

**Effectiveness of the implementation of psycho-
educational sessions on parental stress in a
neonatal intensive care unit**

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**EFFECTIVENESS OF THE IMPLEMENTATION OF PSYCHO-EDUCATIONAL
SESSIONS ON PARENTAL STRESS IN A NEONATAL INTENSIVE CARE UNIT**

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DECLARATION

I declare that:

“Effectiveness of the implementation of psycho-educational sessions on parental stress in a neonatal intensive care unit”

is my original work and that it has not been submitted before for any degree or examination at any other institution. All sources that have been used or quoted have been acknowledged by means of complete reference in text and bibliography.

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Tanya Coertze

January 2019

ABSTRACT

The topic of parental stress in the neonatal intensive care unit is widely researched in literature. For parents, the hospitalisation of their neonate is regarded as a stressful experience, and therefore, many interventions are based on reducing parental stress. Research has indicated the effectiveness of interventions to reduce parental stress in the Neonatal Intensive Care Unit (NICU); however, to our knowledge, no studies have been conducted in the South African context with the aim of reducing parental stress in the NICU.

The aim of this study was to determine the effectiveness of the implementation of psycho-educational sessions on parental stress in a NICU of a private hospital in Gauteng, South Africa.

Following a quantitative research approach, a quasi-experimental research design with a control group and a treatment group was used to determine the effectiveness of psycho-educational sessions to reduce parents' stress levels, when they had a neonate admitted to the NICU. The study included a control group and a treatment group, of which the latter underwent the intervention, namely psycho-educational sessions. A self-report stress scale, the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) was used to measure the levels of stress that parents in both groups experienced.

The results indicated that parents experience stress when their neonates are hospitalised in the NICU. The most stressful aspect for parents in both groups was the alteration in parental role. Furthermore, there was no statistically significant difference in the subcategory scale mean between the mothers and fathers, with no statistically significant difference in the total means scores either ($p > 0.05$), indicating that both groups experienced a moderate level of stress and neither group experienced less stress than the other. The current study found that both the control group and the treatment group participants' PSS: NICU scores were affected by Apgar score at one minute ($p < 0.05$).

Although the results of this study were not statistically significant, it confirmed previous literature which showed that parents who have a neonate admitted to the NICU experience some form of stress or psychological distress. The results showed that the intervention did not reduce parental stress as hypothesised, using the PSS: NICU as the primary measurement tool. In conclusion, it is suggested that further research is necessary in South Africa, using a different research design, a larger population (including other institutions) and an adapted

intervention where parents are approached and accommodated before admission to the NICU.

Keywords: neonate, Neonatal Intensive Care Unit, parental stress, psychological distress, stress

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ABBREVIATIONS

CPAP – Continuous Positive Airway Pressure
NICU – Neonatal Intensive Care Unit
NIDC – Neonatal Integrative Developmental Care Model
PSS: NICU – Parental Stressor Scale: Neonatal Intensive Care Unit
SiPAP – Biphasic Continuous Positive end-expiratory Pressure
STTI-MCHNLA – Sigma Theta Tau International Honor Society – Maternal Child Health Nurse Leadership Academy
WHO – World Health Organization

CHAPTER 1

INTRODUCTION TO THE STUDY

1.1. INTRODUCTION

The birth of a child should be regarded as a wonderful experience. However, in cases where the mother or her neonate require emergency or extended care, the taken-for-granted expectations of parenthood are shattered and may result in a traumatic experience for the new parent. Preterm or ill neonates may require specialised care during the early days of life, which may be provided in a neonatal intensive care unit (NICU).

The parent of a neonate in NICU has an elevated risk for a number of adverse outcomes due to the traumatic experience of having a neonate in intensive care, resulting in a symptomatic profile which is not limited to the period of hospitalisation and may lead to the development of parental psychological reactions such as anxiety, depression, acute stress disorder, post-traumatic stress disorder, dysfunctional parenting and negative parent-neonate interactions (Purdy, Melwak, Smith, Kenner, Chuffo-Siewert, Ryan et al 2017:33). Furthermore, the neonate may develop emotional, behavioural and cognitive problems that often persist through childhood and adolescence (Purdy, Craig & Zeanah 2015:S25; Hynan, Mounts & Vanderbilt 2013:748).

To prevent these adverse outcomes, pre- and post-discharge care should include early identification and treatment of at-risk parents within the NICU, and where necessary, referral to the appropriate mental health and psychological services (Purdy et al 2017:39; Chang, Chen, Huang, Yeh, Huang, Su et al 2016:100; Barbosa 2013:7). Although attempts are made to meet the parents' psychological needs, in reality many of the NICU staff may feel ill equipped to attend to parents' psychological needs, resulting in the psychological deteriorating cycle persisting and influencing the parent-neonate relationship long after discharge (Hall, Cross, Selix, Patterson, Segre, Chuffo-Siewert et al 2015:S29; Yaman & Altay 2015:141).

1.2. BACKGROUND

With modern technological advances, medical outcomes for ill and preterm neonates have markedly improved. Neonatal intensive care units provide a complex, highly technological environment of care for neonates, but generate an environment that can greatly contribute to the stress levels among parents (Cano Giménez & Sanchez-Luna 2015:e300). The Neonatal Integrative Developmental Care Model (NIDC) (Phillips Healthcare Andover, MA, USA) provides a broad category of interventions designed to guide clinical practice and minimise

the stress placed on neonates and the family by the NICU environment (Altimier & Phillips 2016:230; Barbosa 2013:7). Family-centred care, which is one of the seven core measures of the NIDC, encourages greater parent involvement and thereby aids in minimising stress (O'Brien, Bracht, Macdonell, McBride, Robson, O'Leary et al 2013:1). One of the guiding principles of family-centred care encompasses providing and/or ensuring formal and informal support for the neonate and family (Balbino, Balieiro & Mandetta 2016:2; Voos, Miller, Park & Olsen 2015:119; Committee on Hospital Care and Institute for Patient- and Family-centered Care 2012:395). To meet the needs of parents, the NIDC model provides emotional support, facilitates parent empowerment, creates a welcoming environment and educates parents on new skills through guided participation.

Literature confirms the need for psychological and social support as part of a family-centred care approach (Voos et al 2015:119). Such support is vital for parents in the NICU, to ensure that parents experience less stress, better equipped to manage stress and form early attachments with their sick neonates (Altimier & Phillips 2016:233; Hynan 2016:287; Magliyah & Razzak 2015:156; Purdy et al 2015:S24; Hynan et al 2013:751). However, the NICU environment is often neonate-centred instead of family-centred (Agrawal & Gaur 2016:151). In such situations, the NICU staff steps into the role of the primary caregiver, resulting in most parents feeling disregarded and separated from their neonates, doubting their capabilities and being unable to contribute meaningfully to their neonate's care (Smith, Desai, Sira & Engelke 2014:346; Galarza-Winton, Dicky, O'Leary, Lee & O'Brien 2013:336).

There is no doubt that developmental care and family-centred care are beneficial in reducing stress among neonates and their parents in the NICU. Mental health and wellbeing are needed by all people. The World Health Organization (WHO) acknowledges mental health as the "foundation for wellbeing and effective functioning for both the individual and community" and defines it as a state "which allows individuals to realise their abilities, to cope with normal stresses of life, work productively and fruitfully, and make a contribution to their community" (WHO: Promoting Mental Health 2004). High stress levels in parents may lead to dysfunctional parenting and negative parent-neonate interactions. Dysfunctional parenting may result in hindrance to the development of secure attachment and their ability to take care of their neonate, and may affect their long-term relationship with their children. The affected relationship between parent and neonate may influence the future social, behavioural and functional development of the neonate (Musabirema, Brysiewicz & Chipps 2015:1; Turner, Chur-Hansen, Winefield & Stanners 2015:252; Wormald, Tapia, Torres, Cánepa, González, Rodríguez et al 2015:303; Melnyk, Oswald & Sidora-Arcoleo 2014:106; Hynan et al 2013:749).

Helping parents in the NICU setting who are at risk for psychological distress may reduce their level of symptomatic response to stress and alleviate such distress (Chang et al 2016:100; Barbosa 2013:7). Psychological support is described as “any activity that improves a person’s ability to function under extraordinary levels of stress observed in the context of a critical event” (Simonsen & Reyes 2003:24). To minimise the long-term concerns of the NICU experience, suitable psychological support is important to improve parents’ functioning. Such support should complement the medical needs of the neonate and improve the parent-neonate relationship (Purdy et al 2017:37; Cano Giménez & Sanches-Luna 2015:e304; Hall et al 2015:S29; Magliyah & Razzak 2015:156; Turner et al 2015:252; Hynan et al 2013:751; O’Brien et al 2013:2). It is imperative to highlight the significance of early identification and screening of parents at risk for extended physical and emotional difficulties and make the subsequent referral to a support network where necessary (Purdy et al 2017:39; Cano Giménez & Sanchez-Luna 2015:e304; Busse, Stromgren, Thorngate, & Thomas 2013:53; Hynan et al 2013:751; Lasiuk, Comeau & Newburn-Cook 2013:9).

Psychosocial support pertains to “a combination of psychological and social factors” (Mosby’s Medical Dictionary 2009). It is often defined and determined by the indication for psychosocial interventions which are based on subjective needs voiced by persons involved and the objective needs determined by experts. Hynan (2016:286) provides recommendations for psychosocial support of parents in the NICU, namely, family involvement in developmental care; peer-to-peer support; involvement of mental health specialists and support programmes. While the author advocates for the appointment of psychologists to complement the role of social workers, research indicates that many NICUs do not have social workers as part of their multi-disciplinary team.

1.3. PROBLEM STATEMENT

Parents of neonates admitted to the NICU experience stress. They are subjected to a complex physical environment and a number of potential stressors (Cano Giménez & Sanches-Luna 2015:e300; Musabirema, Brysiewicz & Chipps 2015:1; Wormald et al 2014:303). The stress emanating from the NICU experience may potentially impact on a parent’s behaviour. Further, it may produce long-term emotional problems that continue beyond hospitalisation of the neonate and subsequently influence parental mental health (Turner et al 2015:252; Busse et al 2013:53). It is important to recognise that the NICU experience is not uniform; family responses differ, and parents face an array of psychological, emotional and social changes (Hynan 2016:286).

Much of the care provided in the NICU is focused on the neonates, and parental stress is often neglected. Parents are consigned to a supportive role in the NICU as NICU professionals provide the majority of care to the neonates. Some parents have described themselves as only visitors, which compound their anxiety and feeling of inadequacy after discharge (O'Brien et al 2013:1). To address these issues and reduce parental stress, family-centred care encourages greater parent involvement that should be the standard of care in NICUs (Balbino et al 2016:2). Family-centred care emphasises and promotes the importance of family involvement in the care, planning and decision-making processes.

In the particular NICU used in this study, the NICU staff is dedicated to a family-centred care approach. In April 2016, the researcher embarked on a journey to understand and develop strategies to reduce parental stress within the unit. This quality-improvement initiative was conducted in collaboration with the Sigma Theta Tau International Honor Society of Nursing, and the Maternal Child Health Nurse Leadership Academy (STTI – MCHNLA). The project was grounded on the principles of the Kouzes-Posner Model of Leadership. The nursing staff collaborated in formulating and implementing strategies to reduce parental stress in the NICU. The staff described their observations of parental stress in a questionnaire prior to and 24 months after implementation. Parents had an opportunity throughout the quality improvement initiative to write comments on their stress experience in a book. However, in spite of the attempts to reduce parental stress within the unit, parental stress still appears to be high, based on the feedback from staff and parents. The quality improvement initiative findings lead to the research question for this research study. Limited research is available in South Africa pertaining providing a focused intervention, such as psycho-educational sessions, to reduce the stress levels of parents. Psycho-educational sessions are an ideal form of support, as identified by Parker (2011:183). Mental health professionals consist of persons in disciplines that vary in speciality and training and include social workers, psychologists, psychiatrists and other trained staff (Hall, Hynan, Phillips, Lassen, Craig, Goyer et al 2017:6). Obstacles exist when undergoing psychological treatment, which may include shame, lack of access to mental health services, financial constraints, mistrust of health professionals, and lack of resources, staff and time (Purdy et al 2017:37).

Providing psycho-educational sessions to the parents might improve their functioning, as well as their relationship with their neonates, and may have long-term benefits for the families (O'Brien et al 2013:2). In the particular NICU used in this study, although family-centred care has been implemented, there were no psycho-educational sessions available to parents. This study will focus on the effectiveness of the implementation of psycho-educational sessions on parental stress in the particular NICU.

1.4. NULL HYPOTHESIS AND ALTERNATIVE HYPOTHESIS

The null hypothesis (H_0) was: there is no significant difference between the parents exposed to psycho-educational sessions (treatment group) and those that are not exposed (control group receiving routine care) in terms of the levels of stress they experienced in the NICU environment.

The alternative hypothesis (H_1) was: there is a significant difference between the parents exposed to psycho-educational sessions (treatment group) and those that are not exposed (control group receiving routine care) in terms of the levels of stress they experienced in the NICU environment.

H_1 is the alternative hypothesis, if H_0 is not true.

1.5. RESEARCH QUESTION, PURPOSE AND OBJECTIVES

1.5.1. Research question

The following research question was derived from the problem statement: Would there be any significant difference between parents exposed to psycho-educational sessions and those not exposed, in terms of the levels of stress they experienced in relation to (1) sight and sound; (2) behaviour and appearance; and (3) alteration in parental role, in the NICU environment of a private hospital?

1.5.2. Purpose

The purpose of the study was to determine the effectiveness of the implementation of psycho-educational sessions on parental stress in a NICU. Parental stress was determined by means of the Parental Stressor Scale: Neonatal Intensive Care (PSS: NICU) (Miles, Funk & Carlson 1993:149) (Annexure A).

1.5.3. Objectives

To correspond with the PSS: NICU, the objectives of the study were:

- To determine the effectiveness of the implementation of psycho-educational sessions on overall parental stress in the NICU environment in a private hospital.
- To determine the effectiveness of the implementation of psycho-educational sessions on stress related to sight and sound in the NICU environment in a private hospital.
- To determine the effectiveness of the implementation of psycho-educational sessions on stress related to infant behaviour and appearance in the NICU environment in a private hospital.

- To determine the effectiveness of the implementation of psycho-educational sessions on stress related to alteration in the parental role in the NICU environment in a private hospital.

1.5.4. Importance and benefits of the proposed study

The study served as a pilot study for a bigger study in the private healthcare group. The findings of the study assisted healthcare professionals to gain a better understanding of reducing parental stress in the NICU and to make recommendations for possible changes to clinical practice. Part of the study was to provide early focused interventions, such as psycho-educational sessions, to reduce the stress levels of parents and provide supportive care for them throughout their neonate's hospitalisation. These interventions were expected to improve the parents' functioning as well as their relationship with their neonates. Additionally, the results of this study would be valuable to the industry, which may enhance collaboration between disciplines such as nursing and psychology.

1.6. DELIMITATIONS AND ASSUMPTIONS

1.6.1. Delimitations

The study was limited to a single setting (the NICU of a private hospital) where confounding variables could not be controlled, as indicated in the assumptions of the study.

1.6.2. Assumptions

The assumptions of the study were as follows:

- Prolonged exposure to psychological stress is expected to increase the risk for anxiety, depression, acute stress disorder and post-traumatic stress disorder.
- Current practices in the NICU to minimise stress emanating from NICU admission and the physical environment include the following: developmental care of the neonate, application of family-centred care, with greater parent involvement in routine neonate care and decision-making, as well as adequate communication between parents and healthcare professionals to keep parents informed.
- Offering access and possible referral to mental healthcare services and psycho-educational sessions in the NICU is expected to reduce parental stress and anxiety, thereby preventing the development of acute stress disorder and post-traumatic stress disorder.
- There are various factors associated with admission of a neonate to the NICU that may influence the stress levels of parents, which cannot be controlled by the researcher, such as: uncertainty of their neonate's survival; increased risk for medical

complications; concerns about the long-term effects of prematurity; parents' lack of control of their circumstances; parents' past experiences (e.g. previous hospitalisation of a child); and disruption of their parental role.

- Pre-existing and concurrent personal and family factors that influenced the stress levels of parents included: parents losing family members due to illness; and other siblings at home that required attention and care.
- Models or grand theories are used as frameworks for research studies. Any research project is guided by a basic set of beliefs and assumptions which assist research thinking and practice. The assumptions are grounded on a middle range theory of nursing, The Theory of Family Stress and Adaptation, from which specific hypotheses are derived and confirmed by empirical investigation, which will be discussed in detail in Chapter two.

1.7. DEFINITION OF KEY TERMS

1.7.1. Stress/distress

Stress is defined as “psychological and physical strain or tension generated by physical, social, economic, or occupational circumstances, events, or experiences that are difficult to manage or endure” (Colman 2003:711). In this study, stress/distress refers to psychological and physical strain or tension experienced by a parent because of the admission of their neonate to the NICU.

1.7.2. Parents

A parent refers to “a mother or father; one who bears offspring” (Mosby’s Medical Dictionary 2009). The term can also be used to denote an “adoptive parent, genetic parent, grandparent, psychological parent, step-parent, surrogate parent or unwed parent” (McGraw-Hill concise dictionary of modern medicine 2002).

A primary care giver/caregiver can be described as “a single individual responsible for the care of one or more young children” (World Health Organization 2004:11). A caregiver is also described as “a lay individual who assumes responsibility for the physical and emotional needs of another who is incapable of self-care” (Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing and Allied Health 2003).

In this study, parents refer to the person(s) acting as primary care giver(s), whether biological parent(s), adoptive parent(s), grandparent(s), step-parent(s), or surrogate parent(s).

1.7.3. Psycho-education

Baumli, Frobose, Kraemer, Rentrop and Pitschel-Walz (2006:S3) indicate that psycho-education in behaviour therapy has its origin in client-centred therapy to a varying degree. The authors further note that within the framework of psychotherapy, psycho-education refers to the components of treatment where active communication of information, exchange of information among those afflicted, and treatment of general aspects of the illness is prominent (Baumli et al 2006:S3).

Bolat, Eliacik, Sargin, Kanik, Bayden and Sarioglu (2016:227) note in their research that psycho-education is a flexible model, which incorporates illness-specific information and tools for managing related circumstances, providing potential applications for many forms of illnesses and life challenges.

For the purpose of this study, psycho-education refers to a treatment modality that combines psychotherapeutic and educational interventions through which parents are able to obtain relevant information, develop and receive support within the group, learn to cope with the emotional aspects of caregiving, learn to recognise the need for self-care and learn to make use of available formal services. Topics are flexible and adjusted according to the needs of the participants.

In this study, psycho-education refers to sessions run by a trained clinical psychologist to provide appropriate psycho-educational support to parents, in a group context. One clinical psychologist leads a group of two to approximately 12 parents. Typically, group members meet for an hour each week, with the group being available twice a week at different times to accommodate group members' responsibilities outside the hospital.

1.8. RESEARCH METHODOLOGY

1.8.1. Research design

During this quantitative research approach, a quasi-experimental research design with a control group and a treatment group was utilised, as described by Botma, Greeff, Mulaudzi and Wright (2010:118-9), to determine the effectiveness of the implementation of psycho-educational sessions on parental stress in the NICU of a private hospital.

The study was quasi-experimental because it was not possible to have randomised groups, as the study took place in the natural setting. It included a control group and a treatment group, the latter of which underwent the intervention, namely psycho-educational sessions. The research design will be discussed in detail in Chapter three.

1.8.2. Measuring parental stress

In this study, the method of measurement was an existing validated and reliable 26-item self-report stress scale, namely the Parental Stressor Scale: Neonatal Intensive Care (PSS: NICU) (Annexure A) to measure stress experienced by parents in the NICU. Consent was obtained from the developer of the questionnaire via email correspondence, prior to commencement of the study. The PSS: NICU was designed to measure the amount of stress experienced by parents during hospitalisation related to sight and sounds of the unit, the appearance and behaviour of their neonate, and the alterations in their parental role. The framework of the instrument is based on stress theory and it was designed to measure parental perceptions of stressors emerging from the physical and psychosocial environment of the NICU (Miles et al 1993:149). The framework will be discussed in Chapter two.

Parents who agreed to participate in the control group completed the self-report questionnaire (Annexure A) from day two, then biweekly, and finally at discharge. Routine care was continued in its natural setting and was provided to all neonates. After the target sample size for the control group was reached, subsequent patients were recruited to the treatment group and treatment commenced, which included psycho-educational sessions for the parents in addition to routine neonatal care. Parents who agreed to participate in the treatment group completed the self-report questionnaire (Annexure A) from day two, then biweekly, and finally at discharge. The PSS: NICU will be discussed in detail in Chapter two.

1.8.3. Validity and reliability of the Parental Stressor Scale: Neonatal Intensive Care Unit

For the purpose of this study, the original psychometrics and scoring of the PSS: NICU (Annexure A) were utilised. The validity and reliability of the instrument had been proven by Miles et al (1993:149) and will be discussed in detail in Chapter three.

1.8.4. Setting

The study took place in the NICU of a private hospital. The unit has a 14-bed all in one ICU and high care area. An average of 19 neonates is admitted per month.

All premature neonates below 36 weeks' gestation and neonates weighing less than 2 kg are admitted to the unit. Any other neonate with unstable physiological function, congenital abnormalities or congenital infection is also admitted and given appropriate treatment. Treatment commonly includes the use of technology such as Infant Flow SiPAP (biphasic continuous positive end-expiratory pressure with additional intermittent sigh pressure), CPAP (continuous positive airway pressure), invasive mechanical ventilation, high-frequency

oscillation and high-flow nasal cannula oxygen therapy. Most neonates receive intravenous therapy during the first days of life, including antibiotics.

In the NICU, the neonates are nursed under open radiant warmers or in closed incubators. Neonates are nursed by professional nurses, enrolled nurses or auxiliary nurses registered with the South African Nursing Council in terms of the Nursing Act 33 of 2005 (South Africa 2005). Staff is allocated on a 1:1 ratio when the neonate is in a critical condition or receiving invasive ventilation, and on a 1:2 ratio when the neonate is not receiving invasive ventilation.

The NICU staff is dedicated to a family-centred care approach and developmental supportive care is implemented to the best of the staff's ability. The private hospital group provides compulsory training modules to all staff working in the NICU that cover family-centred care and developmental supportive care and its principles. A developmental supportive care audit of the NICU is conducted every month to establish the unit's compliance with these principles.

Most neonates admitted to the NICU have both the mother and father present as parents. These include family units where the parents may or may not be married, but both are involved in the care of the neonate. Some mothers who are single, without a partner present, rely on family members to provide a support structure. Grandparents are granted access for visitation on admission and every Sunday thereafter. Siblings are granted access for visitation depending on the neonate's condition (no oxygen or intravenous therapy) and the discretion of the nursing staff.

Some parents come from far because they opt for treatment at the particular hospital selected for this study, or because their neonates are transferred from surrounding areas and hospitals to receive specialised care. This implies that they are not able to travel back and forth to see the neonate every day. Lodging facilities are available in the hospital for parents, but not for other family members.

1.8.5. Population and sampling

The population for the control group and the treatment group were the parents of neonates admitted to the NICU of the study hospital. The population were all mothers and fathers and acted in their role as primary caregivers. The sample consisted of 20 participants in the control group and 20 participants in the treatment group. The sample size was determined by taking the study duration and the admission rate into consideration. A power analysis using G*Power version 3.1.9.2 indicated that for a significance of 5% and an effect size of 0.85, a sample size of 18 per group would be sufficient to ensure a power of 80%. The estimated effect size is

based on the assumption that there would be a large difference between the scores observed in the two groups. The study served as a pilot study in the private hospital group, and the results were not generalised. The sample size corresponds to that used in a similar study using the PSS: NICU (Turan, Basbakkel & Ozbek 2008:2856-2866). A statistician was consulted regarding the sample size.

Total population sampling, which is a non-probability sampling technique, was used to sample the willing NICU parents of all the neonates who were admitted to the specific NICU during the period of the study, which started on the 19th of July 2018 and ended on 23rd of November 2018. Since the period in which the data could be collected was limited, it was decided to utilise all willing participants.

1.8.6. Inclusion and exclusion criteria

Inclusion criteria: Mothers and/or fathers who had a neonate admitted to the NICU for two days or longer, who were 18 years or older, and who provided informed consent to participate in the study.

Exclusion criteria: All mothers or fathers who did not meet the inclusion criteria.

1.9. DATA COLLECTION

A non-probability sampling approach was utilised for data collection. Data collection took place over a period of four months and was divided into a control group and a treatment group. The first group was the control group to determine parental stress levels during routine care utilising the PSS: NICU (Annexure A). After the target sample size for the control group was reached, recruitment began for the second group, who was exposed to routine care with the addition of the intervention (psycho-educational sessions). The study occurred in the natural setting.

The control group was exposed to routine care as it is currently practiced in the NICU. Parents who consented to participate completed the self-report questionnaire (Annexure A) from day two, then biweekly, and finally at discharge. After the target sample size for the control group was reached, recruitment began for the treatment group and implementation commenced, which entailed the addition of psycho-educational sessions to routine care. Participants in the treatment group completed the self-report questionnaire (Annexure A) from day two, then biweekly, and finally at discharge. Psycho-educational sessions are discussed below.

1.10. INTERVENTION FOR THE TREATMENT GROUP: PSYCHO-EDUCATIONAL SESSIONS

The primary focus of psycho-education is to bring about emotional and behavioural changes through education. Psycho-education is the education provided to individuals who are living with emotional disturbances. Bolat et al (2016:227) note that psycho-education is a flexible model, which incorporates illness-specific information and tools for managing related circumstances, providing potential applications for many forms of illnesses and life changes.

Psycho-education may be provided in different contexts by a variety of professionals, each with a differing emphasis; however, for the purpose of this study, group psycho-educational sessions involved one clinical psychologist who led a group of one to six participants. Group members met for an hour each week with the group being available twice a week at different times to accommodate group members' responsibilities outside the hospital. Due to personal or logistical factors (for example, length of stay of their neonate), the parents attended as many sessions as they felt they needed. The researcher could not control the number of sessions attended, but the assumption was that even a single attendance would have an effect on their stress levels. The number of sessions attended was recorded by the researcher and included in descriptive statistics to determine the effectiveness of the intervention on their stress levels.

Topics of discussion included implications of having an infant in the NICU, anxiety, depression, acute stress disorder, post-traumatic stress disorder, dysfunctional parenting, negative parent-neonate interactions, and how to cope with stressful situations among other things. Topics were flexible and adjusted according to the needs of the participants.

Yalom's (1995) interactional group process model was utilised throughout the intervention. The model is applied to group therapy where the group context and group process is utilised as a mechanism of change by attending to the relationship within the group (Yalom 1995:17-24). This process provides individuals with important information about how their behaviour affects others and how they are in turn affected by other members (Yalom 1995:24-6).

1.11. DATA ANALYSIS

Interval measurements were used to describe the amount of stress experienced by the parents at the moment of data collection, first on day two, then biweekly, and finally at discharge. Bivariate descriptive statistics were used, along with a contingency table, to show stratified characteristics (demographic data) (Polit & Beck 2017:364-5) associated with parental stress in both the control group (the group receiving routine care), and the treatment group (the group receiving psycho-educational sessions in conjunction with routine care). Inferential statistics

were utilised to establish if there was a difference in the stress levels of parents in the control group and those in the treatment group, as suggested by Polit and Beck (2017:376-401). Both the researchers and a statistician of the University of Pretoria were involved in data analysis.

1.12. ETHICAL PRINCIPLES FOR PROTECTING STUDY PARTICIPANTS

Extreme care should be exercised when humans are used as study participants, to ensure that their rights are protected. Over the course of a few decades, various codes of ethics have been developed in an international effort to establish ethical standards and to guide the researchers' efforts to prevent situations posing a threat to the participants' rights (Polit & Beck 2017:137).

In this quantitative approach, a quasi-experimental design with a control group and a treatment group was utilised, as described by Botma et al (2010:118-9). The study was quasi-experimental in that it was not possible to have randomised groups, as the study took place in a natural setting. It comprised a control group and a treatment group, which underwent the intervention, namely psycho-educational sessions. No control was applied over the independent variables (routine care continued in its natural setting). The researcher had no control over the confounding variables either, and data were collected in the natural setting. Before the initiation of data collection, the researcher obtained consent to do research in a private hospital (Annexure F) and ethical approval from the Ethics Committee of the University of Pretoria's Faculty of Health Sciences (Annexure D).

Three broad principles are stipulated in the Belmont report, on which standards of ethics are based. Researchers are expected to adopt and comply with these principles (Polit & Beck 2017:139), namely beneficence, respect for human dignity and justice.

1.12.1. Principle of beneficence

Polit and Beck (2017:139) refer to beneficence as the principle to minimise harm and to maximise benefits, and state that participants has the right to freedom from harm and discomfort and the right to protection from exploitation.

1.12.1.1. Freedom from harm

In this study, the nature of the intervention did not have a negative effect on the parents. No harm or discomfort was inflicted on the parents, and if they chose not to participate, it was not held against them. Participation in the study was voluntary and the parents were not forced in any way to participate.

1.12.1.2. Freedom from exploitation

Involvement in the study did not place participants (mothers and/or fathers) at any disadvantage. Parents in the control group benefitted from current routine care with family-centred care, which was provided to all neonates and their parents and was considered to be of the highest quality possible. Parents from the treatment group benefitted from the additional provision of early focused interventions, namely psycho-educational sessions, in addition to the current routine care and family-centred care, which was expected to further reduce their stress levels.

1.12.1.3. Risk/benefit ratio

The study did not place any participants at a disadvantage regarding health treatment. There were no extra costs involved for the parents. The information gained by this study would positively contribute to future care plans. The intervention was only implemented after the data were collected with current practice in place, as it is unethical to have the intervention of psycho-educational sessions available and prevent some parents from attending because they happen to be in the control group.

1.12.2. Principle of respect for human dignity

The second ethical principle includes the right to self-determination and the right to full disclosure (Polit & Beck 2017:140).

1.12.2.1. Right to self-determination

Informed consent was obtained from each participant (Annexure B (control group) or Annexure C (treatment group)). Participation in the study was voluntary, and the participants had the right to refuse participation and could withdraw from the study at any time. Participants had the right to ask questions and the right to refuse to give information.

1.12.2.2. Right to full disclosure

The researcher fully described the study to the participants, which included the role and responsibilities of the researcher as well as the risks and benefits of being involved in the study. All parents' exposure to routine care in combination with family-centred care in the NICU was similar, but the participants were expected, in addition, to complete the self-report questionnaire, as discussed. The participants in the experimental group were also expected to attend one or more psycho-educational sessions on a twice-weekly or weekly basis until discharge.

1.12.2.3. Informed consent

After full disclosure, parents were asked to sign an informed consent document for the control group and for the treatment group. These documents specified the completion of a questionnaire on perception of stress, the specific intervention that was done, the timeframe in which the questionnaire was to be completed as well as the expectations regarding the parents' participation (Annexures B and C).

1.12.3. Principle of justice

The third principle concerns the right to fair treatment and the right to privacy (Polit & Beck 2017:141).

1.12.3.1. Right to fair treatment

The parents had the right to fair and equitable treatment before, during and after their participation in the study. Either parent could be included in the study if they chose to and if they met the inclusion criteria. There was no prejudicial treatment of parents who declined to participate or withdrew from the study. The parents involved in the study were able to access the researcher to address any questions or concerns during the research process. The researcher showed sensitivity to and respect for the beliefs, habits and lifestyle of participants from different cultures.

1.12.3.2. Right to privacy

Participants' confidentiality was upheld at all times. Numbers were assigned to each participant and only the researcher had access to which numbers were assigned to which participant. All data collected were kept anonymous throughout the research process. The researcher was not able to trace specific data back to a specific participant. No names or other information regarding the participants was made public at any time. The name of the institution where the study was conducted was kept anonymous throughout the study.

1.13. CONCLUSION

This chapter provided an overview of the study. Chapter two consists of an in-depth literature review, which is followed by the methodology in chapter three. The research results and conclusion will be presented in Chapters four and five respectively.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

In a private NICU, the researcher observed that most parents who had a neonate admitted to the NICU experienced some form of stress or psychological distress. This distress may result in short- and long-term challenges for the parents and their neonate. It is the researcher's experience that the neonatal intensive care team members are equipped to provide specialised medical care to ensure that premature or sick neonates admitted to the NICU receive the best care available. Therefore, the focus is primarily on the neonate, resulting in the parent's psychological needs being neglected.

Through conducting this literature review, the researcher discovered that much thought and deliberation has been invested into analysing parental stress from different aspects. There is a definite lack of both psychological support and psychological services, within the South African context, available to parents following the birth of their neonate. Although Purdy, Craig and Zeanah (2015:S25) and Hynan (2016:286) state that an intervention could decrease stress experienced by parents in the NICU, no significant evidence was found in the South African context in support of this statement. The purpose of this literature review was to explore the short- and long-term family impact of having a neonate in the NICU and possible interventions to reduce parental stress that emanates from the NICU experience.

This chapter provides a discussion on the literature related to this study, namely: family stress and adaptation theory; adaptation of a family, bonding and attachment; the neonatal intensive care environment; stress and psychological distress responses of parents due to the NICU environment; causes of stress and psychological distress; the impact parental stress has on the parent-neonate relationship and the neonate's emotional and behavioural development; the adaptation to the neonatal intensive care environment; and the measuring of stress.

2.2. FAMILY STRESS AND ADAPTATION THEORY

Any research project is guided by a basic set of beliefs and assumptions which assist research thinking and practice. In this regard, it was decided to ground the research on a middle range theory of nursing, the theory of family stress and adaptation by Geri LoBiondo-Wood. Middle range theories are derived with linkages to models or grand theories and are used as frameworks for research studies (Lobiondo-Wood & Haber 2018:72; Alligood 2010:482). A characteristic of a middle range theory is its attentiveness to the details of actual clinical practice situations (Alligood 2010:482). Furthermore, middle range theories comprise a

definite number of concepts and are focused on a particular aspect of reality, and as a result, are more easily tested through research (Lobiondo-Wood & Haber 2018:72).

LoBiondo-Wood's theory of family stress and adaptation stemmed from her working experience of children who had undergone liver transplants (LoBiondo-Wood, Williams, Kouzekanani & McGhee 2000:81). LoBiondo-Wood found that limited research had been done on the impact a stressful situation had on family. She called upon McCubbin and Patterson's Double ABCX model of family adaptation (1982), which consisted of certain elements with a well-developed theoretical framework to guide her research in developing the theory of family stress and adaptation (Liehr & Smith 2008:94-95; Fitzpatrick & Wallace 2006:343). The theory of family stress and adaptation offers a theoretical framework for exploring the process of how the family copes in response to a crisis within the context of time and environment (Liehr & Smith 2008:95), where the metaparadigm represents the person, their state of health, the environment and the nurse (Lobiondo-Wood et al 2000:82). Thus, the theory of family stress and adaptation calls upon the holistic, family-centred approach, incorporating the patient's needs with the psychosocial needs of the patient's family (Liehr & Smith 2008:95).

A theory provides direction when viewing facts and events. It includes:

- concepts (concrete or abstract ideas),
- a conceptual definition (general meaning of the concept),
- a conceptual/theoretical framework (structure that provides guidance for research),
- a construct (complex concepts),
- a model (graphic or symbolic representation of a phenomenon),
- an operational definition (measurement instrument), and
- a theory (a set of interrelated concepts that provides a systematic view of the phenomena) (Lobiondo-Wood & Haber 2018:69).

According to Lobiondo-Wood's theory, the middle range theory of family stress and adaptation focuses on:

- a stressor the family faces;
- how the family perceives the stressor;
- how the family responds to the stressor;
- existing and new resources;
- coping; and
- adaptation (Fitzpatrick & Wallace 2006:344).

Lobiondo-Wood's theory of family stress and adaptation guided the researcher in her search of information regarding the adaptation process of a family and the effect stress has on parents, especially when their neonate is hospitalised in the NICU. The theory guided the researcher in explaining and describing concepts within the study, to devise a mechanism to identify and confirm the concepts of interest and determine a method to measure or quantify it (operational definition – Likert scale-like questionnaire). The aspect of the experience of parental stress in a NICU will be discussed further, focusing on what the adaptation process entails and briefly explaining bonding and attachment between a parent and his/her neonate.

2.3. ADAPTATION OF A FAMILY, BONDING AND ATTACHMENT

Few things in life are more exciting than the birth of a baby. An easy and perfectly executed birth is ideal. The ideal birth is usually an all-natural, non-medical-intervention birth, but even the most carefully planned birth can change and be unpredictable. The birth process is an evolutionary event, where adults find themselves transitioning and facing personal and social changes with important and complex consequences.

Adaptation of a family is described by Eskandari, Simbar, Vadadhir and Baghestani (2016:1) as the...“result of a family's effort to cope with the stressful condition of a child's presence in the family and the interactions between personal and environmental systems”. The effectiveness of the transition into parenthood refers to how well parents adjust to changes in their lives relating to their newfound responsibilities, their level of happiness since becoming parents and how worried they are as new parents (Ter Kuile, Kluwer, Finkenauer & Van der Lippe 2017:663).

Many parents adapt well to the demands of parenthood, but the transition into parenthood is mostly associated with adverse effects on the parents. The quality of their relationship is one of the key contributors in adjusting to parenthood, and in many cases, parents report a reduction in their relationship satisfaction following childbirth. Adverse effects include a decrease in the frequency and quality of their sexual activity and instances where one partner perceives the other as not providing adequate support (Parfitt & Ayers 2014:265). Research has shown that the period of adaptation to parenthood is a time when parents are at risk to develop mental health problems, such as depression, anxiety and post-traumatic stress disorder. Sleep deprivation, both during pregnancy and post-natal, could also contribute to the development of mental health problems, and could potentially have negative implications for the parent-neonate relationship (Parfitt & Ayers 2014:264-265).

The vast majority of studies focus on the adverse effects adaptation has on parenthood, but there are factors that can increase the coping capacity of parents. Positive relationship practices, such as perceived partner responsiveness, gratitude and trust, increase personal and relationship well-being by producing positive emotions. Being understanding, caring and validating the self lowers emotional distress, increases marital satisfaction and has the potential to increase psychological resources in both men and women (Ter Kuile et al 2017:663-664). Gratitude towards one's partner for their efforts is valuable, strengthens the relationship and could potentially lower levels of stress and depression, thereby increasing the relationship quality. Trust is identified as one of the most desirable qualities in a relationship and the cornerstone for relationship satisfaction (Ter Kuile et al 2017:665).

Adaptation to parenthood is further influenced by the quality of bonding and attachment between the parents and the neonate. Bonding and attachment are terms used to describe a process of adjustment, changing of identity and establishing a relationship between the parent and the neonate. An emotional investment in a neonate begins during pregnancy and continues immediately after birth, where both the parent and neonate are ready for physiological and psychological interaction. Physiologically, most mothers feel a high accompanied by high levels of energy, and the neonate is alert and awake, making eye contact, fixes and follows and starts searching for the mother's nipple to feed. Psychologically, the family is ready to meet and interact with the neonate (Gardner, Carter, Enzman-Hines & Hernandez 2011:850). This is a period of mutual readiness and a critical and sensitive period of bonding and attachment.

Bonding is the building of an emotional bond between the parent and the child, which manifests itself in a series of feelings of warmth, love, protectiveness, possession, devotion and concern (Lee 2003:289). Bonding refers to that critical or sensitive period after birth during which close physical contact exists between a mother and her neonate, where skin-to-skin contact is necessary and the lack thereof may lead to significant long-term consequences, affecting the development of later relationships and child development (Redshaw & Martin 2013:219; Gunning, Waugh, Robertson & Holmes 2011:27). To secure bonding, not only is skin-to-skin contact advised, but early and prolonged contact between the mother and neonate in the post-natal period is very important. Early skin-to-skin contact has the benefits of maintaining the body temperature of the neonate, promoting better breastfeeding practices, increasing the blood glucose levels of the neonate, regulating the respiration of the neonate, increasing maternal affection behaviour and resulting in less crying of the neonate (Gardner et al 2011:850). Neonates have access to other primary caregivers, such as their fathers, who provide a bonding relationship with the neonate and the necessary sensory stimulation needed

for normal development (Sullivan, Perry, Sloan, Kleinhaus & Burtchen 2011:646). The bonding process between parent and neonate, which takes place throughout the neonatal period, establishes the foundation for a lifelong relationship (Agrawal & Gaur 2017:148).

Immediate contact and bonding is not always possible directly after labour. Early separation between the mother and neonate, especially in the early neonatal period, may result in bonding failure (Lee 2003:290). Mothers with bonding failure report a variety of feelings, which include indifference, hostility, impulses to harm or neglect the neonate, and are mostly associated with severe pain in labour and postnatal mental illness, particularly depression and psychosis (Lee 2003:290). However, it must be understood that medical interventions are occasionally needed to sustain life, and while separating the neonate from the mother is not ideal for bonding, it does not undermine the entire process of bonding. Bonding is not considered attachment, and attachment is not an immediate process and continues beyond the neonatal period (Redshaw & Martin 2013:219; Lee 2003:289).

Attachment involves a series of steps: planning the pregnancy, confirming the pregnancy, accepting the pregnancy, foetal movement, accepting the foetus, labour and birth, seeing, touching and caregiving, as discussed by Gardner et al (2011:851-855). The British child psycho-analyst John Bowlby (1907–1990) was one of the founders of the attachment theory. According to Bowlby's attachment theory, children need a constant nurturing connection with one or more primary caregivers to develop into healthy individuals. This connection will influence how they engage in close relationships (Van Rosmalen, Van der Horst & Van der Veer 2016:22; Gunning et al 2011:27). Once a child has formed an attachment to a caregiver, the child will use the caregiver as security to explore his/her surroundings and develop relationships with other people (Sullivan et al 2011:647).

Early attachment has two main functions: to keep the neonate in close proximity to the mother and to guide neural development (Sullivan et al 2011:646). Parental attachment and appropriate caregiving are vital for the neonate's physical, psychological and emotional health and survival (Gardner et al 2011:849). The quality of care rendered by the mother will ultimately programme the neonate's emotional and cognitive development, by helping to sculpt the developing brain (Sullivan et al 2011:643). In a case where the connection between a mother and neonate is disrupted during the prenatal and postnatal period, especially with high-risk neonates, such as those who are premature and sick - they become vulnerable to forming lower quality attachments to their primary caregivers (Sullivan et al 2011:644). It is imperative to understand that hospitalisation of a neonate may potentially disrupt the connection between the parents and the neonate. NICU's provide a complex, highly

technological environment that can greatly contribute to the stress levels of parents in the NICU (Cano Giménez & Sanchez-Luna 2015:e300). The NICU, one of the catalysts of parental stress, will be discussed in the next section.

2.4. THE NEONATAL INTENSIVE CARE ENVIRONMENT

Since the 1960s, when specialised units were created for the care of sick and premature neonates, research has focused on the emotional response parents have to the birth of their neonate and how they respond to the subsequent separation from their neonate during a long period of hospitalisation (Miles et al 1993:148). Neonatal intensive care units provide a complex, highly technological environment of care for ill and preterm neonates, markedly improving the medical outcome of these neonates, but which can greatly contribute to the stress levels of parents in the NICU (Cano Giménez & Sanchez-Luna 2015:e300). A lot of thought and deliberation has been invested into analysing stress from different aspects. Parental stress resulting from experiences with their neonate hospitalised in a NICU has received considerable attention in the past few decades and is well documented. Stress may lead to a variety of reactions such as sadness, fear, anger, anxiety, grief, depression and helplessness (Purdy et al 2015:S24). This may result in a number of adverse outcomes, which may lead to parents experiencing psychological difficulties such as anxiety, depression, acute stress disorder and post-traumatic stress disorder. These psychological difficulties may then affect attachment and parenting styles, resulting in a negative parent-neonate relationship. Negative parent-neonate relationships inevitably influence the development of emotional, behavioural and cognitive problems in the neonate throughout childhood and adolescence (Purdy et al 2017:33; Purdy et al 2015:525; Hynan et al 2013:748).

Having a neonate in the NICU is a crisis for parents, regardless of their acuity level or the length of stay (Yaman & Altay 2015:140). Parents are flung into the unfamiliar environment of the NICU, where they are dependent on strangers to safeguard the survival of their neonates. The normality of everyday life diminishes, and their only concern becomes the survival of their neonate, where the smallest change is perceived as either a crisis or an accomplishment. The parents' responses to these changes (sensory environment of the NICU, appearance of their neonate and parental role alteration) are discussed in the following section.

2.4.1. Sensory environment (sights and sounds)

While the ideal scenario is a healing NICU environment, free from any stressors, neonates are exposed to an array of environmental stressors which include technological equipment such ventilators and monitoring equipment with their accompanying disturbing sounds and lights (Musabirema et al 2015:2; Miles et al 1993:148). Lights are flashing, sounds are loud

and disturbing, and machines are buzzing and beeping, creating an environment that is overwhelming to both the parent and the neonate. Some parents perceive the sounds of the NICU as very stressful and may be uncomfortable in the environment due to the noise. They may feel the need to continuously stay at the bedside and protect their infant from the environment (Prouhet, Gregory, Russell & Yaeger 2018:105). Parents are either in awe or feel extremely uncertain when they are faced with a sophisticated, technological environment whose sole function is to provide the necessary care for the survival of neonates (Gardner et al 2011:878).

2.4.2. Physical appearance of the neonate

An additional source of stress is that admission to the NICU is unexpected. The length of stay, complex medical procedures and changes in the neonate's physical appearance and behaviour contribute to elevated parental stress (Musabirema et al 2015:1; Yaman & Altay 2015:140; Smith et al 2014:348). The physical appearance of the neonate includes aspects that contribute to parental stress, such as: tubes and intravenous lines attached to the neonate; bruises, cuts and incisions on the neonate; unusual skin colour; unusual breathing patterns; size of the neonate; jerky and restless movements; and exposure to painful and invasive procedures (Musabirema et al 2015:2; Gardner et al 2011:291; Miles et al 1993:148).

2.4.3. Parental role alteration

Research into the needs of mothers in the NICU indicates that the mother's priority is to safeguard her neonate and maternal needs also include information and interaction with the neonate, emotional safety and a supportive NICU environment (Gardner et al 2011:879). Thus, the disruption of the parental role contributes significantly to the amount of stress parents experience in the NICU (Musabirem et al 2015:2). In the NICU, parents must learn an unfamiliar medical language and establish trust in strangers taking care of their vulnerable neonates (Gardner et al 2011:878). The medical language used by healthcare professionals is often confusing, and the inability of healthcare professionals to communicate effectively can exacerbate parental stress (Yaman & Altay 2015:140; Smith et al 2014:348). When the needs of parents are not taken into account, it increases feelings of helplessness, powerlessness and vulnerability, and the parents are less able to interact with their neonate (Gardner et al 2011:879). Adaptation to an unfamiliar environment and their role in this setting makes it a frightening experience. Thus, the admission of a neonate to the NICU results in stress or psychological distress as a result of the exposure to the NICU environment.

2.5. STRESS AND PSYCHOLOGICAL DISTRESS RESPONSES OF PARENTS DUE TO THE NEONATAL INTENSIVE CARE ENVIRONMENT

To gain a better understanding of the stressors parents face in the NICU, one has to understand what stress and psychological distress entail. In this section, a discussion of the difference between stress and psychological distress will be explained.

Giving birth to an ill or premature neonate that requires admission to the NICU creates emotional trauma and distress for parents and may bring about difficulties in adjusting to new life circumstances. Parenting is a major adjustment from pregnancy, and the birth of an ill or premature neonate causes family disruption with consequent psychological disorganisation of the family, affecting problem-solving mechanisms, which in turn results in poor coping skills (Gardner et al 2011:856). Parents experience an array of emotions when their neonate is admitted to the neonatal intensive care unit, and the intense and chaotic appearance of the neonatal intensive care unit makes it a frightening experience for parents and results in stress and/or distress.

2.5.1. Stress and distress

According to concept analysis done by Ridner (2004:538), stress is described as...“a physical and emotional state always present in the person as a result of living: it is intensified in a non-specific response to an internal or external change or threat”. Stress can be viewed as a non-specific response to any demand, good (stress) or bad (distress) (Ridner 2004:539).

The term distress (bad stress) refers to...“physical or mental anguish or suffering resulting from the experience of symptom occurrence and/or feeling states” and can be defined as...“harmful, unpleasant stress” (Ridner 2004:538). In cases where a compensatory reaction is triggered in the body due to stress or distress, it may result in a physiological stress response (Marieb & Hoehn 2010:619), which will be discussed in the next paragraph.

2.5.1.1. Physiological stress response

To consider the physiological effects of prolonged stress on the body, we should first discuss the acute changes that occur during brief periods of stress. The fight-or-flight status is triggered in the body by a form of short-term stressor, activating the sympathetic nervous system. Nerve impulses move from the hypothalamus, through the spinal cord to the adrenal medulla, signalling the release of the catecholamines adrenaline and noradrenaline. These two hormones result in the following short-term stress responses: increased heart rate, increased blood pressure, increased blood glucose, dilation of bronchioles, increased blood

flow to the skeletal muscles and heart, and increased metabolic rate (Marieb & Hoehn 2010:619).

In the event of prolonged or chronic exposure to stress, the adrenocortical hormones are activated, and this promotes long-lasting body responses to stressors. The hypothalamus is the director of the stress response and in the event of prolonged or chronic stress, it releases corticotropin-releasing hormones. The corticotroph cells of the anterior pituitary gland are stimulated and release adrenocorticotrophic hormone into the blood stream, stimulating the adrenal cortex and resulting in the secretion of steroid hormones (glucocorticoids) cortisol, cortisone and corticosterone. The long-term stress response and excessive levels of glucocorticoids results in retention of sodium and water by the kidneys, increased blood volume and blood pressure, proteins and fats being converted to glucose or broken down for energy, increased blood glucose and suppression of the immune system (Marieb & Hoehn 2010:619).

2.5.2. Psychological distress

According to Prouhet et al (2018:106), psychological distress occurs...“when an individual cannot adequately cope with situational demands or threats to his or her well-being”. Psychological distress is thus...“the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person” (Ridner 2004:539). To adequately cope, an individual needs to manage and regulate emotional responses to stressors, which could be affected by both personal and environmental factors (Prouhet et al 2018:106). Emotional responses due to stressors have been identified as “one of the most poignant problems faced by individuals and admonished professionals not only for failing to acknowledge the impact of distress on individuals, but also for judging those suffering from distress as failures for not being able to cope” (Ridner 2004:536).

2.6. CAUSES OF STRESS AND PSYCHOLOGICAL DISTRESS

Stress and psychological distress can be understood as a biophysical or psychological response to a stressor, altering a person’s equilibrium, resulting in bodily or mental tension. How a family perceives or responds to a stressor is greatly dependent on what the cause is. Having discussed the NICU environment as the primary cause of stress for parents with a hospitalised neonate, there are a variety of other factors that can likely contribute to elevated stress levels as well.

2.6.1. Causes of stress

Firstly, emotional factors are associated with admission to the NICU and contribute to parental stress. Such emotional responses are described by Cano Giménez and Sanches-Luna (2015:e300), Musabirema et al (2015:2) and Yaman and Altay (2015:140) as: inability to provide routine care, a sense of lack of control, the feeling of disruption or change in the parental role imposed by the environment, and the feeling of being physically and emotionally isolated from the neonate. As a result, parents experience difficulties with caregiving and feel alienated regarding everything that happens postnatally (Hagen, Iversen & Svindseth 2016:7).

Secondly, a neonate's health characteristics can be a major stressor for parents. It is indicated in literature that with premature neonates (lower birthweight and gestational age), parents experience more stress (Schappin, Wijnroks, Venema, & Jongman 2013:3). Other health characteristics indicated are critically ill neonates, neonates with congenital anomalies, expressions of the neonate's distress and fear, and the need for prolonged respiratory support (Cano Giménez & Sanches-Luna 2015:e300; Schappin et al 2013:3). Parents experience increased stress when their neonates are difficult to soothe, smile less and experience pain during procedures, as explained by Smith et al (2014:348). Parents are also uncertain about the increased risk of medical complications, survival of the neonate and the long-term consequences of prematurity (Schappin et al 2013:1).

Thirdly, pre-existing and concurrent personal and family factors may influence parenting ability. Personal resources of parents are referred to by Musabirema et al (2015:4) as comprising socio-economic status, family functioning and social support. Low socio-economic status is consistent with an increase in parental stress, and improved social support correlates with a decrease in parental stress, according to Schappin et al (2013:3). Other sources of stress can include loss of work, decreased income and limited job options, where parents generally experience high levels of stress with costly medical bills and costs involved with caring for a premature infant post discharge (Purdy et al 2015:S24).

Fourthly, a link exists between parental stress and past experiences. Past experiences are thought to influence later psychological functioning, for example, positive past experiences are thought to be conducive to healthy functioning, whereas negative or unpleasant past experiences may increase a person's predisposition to stress (Musabirema et al 2015:3). Thus, parents' coping mechanisms are negatively influenced when they had a previously ill or premature neonate in the NICU or if the neonate is deceased (Hagen et al 2016:7).

Lastly, there are differences in stress levels between mothers and fathers of neonates in the NICU. According to most existing studies, mothers experience more stress than fathers. The assumption is that mothers have a higher psychological involvement with their neonate and higher expectations of their role as a caregiver, and that they feel they lose that role as primary caregiver when hospital staff steps into the role as the experts, which subsequently causes stress (Schappin et al 2013:2). A study found that mothers are more reluctant to prepare for the future and feared the passing of their neonate (Hagen et al 2016:2). Mothers use different coping mechanisms compared to fathers; they seem to get most of their support from their spouse and focus more on the positive in each situation, whereas fathers seem to get most of their support from healthcare professionals and are more oriented towards problem-solving as a coping strategy (Hagen et al 2016:2). Nevertheless, literature also indicates that stress is more likely to be caused by the traditional roles mothers and fathers play in Western society and are not related to prematurity itself (Schappin et al 2013:2).

Contrary to the above findings, other studies report that fathers experience more stress than mothers. One explanation is that fathers may have greater difficulty in understanding their neonate's behaviour, which may lead to increased stress (Schappin et al 2013:2). Although fathers play a dynamic role in caring for their neonates, they play a traditional paternal role in upholding family solidity, where they need to balance their role as husband, father and provider (Weis, Zoffmann, Greisen & Egerod 2013:1134). Fathers take on the supportive role to mothers during the neonatal phase, hiding their own needs and only expressing their stress later on, even up to 18 months of corrected age of their neonate (Hagen et al 2016:7; Koliouli, Gaudron & Raynaud 2016:112). Some fathers have a sense of guilt, because they are torn between work and other family members and are therefore more absent from the neonate (Hagen et al 2016:2). In cases where the mother is seriously ill during the postnatal period, the father is more concerned about the mother's well-being than the neonate's, adding to the feelings of guilt (Hagen et al 2016:7).

2.6.2. Causes of psychological distress

In light of the discussion on the causes of stress in the previous sections, one should understand that the stress emanating from the NICU experience may produce long-term emotional problems that may continue beyond hospitalisation of the neonate and subsequently influence parental mental health (Turner et al 2015:252; Busse et al 2013:53). It is important to recognise that the NICU experience is not uniform; family responses differ and parents face an array of psychological, emotional and social changes, which may include depression, acute stress disorder and post-traumatic stress disorder (Hynan 2016:286). These parental behavioural changes can interfere with the parent-neonate relationship and

increase the neonate's risk of future emotional and behavioural problems (Kim, Lee, Namkoong, Park & Rha 2015:575).

2.6.2.1. Antenatal and postnatal depression

Antenatal depression is referred to by Brummelte and Galea (2016:153) as depression that occurs during pregnancy and postnatal depression occurs after birth. According to Leung, Letourneau, Giesbrecht, Ntanda and Heart (2017:420), postnatal depression can be characterised as...“a depressed mood, loss of interest and pleasures in daily activities, psychomotor agitation or retardation, insomnia or hypersomnia, reduced concentration and decisiveness, fatigue or loss of energy, suicidal ideation and mental confusion”.

Depression during the antenatal and postnatal period is common and can negatively affect the developing foetus as well as the mother's parenting style. Even mild degree of maternal depression has been shown to impact psychosocial functioning (Guyon-Harris, Huth-Bocks, Lauterbach & Janisse 2016:153). Women are twice as likely to develop depression compared to men, and it is accompanied by more severe symptoms and anxiety (Brummelte & Galea 2016:153). Antenatal depression can result in reprogramming of the foetus, while postnatal depression can negatively interfere across the cognitive, emotional, social and physical domains of the child (Leung et al 2017:421; Brummelte & Galea 2016:154). Postnatal depression presents during a unique time of physiological changes, with onset of symptoms occurring one to 14 days post-delivery (Brummelte & Galea 2016:154).

Paternal postnatal depression is neither a commonly used term nor is it a commonly recognised phenomenon compared to maternal postnatal depression, but there is growing evidence that fathers also experience depression after the birth of a child (Zhang, Zhang, Wei, Zhang, Zhang et al 2016:47). The occurrence of paternal postnatal depression is highest at three days postnatal and declines by six weeks postnatal (Zhang et al 2016:47). It has a negative impact on family health and well-being and has been linked with the level of the mother's depressive symptoms – 24–50% of partners of mothers with depression may also experience postnatal depression (Leung et al 2017:421). Approximately 10% of fathers experience depression during the first postnatal year, which is greater than the overall population rates (Leung et al 2017:420). Factors that may precipitate paternal postnatal depression are poor marital relationships, adverse life events, employment status, insufficient antenatal information and education, and men's tendency to conceal their emotions to conform to social expectations (Zhang et al 2016:48). Furthermore, increased societal expectations, demands and financial responsibilities, a history of depression are factors associated with postnatal depression in fathers (Leung et al 2017:421).

2.6.2.2. Acute stress disorder

The diagnostic criterion for acute stress disorder is described by Lasiuk et al (2013:8) as: ...“exposure to a traumatic event, which an individual perceives as life threatening and to which he/she responded to with intense fear, helplessness, or horror”. Lasiuk et al (2013:8) go on to explain that...“the individual must also experience an increased autonomic arousal, dissociative symptoms and re-experiencing of the event through intrusive thoughts, dreams, or flashbacks”. Clotney and Dillard (2013:23), however, describe acute stress disorder as...“a stress related anxiety disorder comprised of exposure to a traumatic stressor, intrusive thoughts, avoidance, arousal or reactivity symptoms and negative mood and cognitions”. Acute stress disorder should resolve within four weeks of exposure, but if not treated in time, it may progress to post-traumatic stress disorder.

2.6.2.3. Post-traumatic stress disorder

Post-traumatic stress disorder is described by Clotney and Dillard (2013:23) as...“a feeling of extreme anxiety that is brought about by fearful and threatening experiences in which the individual experiences a lack of control”.

The diagnosis of post-traumatic stress disorder has a widespread link with depression and anxiety disorders (Van Ee, Kleber & Jongmans 2016:186). The development of post-traumatic stress disorder is significantly correlated with the presence of acute stress disorder, where the disturbances resulting from acute stress disorder can cause significant social and occupational impairment, or have an impact in other areas of functioning (Clotney & Dillard 2013:23; Lasiuk et al 2013:8). If these symptoms last longer than one month, the individual meets the diagnostic criteria for post-traumatic stress disorder (Lasiuk et al 2013:8). Early research demonstrates that parents of neonates admitted to the NICU have an increased risk of developing post-traumatic stress disorder, possibly caused by the initial hospitalisation of their neonate. Even short-term hospitalisation is considered traumatic by parents (Månsson, Jakobsson & Lundqvist 2016:193; Yaman & Altay 2015:140; Hynan et al 2013:750).

Post-traumatic stress is disabling and disrupts parents' lives; a study suggests that indicators of post-traumatic stress in parents can still be observed six to 18 months after hospitalisation of their neonate (Yaman & Altay 2015:141), and distressing memories may persist as long as three years after birth. The risk factors for post-traumatic stress disorder are anxiety, feelings of loss of control over the situation, lack of partner support and maternal morbidity, and that the severity of these feelings are probably related to preterm neonate factors (Chang et al 2016:96). Post-traumatic stress may negatively affect parents' self-care as well as the

neonates' care, putting the physical health of the neonates at risk and jeopardising their developmental and behavioural outcomes (Yaman & Altay 2015:145).

Parental roles in the NICU are directly related to the interaction between parents and their neonate, which is regarded as a crucial activity that may have significant impact on how a parent cares for a child and influence parenting behaviour in the future (Musabirema et al 2015:3). The causes of psychological distress mentioned above are predominant among families experiencing the birth of an ill or preterm neonate and may have lifelong implications for both the family and the neonate. Although attempts are made to meet the parents' psychological needs, the reality is that many of the NICU staff may feel ill equipped or unprepared to give attention to parents' psychological needs, leading to the persistence of the psychological deteriorating cycle, which will influence the parent-neonate relationship long after discharge (Hall et al 2015:S29; Yaman & Altay 2015:141). The impact parental stress has on the parent-neonate relationship, will be discussed in the following section.

2.7. THE IMPACT PARENTAL STRESS HAS ON THE PARENT-NEONATE RELATIONSHIP AND THE NEONATE'S EMOTIONAL AND BEHAVIOURAL DEVELOPMENT

An in-depth discussion regarding the causes of stress and psychological distress was important to set the background for the next discussion. It is important to identify where the stressors originate from as this will lead to a better understanding of how the family responds to such stressors. The stress the family has to deal with changes and builds up over time and can affect each member. Stress can negatively affect the relationship between a parent and the neonate.

2.7.1. Parent-neonate relationship and risk factors

When the attachment steps of labour and birth, seeing, touching and caregiving are interrupted, the challenges of parenthood become a reality and a surprising lack of compatibility exists between the wished-for and actual neonate. Parents who have been separated from their neonate or have not experienced the kind of birth they planned for often worry about the new relationship and bonding (Redshaw & Martin 2013:219).

Parents of preterm neonates are more prone to overprotective parenting styles that are rigid, intrusive and controlling in nature. Furthermore, parent-neonate interactions and the perception parents have of their neonate can be influenced by trauma and intensified by the presence of post-traumatic stress disorder (Van Ee et al 2016:192; Shaw, St John, Lilo, Jo, Benitz, Stevenson et al 2013:e886-887). Parents in the NICU tend to cope with stress through

avoidance of negative and distressing experiences, which can lead to a maladaptive parent-neonate relationship (Turner, Winefield & Chur-Hansen 2013:438) and has been associated with child behavioural and emotional problems and abuse (Agrawal & Gaur 2017:148).

Some parents who present with symptoms of post-traumatic stress disorder are more likely to report moderate or severe aggression towards their children, which in turn increases the risk of physical child abuse, while others are more prone to withdraw from interaction with their children, making it less likely that they will be physically abusive (Van Ee et al 2016:192). Van Ee et al (2016:192) reported that parents who tend to withdraw are less likely to soothe or comfort their children, which may lead to the development of disorganised attachment.

2.7.1.1. Maternal-neonate relationship and risk factors

According to Greene, Rossman, Patra, Kratovil, Janes and Meier (2015:362), mothers of preterm or sick neonates experience disproportionately raised degrees of postpartum psychological distress. Greene et al (2015:362) describe postpartum psychological distress as an all-encompassing term that integrates varying degrees of depression, anxiety and general post-traumatic stress. The onset and timing of maternal psychological distress result in different consequences for children (Brummelte & Galea 2016:158). These mothers tend to exhibit a higher prevalence of PTSD that can interfere with the mother-neonate relationship (Kim et al 2015:575).

Maternal depression is believed to disrupt the bond between mother and neonate by limiting the mother's parenting resources, impairing mother-neonate interactions and negatively affecting affect expression and the general emotional development of infants and toddlers (Guyon-Harris et al 2016:155). Mothers with depression tend to touch their neonate less and in a less affectionate manner, have less face-to-face interactions and less neonate-directed speech or storytelling (Brummelte & Galea 2016:157). Thus, facial expressions and verbal/non-verbal behaviours convey negative feelings and may hinder healthy emotional development (Guyon-Harris et al 2016:155). This may result in neonates and toddlers displaying more negative affect than positive and being at greater risk for emotional, behavioural and psychological problems (Brummelte & Galea 2016:158). This may result in cognitive and language development delays beyond early infancy. Children of mothers with postnatal depression are more likely to have affective disorder and anxiety, be unable to handle stress effectively, show signs of depression at the age of 16 and have difficulty in engaging with their peers (Leung et al 2017:421; Hynan et al 2013:749).

Mothers with depression are more likely to breastfeed or start with formula feeds and solids prematurely, thus increasing the risk for negative neonatal feeding outcomes and reducing the benefits of immune protection provided by breastfeeding (Brummelte & Galea 2016:158).

2.7.1.2. Paternal-neonate relationship and risk factors

Adverse child outcomes associated with fathers with depression are less well documented. Paternal postnatal depression may affect parent-neonate interactions, child physical growth, social and emotional health and psychological development, which is associated with undesirable parenting behaviour (Zhang et al 2016:48). Fathers', who experienced depressive prenatal symptoms, are predictive of behavioural problems with their children between the ages of two and three years, and the impact of paternal postnatal depression can have a long-lasting effect on their children, even seven years later (Leung et al 2017:421). Fathers with depression are more likely to spank their children, are less likely to read to them, correlates with partner disharmony and children who present with defiant behaviour disorders at school age (Hynan et al 2013:749). The reality is that postnatal depression also affects fathers, either directly or indirectly, in supporting or coping with their partners' symptoms.

2.8. THE ADAPTATION TO THE NEONATAL INTENSIVE CARE ENVIRONMENT

The NICU environment is complex and chaotic and creates trauma and distress for parents. The adaptation to the intensive care should be approached with extreme caution and sensitivity. To facilitate the adaptation to the NICU environment, many interventions can be employed to familiarise and orient families. Several formal interventions and caregiving practices have been developed over the years to optimise the NICU environment. Such formal interventions and caregiving practices include: family-centred care, psychological support and the involvement of mental health care professionals in the NICU.

2.8.1. Optimising the Neonatal Intensive Care environment

In any modern NICU, family-centred care prevails and has become the standard in health care provision (Himuro, Miyagishima, Kozuka, Tsutsumi & Mori 2015:284). Family-centred developmental care is an all-inclusive philosophy of care, which is guided by the individual needs of the neonate and family, to support and coach families to be able to take care of the overall health and development of their neonate (Purdy et al 2017:35). Family-centred care is a collaboration between parents and healthcare professionals in the NICU, to allow families to become more involved in the decision-making processes and permit them to have an input on their neonate's recovery process (Himuro et al 2015:284).

There are several family-centred care models available and recognised, but the model of care in this specific NICU is based on the Neonatal Integrative Developmental Care Model (NIDC). The NIDC provides a broad category of interventions designed to guide clinical practice and minimise stress placed on neonates and the family by the NICU environment (Altimier & Phillips 2016:230; Barbosa 2013:7). A key element of the NIDC is to identify the strengths and weaknesses of the neonate, enabling individualised care within direct nursing care and the environment, supported by research from disciplines such as nursing, medicine, neuroscience and psychology (Van den Berg, Back, Hed & Edvardsson 2017:76; Altimier, Kenner & Damus 2015:6; Smith et al 2014:346).

Family-centred care, which is one of the seven core measures of the NIDC, encourages greater parent involvement and thereby aides in minimising stress (O'Brien et al 2013:1). One of the guiding principles of family-centred care involves provides and/or ensure formal and informal support to the neonate and family (Balbino, Balieiro & Mandetta 2016:2; Voos et al 2015:119; Committee on Hospital Care and Institute for Patient- and Family-centred Care 2012:395). Ultimately, the well-being of the parents affects the well-being of the neonate. The literature confirms the need for psychological support and social support as part of a family-centred care approach, to minimise stress generated by the NICU environment (Voos et al 2015:119). Although family-centred care can be implemented by the nursing staff in the NICU, nurses working in the NICU often find themselves feeling overwhelmed and ill equipped to provide the psychosocial, psychological and emotional support that parents of a neonate often require.

2.8.2. Psychological support in the Neonatal Intensive Care Unit

Layered levels of psychological support should be available, starting with a foundation of family-centred developmental care and peer-to-peer support of parents, with additional levels of services provided by psychologists (Purdy et al 2017:37). To meet the psychosocial needs of the parents, one should provide emotional support, allow parent empowerment, create a welcoming environment and educate parents on new skills through guided participation. Such support is vital for parents in the NICU as it ensures that parents experience less stress and are better equipped to cope with stress and form early attachments with their sick neonates (Altimier & Phillips 2016:233; Hynan 2016:287; Magliyah & Razzak 2015:156; Purdy et al 2015:S24; Hynan et al 2013:751).

Psychosocial support pertains to...“a combination of psychological and social factors” (Mosby’s Medical Dictionary 2009) and is often defined and determined by the indication for psychosocial interventions that are based on subjective needs voiced by the persons involved

and the objective needs determined by experts. The NICU environment is often neonate-centred instead of family-centred (Agrawal & Gaur 2016:151), where the NICU staff steps into the role of the primary caregiver and most parents feel disregarded and separated from their neonates and doubt their capabilities and ability to contribute meaningfully to their neonate's care (Smith et al 2014:346; Galarza-Winton et al 2013:336).

Psychological support is described as...“any activity that improves a person's ability to function under extraordinary levels of stress observed in the context of a critical event” (Simonsen & Reyes 2003:24). To minimise the long-term consequences of the NICU experience, such as psychological distress, suitable psychological support is important to improve parents' functioning and should complement the medical needs of the neonate to improve their relationship with their neonate (Purdy et al 2017:37; Cano Giménez & Sanches-Luna 2015:e304; Hall et al 2015:529; Magliyah & Razzak 2015:156; Turner et al 2015:252; Hynan et al 2013:751; O'Brien et al 2013:2). Helping parents in the NICU setting who are at risk for psychological distress may reduce their level of symptomatic response to the event and alleviate such distress (Chang et al 2015:100; Barbosa 2013:7). It is imperative to highlight the significance of early identification and screening of parents at risk for extended physical and emotional difficulties and to refer them to a support network where necessary (Purdy et al 2017:39; Busse et al 2015:53; Cano Giménez & Sanchez-Luna 2015:e304; Hynan et al 2013:751; Lasiuk et al 2013:9).

A review of the literature indicated a variety of psychological interventions to provide psychological support to parents in the NICU. Some of these psychological interventions include peer-to-peer support groups and counselling performed by healthcare professionals such as nurses, social workers and psychologists (Hynan 2016:286; Parker 2011:182; Fabris, Coscia, Bertino, Prete, Occhi, Giuliani et al 2009:S47). For example, peer support groups create a feeling of non-judgemental acceptance based on mutual respect, where parents feel safe to share their fears with their peers rather than the medical team, and where peers can offer support and help interpret medical language (Hall et al 2017:6). Mental health professionals comprise of a spectrum of disciplines which include social workers, psychologists, psychiatrists and other professionally trained staff who play an important role in addressing mental health challenges (Hall et al 2017:6).

2.8.3. The provision of support in the Neonatal Intensive Care Unit

In the NICU environment, there is a risk that little attention is being paid to the psychological needs of the family and the neonate. According to Stacey, Osborn and Salkovskis (2015:140) parents in the NICU cope better when they have a healthy-looking neonate, a calm

environment, flexible and friendly professionals caring for their neonate, peer support with values similar to their own and professionals dedicated to promoting parent involvement in the care of their neonate. However, if any of these elements are missing, worsened or replaced by an opposing action, parents felt less equipped and found it harder to cope (Stacey et al 2015:140). Magliyah and Razzak (2015:153) confirm that to enable healthcare professionals in reducing parental stress and anxiety, attention should be focused on providing consistent information, improving interventions and family-centred care and increasing parent satisfaction and participation in the NICU.

Appropriate psychological support is vital in order to assist parents in coping with the traumatic experience of their infant being hospitalised in the NICU and to minimise the severe long-term consequences of this experience (Parker 2011:182). Despite this finding, it was observed that parents do not necessarily ask for psychological interventions, while there is a demand for information. Most parents are unable to obtain psychological or emotional support during their neonates' hospitalisation because they are pre-occupied with the welfare of their neonate and do not put time aside to seek help for themselves (Purdy et al 2017:37; Clotney & Dillard 2013:25). Other obstacles exist when obtaining psychological treatment, which may include shame, lack of access to mental health services, financial restrictions, mistrust of health professionals, lack of resources, staff and time, and inadequate training and education (Purdy et al 2017:37).

The hospitalisation of a neonate in the NICU brings about a set of challenges where a variety of trajectories disrupt the normal attachment process between parents and their neonate, which may have lifelong implications for the family unit (Purdy et al 2017:37; Hynan, Steinberg, Baker, Cicco, Geller, Lassen et al 2015:S14). Supporting the attachment process and providing attention to the psychological needs of the parents should be in synchrony with the medical needs of the neonate (Purdy et al 2017:37). In this regard, there exists a gap between the psychological or mental needs of NICU parents and the availability of help, which may spill over into other areas of their lives and disrupt the formation of a healthy parenting relationship and involvement with their neonate, and later impair the growth and development of their neonate and child (Purdy et al 2017:37; Hynan et al 2015:S14).

Screening, psychosocial support for parents and referral when necessary may help to minimise both traumatic reactions in parents, the negative effects of such reactions on child development (Hynan et al 2013:748) and improve long-term outcomes such as increased maternal sensitivity and a positive mood in neonates (Smith et al 2014:349). Layered levels of support should be available to all parents in the NICU. Hynan et al (2015:S15) specify the

following levels of support: emotional and systematic support and education of parents in the developmental needs of their neonate. The last mentioned authors recommend that for parents who present with multiple risk factors or display acute distress, a multidisciplinary approach to support them should be considered. This support includes social workers, psychologists, psychiatrists and trained counsellors. Any NICU should have a referral system in place for psychological and psychiatric treatment outside the NICU, for those parents who require clinical levels of care that cannot be dealt with by the NICU (Hynan et al 2015:S15).

As discussed, parents in the NICU face an array of challenges and stressors when their neonate is hospitalised. Acute and prolonged stress has a physiological and psychological impact on the parents, which, if left untreated, may lead to traumatic reaction and adversely affect the parent-neonate relationship. The neonate may face adverse behavioural and cognitive outcomes due to a dysfunctional parent-neonate relationship. There are many treatment modalities and interventions available to aid in reducing stress in NICU parents and promote a positive, healthy and functional relationship between the parent and the neonate. Research has indicated the benefits of psychosocial support and other psychological interventions to reduce parental stress in the NICU. For the purpose of this study and to answer the hypothesis, it was decided to utilise a clinical psychologist to implement psycho-educational sessions to aim to reduce stress among NICU parents. The following section deals with the important role psychologists play in the NICU.

2.8.3.1. Psychologists in the Neonatal Intensive Care Unit

Psychological support in the NICU is imperative for parents with emotional distress, with the goal to improve family functioning and developmental outcomes for the neonates, and should be regarded as a high priority (Purdy et al 2015:S24-25). It is imperative to evaluate parents during the period of their neonate's hospitalisation in the NICU. The reason is to effectively assess parental responses to stress originating from the NICU environment and to identify parents at risk for prolonged physical and emotional consequences (Busse et al 2015:53). Parents should promptly be referred to an allied psychological professional, such as a psychologist. Psychologists in the NICU play a pivotal role in the community to provide a wide range of clinical and consultative services (Purdy et al 2015:S25). They provide valuable nonmedical support to parents of neonates in the NICU, as they are uniquely qualified to work with families in crisis (Barbosa 2013:18). Barbosa (2013:18) makes reference to psychology intervention programmes in the early days after birth that focus on helping parents cope with the trauma of premature birth or having a sick neonate admitted to the NICU and offering additional psychological support throughout the neonate's hospitalisation. Early intervention programmes, especially for parents of preterm neonates, have included supportive therapy

and self-help techniques to address parental psychological distress (Shaw et al 2013:e887). Researchers have evaluated intervention programmes that focus on reducing parental anxiety and trauma symptoms.

2.8.3.2. Psycho-educational sessions

Literature argues the importance of psychological intervention programmes for parents who have a neonate hospitalised in the NICU. Intervention approaches and tools to reduce stress in the NICU parent have been developed, and evidence exists on the effectiveness of various approaches (Chertok, McCrone, Parker & Leslie 2014:31). To improve the outcomes in parent-neonate relationships, it is crucial to find and introduce methods to decrease parental stress and improve parental well-being while in the NICU (Turner et al 2015:252). It has been reported that parents who participate in educational-behavioural intervention programmes report less stress, depression and anxiety and result in a more positive parent-neonate interaction, a self-assured parental role and a better understanding of their neonate's behaviour (Friedman, Kessler, Yang, Parsons, Friedman & Martin 2013:e396). In a study conducted by Abdeyazdan, Shahkolahi, Mehrabi and Hajiheidari (2014:349), two subject groups participated, where one group received routine care and the intervention group participated in an intervention support programme. The results showed a significant reduction in stress following the intervention and the conclusion was that early educational and emotional support of parents of preterm neonates decreases stress.

The extent of support available to these parents may affect how well they cope in this stressful situation, and psycho-educational sessions, for example, are an ideal form of support (Parker 2011:183). Groups with a psycho-educational objective provide the support in the context of partnership and collaboration, along with specific instruction about the nature of the life situation in question (Yalom & Leszcz 2005:9-10). Thus, psycho-education is a treatment modality that combines psychotherapeutic and educational interventions performed by mental health professionals. Mental health professionals consist of persons in disciplines that vary in speciality and training and include social workers, psychologists and psychiatrists (Hall et al 2017:6).

Lukens and McFarlane (2004:206) note that psycho-education embraces several complementary theories and models of clinical practice which include ecological systems theory, cognitive-behavioural theory, learning theory, group practice models, stress and coping models, social support models and narrative approaches. The primary focus of psycho-education is the understanding that education plays a role in emotional and behavioural change, and general group mechanisms of support and reinforcement are important (Alonso

& Swiller 1993:427). According to Bauml et al (2006:S1), psycho-education has evolved into an independent therapeutic programme, where individuals and families are empowered to understand and accept related circumstances, and which enable them to cope appropriately. Such groups can be very useful in coming to terms with a specific stress issue. Psycho-education is often viewed as the education provided to individuals who are living with emotional disturbances. Bolat et al (2016:227) note that psycho-education is a flexible model, which incorporates illness specific information and tools for managing related circumstances and provide potential applications to many forms of illness and life changes. Lukens and McFarlane (2004:206) further explain that psycho-education is a professionally delivered modality that integrates psychotherapeutic interventions and educational interventions. The last mentioned authors argue that psycho-education reflects a paradigm shift from traditional medical models to a more holistic and competence-based approach. This approach focuses on strengths and the present. Psycho-education may be provided in different contexts by a variety of professionals, each with a differing emphasis.

Beneficial factors of group sessions for psycho-education is the following: (1) participants obtain a new approach to how they view themselves and their situation; (2) participants feel empowered through acquired knowledge, which improves their coping abilities; (3) participants become more optimistic by being around others in similar situations and challenges; and (4) participants feel assured, because they view themselves as not being alone, which reduces their feelings of isolation (Gitterman & Knight 2016:104). Furthermore, psycho-education has the potential to extend the impact of care provision beyond the immediate circumstances by activating and reinforcing both formal and informal support systems, while teaching participants how to anticipate and manage periods of transition and crisis (Lukens & McFarlane 2004:221).

Yalom's interactional group process model was utilised throughout this study. The model advocates that attending to the relationships within the group helps individuals understand themselves within the relational framework (Yalom 1995:17-24). This process provides individuals with important information about how their behaviour affects others and how they are in turn affected by other members (Yalom 1995:24-6).

2.9. MEASURING OF STRESS

Research studies utilising various designs and methods are in support of the effectiveness of an intervention aimed at decreasing the level of stress experienced by parents in the NICU. These studies utilised assessment tools and outcome measures involving parents of neonates admitted to the NICU. Researchers use a diverse range of questionnaires to measure parental

stress, which can include one or more questionnaires. In the review of literature, the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) by Miles et al (1993) is the most widely used instrument to measure stress among parents in the NICU.

Using the PSS: NICU, researchers have been able to indicate the amount of stress parents experience, the difference in stress levels between mothers and fathers and stress experienced according to the questionnaire's subscales of sight and sound, infant appearance and parental role alteration (Agrawal & Gaur 2017:149-150; Al Maghaireh, Abdullah, Chong, Chau & Al Kwafha 2017:135-136; Musabirema et al 2015:5-6; Turner et al 2015:254; Wormald et al 2015:305; Schappin et al 2013:10; Weis et al 2013:1134). Furthermore, the PSS: NICU has been utilised to measure the effectiveness of interventions aimed at reducing parental stress in the NICU (Cano Giménez & Sanches-Luna 2015:e300-e305; Abdeyazdan et al 2014:349-353; Chertok et al 2014:30-37). In addition, the instrument has been translated into different languages worldwide (Enke, Hausmann, Miedaner, Roth & Woopen 2017:712; Månsson et al 2016:193-201). The development, reliability and validity of the PSS: NICU will be discussed in detail in Chapter three.

2.10. CONCLUSION

Interpreting and utilising current best evidence and translating it into recommended neonatal care practices, requires a commitment to make care decisions to benefit both neonates and their families. Appropriate psychological support is vital to assist parents in coping with stress resulting from their neonate's hospitalisation. The reality is that parents refrain from asking for help, and mental health services are not readily available or easily accessible. Through an extensive review of the literature during this literature review, it is evident that parents experience stress in the NICU and psychological interventions are beneficial in reducing parental stress levels.

It is clear that more concrete evidence is needed to confirm the statement that psycho-educational sessions are effective in reducing parental stress in a NICU. The methodology used in this study will be discussed in the next chapter.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. INTRODUCTION

This chapter is about the methodology used in the study, including the research approach, design and method. In addition, the chapter will present and discuss the sampling procedure and data collection instrument, its reliability and its validity.

A quantitative research approach was used, through a quasi-experimental design with a control group and a treatment group. The purpose of the study was to determine the effectiveness of the implementation of psycho-educational sessions on parental stress in the NICU environment. In the particular NICU in this study, there were no psycho-educational sessions available to parents prior to the study. The study served as a pilot study of a bigger study in the private healthcare group.

3.2. RESEARCH QUESTION

Would there be any significant difference between parents exposed to psycho-educational sessions and those not exposed, in terms of the levels of stress they experienced in relation to (1) sight and sound; (2) behaviour and appearance; and (3) alteration in parental role, in the NICU environment of a private hospital?

3.3. PURPOSE OF THE STUDY

The purpose of the study was to determine the effectiveness of the implementation of psycho-educational sessions on parental stress in the NICU environment. Parental stress was determined by the application of the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) (Annexure A) (Miles et al 1993:149).

3.4. OBJECTIVES OF THE STUDY

To correspond with the PSS: NICU, the objectives of the study were:

- To determine the effectiveness of the implementation of psycho-educational sessions on total parental stress in the NICU environment of a private hospital.
- To determine the effectiveness of the implementation of psycho-educational sessions on stress related to sight and sound in the NICU environment of a private hospital.
- To determine the effectiveness of the implementation of psycho-educational sessions on stress related to infant behaviour and appearance in the NICU environment of a private hospital.

- To determine the effectiveness of the implementation of psycho-educational sessions on stress related to the alteration in the parental role in the NICU environment of a private hospital.

3.5. NULL HYPOTHESIS AND ALTERNATIVE HYPOTHESIS

The null hypothesis (H_0) was: there is no significant difference between the parents exposed to psycho-educational sessions (treatment group) and those that are not exposed (control group receiving routine care) in terms of the levels of stress they experienced in the NICU environment.

The alternative hypothesis (H_1) was: there is a significant difference between the parents exposed to psycho-educational sessions (treatment group) and those that are not exposed (control group receiving routine care) in terms of the levels of stress they experienced in the NICU environment.

H_1 was the alternative hypothesis, if H_0 was not true.

3.6. RESEARCH DESIGN

A quantitative research approach was utilised to determine the effectiveness of the implementation of psycho-educational sessions on parental stress in the NICU of a private hospital. A quantitative research approach was chosen due to the nature of the research question posed, determining the research methodology to be used. During quantitative research, the researcher developed a pre-understanding of the relationship between the dependant variable (parental stress levels) and the independent variable (psycho-educational sessions), and developed a systematic and logical path from the definition and problem statement to the solution of the problem.

In this quantitative research approach, a quasi-experimental design with a control group and a treatment group was utilised, as described by Botma et al (2010:118-9). Quasi-experiments are often called controlled trials without randomisation, which involves an intervention in the absence of randomisation (Polit & Beck 2017:197). The study was quasi-experimental because it was not possible to have randomised groups, as the study took place in the natural setting. In the emotionally sensitive NICU setting, it seemed unjustifiable to provide some parents with psycho-education but deny it to others for reasons of randomisation. Therefore, it started with a control group, with psycho-educational sessions implemented in the treatment group a week after data collection had been completed for the control group. The population for each group consisted of parents who had a neonate admitted to the NICU of a particular

private hospital. The intervention, namely psycho-educational sessions, was introduced in the treatment group. To avoid ethical problems, no control was applied over the independent variables (routine care continued in its natural setting). The researcher had no control over the confounding variables (as discussed as part of the assumptions of the study) and data were collected in the natural setting.

A major strength of quasi-experiments is that they are practical. They are expected to be more suitable to a wide-ranging group of people because they do not involve random assignment. This has positive implications for the generalisability of the results, but the results may be less conclusive (Polit & Beck 2017:203). However, when a quasi-experimental design is used, there are rival hypotheses opposing the intervention as the reason for the results. The probability of any particular rival explanation typically cannot be answered indisputably. Conclusions from quasi-experimental experiments ultimately depend in part on human decree, rather than on more objective criteria; cause-and-effect interpretations are less compelling (Polit & Beck 2017:203).

Data through a quantitative approach were gathered according to an established plan, using structured methods or instruments (a validated self-report questionnaire) to collect the needed information. The instrument used in this study, the PSS: NICU, will be discussed in the following section.

3.7. MEASURING OF STRESS

A psychological questionnaire is used to measure stress, covering a range of psychological symptoms induced by exposure to stress (Centre for Studies on Human Stress 2007:6). The focus of the questionnaire was general, not specific to the intervention. The researcher was of the opinion that a shift in the stress levels of parents might indicate the value of psycho-educational sessions. In addition to the PSS: NICU tool, the researcher added demographic items (Annexure A) to provide relevant information that gave an indication of the characteristic of the population and assisted in determining factors that may influence a participant's choice of answers through stratified data analysis. The values of the stress scale were calculated by a statistician, thereby decreasing researcher bias.

An existing validated and reliable 26-item self-report stress scale, namely the PSS: NICU (Annexure A), was chosen for this study to measure stress experienced by parents in the NICU. The PSS: NICU was designed to measure the amount of stress experienced by parents during hospitalisation related to the sights and sounds of the unit, the appearance and behaviour of their neonate, and the alterations in their parental role. The principle underpinning

the instrument is based on stress theory, and it was designed to measure parental perception of stressors emerging from the physical and psychosocial environment of the NICU (Miles et al 1993:149).

The PSS: NICU (Annexure A) was developed by Miles and Funk in 1987 and further refined by Miles et al in 1993. From the information provided regarding this measure, psychometrics and scoring were conducted in three NICUs in the United States of America and one in Canada (Miles, Funk & Carlson 1993:151). The PSS: NICU of 1993 consisted of a 46-item scale and was updated in 2007 to a 26-item scale. Internal consistency was established by calculating Cronbach's alpha coefficients for each subscale and total instrument. Alpha coefficients were >0.70 for all scales and metric 1 (0.94) and metric 2 (0.89) in the original PSS: NICU. Cronbach's alpha was 0.92 for both scales in the updated PSS: NICU of 2007. The PSS: NICU had good test-retest reliability and internal consistency of 0.88 in studies evaluating its validity (Miles et al 1993:149; Shields-Poë & Pinelli 1997:29).

3.7.1. Psychometrics and subscales

An updated factor and psychometric analysis of the PSS: NICU was conducted in 2007 in a NICU in the south-eastern United States of America (Miles, Holditch-Davis, Schwartz & Sher 2007:36), which indicated that the instrument was best conjectured as having two subscales instead of three. The sights and sounds of the NICU environment (five items) should be combined with the neonate's appearance subscales (14 items) and scored as one subscale, and parental role alteration remains the second subscale (seven items). Total stress refers to the combination of the subscales. The neonate's appearance (factor 1) explained 7.6% of variance and parental role alteration explained 6.03% of the variance. Cronbach's alpha was 0.92 for both subscales. Factor analysis was conducted on the PSS: NICU at enrolment. Principal component axis factor analysis suggested three factors with Eigen values over 1.5. A three-factor solution was not conceptually interpretable. A two-factor solution explained 7.7% of the variance in factor 1 and 6.0% of the variance in factor 2. None of the added items contributed to the factors, so they were eliminated. The two factors were used in all further analyses.

3.7.2. Scoring and metric considerations

Parents were asked to rate the stressfulness of each item on a Likert scale, ranging from 1 (not at all stressful) to 5 (extremely stressful). However, not all parents will experience every situation indicated on the stress scale, and they may indicate N/A (not applicable) for items they do not experience.

According to Miles (2015:4), the PSS: NICU can be scored in two ways:

- Metric 1 – Stress occurrence level: the level of stress that is experienced by parents related to their particular situation.
 - Only those who report their experience receive a score.
 - Those who do not report on an item are omitted.
 - The commonality is the number of parents who experienced the particular stress.
 - Scale scores are then calculated by averaging stress responses for the items experienced on each scale and for the total scale.
 - The denominator for obtaining the average for each scale is the number of items on that scale experienced by the parent.
- Metric 2 – Overall stress level: the overall level of stress triggered by the NICU environment.
 - Parents who do not report on an item are given a score of 1.
 - The commonality is the number of items on the scale.
 - Scale scores are calculated by averaging these stress responses for the items on each scale and for the total scale.
 - The denominator for obtaining the average for each scale is the number of items on the scale.

The clinical sensitivity of the instrument is strengthened by providing two possible methods of scoring the stress of parents. The scoring methods provide different but important pieces of information about stress in the NICU. One should choose the metric that is most conceptually appropriate for one's study. For example, using metric 1, as described in the previous section, is deemed to be more appropriate if the focus is on how much stress each aspect of the NICU environment causes. If, however, the study focuses on the stress levels of parents, metric 2 would best describe the levels of stress parents have experienced in the NICU environment.

3.8. RIGOUR

3.8.1. Validity

Botma et al (2010:174) state that...“validity indicates whether the conclusions of the study are justified based on the design and interpretation” and that...“it refers to the degree to which a measurement represents a true value”.

3.8.1.1. Internal validity

Internal validity is concerned with the validity of an assumption, given that a verifiable relationship exists, it is the independent variable rather than something else, and that it causes the outcome (Polit & Beck 2017:216). Thus, the assumption in this study is that psycho-

educational sessions are reducing stress levels. Researchers should develop strategies to rule out factors other than the independent variables that might be the reason for the observed relationship. Using a quasi-experimental design, the researcher should withstand competing explanations of what caused the outcomes, as stated by Polit and Beck (2017:224).

The following are included as potential competing threats to the internal validity of the study, as suggested by Polit and Beck (2017:224):

- a) **Selection:** Selection plays an important role in improving internal validity, suggesting that if participants are placed purposefully into groups to meet the desired outcome of the study, the internal validity will be low. Using randomly assigned groups is the best way of eliminating this threat to validity. For the purpose of this study, a non-probability total sampling was used, as it was not possible to conduct randomised sampling. The researcher could not choose who would be parents of sick or prematurely born neonates. When participants are not randomly assigned to groups, the groups compared may not be equivalent and the differences in outcomes may reflect group differences or population changes over time, rather than the effect of the independent variable (Polit & Beck 2017:224).
- b) **History:** History and other non-related influences refer to external factors that take place concurrently with the independent variable and might influence the outcome of the study at hand, over which the researcher does not have any control. For the purpose of this study, an open-ended question was included at the end of the questionnaire, where participants were asked to write about other situations that they found stressful during the time that their neonate was in the NICU. It is assumed that external factors are likely to affect the control group and the treatment group, and therefore, group differences in the dependant variables signify effects other than those created by external factors (Polit & Beck 2017:224).
- c) **Maturation:** The threat of maturation plays an important role in influencing the internal validity of a study. It refers to changes that occur within participants during the course of the study as a result of time elapse, rather than as a result of the independent variable (Polit & Beck 2017:224). Examples include exhaustion, coping mechanisms and emotional maturity. Data for the control group and treatment group were collected over a period of four months, during which participants completed the questionnaire two days after admission, then biweekly, and finally upon discharge. Some participants completed only two questionnaires (after two days and upon discharge), but other participants completed up to four questionnaires. As time elapsed, it is possible that parents just managed to cope better with the situation and settled into their new routine, and that resulted in their stress levels decreasing. On the other hand, in cases

where the parents became exhausted from travelling to and from the hospital and having to juggle life inside and outside the NICU, this may have resulted in an increase in stress levels.

- d) **Attrition:** When using different participants in separate groups, differences other than the independent variable could account for observed differences in the dependent variables. In this study, two groups were used, a control group and a treatment group, with the expectation that the implementation of psycho-educational sessions with the treatment group would yield the desired result of reducing parental stress. The respective groups consisted of different participants and did not run concurrently, which may account for differences in their stress levels, not necessarily due to the psycho-educational sessions, but due to the differences in the participants.
- e) **Instrumentation:** Instrumentation is a threat related to changes in the instrument used for measurement between two points of data collection. For example, the measuring tool might yield less accurate measures the second time around if the participants become bored and answer haphazardly (Polit & Beck 2017:226). The results could be biased if there are such differences in the measures. In this study, some parents had to be asked repeatedly to complete the questionnaire upon discharge, mostly because they were distracted and nervous about taking their neonate home. This resulted in haphazard answers. Some parents who had to complete the questionnaire as many as four times seemed bored with the process. This may result in less accurate measures the second, third or fourth time around.

3.8.1.2. Construct validity

Construct validity is concerned with the degree to which an intervention is a good depiction of the potential the theorised construct has to cause instrumental outcomes (Polit & Beck 2017:216). Construct validity is important because constructs can form a link between operations used in the study and a relevant approach, and between the operations used and processes for translating the results into practice.

The following are included as potential threats to the construct validity of the study, as suggested by Polit and Beck (2017:228-229):

- a) **Reactivity to the study situation:** Also referred to as the Hawthorne effect, reactivity to the study situation refers to participants changing their behaviour due to the knowledge that they play a role in the study. One of the participants completed the questionnaire based on his traditional role in the family and not based on how he was feeling. He verbalised his distress, but refrained from answering the questionnaire truthfully, due to being bound by tradition.

- b) Researcher expectancies:** This threat stems from how the researcher might influence the participant's response through subtle/not-so-subtle hints about what the outcome should be. The researcher had to explain some of the questions in the questionnaire by providing the participants with examples, which may have resulted in subtle hints about how they should answer.

3.8.1.3. External validity

External validity is concerned with whether the assumptions about the observed relationship will remain valid if there are variations in people, surroundings, time, or procedures of the outcomes (Polit & Beck 2017:216). It entails the generalisability of causal assumptions. Non-probability total population sampling was utilised, where the entire population was recruited based on a particular set of characteristics. The researcher had access to parents whose neonates were admitted in the NICU of a specific hospital, during a limited period in which data collection could take place. This was done by selection of the participants based on the inclusion and exclusion criteria discussed previously. Total population sampling was chosen due to the small sample size available. Smaller sample sizes result in smaller groups, which may impede the ability to detect differences between groups. Generalisability of the current study findings is limited because data were collected from parents at one hospital and in one geographical location, thus the results may not be typical of other NICUs, due to variations in people, surroundings, time and procedures.

3.8.1.4. Validity of the instrument

The validity of an instrument refers to the degree to which an instrument measures what it is supposed to measure.

There are three aspects that need to be evaluated when assessing the validity of an instrument (Polit & Beck 2017:309-319):

- a) Content and face validity:** Content validity refers to the degree to which an instrument's content covers the construct being measured. Face validity refers to whether the instrument appears to be measuring the specific construct.
- b) Criterion validity:** Criterion validity refers to whether the researcher can compare scores of an instrument with external, reliable and valid criteria, seeking a relationship between the scores.
- c) Construct validity:** Construct validity refers to the construct that an instrument is truly measuring.

The content and face validity, criterion validity and construct validity of the particular instrument used in this study, the PSS: NICU, were established by Miles et al in 1993 and updated by Miles et al in 2007.

3.8.2. Reliability

Reliability is a representation of the consistency that the measure has achieved. That is, if the valid measuring instrument is applied to any other group, under different conditions, it ought to yield the same results (Botma et al 2010:177). The less variation an instrument produces when repeating the measure, the higher the reliability.

There are two aspects of importance when measuring reliability, as indicated by Botma et al (2010:177-178):

- a) Stability:** Stability refers to the extent to which the same scores are obtained when the instrument is used with the same people on different occasions. The purpose of the study was to determine if the stress levels of parents would reduce over time with the addition of an intervention; thus, to achieve the same scores on different occasions would not yield the desired outcome of the study. It is hypothesised that there will be a difference between scores.
- b) Homogeneity:** This is used primarily for pencil-and-paper tests. The test to examine reliability is a Chronbach's alpha test, which tests internal consistency. The internal consistency of the PSS: NICU was proven by Miles et al (1993:151) during the scale's development. The PSS: NICU had a good test-retest reliability and internal consistency in studies evaluating its validity by Miles et al (1993:149) and Shields-Poë and Pinelli (1997:29).

3.9. SETTING

The study took place in the NICU of a private hospital. The unit allowed for a 14-bed ICU and high care. An average of 19 neonates was admitted per month with an average length of stay of 84 days. The setting was discussed in chapter one.

3.10. POPULATION AND SAMPLING

The populations for the control group and the treatment group consisted of parents (mothers and fathers) of neonates admitted to the NICU of a particular private hospital. An approximate sample size will be discussed shortly.

Non-probability total sampling was used, but a minimum sample size was calculated that made sense in the context of the study and an appropriate data analysis technique was determined

based on this sample size. The number of admissions from November 2016 until May 2017 was used to calculate the possible sample size. The sample size was determined by taking the study duration and the admission rate into consideration. A power analysis using G*Power version 3.1.9.2 indicated that for a significance of 5% and an effect size of 0.85, a sample size of 18 per group would be sufficient to ensure a power of 80%. The estimated effect size is based on the expectation that there would be a large difference between the scores observed in the two groups. A statistician was consulted regarding the sample size and identified that a total of 20 participants for the control group and 20 participants for the treatment group was adequate to achieve the objectives of the study. Thus, the sample size consisted of 20 participants in the control group and 20 participants in the treatment group. The study served as a pilot study in the private hospital group, and the results were not generalised. The sample size corresponded with a similar study that utilised the PSS: NICU (Turan, Basbakkel & Ozbek 2008:2856-2866).

Non-probability total population sampling was utilised as randomised sampling was not possible and where an entire population was recruited based on a particular set of characteristics. Furthermore, data collection could only take place during the limited period in which the researcher had access to the parents whose neonates were admitted in the NICU, which limited the size of the total available population and number of potential participants. The sample provided an accurate representation of the population under study in terms of their specific attributes/traits, experience, knowledge and exposure to an event, among other aspects. In total population sampling, the entire population is chosen for the study, because the size of the population is typically very small (Etikan, Musa & Alkassim 2016:3).

Data collection took place over a period of four months and was divided between a control group and a treatment group. The first group was the control group, whose data were used to determine parental stress levels during routine hospitalisation in the NICU. The control group was exposed to routine family-centred care as it is currently practised in the particular NICU. After the target sample size for the control group was reached, the second group, namely the treatment group, was exposed to routine family-centred care with the addition of psycho-educational sessions. The groups were not homogenous, as the study occurred in the natural setting. Participants in the control group and the treatment group completed the self-report questionnaire (Annexure A) from day two, biweekly and at discharge.

3.10.1. Inclusion criteria:

- Mothers and/or fathers whose neonate was admitted to the NICU of a particular private hospital for two days or longer.
- Mothers and/or fathers who were 18 years or older.
- Mothers and/or fathers who provided consent to participate in the study (ethically, it is required for either of the parents to agree to participate in the study).

3.10.2. Exclusion criteria:

- Mothers and/or fathers whose neonate was admitted to the NICU of a particular private hospital for less than two days.
- Mothers and/or fathers who were younger than 18 years.
- Mothers and/or fathers who could not provide consent to participate in the study.

3.11. THE INTERVENTION – PSYCHO-EDUCATIONAL SESSIONS

The basis of psycho-education is the understanding that education plays a vital role in emotional and behavioural change. Psycho-education was discussed in detail in chapter two.

Group psycho-educational sessions involved one clinical psychologist, who led a group of one to six participants at a time. Typically, group members met for an hour each week, with the group being available twice a week at different times to accommodate members' responsibilities outside of the hospital. Due to personal or logistical factors (for example, the length of hospitalisation of their neonate), the parents attended as many sessions as they felt they needed. The researcher could not control the number of sessions attended, but the assumption was that even a single attendance would have had an effect on their stress levels. The number of sessions attended was recorded by the researcher and included in descriptive statistics in Chapter four to determine the effectiveness of the intervention on their stress levels.

3.12. DATA COLLECTION

Data collection took place over a period of four months and was divided into a control group and a treatment group. The first group was the control group, whose data were used to determine parental stress levels during routine care utilising the PSS: NICU (Annexure A). After the target sample size for the control group was reached, the second group was exposed to routine care with the addition of the intervention (psycho-educational sessions). The groups were not homogenous, as the study occurred in the natural setting. Data collection will be discussed in more detail in Chapter four.

3.13. DATA ANALYSIS

Interval measurements were used to describe the amount of stress experienced by the parents at the moment of data collection, which was from day two, then biweekly, and finally at discharge. Bivariate descriptive statistics were used along with a contingency table to show stratified characteristics (demographic data) (Polit & Beck 2017:364-5) associated with parental stress in both the control group (the first group receiving routine care) and the treatment group (the second group receiving psycho-educational sessions in conjunction with routine care). Inferential statistics were utilised to establish if there was a difference in the stress levels of parents in the control group and those in the treatment group, as suggested by Polit and Beck (2017:376-401). A statistician of the University of Pretoria was involved in data analysis (Annexure E). The findings are discussed in Chapters four and five.

3.14. STATISTICAL SIGNIFICANCE

Statistical significance implies that the findings are probably reliable and can be replicated with a new sample (Polit & Beck 2017:62). Statistical information is used to draw conclusions about the usefulness or importance of the research findings. A statistician from the University of Pretoria (Annexure E) aided in determining the statistical significance of this study. The statistical significance will be discussed in Chapter four.

3.15. ETHICAL AND LEGAL CONSIDERATIONS

A quasi-experimental design with a control group and a treatment group was utilised. To avoid ethical problems, no control was applied over the independent variables (routine care continued in its natural setting and the same degree of family-centred care was provided to all neonates). The researcher had no control over the confounding variables either, and data were collected in the natural setting.

3.15.1. Ethical principles for protecting study participants

Before the initiation of data collection, the researcher obtained consent to do research in a private hospital (Annexure F) and ethical approval from the Ethics Committee of the University of Pretoria's Faculty of Health Sciences (Annexure D). As discussed in Chapter one, three broad principles are stipulated in the Belmont report, on which standards of ethics are based. Researchers are expected to adopt to comply with these principles (Polit & Beck 2017:139), namely beneficence, respect for human dignity and justice. The ethical principles were adhered to throughout the study.

3.16. CONCLUSION

This chapter outlined the research methodology used in this study. It included the research question, purpose, objectives, hypothesis, as well as the research design and research methods. The research setting and the population used for the study were discussed. The chapter also included discussions on psycho-educational session, the realisation of data collection and the method for data analysis. The results of the study will be presented in Chapters four and five.

CHAPTER 4

RESULTS

4.1. INTRODUCTION

During the researcher's experience working in the NICU of a private hospital, the question arose whether the implementation of psycho-educational sessions, would be effective in reducing parental stress in the NICU environment.

This study took a quantitative research approach with a quasi-experimental design consisting of a control group and a treatment group. The design excluded manipulation of the independent variable (routine care continued in its natural setting), focused on the introduction of psycho-educational sessions presented by a clinical psychologist, in the absence of randomisation and the description of the relationship between the dependant (stress levels of parents) and independent variables. Total population sampling, which is a non-probability sampling technique, was used to sample the willing parents of all the neonates who were admitted to the specific NICU during the period of the study. View Chapter three for a more in-depth discussion of the study design and methodology.

4.2. DATA ANALYSIS

Statistical hypothesis testing was performed, as discussed in chapter three. A chi-square test and a t-test were used to determine the difference between the control group and treatment group in terms of demographic and neonate characteristics. The independent t-test determined whether a significant difference existed between the two groups (null hypothesis states that no significant difference exists), while the chi-square test determined whether an association existed between the categorical variables and the two groups (null hypothesis states that no association exists). The mean stress scores for the mothers and fathers in the control group and the treatment group were examined. To compare the differences between the two independent groups, the non-parametric equivalent, this study used the Mann-Whitney U-test, which is used for paired groups that do not have normal distributions, and the Kruskal-Wallis test, which is used for groups when the comparison consists of more than two characteristics.

For PSS: NICU outcomes, raw scores are computed as effect sizes, with calculations for metric 2 of the scale. Continuous outcome measures were reported as mean and standard deviation, while categorical outcome measures were described as frequency and percentage. A p-value below 0.05 was considered significant. Statistical analyses were performed using R for statistical computing version 3.5.0. All calculations were done with the assistance of a statistician from the University of Pretoria.

The raw data were captured on the SPSS system for analysis, checked by the researcher and sent to the statistician for analysis. The statistician utilised R version 3.5.0. for statistical analysis.

4.3. RESULTS

4.3.1. COMPARING BASIC CHARACTERISTICS BETWEEN GROUPS

Detailed demographic data were collected from the samples. Although the majority of parents were white (65%), blacks (25%) and other races (coloured – 5%, Indian – 5%) were represented. Most parents were married (90%), 27.5% had completed high school and 25% had attended college or had some graduate education (47.5%). The average age of the parents was 33 years, and 17.5% had previous NICU experience while 82.5% had none.

Basic characteristics were calculated between the control group and the treatment group populations. The t-test was used for age (since data were normally distributed), and the chi-square tests were used for all other variables. Tests applied to each variable: t-test (age) and chi-square test (gender, marital status, race, education, type of delivery and previous NICU experience).

Across all of these variables, it can be seen in Table 4.1 that the p-values are all greater than 0.05. This means that, at a 5% level of significance, there is not enough information to reject the null hypothesis and that the populations are similar with respect to these characteristics. There were no statistical differences ($p > 0.05$) between the control group and the treatment group in terms of demographic characteristics, type of delivery and previous NICU experience.

Table 4.1 Comparing basic characteristics between groups

	Control (N = 20)	Treatment (N = 20)	P-value
Age *			
Min	25	25	
Max	43	45	
Mean (SD)	33.45 ± 4.95	33.80 ± 5.34	0.83
Gender †			
Female	12 (60)	11 (55)	
Male	8 (40)	9 (45)	1

Table 4.1 Comparing basic characteristics between groups

	Control (N = 20)	Treatment (N = 20)	P-value
Marital Status †			
Married	18 (90)	18 (90)	
Single	2 (10)	2 (10)	
Separated	0 (0)	0 (0)	
Divorced	0 (0)	0 (0)	1
Race †			
White	15 (75)	11 (55)	
Black	5 (25)	5 (25)	
Coloured	0 (0)	2 (10)	
Indian	0 (0)	2 (10)	
Asian	0 (0)	0 (0)	
Other	0 (0)	0 (0)	0.2
Education †			
University	11 (55)	8 (40)	
Grade 12	5 (25)	3 (15)	
College	4 (20)	6 (30)	
Other	0 (0)	3 (15)	0.22
Type of delivery †			
Caesarean section	20 (100)	17 (85)	
Normal vaginal	0 (0)	3 (15)	0.23
Previous NICU experience †			
Yes	5 (25)	2 (10)	
No	15 (75)	18 (90)	0.41

* Independent t-test

† Chi-squared test

SD = Standard deviation

4.3.2. COMPARING STRESS SCORES BETWEEN GROUPS

The stress scores were determined using the following rules:

- Metric 2 – Overall stress level: the overall level of stress triggered by the NICU environment
 - Parents who do not report on an item are given a score of 1.
 - Scale scores are calculated by averaging these stress responses for the items on each scale and for the total scale.
 - The denominator for obtaining the average for each scale is the number of items on the scale.

The median results were obtained per participant across the repeated measures.

4.3.2.1. Overall stress scores

The overall stress level refers to the overall level of stress that was triggered by the NICU environment. Scale stress scores were calculated by averaging stress responses for the items on each scale and for the total scale.

Across all 20 participants (N=20 for both groups), we evaluated the normality of the stress scores for sections B, C and D as well as the overall stress scores. The normality was tested using the Shapiro-Wilk test of normality (null hypothesis states that the data is normally distributed). At a 5% level of significance, all the p-values were greater than 0.05, hence the null hypothesis could not be rejected. This means that the data were normally distributed and the independent t-test could be used. The non-parametric equivalent, the Mann Whitney U test (Table 4.2) was included and the final results remained the same.

Table 4.2 Overall stress scores – Non-parametric Mann Whitney U test results

	Control (N = 20)	Treatment (N = 20)	P-value
Sights and sounds (B)			
Min	1.2	1.0	
Max	3.8	4.2	
Mean (SD)	2.38 ± 0.74	2.55 ± 0.95	0.64
Behaviour and appearance (C)			
Min	1.428571	1.000000	
Max	4.285714	4.000000	
Mean (SD)	2.64 ± 0.95	2.52 ± 0.98	0.8
Parental role (D)			
Min	1.571429	1.142857	
Max	5	5	
Mean (SD)	3.24 ± 0.87	3.31 ± 1.12	0.82
Total score			
Min	1.846154	1.115385	
Max	4.192308	4.307692	
Mean (SD)	2.75 ± 0.81	2.74 ± 0.96	0.98

4.4. FINDINGS RELATED TO THE MOTHERS' PSS: NICU SUBSCALE AND TOTAL STRESS SCORES

As can be seen in Table 4.3, the stress score differences were as follows:

- In the sights and sounds (B) subscale, the mean stress score for mothers in the control group was 2.35, and for mothers in the treatment group was 2.47. The difference between the two groups for this section was not found to be statistically significant (0.78) ($p > 0.05$).
- In the infant's appearance and behaviours (C) subscale, the mean stress score for mothers in the control group was 2.57, and for mothers in the treatment group was 2.42. The difference between the two groups for this section was not found to be statistically significant (0.78) ($p > 0.05$).
- In the parental role (D) subscale, the mean stress score for mothers in the control group was 3.19, and for mothers in the treatment group was 3.17. The difference between the two groups in this section was not found to be statistically significant (0.83) ($p > 0.05$).

- The general mean stress score for mothers in the control group was 2.70, and for mothers in the treatment group was 2.63. The difference between the two groups was not found to be statistically significant (0.88) ($p > 0.05$).

Since the group of mothers was not normally distributed (smaller group), a non-parametric test was advised. For this test, the stress scores between the two groups were compared and it was found that no significant difference existed between the two groups – all the p-values were greater than 0.05, hence the null hypothesis could not be rejected.

Table 4.3 Scores for mothers' PSS: NICU subscale and total stress scores

	Control (N = 12)	Treatment (N = 11)	P-value
Sights and sounds (B)			
Min	1.2	1.0	
Max	3.8	4.2	
Mean (SD)	2.35 ± 0.88	2.47 ± 0.96	0.78
Behaviour and appearance (C)			
Min	1.428571	1.000000	
Max	4.285714	4.000000	
Mean (SD)	2.57 ± 1.00	2.42 ± 1.04	0.78
Parental role (D)			
Min	1.571429	1.142857	
Max	4.571429	5.000000	
Mean (SD)	3.19 ± 0.86	3.17 ± 1.31	0.83
Total score			
Min	1.846154	1.115385	
Max	4.192308	4.307692	
Mean (SD)	2.70 ± 0.85	2.63 ± 1.05	0.88

4.5. FINDINGS RELATED TO THE FATHERS' PSS: NICU SUBSCALE AND TOTAL STRESS SCORES

The comparison of the PSS: NICU mean stress scores obtained by the control group and the treatment group fathers is shown in Table 4.4.:

- The sights and sounds (B) subscale mean stress score for fathers in the control group was 2.42, and for fathers in the treatment group was 2.64. The difference between the two groups for this section was not found to be statistically significant (0.73) ($p > 0.05$).
- The infant's appearance and behaviours (C) subscale mean stress score for fathers in the control group was 2.75, and for fathers in the treatment group was 2.66. The difference between the two groups for this section was not found to be statistically significant (0.89) ($p > 0.05$).
- The parental role (D) subscale mean stress score for fathers in the control group was 3.30, and for fathers in the treatment group was 3.49. The difference between the two groups in this section was not found to be statistically significant (0.7) ($p > 0.05$).

- The general mean stress score for fathers in the control group was 2.84, and for fathers in the treatment group was 2.88. The difference between the two groups was not found to be statistically significant (0.92) ($p > 0.05$).

Since the group of fathers was not normally distributed (smaller group), a non-parametric test was advised. For this test, the stress scores between the two groups were compared and it was found that no significant difference existed between the two groups – all the p-values were greater than 0.05, hence the null hypothesis could not be rejected.

Table 4.4 Scores for fathers' PSS: NICU subscale and total stress scores

	Group: Control (N = 8)	Group: Treat (N = 9)	P-value
Sights and sounds (B)			
Min	1.8	1.2	
Max	3.4	4.2	
Mean (SD)	2.42 ± 0.52	2.64 ± 0.99	0.73
Behaviour and appearance (C)			
Min	1.714286	1.285714	
Max	4.071429	4.000000	
Mean (SD)	2.75 ± 0.91	2.66 ± 0.93	0.89
Parental role (D)			
Min	2.285714	2.285714	
Max	5.000000	4.571429	
Mean (SD)	3.30 ± 0.94	3.49 ± 0.90	0.7
Total score			
Min	1.923077	1.576923	
Max	4.076923	4.076923	
Mean (SD)	2.84 ± 0.79	2.88 ± 0.87	0.92

There was no statistically significant difference in the subcategory scale mean between the mothers and fathers, and no statistically significant difference in the total mean stress scores either ($p > 0.05$). Thus, it may be concluded that both groups experienced a moderate level of stress and neither the mothers nor the fathers experienced less stress.

4.6. COMPARING CHARACTERISTICS BETWEEN PARTICIPANTS WITHIN THE GROUPS

The following section compared the total stress score results between participants within the same group, but with different characteristics, in order to determine if differences exist. Since the comparison was between two characteristics at a time, the Mann Whitney U test was used to test the significance at a 5% level. For those groups which consisted of more than two characteristics, the Kruskal-Wallis test was used (e.g. ethnicity in the treatment group). Where this test found that significant differences exist between the groups, a post hoc Dunn test with

Bonferoni adjustments was used to determine which groups differ from each other. The adjusted p-value can be used to determine which groups differ from each other.

The control group participants' PSS: NICU total stress scores were not found to be different according to their gender, ethnicity or age, the neonate's Apgar score at five minutes, birthweight, support, or number of other siblings ($p > 0.05$), but the participants' Apgar score at one minute and previous NICU experience were found to affect the stress scores received from the PSS: NICU ($p < 0.05$) (Table 4.5).

The treatment group participants' PSS: NICU total stress scores were not found to be different according to their gender, age, previous NICU experience, the neonate's birthweight, or the number of other siblings ($p > 0.05$), but the participants' ethnicity, Apgar score at one minute and Apgar score at five minutes were found to affect the stress scores received from the PSS: NICU ($p < 0.05$) (Table 4.5).

It was found that neither the control group nor the treatment group participants' PSS: NICU stress scores were affected by gender, age, birthweight and number of other siblings ($p > 0.05$), and that both were affected by Apgar score at one minute ($p < 0.05$) (Table 4.5).

Table 4.5 Comparison of characteristics of participants within the groups

Variable and group	N	N	P-value
Gender			
Control group	1 (N = 8)	2 (N = 12)	
Mean (SD)	2.84 ± 0.79	2.70 ± 0.85	0.59
Treatment group	1 (N = 9)	2 (n = 11)	
Mean (SD)	2.88 ± 0.87	2.63 ± 1.05	0.62
Ethnicity			
Control group	1 (N = 5)	2 (N = 15)	
Mean (SD)	2.53 ± 0.32	2.83 ± 0.91	0.97
Treatment group *	1 (N = 5) ; 2 (N = 11)	3 (N = 2) ; 4 (N = 2)	
Mean (SD)	3.86 ± 0.58 ; 2.31 ± 0.69	1.87 ± 0.90 ; 3.19 ± 0.44	0.01
Comparison †	(Z)	(P.unadj)	(P.adj)
1 - 2	2.866	0.00415	0.0249
1 - 3	2.377	0.01748	0.1049
2 - 3	0.5754	0.565	1
1 - 4	0.6068	0.544	1
2 - 4	-1.351	0.1767	1
3 - 4	-1.481	0.1387	0.8321

Table 4.5 Comparison of characteristics of participants within the groups

Variable and group	N	N	P-value
Age category			
Control group	32 and Below (N = 9)	Older than 32 (N = 11)	
Mean (SD)	2.94 ± 1.02	2.60 ± 0.58	0.7
Treatment group	32 and Below (N = 8)	Older than 32 (N = 12)	
Mean (SD)	2.57 ± 0.98	2.86 ± 0.97	0.59
Apgar score at 1 minute			
Control group	7 and Below (N = 9)	More than 7 (N = 11)	
Mean (SD)	2.24 ± 0.41	3.17 ± 0.82	0.02
Treatment group	7 and Below (N = 10)	More than 7 (N = 10)	
Mean (SD)	2.18 ± 0.76	3.30 ± 0.81	0.01
Apgar score at 5 minutes			
Control group	8 and Below (N = 8)	More than 8 (N = 12)	
Mean (SD)	2.29 ± 0.41	3.06 ± 0.87	0.12
Treatment group	8 and Below (N = 12)	More than 8 (N = 8)	
Mean (SD)	2.40 ± 0.90	3.25 ± 0.85	0.05
Previous NICU experience			
Control group	1 (N = 5)	2 (N = 15)	
Mean (SD)	2.16 ± 0.62	2.95 ± 0.78	0.02
Treatment group	1 (N = 2)	2 (N = 18)	
Mean (SD)	2.12 ± 0.44	2.81 ± 0.98	0.23
Support			
Control group	1 (N = 19)	2 (N = 1)	
Mean (SD)	2.76 ± 0.83	2.65 ± NA	1
Birthweight category			
Control group	2.2kg and Below (N = 9)	More than 2.2kg (N = 11)	
Mean (SD)	3.00 ± 0.82	2.55 ± 0.77	0.25
Treatment group	2.2kg and Below (N = 8)	More than 2.2kg(N = 12)	
Mean (SD)	2.77 ± 1.11	2.72 ± 0.89	0.88
Number of other siblings			
Control group	No Siblings (N = 8)	Siblings (N = 12)	
Mean (SD)	2.81 ± 0.83	2.71 ± 0.82	0.82
Treatment group	No Siblings (N = 8)	Siblings (N = 12)	
Mean (SD)	2.30 ± 0.78	3.04 ± 0.98	0.16

*Kruskal-Wallis test

†Dunn test with Benferoni adjustments

4.7. DISCUSSION

The birth of a neonate is a stressful event, and is even worse if the neonate is admitted to the NICU. During the researcher's experience working in the NICU of a private hospital, she observed parental stress. The question was: would there be any significant difference between parents exposed to psycho-educational sessions and those not exposed, in terms of the levels of stress they experienced in relation to (1) sight and sound; (2) behaviour and appearance; and (3) alteration in parental role, in the NICU environment of a private hospital.

Using a quasi-experimental design, a control group of parents was exposed to the routine care provided in the NICU and a treatment group of parents was exposed to the routine care as well as psycho-educational sessions. Both groups of parents were requested to indicate their levels of stress by completing the PSS: NICU. The null-hypothesis (H_0) was: there is no significant difference between the parents exposed to psycho-educational sessions (treatment group) and those that are not exposed (control group receiving routine care) in terms of the levels of stress they experienced in the NICU environment.

The difference between the sight and sound (B) subscale mean stress score obtained by the mothers in the control group and that of the treatment group was found not to be statistically significant (0.78) ($p > 0.05$). Mothers in the treatment group (2.47) experienced slightly more stress than the mothers in the control group (2.35). Admission of a neonate to the NICU is a very unique experience. Parents are taken into the NICU, which is equipped with monitors and machines. Cano Gimenez and Sanches-Luna (2015:e304) and Chertok et al (2014:30) indicate that the physical NICU environment includes monitors with beeping sounds and flashing lights, which contributes to the stressful experience.

The difference between the behaviour and appearance (C) subscale mean stress score obtained by the mothers in the control group and that of the treatment group was not found to be statistically significant (0.78) ($p > 0.05$). Mothers in the control group (2.57) experienced their neonate's behaviour and appearance as being more stressful than those in the treatment group (2.42). Cano Gimenez and Sanches-Luna (2015:e304) confirm that the behaviour and appearance of a neonate evokes an array of emotions and can be very stressful for parents.

Although the difference between the parental role alteration (D) subscale mean stress score obtained by the mothers in the control group and that of the treatment group was not found to be statistically significant (0.83) ($p > 0.05$), this subscale scored the highest mean scores for the mothers. This finding is consistent with results of other studies, which found that parental role alteration was the most stressful aspect of having a neonate in the NICU (Agrawal & Gaur 2017:150; Musabirema et al 2015:7; Wormald et al 2015:305; Chertok et al 2014:28; Schappin et al 2013:e54992). Mothers tend to have a greater psychological involvement with their neonate and find the loss of their maternal role very stressful (Chertok et al 2014:30; Lasiuk et al 2013:10).

At the conclusion of the research, no statistically significant difference was found between the PSS: NICU total mean stress scores for the control group and the treatment group mothers (p

> 0.05). The null-hypothesis could therefore not be rejected and it appears that the psycho-educational sessions were not effective in reducing the mothers' stress levels.

In the case of the fathers, the difference between the sight and sound (B) subscale mean stress score obtained by the control group and that of the treatment group was not found to be statistically significant (0.73) ($p > 0.05$). Fathers in the treatment group (2.64) experienced more stress than the fathers in the control group (2.42). Koliouli et al (2016:112) confirm that fathers try to manage the technical environment during their neonate's hospitalisation, but sights and sounds are a principle source of stress for fathers.

The difference between the behaviour and appearance (C) subscale mean stress score obtained by the fathers in the control group and that of the treatment group was not found to be statistically significant (0.89) ($p > 0.05$). Fathers in the control group (2.75) experienced their neonate's behaviour and appearance as being more stressful than those in the treatment group (2.66). Fathers are stressed by the neonate's fragile appearance and they are likely to keep an emotional distance when their neonate is at risk (Koliouli et al 2016:112). A fragile appearance has been shown in studies to frequently provoke post-traumatic stress disorder in fathers (Koliouli et al 2016:112). Even though their neonates gain weight and become more stable, fathers still perceive them as being fragile.

Although the difference between the parental role alteration (D) subscale mean stress score obtained by the fathers in the control group and that of the treatment group was not found to be statistically significant (0.7) ($p > 0.05$), this subscale scored the highest mean scores for the fathers. Agrawal and Gaur (2017:152) indicate that with modern-day transition into parental roles, there is a greater demand for involvement from both parents to ensure the best possible outcome for their neonate. This probably explains why the parental role alteration is more stressful for fathers in this study. Upon examination, it was seen that the fathers' stress score mean was higher than the mothers', specifically the treatment group's fathers. According to Purdy et al (2015:S25), it is believed that fathers may experience more stress because they have to assume more responsibility due to the mother's health status, as well as returning to work while carrying the emotional responsibility of caring for the mother, a neonate and possibly other siblings. Being forced to face their feelings during therapy and psycho-education resulted in an awareness of their feelings towards the neonate in the NICU. This may explain why the treatment group fathers' total mean score was higher.

The purpose of the study was to determine the effectiveness of the implementation of psycho-educational sessions on parental stress in the NICU environment. The study results indicated

that no statistically significant difference was found between the PSS: NICU subscale or general stress score means of the control group and the treatment group. Thus, the null-hypothesis could not be rejected.

The present results are difficult to compare with data previously reported by other authors because a variety of interventions were performed, and not psycho-education per se. To our knowledge, no specific studies assessing the effectiveness of psycho-education to reduce parental stress have been published.

Research investigating the effectiveness of interventions to reduce parental stress in the NICU has generally produced variable and conflicting results. Some studies have reported beneficial effects, others have failed to detect an effect. Chertok et al (2014:30-37) conducted a review of various interventions to reduce stress among mothers of neonates in the NICU. The intervention studies demonstrated various levels of effectiveness. Although two studies showed significant improvement in maternal stress levels and a few indicated some measure of stress reduction, there were a few studies that showed no significant improvement. Although there was no significant reduction in stress levels, other benefits may have been achieved where other measurement tools have been used for other defined outcomes (Chertok et al 2014:35). For example, a study showed that maternal stress levels did not show a significant reduction, but utilising another measuring tool to investigate how they perceived the mood of their neonates, the mothers perceived their neonates as happier.

The intervention for this study comprised psycho-educational sessions conducted by a clinical psychologist and entailed open groups which focused on the parents' shared experience and psycho-education. Yalom and Leszcz (2005:9-10) note that psycho-education is a treatment modality that combines psychotherapeutic and educational interventions performed by mental health professionals, providing group support in the context of partnership and collaboration, along with specific instructions about the nature of a life situation. Gitterman and Knight (2016:104) explain that the beneficial factors of group psycho-education include individual empowerment, improved coping abilities, increased optimism and reassurance, feeling less alone and isolated, and approaching new situations differently.

The current research did not detect a beneficial effect of psycho-educational sessions in reducing parental stress. Inconsistencies between the present study and previous research can be justified by the fact that, despite the obvious and clear benefits of interventions to reduce parental stress in the NICU, both parents still have to deal with environmental stressors and their neonate's hospitalisation. There are various factors associated with admission of a

neonate to the NICU that may influence the stress levels of parents, which cannot be controlled and likely played a major role in the consistent elevated stress levels of parents. Research conducted by Steyn, Poggenpoel and Myburgh (2017:7) highlight the fact that parents have intense experiences when their neonates are in the intensive care unit (ICU), and these have an impact on their thoughts, feelings and relationships, including their relationship with their premature neonate. Steyn et al (2017:2), discuss the fact that research has consistently reported that parents play a lesser role in the care of their neonate when they are admitted in an intensive care unit. The last mentioned authors further discuss that, along with the fact experts like doctors and nurses are more involved in their care, these neonates' condition may fluctuate, which creates uncertainty for the parents. The researchers argue that this might cause the experience of parents with premature neonates in the ICU to be traumatic (Steyn et al 2017:2). With regard to the current study, it may be concluded that this particular intervention was ineffective in reducing parental stress. Possible reasons for this will be discussed in the following chapter.

4.8. CONCLUSION

A discussion and interpretation of the results will follow in Chapter 5. Furthermore, recommendations will be given for nursing practices as well as further research.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The following chapter will focus on the conclusions, recommendations and limitations of this study.

5.2 SUMMARY OF THE STUDY

This study determined the effectiveness of the implementation of psycho-educational sessions to reduce parental stress levels in a NICU. As discussed in the literature review, research indicated that several factors increase parents' experience of stress when their neonate is admitted to a NICU, namely the NICU environment, circumstantial factors, individual differences, the neonate's health characteristics, personal resources, past experiences, mother-father differences, and poor emotional support. Apart from the NICU environment, these are mostly factors that the medical and nursing staff cannot control or change.

Research identified the existence of external and environmental factors that can be manipulated to reduce the level of stress experienced by parents. These include optimising the NICU environment by focusing on family-centred developmental care and providing psychological support in the NICU. Psychological support in the NICU should include the following: peer support and mental health professionals such as psychologists who can provide counselling and psycho-educational sessions.

The literature review discussed the abovementioned factors which influence the levels of stress parents' experience, with the aim of reducing stress levels. This study was designed to determine the effectiveness of implementation of psycho-educational sessions on parental stress in a NICU.

Data were collected in a 14-bed NICU of a private hospital group in Pretoria, Gauteng. Five paediatricians, 15 professional nurses, four staff nurses and two auxiliary nurses work in the unit. Staff is allocated according to the number of patients admitted to the unit. Additionally, the hospital makes use of agency staff when the unit is fully occupied.

The research population comprised of parents of neonates admitted to the NICU. Parents, who met the inclusion criteria and agreed to participate in the research study made up the sample. In total, 40 parents were included, consisting of 20 participants in the control group and 20 participants in the treatment group. The period for data collection was over four months, and therefore all willing participants who met the inclusion criteria were included in

the study. Parents were approached when they came to visit their neonates, and eligible parents were informed about the purpose of the study. Written consent was obtained prior to participation in the study. Parents were assured that their participation was voluntary, that data could not be traced back to them, that they could withdraw from the study at any time, and that their refusal to participate would in no way affect the care that their neonate would receive.

Parents in the first group of this study, the control group, were recruited by the researcher two days post admission, depending on the medical condition of the neonate. Parents were asked to complete an information document which consisted of demographic data and a self-report stress scale (Annexure A) from day two, biweekly and at discharge. The number of questionnaires completed by each participant was dependent on the length of stay of the neonate. Recruitment took place from the 19th of July 2018 and ended on the 2nd of September 2018, during which period 31 neonates were admitted to the NICU. Of the 31 admissions, 15 neonates' parents met the inclusion criteria for the study and were approached for participation. The control group initially consisted of 24 participants, of whom two declined further participation, and one failed to complete the second questionnaire on discharge and had to be eliminated. One neonate passed on and the participant was not approached to complete the questionnaire out of respect and sensitivity. Sixteen of the participants were couples, including both the mother and father, while four were mothers, where the father was either unavailable or chose not to participate.

Parents included in the treatment group, the second group in this study, were recruited one week after the completion of data collection from the control group. Parents in the treatment group were recruited in an identical manner as parents in the control group. The treatment group included psycho-educational sessions provided by a clinical psychologist, combined with standard care as routinely practised in this particular NICU. Recruitment took place from the 11th of September 2018 and ended on the 23rd of November 2018, during which period 43 neonates were admitted to the NICU. Of the 43 admissions, 22 neonates' parents met the inclusion criteria for the study and were approached for participation. Of the 44 parents (both mothers and fathers) approached to participate in the study, 23 agreed to partake. The treatment group initially consisted of 23 participants, of whom one participant's neonate was discharged before she could attend a psycho-educational session and two participants failed to complete the second questionnaire because their neonates suddenly passed on. Sixteen of the participants were couples, including both the mother and father, while four were mothers, where the father was either unavailable or chose not to participate.

During the course of the study, it was identified that the mothers were more readily available to attend the psycho-educational sessions, while the fathers, despite indicating a need to attend, were often unable to do so due to work commitments.

Psycho-educational sessions were conducted by a clinical psychologist and entailed open groups which focused on the parents' shared experience and psycho-education. The sessions were conducted by a clinical psychologist in a counselling room close to the NICU and comprised of face-to-face sessions lasting approximately one hour each. Sessions included as few as one and as many as six people, depending on the availability of the participants. The content of the sessions was versatile and was adapted to meet the needs of the parents that participated. The content included the following: a brief introduction to the facilitator, the clinical psychologist, followed by the proposed purpose of the group with the focus being on the parents' experience of their neonates being admitted to the NICU. Throughout the process, the parents were given the opportunity to check in with the clinical psychologist should they require any additional support. Parents were encouraged during the sessions to acknowledge how they were feeling and to share their emotions as a means of normalising their experiences. Areas of discussion included: how they found out their neonates needed to be admitted to the NICU; the process of the birth of their neonates; their first encounter with the NICU environment and the NICU staff; seeing their neonates in the NICU for the first time; being discharged from the hospital and leaving their neonates in the care the NICU staff; the range of emotions that they have experienced; the need for information; their emotional wellbeing, with focus on post-natal depression; major depressive disorder and post-traumatic stress disorder; and the availability of support and the attachment process.

5.3. LIMITATIONS OF THE STUDY

Several limitations were identified during the study. Firstly, the findings were from a study within a single NICU of a private hospital and involved a limited sample size. Smaller samples result in smaller groups, which may impede the ability to detect differences between groups. Small sample sizes may also reduce the power of the results of the study. Generalisation of the current study findings is limited because data were collected from parents at one hospital and in one geographical location, thus the results may not be typical of other NICUs. In addition, the sample of this study was not representative of the entire population because of the nature the sampling technique. Further studies should include a broader range of units, both in the private and public sector. Furthermore, aspects of cross-cultural comparability were noted. The ethnic grouping of the sample was homogenous, and the intervention concept can be assessed only within its cultural context.

Secondly, there was a lack of randomisation in this study. This was considered inevitable for ethical reasons. In the emotionally sensitive NICU setting, it seemed unjustifiable to provide some parents with psycho-education but deny it to others for reasons of randomisation.

Thirdly, it is difficult to compare the results of the study with other intervention studies involving NICU parents, which differed in their theoretical background or used different instruments or outcome variables.

Fourthly, the researcher based this study on the use of one of the most common used instruments for to determine stress levels of parents of neonates in the NICU, the PSS: NICU scale. The use of only one questionnaire raises the question whether this instrument covered the full scope of parental stress in this particular NICU setting. It may increase the chances that the findings are merely an artefact of the questionnaire and do not represent the real-world situation. Although self-reporting questionnaires are valuable instruments in psychological research, sole reliance on such questionnaires is a limitation, as the potential for subjective and reporting bias exists. The validity of the PSS: NICU has been extensively established, but it remains a subjective instrument that measures parents' perceptions of stress. The use of additional questionnaires and scales used to assess stress-related components would potentially be more representative of the true nature of the level of stress experienced by the parents, and this approach should be considered in future studies.

Fifthly, predictors of attending the psycho-educational sessions need further investigating using a larger sample size. The possible use of an instrument for parents reporting their experience of psycho-educational sessions may delineate the specific gains that the parents make through attending. The psychologist provided a report on her reflections with regard to her role as a psychologist in the NICU and the experiences of the parents, based on her interactions and observations. An additional concern was identified during the research process where some of the participants had a history of psychiatric illness that was not surveyed and could have provided vital information regarding their ability to cope with stress or distress. The lack of pre-birth assessment of stress limits the researcher's ability to infer causality. And lastly, the low dose of the intervention might have resulted in the lack of significant differences between the control and treatment group.

However, while parental stress may not have been significantly reduced in this study, other benefits may have been achieved. Due to the fact that no additional measuring tools were utilised, the researcher was unable to determine other benefits and had to rely on the verbal feedback of parents. Parents reported to the clinical psychologist that they benefitted from the

psycho-educational sessions and the general feedback was positive. Most of the parents requested follow-up sessions and remained in contact with the clinical psychologist via text messages and phone calls on a regular basis. The researcher is of the opinion that although the results were not statistically significant, the involvement of a clinical psychologist is vital in providing clinical services to manage and treat any identified social and psychological risks in parents. Such support is vital for parents in the NICU to reduce parental stress and improve parent functioning, thereby enabling parents to form early attachments with their sick neonates.

5.4. REFLECTIONS BY THE RESEARCHER

Parents were willing and eager to participate in the study. However, during data collection it was observed that the completion of the questionnaires posed to be a challenge. Most parents would complete the questionnaire directly after the study was discussed by the researcher. However, in some cases, parents had to be encouraged and reminded to complete the questionnaire. This may have been due to the fact that they were visiting their neonate in the NICU and were distracted by the environment and the current condition of their neonate. The completion of the questionnaire at discharge was also observed to be problematic as some parents were worried and stressed about the discharge of their neonate or were simply distracted by their eagerness to leave the hospital and start their lives as parents. Overall, it was observed that parents had to be reminded to complete the questionnaire on discharge. Staff in the NICU were helpful in assisting the researcher in handing questionnaires to the parents when the researcher was not present in the NICU.

Data collection during the treatment group process was dependent on the admission rate and was observed to be timeous due to a sudden decline in the admission rate. This halted the research process as days would go by without any new admissions. The researcher also observed that some parents were uncomfortable or wary when being approached about attending psycho-educational sessions. However, when the researcher explained the purpose of these sessions and that they were available free of charge, parents were more enthusiastic and would give consent to participate. Most parents who participated in the psycho-education sessions did so with the aim of reducing their stress levels and utilising the available support. The researcher approached the completion of the questionnaires in a different manner than with the control group, encouraging participants to complete it directly after the discussions. A few parents insisted on completing the questionnaires in their own time and had to be reminded to complete and return it to the researcher.

5.5. REFLECTIONS BY THE CLINICAL PSYCHOLOGIST

Despite sufficient evidence in literature that mothers of premature neonates are at far greater risk of postnatal depression and that parents with neonates in the NICU are at risk for the development of post-traumatic stress, neonatal units do not have access to a trained mental healthcare worker like a psychologist.

It was clear that parents were reluctant to seek out the services of a psychologist because of the perceived additional cost involved in this process, despite the need to do so. Parents indicated that they were very grateful for the opportunity to share their experiences and to simply have someone to talk to should they require it and they felt this service should be available to all parents whose neonates are admitted to the NICU. Simply knowing that the resource was available appears to have provided a sense of comfort to the parents, who felt that despite the attempts of the NICU staff to provide support and comfort, their focus was on the neonates.

Upon reflection, it is clear that both the mothers and the fathers reported being filled with a range of emotions when finding out that they would be delivering their neonates early or when their neonates had to be sent to the NICU following their birth. Parents often indicated that they had never heard of such a thing and that they could not imagine that a neonate born that early or ill could survive outside the womb. Some mothers felt that it was their fault that their neonates were born prematurely or medically unwell, as if their bodies had failed them. Despite their lack of knowledge, all reported that they were amazed by and thankful for the advances in neonatal medicine and to the skilled doctors and nurses working in the NICU.

Most parents dream of the moment their neonate is born, holding them only seconds afterwards, and then being able to take them home and start the journey of being a parent. Parents involved in the psycho-educational sessions reported that the greatest challenge was accepting that it would possibly be a very long time before they could hold and touch their neonates and eventually take them home. Leaving their neonates in the NICU once the mothers had been discharged elicited fear and uncertainty and was exhausting for all the parents involved. The experience of initially feeling overwhelmed was replaced by one of acceptance and gratitude to the staff caring for their neonates.

Although everyone's situation is different, the researcher believes that all the parents involved in the psycho-education groups were able to take solace in the knowing the commonality of the emotional pain, trauma, and uncertainty that they had endured. This alone was a therapeutic experience; however, the researcher has highlighted in the previous chapters that the experience of trauma can have a long-term effect on the mental health and functioning of the parents of premature neonates and that this too can have an impact on the normal

attachment process which is the foundation of healthy parent-neonate relationships and the neonates' mental health. In light of this, it is the clinical psychologist's opinion that while providing focused, specialised care to the neonate is vital within the NICU, additional support and care that focuses on the parents is vital, because when premature or ill babies are discharged from the NICU and get out of hospital, they require their parents more than they need anyone else.

5.6. RECOMMENDATIONS FOR PRACTICE

The sources of stress for parents with a neonate admitted to a NICU have been explained, and it is important for health professionals who practice in a NICU to be aware of the sources of stress and reduce them where possible. Recommendations will be discussed under the following points: inform and educate the parents, recommendations for sustained family-centred care and developmental care practices, and recommendations for NICU mental health professionals. The recommendations are based not only on the outcomes of the study, but also on the observations and reflections of the researcher and the psychologist responsible for the psycho-educational sessions, and comments made by the parents.

5.6.1. Inform and educate the parents

The first and most important recommendation is that the staff of the NICU should inform and educate parents to ensure that they understand what is to be expected when their neonate is admitted to the NICU. Communication in the NICU is an important interaction that takes place throughout the day.

- Information and education can commence prior to admission to the NICU.
 - It is important to provide information on what to expect when a parent's neonate is admitted to the NICU, and this should form part of the antenatal classes provided by the hospital prior to any delivery.
- In cases where a mother is admitted to the antenatal ward as a result of premature labour or health-related complication, it is important to provide information to the parents on what to expect in terms of admission to the NICU, length of stay and possible medical treatment for the neonate.
 - If the mother's condition is satisfactory, a tour of the NICU can be arranged to allow parents to familiarise themselves with the environment and give them the opportunity to ask questions.
- Parents need to be supported throughout their stay in the NICU.
 - When the parents come into the unit for the first time and meet their neonate (especially mothers who were unable to see their neonate for the first 24 hours), it can be extremely overwhelming for them because of the environment and what is

happening in the unit. Parents need to be supported when adapting to the new situation and learning about their new neonates.

- All parents need to be informed and involved in the condition of their neonate – a holistic, family-centred approach with open communication is recommended.
- Nursing staff members need to be trained to give the correct information at all times. All nursing staff members should give the same information so as not to confuse the parents.
 - Training sessions can be organised to educate staff members, especially new members and agency staff.
 - On-the-spot training needs to be done with staff members in the unit.

5.6.2. Recommendations for sustained family-centred and developmental care practices

Secondly, comprehensive family-centred care and developmental care practices must be sustained in the unit. Parents must have the correct example to follow, especially with regard to developmental care practices. It is the responsibility of nursing experts with the adequate knowledge and skills to train staff members according to the needs of the NICU, in order to deliver quality care.

- New staff members should undergo strict training and practise developmental care practices.
- Quality care involves the participation of parents in the care of their neonate. Staff members should encourage such participation by teaching parents how to render basic care for their neonate in the form of nappy changes, feeding and bathing.
- In order for the NICU to effectively deliver the family-centred care approach, siblings should be allowed to visit the neonate in the NICU.
- The attachment and bonding process between the neonate and the parent should be encouraged.
 - Maintain a welcoming and caring environment to increase parental presence and involvement with their neonate.
 - Provide parents with a private area to encourage Kangaroo Mother Care (KMC).
 - Provide access to facilities such as a breastfeeding or pumping room and a bedroom for lodging purposes to make it possible for parents to be near the neonate at all times.

5.6.3. Recommendations for neonatal intensive care unit mental health professionals

Thirdly, in light of the results, psychological counselling should be considered for parents in the NICU who are living with a difficult or unexpected situation, which they are unable to modify or avoid.

- A full-time psychologist should be appointed to this particular hospital.
 - In cases where a mother is admitted for premature labour, it is imperative that the parents receive psychological counselling prior to their neonate being admitted to the NICU. Parents should be psychologically prepared for the journey ahead.
 - The service should be available, but flexible, because parents' needs vary throughout their time spent in the NICU.
 - This service should be available to all parents and their family members.
 - The service should be easily accessible and readily available. The psychologist should have consulting rooms at the hospital and parents should not have to be referred to someone outside of the hospital.
 - The service should be provided by the hospital at no extra cost to the parents. Admission of a neonate to the NICU has major financial implications for the family and parents are very concerned about financial resources. They should not be deterred from making use of psychological services due to their concern about the cost involved.
 - Parents do not necessarily seek out psychological intervention, which may be because they do not know that such services are available to them or recommended. Therefore, parents should be provided with information and orientation by a person who knows how to inform them about the resources available.
 - The psychologist should have time specifically allocated to providing verbal therapeutic support to all parents and their family members.
 - Parents should be encouraged to find a sustainable solution and face up to their emotions.
 - Parents should be assisted with support to acquire an active role and become responsible in the care of their neonate.
 - Psychological services and counselling should be compulsory for all parents who have a neonate in the NICU. Preconceptions of counselling may impact on how accessible the service feels and this may impact on parents' willingness to ask for help.

- Peer support is an invaluable source of support.
 - Psychological interventions such as psycho-education create an environment and opportunity for parents who have a neonate admitted to the NICU to reach out to other parents who understand their situation.
 - The psychologist should provide regular drop-in sessions with other parents who are in a similar position for provision of mutual support.

5.7. RECOMMENDATIONS FOR FURTHER RESEARCH

It would be desirable to compare the intervention described here with others, particularly those based on an intervention that provides emotional support by a psychologist.

- Such comparisons, performed as a randomised, controlled trial, would allow an assessment as to whether one mode of intervention is superior to another.
- Including more than one questionnaire or assessment tool to measure the full scope of parental stress in the NICU will give a clearer indication of the full extent of stress experienced. With the same findings on multiple instruments, indications for the true existence of the effect in the population are stronger.

Future studies recommended include the following:

- Future studies should be conducted to measure physiological stress with a reliable stress hormone test and compare the results with the most commonly used stress tools and questionnaires. This would facilitate assessment of which of these tools most accurately represent the actual stress experienced by individuals. It would also aid future researchers to use the most appropriate and accurate tool/questionnaire to establish the effectiveness of interventions to reduce stress, and to eventually develop new instruments more sensitive to the needs of parents.
- Future studies should include a broader range of units and bigger sample sizes to detect possible differences in the groups. This would enable generalisation of study findings.

5.8. CLOSING STATEMENT

Although the results of this study are not statistically significant, it did confirm previous literature which showed that parents who have a neonate admitted to the NICU experience some form of stress or psychological distress. Evaluation of effective interventions should be done in other locations among diverse populations to examine their reproducibility. This was the first study of its kind in South Africa utilising the PSS: NICU as a measurement tool. The

results showed that psycho-educational sessions did not reduce parental stress as hypothesised, using the PSS: NICU as the primary measurement tool.

Psycho-educational sessions were not mandatory, and parents could choose how many sessions to attend. A difference in the intensity of psycho-educational session exposure could have influenced the outcome. In conclusion, it is suggested that further research is necessary in South Africa, with a different research design, a larger population (including other institutions) and an adapted intervention where parents are approached and accommodated before admission to the NICU.

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ANNEXURE A

Parental Stressor Scale: Neonatal Intensive Care Unit

PARENTAL STRESSOR SCALE: NEONATAL INTENSIVE CARE UNIT

We are interested in knowing more about the stresses experienced by parents when a neonate is sick and hospitalized in a Neonatal Intensive Care Unit (NICU). We would like to know about your experience as a parent whose neonate is presently in the NICU.

SECTION A DEMOGRAPHIC INFORMATION

FOR OFFICE USE ONLY

Participant Number

1. Parent/primary caregiver's age: _____ years

2. Gender of parent/primary caregiver:

1	Male		2	Female	
---	------	--	---	--------	--

3. Number of live births: _____

4. Type of delivery:

1	Normal vaginal		2	C/section	
---	----------------	--	---	-----------	--

5. Educational status:

1	Grade 12		2	College	
3	University		4	Other	

6. Marital status:

1	Single		2	Married	
3	Separated		4	Divorced	
5	Widowed				

7. Presence of a partner if not married:

1	Yes		2	No	
---	-----	--	---	----	--

8. Distance from home to hospital: _____ km

9. Parent/primary caregiver returning to work?

1	Yes		2	No	
---	-----	--	---	----	--

10. Previous NICU experience?

1	Yes		2	No	
---	-----	--	---	----	--

11. Good family support?

1	Yes		2	No	
---	-----	--	---	----	--

12. Race

1	Black		2	White	
3	Coloured		4	Indian	
5	Asian		5	Other	

A0

A1

A2

A3

A4

A5

A6

A7

A8

A9

A10

A11

A12

13. Sex of neonate:

1	Male		2	Female	
---	------	--	---	--------	--

14. Gestational age of neonate: _____ weeks

15. Birth weight of neonate: _____ kg

16. Apgar score (1) at one minute and (2) at 5 minutes:

1	/10		2	/10	
---	-----	--	---	-----	--

17. Number of days in hospital: _____

18. Number of other siblings/children: _____

19. Classification of acuity:

1	ICU		2	High care A	
3	High care B		4	Ward	

A13

A14

A15

A16

A17

A18

A19

SECTION B: EXPERIENCE OF STRESS

This questionnaire lists various experiences other parents have reported as stressful when their neonate was in the NICU. We would like you to indicate how stressful each item listed below has been for you. **By stressful, we mean that the experience has caused you to feel anxious, upset, or tense.** On the questionnaire, circle the single number that best expresses how stressful each experience has been for you. The numbers indicate the following levels of stress:

1 = Not at all stressful (the experience did not cause you to feel upset, tense, or anxious)

2 = A little stressful

3 = Moderately stressful

4 = Very stressful

5 = Extremely stressful

If you have not experienced an item, please circle NA "not applicable".

Now let's take an item for an example: **The bright lights in the NICU.**

If for example you feel that the bright lights in the neonatal intensive care unit were extremely stressful to you, you would circle the number 5 below:

NA 1 2 3 4 **5**

If you feel that the lights were not stressful at all, you would circle the number 1 below:

NA **1** 2 3 4 5

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in a NICU. We are interested in knowing about your view of how stressful these **SIGHTS AND SOUNDS** are for you. Circle the number that best represents your level of stress. If you did not see or hear the item, circle the NA meaning "Not applicable."

1. The presence of monitors and equipment	NA 1 2 3 4 5	Office use B1 <input type="text"/>
2. The constant noises of monitors and equipment	NA 1 2 3 4 5	B2 <input type="text"/>
3. The sudden noises of monitor alarms	NA 1 2 3 4 5	B3 <input type="text"/>
4. The other sick babies in the room	NA 1 2 3 4 5	B4 <input type="text"/>
5. The large number of people working in the unit	NA 1 2 3 4 5	B5 <input type="text"/>

Below is a list of items that might describe the way your **BABY LOOKS AND BEHAVES** while you are visiting in the NICU as well as some of the **TREATMENTS** that you have seen done to the baby. Not all babies have these experiences or look this way, so circle the NA, if you have not experienced or seen the listed item. If the item reflects something that you have experienced, then indicate how much the experience was stressful or upsetting to you by circling the appropriate number.

1. Tubes and equipment on or near my baby	NA 1 2 3 4 5	C1 <input type="text"/>
2. Bruises, cuts or incisions on my baby	NA 1 2 3 4 5	C2 <input type="text"/>
3. The unusual color of my baby (for example looking pale or yellow jaundiced)	NA 1 2 3 4 5	C3 <input type="text"/>
4. My baby's unusual or abnormal breathing patterns	NA 1 2 3 4 5	C4 <input type="text"/>
5. The small size of my baby	NA 1 2 3 4 5	C5 <input type="text"/>
6. The wrinkled appearance of my baby	NA 1 2 3 4 5	C6 <input type="text"/>
7. Having a machine (respirator) breathe for my baby	NA 1 2 3 4 5	C7 <input type="text"/>
8. Seeing needles and tubes put in my baby	NA 1 2 3 4 5	C8 <input type="text"/>
9. My baby being fed by an intravenous line or tube	NA 1 2 3 4 5	C9 <input type="text"/>

10. When my baby seemed to be in pain	NA 1 2 3 4 5	C10 <input type="text"/>
11. When my baby looked sad	NA 1 2 3 4 5	C11 <input type="text"/>
12. The limp and weak appearance of my baby	NA 1 2 3 4 5	C12 <input type="text"/>
13. Jerky or restless movements of my baby	NA 1 2 3 4 5	C13 <input type="text"/>
14. My baby not being able to cry like other babies	NA 1 2 3 4 5	C14 <input type="text"/>

The last area we want to ask you about is how you feel about your own **RELATIONSHIP** with the baby and your **PARENTAL ROLE**. If you have experienced the following situations or feelings, indicate how stressful you have been by them by circling the appropriate number. Again, circle NA if you did not experience the item.

1. Being separated from my baby	NA 1 2 3 4 5	D1 <input type="text"/>
2. Not feeding my baby myself	NA 1 2 3 4 5	D2 <input type="text"/>
3. Not being able to care for my baby myself (for example, diapering, bathing)	NA 1 2 3 4 5	D3 <input type="text"/>
4. Not being able to hold my baby when I want	NA 1 2 3 4 5	D4 <input type="text"/>
5. Feeling helpless and unable to protect my baby from pain and painful procedures	NA 1 2 3 4 5	D5 <input type="text"/>
6. Feeling helpless about how to help my baby during this time	NA 1 2 3 4 5	D6 <input type="text"/>
7. Not having time alone with my baby	NA 1 2 3 4 5	D7 <input type="text"/>

Thank you for your help.

Feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit?

ANNEXURE B

Participant Information Leaflet: Group 1 (control group)

**EFFECTIVENESS OF THE IMPLEMENTATION OF PSYCHO-EDUCATIONAL
SESSIONS ON PARENTAL STRESS IN A NEONATAL INTENSIVE CARE UNIT
(GROUP 1)**

**PARTICIPANT'S INFORMATION & INFORMED CONSENT
DOCUMENT**

Researcher's name: Tanya Coertze
Student Number: 23334437
Department of Nursing
University of Pretoria

Dear Parent,

I am a Master's degree student in the Department of Nursing at the University of Pretoria. You are invited to volunteer to participate in research project on: **Effectiveness of the implementation of psycho-educational sessions on parental stress in a Neonatal Intensive Care Unit.**

1. Introduction

This information leaflet provides you with information to help you decide if you would like to participate in this study. Before you agree to participate in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy about what we expect of you.

2. The nature and purpose of this study

You are invited to take part in a research study. The purpose of this study is to determine the effectiveness of psycho-educational sessions on your stress levels in the NICU. By doing so, the findings of this study will assist health care professionals to gain a better understanding on reducing parental stress in the NICU.

3. Procedures that need to be followed

We would like you to complete a questionnaire related to stress levels of parents in the neonatal intensive care unit. During your baby's admission in the neonatal intensive care unit, you and your baby will receive routine care together with family-centred care as it is provided as the standard of care.

To complete the questionnaire may take about 30 minutes. You will be given a questionnaire to complete from day two after the birth of your baby and then biweekly until discharge. Someone will collect the questionnaire from you before you leave the NICU. It will be kept in a safe place to ensure confidentiality. Please do not write your name on the questionnaire. This will ensure confidentiality. We will be available to help you with the questionnaire or to fill it in on your behalf if you need us to.

4. Risk and discomfort involved

The only discomfort you might experience is the time set aside to complete the questionnaire. If you want to withdraw from the study for any reason, you can do so any time. You do not need to provide any reason and you or your baby will not be penalised in any manner.

5. Possible benefits of this study

The findings of this study will assist health care professionals to gain a better understanding of reducing parental stress in the NICU. The results might contribute to motivate for the involvement of psychologists in the NICU setting.

6. Ethical approval

The Hospital Management as well as the Research Ethics Committee of the University of Pretoria, Faculty of Health Sciences, and telephone numbers 012 356 3084 / 012 356 3085 granted written approval for this study. This study has been structured in accordance with the Declaration of Helsinki (last update: 2013), which deals with the recommendations guiding doctors in biomedical research involving humans/subjects. A copy of the Declaration may be obtained from the researcher should you wish to review it.

7. Confidentiality

Your participation in this study is voluntary. You can refuse to participate or stop at any time without giving any reason. As you do not write your name on the questionnaire, you give us the information anonymously. Once you have given the questionnaire back to us, you cannot recall your consent as we will not be able to trace your questionnaire. Therefore, you will also not be identified as a participant in any publication that comes from this study.

In the event of experiencing any distress as a result of this study, you need to inform me as the researcher so that I can refer you for counselling.

Note: The implication of completing the questionnaire is that informed consent has been obtained from you. Thus any information derived from your form (which will be anonymous) may be used for e.g. publication, by the researchers.

8. Consent to participate

I have read the above information before signing the consent form. The content and meaning of this information have been explained to me. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

Signature of parent

Date

Witness

Date

We sincerely appreciate your help.

Yours truly,

TANYA COERTZE

ANNEXURE C

Participant Information Leaflet: Group 2 (treatment group)

**EFFECTIVENESS OF THE IMPLEMENTATION OF PSYCHO-EDUCATIONAL
SESSIONS ON PARENTAL STRESS IN A NEONATAL INTENSIVE CARE UNIT
(GROUP 2)**

**PARTICIPANT'S INFORMATION & INFORMED CONSENT
DOCUMENT**

Researcher's name: Tanya Coertze
Student Number: 23334437
Department of Nursing
University of Pretoria

Dear Parent,

I am a Master's degree student in the Department of Nursing at the University of Pretoria. You are invited to volunteer to participate in research project on: **Effectiveness of the implementation of psycho-educational sessions on parental stress in a Neonatal Intensive Care Unit.**

1. Introduction

This information leaflet provides you with information to help you decide if you would like to participate in this study. Before you agree to participate in this study, you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy about what we expect of you.

2. The nature and purpose of this study

You are invited to take part in a research study. The purpose of this study is to determine the effectiveness of psycho-educational sessions on your stress levels in the NICU. By doing so, the findings of this study will assist health care professionals to gain a better understanding on reducing parental stress in the NICU.

3. Procedures that need to be followed

We would like you to complete a questionnaire related to stress levels of parents in the neonatal intensive care unit. During your baby's admission in the neonatal intensive care unit, you and your baby will receive routine care together with family-centred care as it is provided as the standard of care. You are also requested to attend the psycho-educational sessions at least once a week. The timeslots and venue will be communicated to you by the staff.

To complete the questionnaire may take about 30 minutes. You will be given a questionnaire to complete from day two after the birth of your baby and then biweekly until discharge. Someone will collect the questionnaire from you before you leave the NICU. It will be kept in a safe place to ensure confidentiality. Please do not write your name on the questionnaire. This will ensure confidentiality. We will be available to help you with the questionnaire or to fill it in on your behalf if you need us to.

4. Risk and discomfort involved

The only discomfort you might experience is the time set aside to complete the questionnaire. If you want to withdraw from the study for any reason, you can do so any time. You do not need to provide any reason and you or your baby will not be penalised in any manner.

5. Possible benefits of this study

The findings of this study will assist health care professionals to gain a better understanding of reducing parental stress in the NICU. Furthermore, it is expected to provide early focussed interventions such as family-centred care and psycho-educational sessions to reduce the stress levels of during the baby's hospitalization. These interventions are expected to improve parents' functioning as well as their relationship with their babies. The results might contribute to motivate for the involvement of psychologists in the NICU setting.

6. Ethical approval

The Hospital Management as well as the Research Ethics Committee of the University of Pretoria, Faculty of Health Sciences, and telephone numbers 012 356 3084 / 012 356 3085 granted written approval for this study. This study has been structured in accordance with the Declaration of Helsinki (last update: 2013), which deals with the recommendations guiding doctors in biomedical research involving humans/subjects. A copy of the Declaration may be obtained from the researcher should you wish to review it.

7. Confidentiality

Your participation in this study is voluntary. You can refuse to participate or stop at any time without giving any reason. As you do not write your name on the questionnaire, you give us the information anonymously. Once you have given the questionnaire back to us, you cannot recall your consent as we will not be able to trace your questionnaire. Therefore, you will also not be identified as a participant in any publication that comes from this study.

In the event of experiencing any distress as a result of this study, you need to inform me as the researcher so that I can refer you for counselling.

Note: The implication of completing the questionnaire is that informed consent has been obtained from you. Thus any information derived from your form (which will be anonymous) may be used for e.g. publication, by the researchers.

8. Consent to participate

I have read the above information before signing the consent form. The content and meaning of this information have been explained to me. I have been given the opportunity to ask questions and am satisfied that they have been answered satisfactorily. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

Signature of parent

Date

Witness

Date

We sincerely appreciate your help.

Yours truly,

TANYA COERTZE

ANNEXURE D

Ethics Department letter of approval

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

20/06/2018

**Approval Certificate
New Application**

Ethics Reference No: 240/2018

Title: Effectiveness of the implementation of psycho-educational sessions on parental stress in a neonatal intensive care unit

Dear Tanya Coertze

The **New Application** as supported by documents specified in your cover letter dated 23/05/2018 for your research received on the 23/05/2018, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 20/06/2018.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (**240/2018**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change **who** the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers; MBChB; MMed (Int); MPharm, PhD

Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 01 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

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✉ Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60 / 61, 31 Bophelo Road, Gezina, Pretoria

ANNEXURE E

Letter of Statistical Support



LETTER OF STATISTICAL SUPPORT

Date: 29 April 2018

This letter is to confirm that **Ms. Tanya Coertze**, studying at the University of Pretoria, discussed the project with the title “***Effectiveness of the implementation of psycho-educational session on parental stress in a neonatal intensive care unit***” with me.

I hereby confirm that I am aware of the project and also undertake to assist with the statistical analysis of the data generated from the project.

The sample will consist of a purposive sample of parents, or primary caregivers, of neonates admitted to the NICU, of a single private hospital (only one hospital can be considered since the procedures from one hospital can differ from the other), for 2 days or longer and who provide consent to participate in the study. The expected sample size will consist of a minimum of 20 participants in the control group and a minimum of 20 participants in the treatment group, but more participants are expected.

The data analysis will consist of descriptive statistics such as frequencies, percentages, means and standard deviations which will be used to describe the sample characteristics. Inferential statistics will be used to determine if the psycho-education had an effect on the parental stress in the NICU. Parental stress will be evaluated by computing the total score PSS: NICU, as well as the scores within the subgroups (sights and sounds, baby looks and behaves and parental role and relationship). Inferential statistics may include independent sample t-test, chi squared test, Mann-Whitney U test or Fishers exact test. Power analysis will be performed in order to determine if the sample size was sufficiently large, alternatively non-parametric tests will be considered to evaluate the significance if the sample proves to be too small for a significant test.

The size of the sample is not a concern since the researcher assumes that the results will reveal a tendency in the effect of the intervention. Non-parametric statistical tests still yield significant and valuable results in studies with smaller samples. The study will serve as a pilot study in the private hospital group and aims to show there is value in doing a larger study.

A handwritten signature in black ink, appearing to read 'Troy' or similar, with a stylized, cursive style.

Ms. [REDACTED]

Department of Statistics

Internal Consultation Service

Tel [REDACTED]

ANNEXURE G

Consent from Hospital Manager

Permission to do research at [redacted] Hospital

To: Hospital Manager [redacted] Hospital

From: The Investigator

Mr. [redacted]

Sr. Tanya Coertze

Re: Permission to do research at [redacted] Hospital

I, Tanya Coertze, am a researcher working at the Neonatal Intensive Care Unit, Department of Nursing at [redacted] Hospital. I am requesting permission to conduct a study on the [redacted] Hospital grounds.

The title of the study is: **Effectiveness of the implementation of psycho-educational sessions on parental stress in a Neonatal Intensive Care Unit.**

The researcher requests access to the family room or training facility, to provide psycho-educational sessions for parents twice a week.

I intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

I intend to protect the personal identity of the parents by assigning each parent a random code number.

I undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely,



Signature of the Principle Investigator

Tanya Coertze

Permission to do the research study at this hospital and to access the information as requested is hereby approved.

Hospital Manager

[redacted] Hospital

Mr. [redacted]

Signature of the Hospital Manager



