 weeks of gestational age, there is an increase in number of births at 38 weeks. This possibly reflects planned delivery by Caesarean section at 38 weeks. The total number of deliveries for the period of the study were 1 502, of which 1 175 were Caesarean sections.

As described in the data analysis, there was no significant correlation between gestational age and stress. This is supported by the findings in a study where stress levels were objectively measured by measuring cortisol levels in parents of premature and term neonates in special care nurseries. The parents of these neonates experienced elevated stress levels, even though these neonates were not critically ill and the stress levels were comparable to those of parents of critically ill neonates (Lau and Morse, 2003). The findings of the current study, and the study by Lau and Morse, suggest that it is the admission of the neonate to the NICU that is stressful and that gestational age does not have an effect on the level of the stress experienced. This is contrary to the findings of two other studies where it was found that gestational age is negatively correlated with stress levels (Dudek-Shriber, 2004, Chourasia, Surianarayanan, Adhisivam & Visnu Bhat, 2013).

Pearson's r calculations between infant birth weight and data obtained on the three factor groupings did not show any correlation. This indicates that the stress revealed by the items on the subscales did not vary with infant birth weight. Viewed another way, whether the infant was small or large, stress related to the three factor subscales remained unchanged. However, the overall stress level was found to be positively correlated with birth weight, meaning that as infant

birth weight increased stress levels increased. This could be because as as pregnancy approaches term, it is thought that the mother has invested in the pregnancy and relationship with the unborn infant for an extended period of time. Viewed in terms of the Conservation of Resources theory, after substantial investment of resources, the mother may be faced with the morbidity and mortality of the infant, and therefore, considerable loss. This is in conflict with the findings in one of the above mentioned studies where infant birth weight was negatively correlated with stress levels (Dudek-Shriber, 2004).

5.6 Previous pregnancy and number of live children

The number of mothers having 1, 2 and 3 live children (46%, 33% and 13% respectively) is similar to the number of mothers having had 1, 2 and 3 pregnancies (46%, 32%, and 13% respectively). There is a discrepancy between the number of mothers having had 4, 5 and 6 pegnancies and number of live children, possibly due to the inclusion of mothers who have had a poor obstetric history with unsucessful pregnancies. This is seen in that 6% of mothers had been pregnant four times but only 3% of mothers had four live children.

The data for previous pregnancy and stress levels did not show any correlation and this supports the view that mothers are stressed with admission of the neonate to NICU regardless of the maternal parameter. This is supported in the literature (Chourasia et al., 2013).

5.7 Previous admission of a neonate to NICU

The vast majority of mothers (84%) had not had previous experience of admission of a neonate to NICU. It is thought that being exposed to the NICU experience for the first time may be

stressful for mothers and for this reason this question was asked in the demographic questionnaire. Because of the very small number of mothers who had had previous experience of neonate admission to NICU, it was not possible to perform statistical analysis on the data.

A bar chart comparing the stress scores in the three factor subscales of mothers with previous experience of NICU admission with those of mothers with no previous experience of NICU admission does, however, show a difference between the two groups. In the Looks and Behaves and Relationship factor subscales, those with no previous experience demonstrated higher stress levels compared with those who have previously had a neonate admitted to NICU. In the Practical Hassles subscale, those with previous experience of admission to NICU demonstrated higher stress scores, perhaps because they had at least 1 child at home who required care. The overall stress experienced by both groups appeared to be the same.

5.8 Discussion in relation to the research objectives for the study

5.8.1 First objective: *To explore and describe the level and source of stress experienced by mothers of neonates in the NICU using the NUPS Scale.*

5.8.1.1 Looks and Behaves factor

The items which made up this factor received a high number of responses, possibly indicating that the items were considered relevant by the respondents. The reason for the high number of responses to this section could also have been that the items were at the beginning of the questionnaire, since it was noted that the items at the end of the questionnaire received fewer responses. The question of whether the questionnaire was too long exists, although the pilot

study did not yield that impression. A high number of responses was given to items 1.3 (The sudden noises of monitor alarms), 3.6 (Feeling helpless about how to help my baby during this time and 3.9 (Feeling worried about how my baby will grow and develop), indicating that the respondents identified with the item or possibly considered the item important.

The items in the Looks and Behaves factor relate to the neonate's appearance, movements of neonate, breathing patterns, neonatal pain and suffering, and the clinical interventions such as being fed by an intravenous line, being monitored, and tubes and equipment being on or near the neonate. Two of the items related to the neonate's future health and growth and development.

All except one item scored above 'Moderately Stressful" (3) on the scale. The one item that scored below 3 (Moderately Stressful) was Item 1.1 (The presence of monitors and equipment – mean 2,766 SD 1,382). The presence of monitors and equipment therefore causes a little stress, or no stress (considering the standard deviation of the score as being an indicator of the wide variation of the scores). The reason for this low score is thought to be because care is improved when the neonate is monitored, alerting the nurse to changes in condition.

Three items, all related to infant suffering, were the highest scoring in this section. These were Item 3.5 (Feeling helpless and unable to protect my baby from pain and painful procedures – mean 4.411 SD 0,993), Item 3.6 (Feeling helpless about how to help my baby during this time – mean 4.366 SD 0,999) and Item 2.7 (When my baby seemed to be in pain – mean 4.294 SD 1,125).

The three highest scoring items all reflect a feeling of helplessness on the part of the parent in the face of infant pain. The aspect of helplessness to protect the infant from pain has been described as the worst part of the NICU experience by mothers in a study by Wereszak, Miles and Holditch-Davis (Franck et al., 2004). The inability to protect the infant during painful procedures has been found to contribute to the development of Acute Stress Disorder in parents (Shaw et al., 2006) and parents may experience strong feelings of anger towards the nurse or doctor inflicting pain on the infant (Reid, 2000).

It is known that pain pathways are established in the preterm infant as early as 20 - 24 weeks gestational age, and that neonates experience greater hormonal, metabolic and physiological instability as a result of pain than do older infants, children and adults (Anand, Phil & Hickey, 1987, Anand, 2001, Sharek, Powers, Koehn & Anand, 2006). Furthermore, critically ill preterm and term neonates may not present a vigorous response to pain and determining pain experience in these infants requires very careful assessment. Despite this knowledge, many neonates are subjected to painful procedures without any analgesia or comfort whatsoever (Anand 2001, Simons, van Dijk, Anand, Roofthooft, van Lingen & Tibboel, 2003). In a study of procedural pain in a NICU, it was found that neonates experienced a mean of 14,3, SD 4, painful procedures per day. The range of procedures experienced per neonate was between 0 and 53. Up to 65% of these infants did not receive analgesia (Simons et al., 2003). In addition to the experience of pain at the time of the procedure, neonates may have the capacity to remember the painful experience, with long term consequences (Anand et al., 1987).

A study in which the parents' feelings and distress regarding neonatal pain were examined, revealed that parent stress experienced was proportional to the parent's estimation of the neonate's worst pain (Franck et al., 2004). Parents were worried about the short and long term effects of pain on the neonate, and desired to be given information on the pain experienced and measures to alleviate pain.

Parents had a need for effective communication from the medical and nursing staff where information was given in sufficient detail but which was still comprehensible (Cescutti-Butler and Galvin, 2003, Cleveland, 2008). Parents, as the primary advocates for their neonates, expressed a desire to be offered the opportunity to stay with the neonate during procedures, or to withdraw at that time, and had a need to be shown how to comfort their neonates. Protecting the infant from pain inflicted during clinical procedures is part of advocacy for the infant, and this corresponds with a general desire among parents a for greater role in advocating for the neonate in NICU (Partridge et al., 2005a). It is therefore considered very important to empower parents in their role as advocates for the neonate.

Although the parent is regarded as the primary advocate for the neonate, this advocacy may be limited because of the parent's limited knowledge relating to medical and nursing care of the neonate. The nurse has a part to play here, both in that she/he is a source of information for the parent, and in that she/he can advocate for the patient in collaboration with the parent, and as a member of the health care team (Monterosso, Kristjanson, Sly, Mulcahy, Holland, Grimwood & White, 2005).

Instruments exist to facilitate the measurement of neonatal pain, such as the Faceless Acute Neonatal Pain Scale (Milesi, Cambonie, Jacquot, Barbotte, Mesnage, Masson, Pidoux, Ferragu, Thevenot, Mariette & Picaud, 2010), for example, as well as others. Suggested strategies for the management of neonatal pain are available, such as those provided in the Consensus Statement for the Prevention and Management of Pain in the Newborn (Anand, 2001), as well as the Potentially Better Practices of the NIC/Quality Collaborative of the Vermont Oxford Network (Sharek et al., 2006). It is extremely important that nurses working in the NICU become aware of the pain their neonatal patients endure, and that pain is correctly monitored and adequately treated. This requires that NICU nursing courses incorporate information on pain and pain relief and that assessing and treating neonatal pain becomes part of hospital and NICU policy. Nurses working in NICU must be able and willing to share information with parents and encourage parents to provide non-pharmacologic comfort measures, and to advocate for their neonates in order to provide pain relief.

If one considers the converse of helplessness as being empowered with the ability and knowledge to help their neonates, parents need information relating to neonatal pain care (Franck et al., 2004).

5.8.1.2 Relationship factor

The relationship factor is made up of items which reflect the functions that a mother performs and as such these actions are important in forming attachment to the infant, maternal role attainment and ultimately the development of maternal identity. Certain of the items seem to cluster around development of the maternal role such as the following:

- 3.1 Being separated from my baby.
- 3.2 Not feeding my baby myself.
- 3.3 Not being able to care for my baby.
- 3.4 Not being able to hold my baby when I want.
- 3.7 Not being able to be alone with my baby.
- 3.16 Feeling worried about going home without my baby.
- 4.13 Not having as much time as I would like with my new baby.
. 3.13 Not feeling like a parent yet.

The remaining items in this factor represent feelings of anger, guilt and jealousy related to not being able to perform the mother role, such as:

- 3.10 Feeling angry that my baby has been born early/sick.
- 3.11 Feeling guilty that my baby has been born early/sick.
- 3.12 Feeling jealous that the nurses are with my baby when I'm not there.
- 3.14 Resenting my baby for causing upheaval in my everyday life.

The items in this section had a wide ranging number of responses, Item 3.1 (Being separated from my baby) having the highest number of responses (95 responses) and Item 3.14 (Resenting my baby for causing upheaval in my everyday life) receiving only 36 responses.

The responses to items which reflected a high level of stress experienced are discussed below. With regard to Item 3.14 (Resenting my baby for causing upheaval in my everyday life), this received only 36 responses, and mean stress score was 1,89 (SD1,449). This reflects stress experienced between the level of 'not at all stressful' and 'a little stressful'. The spread of values

is great, as can be seen from the standard deviation. Literature to support or refute the feeling of resentment towards the neonate in the NICU by the mother was not found.

Item 3.1 (Being separated from my baby) represents a contradiction of the core of the mother role – being present with the infant, and attachment to the infant and this may be the reason for the high number of responses. The mean of responses to Item 3.1 was 4,414 (SD 1,009), and it can be seen from this that the level of stress evoked by this item was at the level of 'very stressful' to 'extremely stressful'. Other items which were rated as very stressful on average by the respondents were Item 3.4 (Not being able to hold my baby when I want) with a mean of 4,34 (SD 1,097), Item 3.16 (Feeling worried about going home without my baby), (mean 4,280, SD 1,033) and Item 3.2 (Not feeding my baby myself) (mean 4,172, SD 1,069). These items represent emotions and actions that are at the core of the role of mother and it is therefore not surprising that they evoke a response indicating a severe to extreme level of stress.

Development of the maternal role and ultimately maternal identity is dependent on the mother being present with the infant, learning mothering behaviors such as feeding, changing, and learning infant behavioral cues and their meaning (Koniak-Griffin, 1993, Mercer, 2006). On the other hand, separation results in an unfulfilled need to parent the infant and the parent not feeling like a parent, that is not identifying with the role of parent (Gavey, 2007, Heermann et al., 2005, Shaw et al., 2006). It appears that the responses of the mothers to the items in the Relationship section of the questionnaire are confirmed by the literature in that the frustration of the drive to mother the neonate and remain close to the neonate is the cause of great stress.

In a systematic review (Cleveland, 2008) it was found that parents felt a need to be near their neonate, to be involved in providing care to the neonate and to have physical contact with the neonate. Nurses were perceived as the "gatekeepers" who regulated the amount of time the mother spent with the neonate. Mothers felt that they were parenting "from a distance" and often felt useless. This type of care was seen as provider centered rather than family centered.
The feeling of jealousy experienced by the mother because the nurses are present with the infant and the feeling of being unwelcome at the baby's bedside has been described in the literature (Schenk and Kelley, 2010), and the feeling of being an outsider, not involved, has been described (Heermann et al., 2005). In the data of the current study, Item 3.12 (Feeling jealous that the nurses are with my baby when I'm not there), (mean 2,6, SD 1,564) was rated as between 'a little stressful' and 'moderately stressful', and this is apparently supported by the findings in the study by Schenk and Kelley.

The negative feelings of the mother in relation to the nurse are supported in the literature and the conflict between the nurse and the mother was described as a situation which the mother would not be able to successfully negotiate, with the nurse removing herself from the neonate's care and the mother being labeled as difficult (Cleveland, 2008). Mothers were described as feeling a need to ingratiate themselves with the nurses in order to be perceived positively.

In a study of effective nurse – parent communication it was found that mothers wanted to be seen as equal partners in the care of their neonates, where the nurse and the mother collaborate to provide care for the neonate (Jones, Woodhouse & Rowe, 2007). This study revealed that mothers wanted to participate in the care of the infant and to have some control over the care.

In line with the concept of the nurse and mother as partners in the care of the infant, is the concept of a negotiated partnership, where the nurse perceives the mother's readiness for involvement in care and guides her cautiously in care giving activities, remaining as a constant presence and providing affirmation to the mother in her mothering activities (Reis et al., 2010). In a systematic review, Cleveland wrote of a therapeutic relationship between the mother and the nurse, in which the nurse guided the mother to provide care for the neonate in a non-judgemental and facilitative environment (Cleveland, 2008).

From the above it can be seen that the nurse is in a unique and powerful position to provide mothers with opportunities to get to know their neonates and to gain confidence in the mother role. When nurses function to empower mothers in the care of their neonates, it may be possible to minimize the severe distress mothers experience when separated from their neonates.

5.8.1.3 Practical Hassles and Social Relationship Strains factor

There were generally fewer responses to the items in this factor than in the **Looks and Behaves** and **Relationship factors.** This is thought to be due to the fact that the questionnaire was completed between 2 and 4 days of the neonate's life at the first time point. Mothers who have undergone Caesarean section in the private hospital were discharged from hospital on the 4th day after surgery and therefore, at the time of first completion of the questionnaire, they had not yet experienced a lot of the difficulties described in these items.

The item which had the fewest responses was Item 4.14 (Feeling worried about how my other children will feel about this baby), with 40 responses (42%). This probably resulted from the fact that 46% of mothers had been pregnant once and had one live child and therefore they had not had the experience of worrying about how other children would feel about the new baby.

The three highest scoring items, Item 4.1 (Having to keep cheerful when I don't feel like it – mean 3.272 SD 1,191), Item 4.3 (Feeling that no-one knows how I feel – mean 3,094 SD 1,517) and Item 4.2 (Not having enough time to do everything – mean 3,064 SD 1,272) all scored at the level of 'Moderately Stressful"' or a '3'. These responses seem to indicate the mothers experiencing a lack of empathy for their situation and feeling pressured in terms of time to do everything required. There is great pressure on the mothers in this unit to produce breast milk and to express breast milk, initially manually and then using a breast pump, and to do this three hourly in order for the neonate to be fed exclusively breast milk. It is thought that the Item 4.2 (Not having enough time to do everything) may reflect this pressure. However, previously, it was found that providing the neonate with breast milk was seen by the mother as one of the few things she could do, and reduced stress levels (Chourasia et al., 2013).

5.8.1.4 Correlation between scores on NUPS Scale and demographic characteristics

The impression gained from a histogram in the Excel program was that the youngest mothers experienced the most stress in the Looks and Behaves and Relationship factor subscales, and that stress decreased as maternal age increased. This was confirmed by calculating Pearson's r using the Statistica program. Significant negative correlations were obtained between both factor subscales and maternal age (Refer to Table 4.9).

The negative correlation between stress demonstrated on the Relationship subscale and maternal age is supported in the literature (Reid, 2005).

A study using the Parental Stress Scale:NICU which was developed by Miles et al.,(Miles et al., 1993) showed an increase in stress level as maternal age increased, and stress levels of mothers of preterm infants was higher than that of mothers of term infants (Chourasia et al., 2013). These findings are contrary to the findings in the current study, in that maternal stress levels are negatively correlated with maternal age, and were not found to be correlated with neonatal characteristics, such as gestational age and birth weight. It appears that the mother is stressed when her neonate is a patient in the NICU, regardless of size or gestational age of the neonate. This finding is supported by the findings in the study cited above, where physiological indicators of stress in the mother were measured (Lau and Morse, 2003)

The data for those mothers who had previous experience of admission to NICU was separated from that of mothers who had no previous experience of admission to NICU. There were 13 mothers who had previously had an infant in NICU and 82 who had not been exposed to this experience. Averages for the data on each of the three factor subscales were calculated using the Excel program and then these data were compared by means of a bar chart.

Stress levels in the Looks and Behaves factor subscale appeared to be slightly higher for those mothers having the first experience of NICU than for those who had previously experienced admission of an infant to NICU. Both groups appeared to experience almost equal stress in the Relationship subscale. In the Practical Hassles subscale those mothers who had previous

experience of NICU appeared to experience more stress than those experiencing NICU for the first time. The overall experience was equally stressful for both groups of mothers. The Practical Hassles subscale seemed to reflect less stress experienced in both groups than the Looks and Behaves and Relationship subscales.

5.8.2 Second objective: *To explore and describe whether change occurs in the level and source of stress over a two week period by comparing level and source of stress experienced by mothers at 2 – 4 days and 10 – 14 days of the neonatal age*.

As seen in section 4.7.2.1, there was no significant difference found between the stress experienced by mothers at the first and second time point in either the factor subscales or the overall stress item. As stated above, there were only 22 respondents who returned the questionnaires at the second time point and it is possible that either no change occurs in stress levels over the two week period or that the study failed to detect a difference which exists between the data at the first and second time points. The literature survey for this study did not reveal any studies which examined the change in stress levels in the mother over the first two weeks of life of neonatal life, with the exception of the study by Reid during which the NUPS scale was developed. This study revealed a significant difference in overall stress experienced between time 1 and time 2, the stress level for mothers being lower at time 2 (Reid, 2005). A study which measured physiological indicators of stress in the mother at birth, at one week of age and at discharge of the neonate from hospital showed a reduction of stress over time (Lau and Morse, 2003). However, these results are not comparable with those of the current study since the measurement intervals in the two studies were different.

As explained in Chapter 4, Paragraph 4.7.2.1, there is a possibility that the failure to detect a difference between stress experienced at the first and second time points represents a Type II error, that is failing to reject the null hypothesis (the hypothesis that no difference exists between the groups). It is possible that there may be a difference in the stress levels experienced at the two time points, which is not detected because of the small sample size. In order to determine the accuracy of this finding, it would be necessary to repeat the study using a methodology which ensures a greater number of second time point respondents.

5.8.3 Third Objective: *To make recommendations for preparation of NICU nurses to enable them to assist mothers effectively in coping with stress associated with the neonate's admission.*

Recommendations for preparation of NICU nurses can be made when the findings are considered in terms of the three factor subscales.

In order to become a reality, the recommendations should form part of the competencies and curricula for Neonatal Intensive Care Nursing courses that may be established in the future. Nurse Educators and Clinical Teaching Associates in the nursing education institutions would be instrumental in providing the theoretical background for the recommendations. Clinical Supervisors and Clinical Preceptors in the NICU would be responsible for ensuring that the recommendations are put into practice. Close collaboration between educators in the nursing education institutions and those in the clinical areas is necessary.

The findings and recommendations should be shared with interest groups such as the Neonatal Nurses Association of Southern Africa, the South African Neonate, Infant & Toddler Support Association and the Neonatal Forum in the hope that the focus on family centered care and the needs of the mother and neonate become central to neonatal nursing practice.

5.8.3.1 Preparation of NICU nurses in relation to neonatal pain

In order to provide effective pain control in neonates, the nurse must undergo preparation which provides information on pain, and pharmacological and non-pharmacological pain control in neonates.

It is important that NICU nurses are provided with information relating to the following points.

- Courses should include information relating to the use of pain scales to assess neonatal pain. In the clinical setting, pain scales should be chosen with a view to established validity and reliability and should be suitable for use in the clinical setting. This should be part of a collaborative process in which clinical and nursing staff members become fully involved in the relief of neonatal pain (Duhn and Medves, 2004).
- Preparation of NICU nurses should include information on communication with parents, and the kind of information that it would be within the scope of nursing practice to provide. Parents require information regarding the type of pain the neonate suffers and pain medication the neonate is receiving, as well as measures such as facilitated tucking, holding, skin to skin care, all of which have been shown to provide comfort to the neonate (Axelin et al., 2010, Franck et al., 2012). This information can be provided by the nurse who has an understanding of pain and measures to relieve it.

- It is important that mothers are given a choice to remain with the neonate to provide comfort during painful procedures, or to withdraw (Cescutti-Butler and Galvin, 2003, Franck et al., 2004). The nurse is responsible for supporting the mother no matter what her decision is in relation to remaining with the infant during procedures. It is important that nursing education prepares the NICU nurse for this role.

5.8.3.2 Preparation of NICU nurses in relation to maternal/neonatal relationship

Considering the situation when a normal vaginal delivery occurs without complications, the mother sees, holds and breast feeds her neonate immediately after birth and, in optimum circumstances, shares the event with her partner and family. The emotional connection with the neonate is continued throughout the process, with the neonate remaining with the mother, and the mother functioning in the mother role from the outset. Conversely, the birth of a premature or ill neonate most often necessitates the separation of the mother from her child and represents a poor and disappointing substitute for the event the mother had envisaged.

The current study has shown increased stress in relation to being unable to function in the normal mothering role because of separation from the neonate, not being able to provide care for the neonate (in terms of holding and feeding), and ongoing separation (going home without the neonate). Stress is experienced by the mother, to a lesser extent, due to resentment of the nurse being in a position to provide care to the neonate.

Considering the findings in the current study, preparation of the NICU nurse should incorporate the following aspects:

- The approach to facilitation of maternal role development in each mother-neonate situation is individualized, since individual mother-neonate situations have different needs (Schenk and Kelley, 2010).
- The nurse is in a unique and strong position to facilitate development of maternal role and identity through the formation of supportive relationships (Fenwick et al., 2001, Schenk and Kelley, 2010), possibly in the form of negotiated partnerships, where the nurse provides the environment and encouragement for the mother to learn to care for neonate, and offers information, encouragement and positive affirmation during performance of tasks which are part of the mother role (Reis et al., 2010). This requires a well developed sense of advocacy in the nurse, where she/he will focus on the best care, both clinical and emotional, for the neonate and the mother.
- Viewing the nurse-patient relationship in terms of Hobfoll's Conservation of Resources theory, the nurse becomes part of the social support structure for the mother. In the South African context, it is often the nurse who shares information most effectively with the parents as she/he may have more in common with the parents culturally and linguistically than medical staff in the NICU (Ranchod et al., 2004). Nurses have a key role in supporting parents in the NICU (Cescutti-Butler and Galvin, 2003), and preparation of nurses should enable them to perform this role.
- The concept of family centered care should be central to nursing care plans for patients in the NICU. Taking into account the concept of family centered care requires considering the mother, or parents, as partners in the care of the neonate and also as the primary advocates for the neonate's health care. Numerous studies have shown that parents have a strong desire to be involved in their neonate's care (Fenwick et al., 2001, Heermann et

al., 2005, Schenk and Kelley, 2010, Cescutti-Butler and Galvin, 2003), and they should be regarded as partners in the neonate's care. This requires a shift in power relationships in nursing, where the patient is often in a subordinate position in relation to the nurse.

Personnel of the NICU should prioritize sharing information with the parents, and involve them in decision making regarding the neonate's health care.

- Nursing courses should incorporate information, which enables the nurse to understand that, regardless of neonatal condition, NICU admission is a very stressful event for the mother.
- Maternal age impacts on maternal stress experience, in that younger mothers experience more stress than older mothers do. Nurses must be prepared to show empathy to the mother and to meet her needs.

5.9 Conclusion

The findings yielded by the descriptive and inferential analysis of the data have been discussed in relation to the research objectives.

NICU nurses are in a unique and powerful position to assist mothers coping with the admission of their neonates to NICU. The preparation of these nurses requires a collaborative approach by Nurse Educators and Clinical Teaching Associates in the nursing education institution, with Clinical Preceptors and Clinical Supervisors in the NICU.

CHAPTER 6

6. CONCLUSION

6.1 Summary of causes of maternal stress

The causes of moderate to severe maternal stress, in terms of the NUPS Scale, are summarized as follows.

6.1.1 Looks and Behaves Factor

- Neonatal pain and discomfort.
- Feelings of powerlessness to help the infant in this situation.
- Factors which indicate an increasing level of illness in the infant, such as sudden activation of monitor alarms.

6.1.2 Relationship Factor

- Separation of neonate and mother.
- Factors which prevent the mother from functioning in the maternal role (not being able to hold the neonate, not feeding the neonate herself, going home without the neonate, and not able to be present continuously).
- Resentment of the nurse who is with the neonate, and providing care to the neonate that the mother feels she should be providing.

6.1.3 Practical Hassles and Social Relationship Strains Factor

- It appears that the mothers in this study experienced a lack of empathy for their situation, as well as time pressure considering tasks they had to perform.

6.1.4 Correlations

- There is a negative correlation between maternal age and level of stress experienced.
- Overall level of stress experienced is positively correlated with infant birth weight.

- When considering the three individual factor subscales, there is no significant correlation with infant characteristics.
- On the three subscales, the experience appears to be stressful regardless of infant characteristics such as gestational age and birth weight.

Although mothers experience stress as shown by the three factor subscales, more stress is demonstrated in the **Relationship** and **Looks and Behaves** subscales than is shown in the **Practical Hassles** subscale.

6.2 Limitations

6.2.1 Second time point responses

The small number of respondents to complete the questionnaire at the second time point (23,15% of total number of respondents) is considered to be a limitation of the study in that it has lessened the statistical power to detect differences that may actually exist between responses at the first and second time points. Given the average length of stay of infants, it was felt that the response at the second time point of only 22 mothers was disappointing. Perhaps an administered questionnaire, with parents in an interview situation would have secured a larger first and second time point response.

6.2.2 The location of the NICU

The study has been carried out in a large, private hospital NICU. An infertility treatment facility exists at the hospital, and this may result in a greater number of multiple births than exists in NICU facilities in hospitals that do not provide infertility treatment. Additionally, the patient

demographic characteristics may be different from that of patients attending public sector hospitals. For these reasons it would not be possible to generalize the findings from this study to the wider population of Gauteng.

6.2.3 Incidence of Caesarean section births

The private hospital which served as the location for the study has a high incidence of Caesarean section births. For the period under study the total number of births was 1 502 and of Caesarean section births was 1 175 (78,22%). This fact has two possible implications for the current study. The first is that the study may be biased in that it may more accurately represent the experience of mothers who have undergone Caesarean section, and this may be different from the stress experienced by mothers who have undergone a normal delivery.

The second implication of the bias in favor of Caesarean section births, is that the Practical Hassles and Social Relationship Strains section of the NUPS questionnaire may not have accurately reflected maternal experience at the first time point. After Caesarean section mothers are discharged home on day four, which was the time limit for the first time response. At the first time point completion of the NUPS questionnaire, these mothers would not yet have had the experience of competing demands of home life and visiting an ill neonate in the NICU. It is not known how many of the respondents to the study underwent Caesarean section delivery.

At day four, however, the mothers would be under considerable pressure to produce breast milk and would be facing the fact of leaving the hospital without the neonate, which has been shown to be a source of stress.

6.3 Recommendations for Further Research

A large study using the NUPS questionnaire is recommended, located in public and private sector NICU's. It would be possible to generalize findings from such a study to the wider population in Gauteng. This should be carried out using an administered questionnaire, which hopefully will result in a greater percentage of second time point responses.

A qualitative study exploring the mother's experience of mothering in NICU, would provide valuable insights which have possibly been overlooked because of the structured nature of the questionnaire. The insights which would be gained are important because the nurse's role in relation to the mother and the neonate is evolving and it is vital to continue to examine ways in which nursing practice can be improved, and to implement improvements.

6.4 Conclusion

The main findings of the study have been summarized in terms of the NUPS questionnaire.

Limitations of the study have been considered and are as follows; the small number of second time point responses, the high incidence of Caesarean section births and lack of generalizability of the study to the wider Gauteng population.

Recommendations for future research into stress experienced by mothers of neonates admitted to NICU have been made. A large quantitative study using the NUPS questionnaire in public and private sector NICU's is recommended, as well as a qualitative study examining the maternal experience of mothering in NICU.

ANNEXURE A

INFORMATION RELATED TO THE STUDY ENTITLED:

STRESS EXPERIENCED BY MOTHERS OF NEONATES IN A PRIVATE HOSPITAL NICU.

Dear Parent,

My name is Lauren Buys and I am an MSc Nursing student at the University of the Witwatersrand. I would like to study the stress experienced by mothers of infants admitted to the NICU.

I am inviting you to participate in the study as your experience of stress during the time of your baby's admission to NICU is most important to the successful completion of this study. With your help, I hope to obtain information about the stress mothers experience which can be used to enable nursing personnel to meet mothers' needs more effectively in the future.

Should you agree to participate, the following will be required of you:

- Complete the yellow questionnaire between 2 and 4 days after your newborn baby's admission to NICU.
- Complete the pink questionnaire between 10 and 14 days after your newborn baby's admission to NICU.
- There will be a box placed near the entrance of the NICU for return of the questionnaires. Please place the completed questionnaires in the provided envelope in the box.
- Should you not wish to participate, please place the blank questionnaires in the provided envelope in the same box.

Pto.

The yellow and pink questionnaires will be marked with the same random number, to enable the matching and comparing of results on your first and second questionnaire. The questionnaire takes approximately 10 minutes to complete.

A notice will be placed near the box to remind mothers who have made the decision to participate, to complete the questionnaire at the second time point.

Confidentiality Issues

Your name will not appear on the questionnaires and your participation or non-participation will be anonymous. Your decision to participate or not to participate will not in any way impact on the care your baby receives. Caring for your baby in the NICU and yourself will always be our primary objective.

Counseling support

The NICU counselor, Ms Rachelle Baitz, is available to all parents of babies who are inpatients in the NICU on a daily basis as a free of charge service. She is present in the unit every week day and she can be contacted on 082 4487 547. Should you feel in need of support or wish to speak to her, please feel free to contact her.

Should you wish to contact me, my telephone number is 079.490.7185

Sincerely,

Lauren Buys.

ANNEXURE B

PATIENT INFORMATION

HOME LANGUAGE:
MOTHER'S AGE:
HOW MANY PREGNANCIES HAVE YOU HAD?
HOW MANY LIVE CHILDREN DO YOU HAVE?
HAVE YOU HAD AN INFANT ADMITTED TO NICU IN THE PAST?
INFANT: GESTATIONAL AGE (the duration of the pregnancy):
INFANT: BIRTH WEIGHT:

ANNEXURE C – 3 Factor for analysis

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 your baby may have received. 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 = not at all stressful, 5 = extremely stressful).

2.1	Tubes and equipment on or near my baby	NA	1	2	3	4	5
1.1	The presence of monitors and equipment	NA	1	2	3	4	5
3.5	Feeling helpless and unable to protect my baby from pain and painful procedures	NA	1	2	3	4	5
3.6	Feeling helpless about how to help my baby during this time	NA	1	2	3	4	5
3.9	Feeling worried about how my baby will grow and Develop.	NA	1	2	3	4	5
1.2	The constant noises of monitors and equipment	NA	1	2	3	4	5
1.3	The sudden noises of monitor alarms	NA	1	2	3	4	5
2.2	Bruises, cuts or wounds on my baby	NA	1	2	3	4	5
2.3	My baby's unusual or abnormal breathing patterns	NA	1	2	3	4	5
2.4	The small size of my baby	NA	1	2	3	4	5
2.5	Seeing needles and tubes put into my baby	NA	1	2	3	4	5
2.6	My baby being fed by an intravenous line or tube	NA	1	2	3	4	5
2.7	When my baby seemed to be in pain	NA	1	2	3	4	5
2.8	When my baby looked sad	NA	1	2	3	4	5
2.9	Jerky or restless movements of my baby	NA	1	2	3	4	5

2.10 When my baby looks uncomfortable	NA	1	2	3	4	5
2.11 My baby not being able to move around properly	NA	1	2	3	4	5
2.12 Feeling worried about my baby's future health.	NA	1	2	3	4	5

The next aspect we want to ask you about is how you feel about your own **RELATIONSHIP** with your baby and your role as a parent. If you <u>have experienced</u> the following situations or feelings, indicate how stressed you have been by them, by circling the appropriate number (1 = not at all stressful, 5 = extremely stressful). Again, circle NA if you <u>did not experience</u> the item.

3.1 Being separated from my baby	NA	1	2	3	4	5
3.2 Not feeding my baby myself	NA	1	2	3	4	5
3.3 Not being able to care for my baby myself (for example, nappy changing, bathing)	NA	1	2	3	4	5
3.4 Not being able to hold my baby when I want	NA	1	2	3	4	5
3.7 Not being able to be alone with my baby	NA	1	2	3	4	5
3.10 Feeling angry that my baby has been born early/sick	NA	1	2	3	4	5
3.11 Feeling guilty that my baby has been born early/sick	NA	1	2	3	4	5
3.12 Feeling jealous that the nurses are with my baby when I'm not there	NA	1	2	3	4	5
3.13 Not feeling like a parent yet	NA	1	2	3	4	5
3.14 Resenting my baby for causing upheaval in my everyday life	NA	1	2	3	4	5
4.13 Not having as much time as I would like with my new baby	NA	1	2	3	4	5
3.16 Feeling worried about going home without my baby	NA	1	2	3	4	5

Listed below are some items which describe the **PRACTICAL HASSLES AND SOCIAL RELATIONSHIP STRAINS** that you may experience. If the item reflects something that you have experienced, circle the number which reflects how stressful you feel it is (1 = not at all, 5 = extremely)

1.4	The other sick babies in the room	NA	1	2	3	4	5
3.8	Feeling worried about how my family will feel about this baby	NA	1	2	3	4	5
1.5	The lack of space around my baby's cot	NA	1	2	3	4	5
3.15	Being afraid to be optimistic	NA	1	2	3	4	5
4.1	Having to keep cheerful when I don't feel like it	NA	1	2	3	4	5
4.2	Not having enough time to do everything	NA	1	2	3	4	5
4.3	Feeling that no-one knows how I feel	NA	1	2	3	4	5
4.4	Being unable to get back to normality	NA	1	2	3	4	5
4.5	Feeling unable to support my partner	NA	1	2	3	4	5
4.6	The demands of home-life and visiting	NA	1	2	3	4	5
4.7	Not knowing what to say to family and friends	NA	1	2	3	4	5
4.8	Having to rely on family and friends for support	NA	1	2	3	4	5
4.9	Feeling worried about my baby coming home from hospital	NA	1	2	3	4	5
4.10	Not knowing how to help my partner	NA	1	2	3	4	5
4.11	Not having enough time to spend with my partner	NA	1	2	3	4	5
4.12	Not having enough time for myself	NA	1	2	3	4	5
4.14	Feeling worried about how my other children will feel about this baby	NA	1	2	3	4	5

The overall experience; not thinking about any particular aspect, but rather how stressful in general the experience of having your baby in NICU has been for you

Using the same rating scale, indicate how stressful in general the experience of having your baby hospitalised in the neonatal unit has been for you

1 2 3 4 5

ANNEXURE D

The Neonatal Unit Parental Stress (NUPS) Scale

Nurses and others who work in neonatal units are interested in how this environment and experience affects parents. We would like to know about your experience as a parent whose infant is presently in the neonatal unit.

This questionnaire lists various experiences other parents have reported as stressful when their baby was in the neonatal unit. We would like you to indicate how stressful each item listed below has been for you. **If you have not had the experience, we would like you to indicate this by circling N/A meaning that you have not experienced this item.**

By stressful, we mean that the experience has caused you to feel anxious, upset or tense.

We intend to explore different aspects of the experience, for example, the clinical environment, your baby's illness and treatments, how you feel about your baby and some practical aspects such as how you are managing at home. On the questionnaire, circle the single number that best expresses how stressful each experience has been for you. The numbers in the key below indicate the following levels of stress:

1 = Not at all 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, the experience upset you and caused a lot of anxiety.

Remember, if you have not experienced the item, please circle NA "not applicable"

Your responses do not indicate any criticism of the unit nor the care that you are receiving. Your responses will not be identifiable to anyone other than the researcher, and will not be discussed with clinical staff.

Now let's take an item for example: The lack of privacy in the neonatal unit.

If for example, you feel that the lack of privacy in the neonatal intensive care unit was extremely stressful to you, you would circle the number 5 below:

NA 1 2 3 4 5

If you feel that the lack of privacy was not stressful at all, you would circle the number 1 below:

NA 1 2 3 4 5

If there was sufficient privacy when you visited you would circle NA indicating "Not applicable" below:

NA 1 2 3 4 5

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in a neonatal unit. We are interested in your view of how stressful these SIGHTS AND SOUNDS are for you. Circle the number that best represents your level of stress (1= not at all, 5 extremely). If you did not experience the item, circle the NA meaning "Not applicable."

1.1 The presence of monitors and equipment	NA	1	2	3	4	5
1.2 The constant noises of monitors and equipment	NA	1	2	3	4	5
1.3 The sudden noises of monitor alarms	NA	1	2	3	4	5
1.4 The other sick babies in the room	NA	1	2	3	4	5
1.5 The lack of space around my baby's cot	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 your baby may have received. 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 = not at all stressful, 5 = extremely stressful).

2.1 Tubes and equipment on or near my baby	NA	1	2	3	4	5
2.2 Bruises, cuts or wounds on my baby	NA	1	2	3	4	5
2.3 My baby's unusual or abnormal breathing patterns	NA	1	2	3	4	5
2.4 The small size of my baby	NA	1	2	3	4	5
2.5 Seeing needles and tubes put into my baby	NA	1	2	3	4	5
2.6 My baby being fed by an intravenous line or tube	NA	1	2	3	4	5
2.7 When my baby seemed to be in pain	NA	1	2	3	4	5
2.8 When my baby looked sad	NA	1	2	3	4	5
2.9 Jerky or restless movements of my baby	NA	1	2	3	4	5
2.10 When my baby looks uncomfortable	NA	1	2	3	4	5

2.11 My baby not being able to move around properly	NA	1	2	3	4	5
2.12 Feeling worried about my baby's future health.	NA	1	2	3	4	5

The next aspect we want to ask you about is how you feel about your own **RELATIONSHIP** with your baby and your role as a parent. If you <u>have experienced</u> the following situations or feelings, indicate how stressed you have been by them, by circling the appropriate number (1 = not at all stressful, 5 = extremely stressful). Again, circle NA if you <u>did not experience</u> the item.

3.1 Being separated from my baby	NA	1	2	3	4	5
3.2 Not feeding my baby myself	NA	1	2	3	4	5
3.3 Not being able to care for my baby myself (for example, nappy changing, bathing)	NA	1	2	3	4	5
3.4 Not being able to hold my baby when I want	NA	1	2	3	4	5
3.5 Feeling helpless and unable to protect my baby from pain and painful procedures	NA	1	2	3	4	5
3.6 Feeling helpless about how to help my baby during this time	NA	1	2	3	4	5
3.7 Not being able to be alone with my baby	NA	1	2	3	4	5
3.8 Feeling worried about how my family will feel about this baby	NA	1	2	3	4	5
3.9 Feeling worried about how my baby will grow and Develop.	NA	1	2	3	4	5
3.10 Feeling angry that my baby has been born early/sick	NA	1	2	3	4	5
3.11 Feeling guilty that my baby has been born early/sick	NA	1	2	3	4	5
3.12 Feeling jealous that the nurses are with my baby when I'm not there	NA	1	2	3	4	5
3.13 Not feeling like a parent yet	NA	1	2	3	4	5

3.14 Resenting my baby for causing upheaval in my everyday life NA 1 2 3 4 5

3.15 Being afraid to be optimistic NA 1 2 3 4 5

3.16 Feeling worried about going home without my baby NA 1 2 3 4 5

Listed below are some items which describe the **PRACTICAL HASSLES AND SOCIAL RELATIONSHIP STRAINS** that you may experience. If the item reflects something that you have experienced, circle the number which reflects how stressful you feel it is (1 = not at all, 5 = extremely)

4.1 Having to keep cheerful when I don't feel like it NA 1 2 3 4 5

4.2 Not having enough time to do everything NA 1 2 3 4 5

4.3 Feeling that no-one knows how I feel NA 1 2 3 4 5

4.4 Being unable to get back to normality NA 1 2 3 4 5

4.5 Feeling unable to support my partner NA 1 2 3 4 5

4.6 The demands of home-life and visiting NA 1 2 3 4 5

4.7 Not knowing what to say to family and friends NA 1 2 3 4 5

4.8 Having to rely on family and friends for support NA 1 2 3 4 5

4.9 Feeling worried about my baby coming home fromhospital NA 1 2 3 4 5

4.10 Not knowing how to help my partner NA 1 2 3 4 5

4.11 Not having enough time to spend with my partner NA 1 2 3 4 5

4.12 Not having enough time for myself NA 1 2 3 4 5

4.13 Not having as much time as I would like with my new baby NA 1 2 3 4 5

4.14 Feeling worried about how my other children will feel about this baby NA 1 2 3 4 5

The overall experience; not thinking about any particular aspect, but rather how stressful in general the experience of having your baby in NICU has been for you

Using the same rating scale, indicate how stressful in general the experience of having your baby hospitalised in the neonatal unit has been for you

1 2 3 4 5

ANNEXURE E

25TH October 2011

Dear Lauren,
I have attached my thesis, all the information you need to construct the scale is there. I have not yet produced an 'off the shelf' scale, as this requires a lot of additional cost and work but you should find this useful
Best wishes, Tilly

From: Andy Buys [mailto:andybuys@mweb.co.za]
Sent: 24 October 2011 13:26
To: Reid, Tilly
Subject: Re: NUPS scale

Dear Dr Reid,

Thank you for replying to my email.

Thank you for the permission to use the NUPS in my study. I am very excited to have finally contacted you. I have the article published in the Journal of Reproductive and Infant Psychology, February 2007 by yourself, Bramwell, Booth and Weindling. I do not have the actual stressor scale that you reported on in that article. I would be grateful if you could tell me how to find the scale that you created, or to send it to me if you can. I have the original PSS:NICU (Dr M. Miles) but really hoped to be able to use the NUPS. I will obviously comply with all requirements and will be happy to send you my results when complete.

Thank you again for the response.

Sincerely,

Lauren.

----- Original Message -----
From: Reid, Tilly
To: andybuys@mweb.co.za
Sent: Monday, October 24, 2011 12:10 PM
Subject: NUPS scale

Dear Lauren,
I am sorry that you were unable to contact me, I have changed jobs several times since publishing the validity of the NUPS scale. My home e mail address is tillyreid@gmail.com if you find I have disappeared from the university address I am using currently.
I have not managed to publish any findings from the main study as I have been in different working environments which are not all that relevant. That is something i do still hope to do as the findings are very interesting, particularly the differences over time and the differences between mothers and fathers.
I am happy for you to use the scale as described, I think there is enough published information to use them in this way. There are another couple of papers in the journal of neonatal nursing (2007 I think)

where a separate parent-staff communication scale is published. I expected some types of communication to be cited as sources of stress from the literature (Jennifer Fenwick specifically) but these were not found so I separated them into another scale.
Please let me know of your results as they may contribute to an international validation process, the scale is being used similary in several other countries, and please acknowledge the original authors in any publications.
Good luck, keep in touch, Tilly

Dr Tilly Reid
Advanced practice learning facilitator
Faculty of Health and Wellbeing
University of Cumbria
Bowerham Rd
Lancaster LA1 3JD
telephone 01524 590800 (x2243)
07796254721
e mail- tilly.reid@cumbria.ac.uk

University of Cumbria is a Company Limited by Guarantee, Registered in England & Wales No. 06033238. Registered Office: University of Cumbria, Fusehill Street, Carlisle, CA1 2HH. Telephone 01228 616234.

Confidentiality: This email and its attachments are intended for the above named only and may be confidential. If they have come to you in error you must take no action based on them, nor must you copy or show them to anyone; please reply to this email and highlight the error.

Security Warning: Please note that this email has been created in the knowledge that Internet email is not a 100% secure communications medium. We advise that you understand and observe this lack of security when emailing us.

Viruses: Although we have taken steps to ensure that this email and attachments are free from any virus, we advise that in keeping with good computing practice the recipient should ensure they are actually virus free.
University of Cumbria is a Company Limited by Guarantee, Registered in England & Wales No. 06033238. Registered Office: University of Cumbria, Fusehill Street, Carlisle, CA1 2HH. Telephone 01228 616234.

Confidentiality: This email and its attachments are intended for the above named only and may be confidential. If they have come to you in error you must take no action based on them, nor must you copy or show them to anyone; please reply to this email and highlight the error.

Security Warning: Please note that this email has been created in the knowledge that Internet email is not a 100% secure communications medium. We advise that you understand and observe this lack of security when emailing us.

Viruses: Although we have taken steps to ensure that this email and attachments are free from any virus, we advise that in keeping with good computing practice the recipient should ensure they are actually virus free.

Dear Ms Bramwell,

I am a student at the University of the Witwatersrand, Johannesburg in the Department of Nursing on a part time basis. I am employed in a large neonatal intensive care unit and have been for the past eighteen years. I have a great interest in the stress experienced by parents of neonates in our unit.

I would like to perform a study of parental stress in the NICU for my MSc. degree, commencing in 2012. I am writing to request permission to use the NUPS for my study. I have tried to contact Ms Reid, and have been unsuccessful. If you could help me by providing permission or contact details, I would be most grateful.

Sincerely,

Lauren Buys.
Student Number 575436

Annexure F

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Lauren Buys

CLEARANCE CERTIFICATE	**M120326**
PROJECT	Stress Experienced by Mothers of Neonates in a Private Hospital NICU
INVESTIGATORS	Ms Lauren Buys.
DEPARTMENT	Department of Nursing Education
DATE CONSIDERED	30/03/2012
+DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 10/05/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr S Armstrong

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Annexure G

Andy Buys

From: "Matshidiso Mhlongo" <Matshidiso.Mhlongo@wits.ac.za>
To: <andybuys@mweb.co.za>
Cc: "Sue Armstrong" <Sue.Armstrong@wits.ac.za>
Sent: 09 May 2012 12:51 PM
Attach: Buys.pdf
Subject: Approval of title

Dear Mrs Buys

Attached, the Approval of Title letter.

You may proceed with your research as long as you have obtained the Ethics Clearance.

Regards

Ms Rosen Mhlongo
Postgraduate Faculty Officer Research
Postgraduate Office
Faculty of Health Sciences
University of the Witwatersrand
7 York Road, Parktown,
Johannesburg, South Africa
2193
Tel: +27 11 717 2125
Fax: +27 11 717 2119
Email: matshidiso.mhlongo@wits.ac.za

VISION 2022
WITS - Knowledge at the Leading Edge

UNIVERSITY OF THE WITWA
JOHANNESBURG

This communication is intended for the addressee only. It is confidential. If you have received this communication in error

2012/05/09

Annexure H

Faculty of Health Sciences
Medical School, 7 York Road, Parktown, 2193
Fax: (011) 717-2119
Tel: (011)717-2075/6

Reference: Ms Salamina Segole
E-mail: Salamina.segole@wits.ac.za
26 April 2012
Person No: 575436
PAG

Mrs LM Buys
P O Box 663
Cresta
2118

South Africa

Dear Mrs Buys

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled "*Stress experienced by mothers of neonates in a private hospital NICU*" has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Annexure I

Faculty of Health Sciences
Medical School, 7 York Road, Parktown, 2193
Fax: (011) 717-2119
Tel: (011) 717-2076

Reference: Ms Salamina Segole
E-mail: salamina.segole@wits.ac.za
16 April 2012
Person No: 575436
TAA

Mrs LM Buys
P O Box 663
Cresta
2118
South Africa

Dear Mrs Buys

Master of Science in Nursing: Change of title of research

I am pleased to inform you that the following change in the title of your Research Report for the degree of has been approved:

From:	**Stress experienced by mothers of premature infants in a private hospital NICU**
To	**Stress experienced by mothers of neonates in a private hospital NICU**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Annexure J

Netcare Limited

Tel: + 27 (0)11 301 0000
Fax: Corporate +27 (0)11 301 0499
76 Maude Street, Corner West Street, Sandton, South Africa
Private Bag X34, Benmore, 2010, South Africa

RESEARCH COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2012-0013

Ms L Buys

E mail: andybuys@mweb.co.za

Dear Ms Buys

RE: STRESS EXPERIENCED BY MOTHERS OF PREMATURE INFANTS IN A PRIVATE HOSPITAL NICU

The above-mentioned research was reviewed by the Research Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at Netcare Park Lane Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Academic Board of Netcare (Research Committee).

ii) All information with regards to Netcare will be treated as confidential.

iii) Netcare's name will not be mentioned without written consent from the Academic Board of Netcare (Research 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) Netcare 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 Academic Board of Netcare (Research Committee) as well as a FINAL REPORT with reference

Executive Directors: R H Friedland *(CEO)*, V E Firman *(CFO)*, V L J Litlhakanyane

Non-Executive Directors: S J Vilakazi *(Chairman)*, T Brewer, A P H Jammine, J M Kahn, M J Kuscus, H R Levin, K D Morcka, M I Sacks, N Weltman

Company Secretary: L Bagwandeen Reg. No. 1996/008242/06

Annexure J

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 Netcare once it is finally approved by the tertiary institution, or once complete.

x) Netcare has the right to implement any Best Practice recommendations from the research.

xi) Netcare 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.

APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER.

We wish you success in your research.

Yours faithfully

Prof Dion du Plessis
Full member: Research Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Shannon Nell
Chairperson: Research Committee
Network Healthcare Holdings Limited (Netcare)
Date: 13/6/2012

REFRENCES

AAGAARD, H. & HALL, E. O. C. 2008. Mothers' Experiences of Having a Preterm Infant in the Neonatal Care Unit: A Meta-Synthesis. *Journal of Pediatric Nursing,* 23**,** e26-e36.

ALS, H., GILKERSON, L., DUFFY, F. H., MC ANULTY, G. B., BUEHLER, D. M., VAN DEN BERG, K., SWEET, SELL, E., PARAD, R. B., RINGER, S. A., BUTLER, S. C., BLICKMAN, J. G. & JONES, K. J. 2003. A Three-Center, Randomized, Controlled Trial of Individualized Developmental Care for Very Low Birth Weight Preterm Infants: Medical, Neurodevelopmental, Parenting, and Caregiving Effects. *Journal of Developmental & Behavioral Pediatrics,* 24**,** 399-408.

ANAND, K. J. S. 2001. Consensus statement for the prevention and management of pain in the newborn. *Archives of Pediatric and Adolescent Medicine,* 155**,** 8.

ANAND, K. J. S., PHIL, D. & HICKEY, P. R. 1987. Special Article: Pain and Its Effects in the Human Neonate and Fetus. *The New England Journal of Medicine,* 317**,** 1321-9.

AROCKIASAMY, V., HOLSTI, L. & ALBERSHEIM, S. 2008. Fathers' Experiences in the Neonatal Intensive Care Unit: A Search for Control. *Pediatrics,* 121**,** e215-e222.

AXELIN, A., LEHTONEN, L., PELANDER, T. & SALANTER, S. 2010. Mothers' different styles of involvement in preterm infant pain care. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing,* 39**,** 415-424.

BALLOT, D. E., CHIRWA, T. F. & COOPER, P. A. Determinants of survival in very low birth weight neonates in a public sector hospital in johannesburg. *BMC Pediatrics,* 10:30.

BURNS, N. & GROVE, S. 2005. *The Practice of Nursing Research, Conduct, Critique and Utilization,* USA, Elsevier Saunders.

CARTER, J. D., MULDER, R. T., BARTRAM, A. F. & DARLOW, B. A. 2005. Infants in a neonatal intensive care unit: parental response. *Archives of Disease in Childhood - Fetal and Neonatal Edition,* 90**,** F109-F113.

CESCUTTI-BUTLER, L. & GALVIN, K. 2003. Parents' perceptions of staff competency in a neonatal intensive care unit. *Journal of Clinical Nursing,* 12**,** 752-761.

CHOURASIA, N., SURIANARAYANAN, P., ADHISIVAM, B. & VISHNU BHAT, B. 2013. NICU Admissions and Maternal Stress Levels. *The Indian Journal of Pediatrics,* 80**,** 380-384.

CLEVELAND, L. M. 2008. Parenting in the neonatal intensive care unit. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing,* 37**,** 666-691.

DE VOS, A., STRYDOM, H., FOUCHE, C. & DELPORT, C. 2011. *Research at Grass Roots,* Cape Town, Van Schaik Publishers.

DUDEK-SHRIBER, L. 2004. Parent Stress in the Neonatal Intensive Care Unit and the Influence of Parent and Infant Characteristics. *The American Journal of Occupational Therapy,* 58**,** 12.

DUHN, L. J. & MEDVES, J. M. 2004. A systematic integrative review of infant pain assessment tools. *Advances in neonatal care : official journal of the National Association of Neonatal Nurses,* 4**,** 126-40.

FENWICK, J., BARCLAY, L. & SCHMIED, V. 2001. 'Chatting': an important clinical tool in facilitating mothering in neonatal nurseries. *Journal of Advanced Nursing,* 33**,** 583-593.

FRANCK, L. S., COX, S., ALLEN, A. & WINTER, I. 2004. Parental concern and distress about infant pain. *Archives of Disease in Childhood - Fetal and Neonatal Edition,* 89**,** F71-F75.

FRANCK, L. S., OULTON, K. & BRUCE, E. 2012. Parental Involvement in Neonatal Pain Management: An Empirical and Conceptual Update. *Journal of Nursing Scholarship,* 44**,** 45-54.

GAVEY, J. 2007. Parental perceptions of neonatal care. *Journal of Neonatal Nursing,* 13**,** 199-206.

GOLEC, L., GIBBINS, S., DUNN, M.S. & HEBERT, P. 2004. Informed Consent in the NICU Setting: An Ethically Optimal Model for Research Solicitation. *Journal of Perinatology,* 24, 783-791.

HEERMANN, J. A., WILSON, M. E. & WILHELM, P. A. 2005. Mothers in the NICU: outsider to partner. *Pediatric Nursing,* 31**,** 176.

HOLLYWOOD, M. & HOLLYWOOD, E. 2011. The lived experiences of fathers of a premature baby on a neonatal intensive care unit. *Journal of Neonatal Nursing,* 17**,** 32-40.

JONES, L., WOODHOUSE, D. & ROWE, J. 2007. Effective nurse parent communication: A study of parents' perceptions in the NICU environment. *Patient Education and Counseling,* 69**,** 206-212.

KONIAK-GRIFFIN, D. 1993. Maternal Role Attainment. *Journal of Nursing Scholarship,* 25**,** 257-262.

LAU, R. & MORSE, C. A. 2003. Stress experiences of parents with premature infants in a special care nursery. *Stress & Health: Journal of the International Society for the Investigation of Stress,* 19**,** 69-78.

LAZARUS, R. S. 1991. *Emotion & Adaptation,* New York, Oxford University Press.

MACKLEY, A. B., LOCKE, R. G., SPEAR, M. L. & JOSEPH, R. 2010. Forgotten Parent: NICU Paternal Emotional Response. *Advances in Neonatal Care,* 10**,** 200-203 10.1097/ANC.0b013e3181e946f0.

MERCER, R. T. 2004. Becoming a mother versus maternal role attainment. *Journal of Nursing Scholarship,* 36**,** 226-232.

MERCER, R. T. 2006. Nursing support of the process of becoming a mother [corrected] [published erratum appears in JOGNN 2007 Jan-Feb;36(1):toc]. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing,* 35**,** 649-651.

MILES, M. S., FUNK, S. G. & CARLSON, J. 1993. Parental Stressor Scale: neonatal intensive care unit. *Nurs Res,* 42**,** 148-52.

MILESI, C., CAMBONIE, G., JACQUOT, A., BARBOTTE, E., MESNAGE, R., MASSON, F., PIDOUX, O., FERRAGU, F., THEVENOT, P., MARIETTE, J.-B. & PICAUD, J.-C. 2010. Validation of a neonatal pain scale adapted to the new practices in caring for preterm newborns. *Archives of Disease in Childhood - Fetal and Neonatal Edition,* 95**,** F263-F266.

MONTEROSSO, L., KRISTJANSON, L., SLY, P. D., MULCAHY, M., HOLLAND, B. G., GRIMWOOD, S. & WHITE, K. 2005. The role of the neonatal intensive care nurse in decision-making: advocacy, involvement in ethical decisions and communication. *International Journal of Nursing Practice,* 11**,** 108-117.

OBEIDAT, H. M., BOND, E. A. & CALLISTER, L. C. 2009. The parental experience of having an infant in the newborn intensive care unit. *Journal of Perinatal Education,* 18**,** 23-29.

ORAPIRIYAKUL, R., JIRAPAET, V. & RODCUMDEE, B. 2007. Struggling to get connected: The process of maternal attachment to the preterm infant in the neonatal intensive care unit. *Thai Journal of Nursing Research,* 11**,** 251-264.

PADDEN, T. & GLENN, S. 1997. Maternal experiences of preterm birth and neonatal intensive care. *Journal of Reproductive & Infant Psychology,* 15**,** 121-121.

PALLANT, J. 2010. *SPSS Survival Manual* Australia, Allen & Unwin.

PARTRIDGE, J. C., MARTINEZ, A. M., NISHIDA, H., BOO, N.-Y., TAN, K. W., YEUNG, C.-Y., LU, J.-H. & YU, V. Y. H. 2005a. International Comparison of Care for Very Low Birth Weight Infants: Parents' Perceptions of Counseling and Decision-Making. *Pediatrics,* 116**,** e263-e271.

PARTRIDGE, J. C., RANCHOD, T. M., BALLOT, D. E., MARTINEZ, A. M., CORY, B. J. & DAVIES, V. A. 2005b. Intensive Care for Very Low Birthweight Infants in South Africa: A Survey of Physician Attitudes, Parent Counseling and Resuscitation Practices. *Journal of Tropical Pediatrics,* 51**,** 11-16.

PHILLIPS, S. J. & TOOLEY, G. A. 2005. Improving child and family outcomes following complicated births requiring admission to neonatal intensive care units. *Sexual & Relationship Therapy,* 20**,** 431-442.

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**,** 913.

RAOSOFT. Sample Size Calculator. Raosoft Inc. Available from: www.raosoft.com/samplesize.html. (Accessed on 3rd September 2013).

REID, T. 2000. Maternal identity in preterm birth. *Journal of Child Health Care,* 4**,** 23-29.

REID, T. 2005. *The Development and Utilisation of the NUPS (Neonatal Unit Parental Stress) Scale.* Doctor in Philosophy, University of Liverpool.

REID, T., BRAMWELL, R., BOOTH, N. & WEINDLING, A. M. 2007. A new stressor scale for parents experiencing neonatal intensive care: the NUPS (Neonatal Unit Parental Stress) scale. *Journal of Reproductive & Infant Psychology,* 25**,** 66-82.

REIS, M. D., REMPEL, G. R., SCOTT, S. D., BRADY-FRYER, B. A. & VAN AERDE, J. 2010. Developing Nurse/Parent Relationships in the NICU Through Negotiated Partnership Reis. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing,* 39**,** 675-683.

RUBIN, R. 1967a. Attainment of the maternal role. Part I: Processes. *Nursing Research,* 16**,** 9.

RUBIN, R. 1967b. Attainment of the maternal role. Part II: Models and referents. *Nursing Research,* 16**,** 5.

SCHENK, L. K. & KELLEY, J. H. 2010. Mothering an extremely low birth-weight infant: a phenomenological study. *Advances in Neonatal Care (Elsevier Science),* 10**,** 88-97.

SHAREK, P. J., POWERS, R., KOEHN, A. & ANAND, K. J. S. 2006. Evaluation and Development of Potentially Better Practices to Improve Pain Management of Neonates. *Pediatrics,* 118**,** S78-S86.

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**,** 206-212.

SIMONS, S. H. P., VAN DIJK, M., ANAND, K. J. S., ROOFTHOOFT, D., VAN LINGEN, R. A. & TIBBOEL, D. 2003. Do we still hurt newborn babies? *Archives of Pediatric and Adolescent Medicine,* 157**,** 7.

SYMINGTON, A. J. & PINELLI, J. 2006. Developmental care for promoting development and preventing morbidity in preterm infants. *Cochrane Database of Systematic Reviews.* Issue 22. Art. No.: CD001814. DOI: 10.1002/14651858.CD001814.pub2.

STATSOFT, I. 2013. Electronic Statistics Textbook. Tulsa, OK: StatSoft.

TAVAKOL, M. & DENNICK, R. 2011. Making sense of Cronbach's alpha. *Int J Med Educ,* 2**,** 53-55.

VELAPHI, S., MOKHACHANE, M., MPHAHLELE, R., BECKH-ARNOLD, E., KUWANDA, M. & COOPER, P. 2005. Survival of very-low-birth-weight infants according to birth weight and gestational age in a public hospital. *South African medical journal,* 95**,** 504-509.