

**THE IMPACT OF STRESSORS ON JORDANIAN PARENTS WITH
INFANTS IN NEONATAL INTENSIVE CARE UNIT**

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ABSTRACT

Admission of an infant to the Neonatal Intensive Care Unit (NICU) is an unexpected event which can cause parents to experience psychosocial distress. The aim of this study was to identify the impact of stressors on Jordanian parents with infants in the NICU. A mixed methods research design was undertaken in three hospitals in Jordan. The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) and Patient-Reported Outcomes Measurement Information System (PROMIS) were used to survey 376 Jordanian parents with infants in the NICU. The quantitative results showed that the most common NICU stressor among parents with hospitalized infants in NICU is infant shape and behaviour ($M = 3.76$, $SD = .914$) whereas the lowest source of stress was sights and sounds ($M = 3.56$, $SD = .918$). There were strong positive associations between depression, anxiety and stress, on the other hand moderate positive association between sleep disturbance, and stress among mothers with hospitalized infant in NICU, with r of depression, anxiety and sleep disturbance equal to .584, .664 and .425 respectively. Moreover, there were strong positive associations between depression, anxiety and stress, on the other hand a weak positive association between sleep disturbance, and stress among fathers with hospitalized infant in NICU, with r of depression, anxiety and sleep disturbance equal to .523, .615, and .210 respectively. In addition, infant characteristics such as gestational age, medical condition classification, and birth weight were significant factors that influence stress levels among parents with hospitalized infants in NICU, whereas infant gender did not significantly impact parental stress. Parent characteristics such as parent age, parent gender, first baby experience, history of infertility, and medical history had significant influence on stress levels among parents with hospitalized infants in NICU. The results also showed the difference of parent and infant characteristics on the impact of stress. Finally, a model

was established to show the relationships between the variables. With regard to qualitative results, many themes were derived: emotional responses, sources of stress in NICU, impact of stress, and coping strategies. In conclusion, the stress and burden of having an infant hospitalized in the NICU cannot be underestimated as parents face exposure to multiple stressors related to the condition of their infant, NICU environment and staff, as well as altered parental roles. The effect of stress extends from their homes to their workplace, and they carry this psychological and emotional burden everywhere they go, even as they fend off societal judgment and prejudice about the health of their offspring. Thus, they inevitably suffer from negative psychological consequences, interrupted development of healthy parent-infant attachment, and changes to anticipated parental roles.

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ABSTRAK

Kemasukan bayi ke Unit Rawatan Rapi Neonatal (NICU) merupakan satu kejadian yang tidak dijangka dan berpotensi menimbulkan tekanan psikologi. Kajian ini bertujuan untuk mengenalpasti impak punca-punca tekanan terhadap ibu bapa Jordan dengan bayi di dalam Unit Rawatan Rapi Neonatal (NICU). Kajian gabungan dijalankan di tiga buah hospital di Jordan. Kajian ini melibatkan seramai 376 orang ibu bapa Jordan dengan bayi di dalam NICU. Data dikumpul melalui Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) dan Patient-Reported Outcomes Measurement Information System (PROMIS). Data kuantitatif menunjukkan bahawa punca tekanan utama adalah rupa dan tingkah laku bayi ($M = 3.76$, $SD = .914$) manakala punca tekanan paling rendah adalah persekitaran NICU dari segi pemandangan dan bunyi ($M = 3.56$, $SD = .918$). Terdapat hubungkait positif yang kuat antara kemurungan, kebimbangan dan tekanan tetapi hubungkait antara gangguan tidur, dan tekanan di kalangan ibu-ibu dengan bayi dimasukkan ke hospital di NICU adalah positif yang sederhana, dengan r kemurungan, kebimbangan dan gangguan tidur adalah bersamaan dengan 0,584, 0,664 dan .425 masing-masing. Selain itu, terdapat hubungkait positif yang kuat antara kemurungan, kebimbangan dan tekanan, akan tetapi hubungkait positif yang sederhana antara gangguan tidur, dan tekanan di antara ibu bapa dengan bayi dimasukkan ke hospital di NICU, dengan r kemurungan, kebimbangan dan gangguan tidur adalah bersamaan dengan 0,523. masing-masing 615 dan 0,210 masing-masing. Ciri-ciri ibu bapa seperti usia, jantina, pengalaman keibubapaan, pengalaman dengan kemasukan bayi ke dalam NICU, sejarah gangguan perubatan, dan sejarah kemandulan merupakan faktor-faktor yang mempengaruhi tahap stres secara signifikan dalam kalangan ibu bapa dengan bayi di dalam NICU. Tambahan pula, ciri-ciri bayi seperti usia kandungan, berat badan lahir bayi, dan klasifikasi keadaan perubatan

merupakan faktor signifikan yang mempengaruhi tahap stres dalam kalangan ibu bapa dengan bayi di dalam NICU, manakala jantina bayi tidak merupakan faktor signifikan. Dapatan kajian turut menunjukkan perbezaan pengaruh ciri-ciri ibu bapa dan bayi terhadap impak-impak tekanan. Berdasarkan dapatan kajian, satu model telah diwujudkan bagi menggambarkan hubungan antara pembolehubah. Melalui data kualitatif, tema-tema berikut telah diperolehi: Tindakbalas emosi, punca tekanan di dalam NICU, impak fizikal and psikologi, dan strategi pengurusan tekanan. Secara keseluruhannya, kemasukan bayi ke NICU merupakan keadaan di mana ibu bapa menghadapi tekanan yang berat, terutamanya disebabkan pendedahan kepada punca-punca tekanan melibatkan keadaan bayi, persekitaran dan kakitangan NICU, serta peranan keibubapaan. Akibatnya, ibu bapa menghadapi pelbagai bebanan seperti kesan negative psikologi, gangguan perkembangan hubungan positif dengan bayi, dan pengubahan peranan keibubapaan.

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LIST OF ABBREVIATION

NICU : Neonatal Intensive Care Unit

PSS:NICU : Parental Stressor Scale: Neonatal Intensive Care Unit

PROMIS: Patient-Reported Outcomes Measurement Information System

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CHAPTER 1: INTRODUCTION

1.0 Background

It is estimated that over 130 million neonates are born worldwide every year (UNICEF, 2013); the World Health Organization (WHO) reported in 2013 that 136 million neonates are born annually. It is difficult, however, to identify exactly how many infants are born worldwide because a number of infants are not registered (UNICEF, 2013; WHO, 2013). The international mortality rate for infants is 24 per 1,000 deaths in the first week of life, and 3 per 1,000 deaths during the first month (WHO, 2013). Nearly 5 million infants die annually. 74% of deaths occur before an infant's first birthday, with most infants dying in the first week of life (WHO, 2013).

In Jordan, the crude birth rate decreased from 31 to 16 births in a span of two decades, from 1990 to 2013 (The World Bank, 2014a). Meanwhile, the crude death rate decreased from 6 to 4 deaths for the same years (The World Bank, 2014b). Between years 2010 and 2014, 10% of infants were born with low birth weight, and in 2015, the neonatal mortality rate was 14.18 per 1000 births (Geoba, 2015). In addition, the infant mortality rate per 1,000 births reduced from 33 deaths in 1990 to 16 deaths in 2014 (The World Bank, 2014a). In 2014, it was reported that the mortality rate in Jordan was 16 per 1,000 births.

In comparison with other Arab countries, the mortality rate in Jordan was lower than that of Egypt (19 per 1,000 births), Yemen (40 per 1,000 births), and Iraq (28 per 1,000 births). On the other hand, it was higher than that of Lebanon (8 per 1,000 births), Saudi Arabia (13 per 1,000 births), Syria (12 per 1,000 births), Bahrain (5 per 1,000 births), Palestine (3 per 1,000 births), Kuwait (8 per 1,000 births), Libya (12 per 1,000 births), Oman (10 per 1,000 births), and Qatar (7 per 1,000 births) (The World Bank, 2014a). Reports by WHO and UNICEF indicate that development of the health care

sector in Jordan has led to improvement of the key human development indicators such as life expectancy at birth, infant and child mortality, and maternal mortality (Kaldewei, 2010).

Preterm birth is a significant public health issue, but not much is known about the extent of the problem, especially in developing nations such as Jordan (Sivasubramaniam et al., 2015). The rate of preterm birth in Jordan in 2010 was ascertained to be 14.4% (WHO, 2012), higher than the international preterm rate of 11.1% (Blencowe et al., 2012); with an estimated 14% of the total population, Jordan registered the highest premature birth rate among Arab nations (UNICEF, 2012).

Stressful situations arise when parents have to handle the unfamiliar NICU environment. A literature review reveals that parents with infants in the NICU receive exposure to many NICU stressors, which elevates stress levels among parents. Stressors faced by parents during infant hospitalization include the NICU physical environment, infant appearance and behaviour, and altered parental role (Grosik, Snyder, Cleary, Breckenridge, & Tidwell, 2013). Parents with infants in the NICU reported more psychological distress, physical complications, and psychosocial problems, compared to parents with healthy full-term infants (Heidari, Hasanpour, & Fooladi, 2012). These parents may be further confronted with lengthy periods of anxiety, depression, stress, and sleep disturbance if the infant requires extended or continued hospitalization in the NICU (Heidari et al., 2012; Obeidat, Bond, & Callister, 2009; Shelton, Meaney-Delman, Hunter, & Lee, 2014).

1.1 Problem Statement

Stressors are stimuli in the environment that cause stress to an individual (Heuser & Lammers, 2003; Miele, 2016; Seaward, 2013). Stress is the feeling

experienced by people when they are under pressure (Heuser & Lammers, 2003; Miele, 2016; Seaward, 2013).

Stress is defined as a state of mental or emotional strain resulting from adverse circumstances, and it often operates by way of an evolutionary concept called the fight or flight response (Heuser & Lammers, 2003; Miele, 2016; Seaward, 2013). A demanding situation exerts stress on a person, triggering the fight or flight response – a physiological enhancement of blood flow, adrenaline, and metabolism throughout the body that enables the person’s self-defending survival mechanism (‘fight’) or causes the person to escape from the situation (‘flight’) (Miele, 2016). This response is often accompanied by a cognitive evaluation of the circumstance, leading to negative emotions such as anger and fear (Heuser & Lammers, 2003; Miele, 2016; Seaward, 2013).

Although generally construed as a negative state, stress may occasionally have positive effects on an individual, for instance when a situation threatens the life and safety of the individual. For example, in the presence of a dangerous predator, the fight or flight response promotes survival and self-preservation. In contrast, negative effects occur when the situation is not immediately threatening to the physical well-being of a person. In the modern world, stressors related to job, health, or important relationships are common. It is important to consider strategies and interventions to offset the effects of stress and stressors, because it may cause the individual to become susceptible to diseases such as heart attack, stroke, hypertension, and cancer, as well as to mental illnesses such as anxiety and depression (Heuser & Lammers, 2003; Miele, 2016; Seaward, 2013).

These potentially fatal or disabling effects on an individual may, in turn, have negative repercussions on the people surrounding the individual. Furthermore, the

economic impact on society could potentially be enormous, directly affecting health care and indirectly causing loss of productivity to the nation as a whole. Therefore, it is imperative to research and understand the nature of stress in order to develop an effective interventions to mitigate its negative effects on individual, economic, and societal levels (Busse, Stromgren, Thorngate, & Thomas, 2013; Heuser & Lammers, 2003; Miele, 2016; Seaward, 2013).

The birth of a child constitutes a stressful life event. The addition of a baby into a family, in itself, already results in vast adjustments to family life, occupation, and responsibilities for parents. It is unsurprising, that the birth of a fragile, ill, perhaps premature child, who is then admitted to the NICU, can cause traumatic levels of stress for parents (Busse et al., 2013). This response has been revealed by comparing, at various intervals, parents of hospitalized infants and parents of full-term infants (Busse et al., 2013). In the first week after childbirth, parents of NICU infants are introduced to many stressors in the NICU, such as sights and sounds, infant appearance and behaviour, and altered parental roles. As a result, they expressed being more upset, anxious, and depressed than parents of full-term infants (Busse et al., 2013). Carter, Mulder, Bartram, and Darlow (2005) conducted a similar study, which demonstrated that a higher number of parents in the NICU group had clinical anxiety and depression within three weeks of infant admission, compared to the control group of parents with full-term infants. A month after the delivery of their infants, mothers of NICU infants scored higher than control parents in terms of depression, anxiety, and obsessive-compulsive behaviours. They also had difficulty making decisions.

The risk of parental stress from having an infant hospitalized in NICU must be examined and understood, and protective factors or best practices established. This is the case particularly in Jordan, where only a few studies have been published to address

this important public health issue. In Jordan, there are seven hospitals with NICU facilities (Ministry of Health, 2014), and approximately 20% of all newborns in Jordan are admitted to any one of these units. Moreover, due to an increase in premature births and decrease in survival rates, the number of infants requiring care in NICU is increasing (Ministry of Health, 2014). Consequently, this means that a substantial proportion of parents may be negatively affected by effects of stress that extend to the long-term.

Another reason in support of increased research is that parental stress can be detrimental to parents' relationship with each other (Rautava, Lehtonen, Helenius, & Sillanpää, 2003); when infants reach one year of age, higher rates of divorce are found among parents who had premature infants, compared to parents of full-term infants. Given the crucial role of parents in an infant's life and in sustaining the basic building block of our society, it is also critical to examine and understand parental stress to prevent adverse effects on infant development (Rautava et al., 2003). Lack of research would mean that significant public health issues go unaddressed, with dire consequences to our society and economy.

1.2 Significance of the Study

The results of this research provide important information for health care professionals working with parents in the NICU. Furthermore, the results of the present study will help nurses to identify factors affecting parental stress, anxiety, and sleep patterns, knowledge of which can be used to develop educational or support programs for parents. In addition, the results serve to increase awareness among health care professionals regarding potential risk factors for parents who experienced poor parental care during childhood. This factor could be identified through individual assessments, and aptly addressed through treatment with psychotherapy or social support.

The results of this study may help to create intervention strategies to overcome the negative impacts of parental stress, which affect the family system in a number of ways, namely: (1) alterations in parental roles, powerlessness, and lack of control when parents are unable to take responsibility for their newborns or to protect them from harm during their admission in the NICU (Fowlie & McHaffie, 2004) ; (2) strained parenting relationships, leading to a higher frequency of divorce in parents with infants admitted to the NICU (Affleck & Tennen, 1991) ; and (3) influences on behaviours, responsibilities, and cognitions displayed by parents to their children (Mash & Johnston, 2013).

Overall, parents achieve satisfactory levels of adaptation to the NICU during the early stages of their infant's admission; therefore, it is commonly deemed an unnecessary measure to provide intervention beyond what is already practiced in the unit, which involves all parents. As the present study demonstrates, however, there are certain populations of parents who do find the NICU environment more stressful, and these parents would undoubtedly benefit from increased clinical attention. This study aimed to provide knowledge and guidance for targeted interventions in the NICU environment, such that the allocation of staff and resources will be able to effectively tackle the issue at hand.

1.3 Research Questions

This study attempted to answer the following questions:

1. What are the stressors experienced by Jordanian parents whose infants are admitted to the NICU?
2. What is the difference in stress levels among Jordanian parents?
3. What is the relationship between stress levels and stressors?
4. What is the relationship between stress levels and the impact of stress?

5. What is the difference in stress level and impact of stress (depression, anxiety, and sleep disturbance) by parent and infant characteristics?
6. Is there a model that describes the relationship between variables?
7. What are parents' emotional responses when their infants are admitted to the NICU?
8. What are factors affecting stress among parents whose infants are admitted to the NICU?
9. What are coping strategies used by Jordanian parents whose infants are admitted to NICU?

1.4 Objectives of the Study

The general objective of this study is to identify the impact of stressors on Jordanian parents with infants in NICU.

The specific objectives of this study are:

1. To identify the stressors experienced by Jordanian parents whose infants are admitted to the NICU.
2. To assess the difference in stress levels among Jordanian parents.
3. To examine the relationship between stress levels and stressors (sight and sounds, infant appearance and behaviour and altered in parent role).
4. To examine the relationship between stress levels and the impact of stress .
5. To compare the difference in stress level and impact of stress (depression, anxiety , sleep disturbance) by parent and on infant characteristics.
6. To establish a model that describes the relationship between variables.
7. To explore parents' emotional responses when their infants are admitted to the NICU.
8. To explore factors affecting stress among parents whose infants are admitted to the NICU.

10. To explore coping strategies used by Jordanian parents whose infants are admitted to the NICU

1.5 Conceptual Definitions and Operational Definitions

Stressors are domains that contribute to stress. In this study, the stressors are sights and sounds, infant appearance and behaviours, and altered parental roles and relationship (Miles, Funk, & Carlson, 1993).

Sights and sounds is defined as the physical environment in the NICU, such as medical equipment, alarms, noise, and light (Miles et al., 1993).

Infant appearance and behaviour is defined as how the baby looks and behaves, as well as how the parents perceive their baby in the NICU, such as small baby size, wrinkled skin, restlessness, and lines connected with the baby's body (Miles et al., 1993).

Altered parental roles and relationship is defined as abnormal parental roles regarding their infant's needs, such as delayed infant-parent relationship, as well as disrupted or impeded caregiving behaviours of feeding, bathing, changing diapers, kissing, and holding them (Miles et al., 1993).

Stress is defined as a particular "relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Folkman, 1984, p. 841). In the present study, stress levels are measured using the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU). The stress level is determined by calculating the mean score of PSS: NICU scale.

Parents refer to the married couples that give birth to a neonate. Parenting is the sense of responsibility towards the infant, including the role of parents in care giving and

protection of the infant. The parent in this study refer to the biological father and mother of the infant (Crittenden, 2013).

Term infant is a neonate born between 37 and 42 completed weeks of pregnancy (Miles, 1989).

Full-term neonate requiring observational-care is a neonate who is potentially at-risk and thus placed under observation in the neonatal intensive care nursery (Miles, 1989).

Prematurity or **preterm neonate** is a neonate born less than 37 completed weeks of pregnancy (Miles, 1989).

Neonatal Intensive Care Unit (NICU) Level III is a neonatal intensive care unit that is capable of providing complex, multisystem life support for an indefinite period, and capable of providing mechanical ventilation and invasive cardiovascular monitoring, or care of a similar nature (Miles, 1989).

Anxiety is defined theoretically as a particular future-oriented mood state associated with preparation for possible upcoming negative events, and fear is an alarm response to present or imminent danger, whether real or perceived (Barlow, 2004). In the present study, anxiety is measured using the Patient-Reported Outcome Measurement Information System (PROMIS). The anxiety is determine by calculating the mean score of PROMIS scale.

Depression is defined as a "lack of tonicity, loss of energy, feelings of weakness, powerlessness, unhappiness, self-punishment, and a whole range of negative feelings" (Barroso, 2005, p. 90). In the present study, depression is measured using PROMIS. The depression determine by calculating the mean score of PROMIS scale.

Sleep disturbance is defined as any alteration in sleep patterns that lead to a disruption in daytime function (Meltzer & Mindell, 2007). Sleep disturbance is measured using

PROMIS in the present study. The sleep disturbance determine by calculating the mean score of PROMIS scale.

Infant characteristics are the neonate's gender, gestational age, birth weight, and severity of medical condition.

Parent characteristics are age, gender, education level, medical history, infertility history, and financial status.

1.6 Organization of the Thesis

The thesis is presented in eight chapters to facilitate understanding and clarity of the research study.

Chapter one presents an introduction to the study, including background, problem statement, significance of the study, research questions, objectives, and conceptual and operational definitions.

Chapter two provides a critical review of extant literature on parental experiences and stressors reported by parents with infants admitted to the NICU. This chapter also addresses the conceptual model which describes the relationship between variables.

Chapter three presents the methodology used to address the research questions of the study. This chapter explains the study design, setting, data collection, and planned data analysis methods, as well as describes how the sample size is determined and the sampling approach used in this study. Ethical concerns are explored and a pilot study is conducted to ensure reliability and validity of the research instrument.

Chapter four explains the reliability and validation of the PROMIS questionnaire by using Structural Equation Modeling (Amos).

Chapter five presents the quantitative results. It begins by providing descriptive results of the demographic characteristics of parents whose infants are admitted to NICU, and then determines the most stressful NICU stressors and the correlations between stress

levels. Following that, tests are used to determine the stress levels among parents and to compute the total scores for stress levels, anxiety, depression, and sleep disturbance. The results are compared between mothers and fathers. Subsequently, comparisons are made between the influences of parent and infant characteristics on stress levels, anxiety, depression, and sleep disturbance. Finally, the chapter presents the model that describes the relationship between the variables by using Structural Equation Modeling analysis with Smart PLS.

Chapter six presents the qualitative component of this study. A brief description of the background characteristics is provided to facilitate the reader's understanding. The chapter also presents various findings from thematic analysis of the interview transcripts and field notes; these are then organized into main themes and subthemes.

Chapter seven discusses the findings of this study and compares the findings with that of previous studies. This chapter also rationalizes the results and explains how the results provide new knowledge.

Chapter eight presents the conclusion of the study, followed by the implications for nursing education, practice, and research. Finally, the chapter considers the strengths and limitations of the study, and suggests recommendations for future research.

1.7 Summary

Preterm birth is a significant public health issue. The admission of infants to the NICU may be an unexpected and stressful event for both mothers and fathers. This situation affects parents negatively, such that symptoms of stress and other psychological problems may occur. This chapter stated the study objectives and research questions that aim to explore stressors which may contribute to stress levels of parents with hospitalized infants in the NICU, as well as to examine the influence of parent and infant characteristics, and the impact of stress. The chapter concluded with

conceptual and operational definitions of terms relevant to the study. The following chapter reviews relevant studies that have been conducted to examine parental stress related to infant hospitalization in the NICU.

University of Malaya

CHAPTER 2: LITERATURE REVIEW

2.0 Introduction

The purpose of this chapter is to provide a critical review of the existing literature related to the parental experiences and stressors reported among parents with infants admitted to the NICU. This review includes studies on factors influencing parental stress and parental response to the NICU admission (anxiety, depression, and sleep disruption), as these are thought to lend understanding to the topic of study. It also addresses the conceptual model that guides the study, as well as the conceptual model which describes the relationships between variables.

In this study, three main approaches were used to explore the understanding of parental experiences of stress and its effects on anxiety, depression, and sleep disruption quantitative, qualitative, and mixed methods approaches. Although quantitative studies are generally regarded as superior to qualitative studies, both sources of evidence are equally important, especially in research that seeks to explore and examine subjective parental experiences. Several other studies which employ the mixed methods design approach are also included in the review.

It was necessary to use different review checklists for the different research approaches, to ensure that all relevant studies are critically reviewed. Thus, the discussion of existing studies is arranged according to the quantitative, qualitative, and mixed methods research approaches which help to inform the design of the present study.

2.1 Literature Review for Quantitative Studies

2.1.1 Searching in Database

The search for quantitative studies was accomplished using ScienceDirect, PubMed, CINAHL EBESCO, SpringerLink, Psychology and Behavioral Sciences

Collection, Web of Science, and Google Scholar. The search terms were explored and combined, including keywords that were a combination of parental experience, parental perception, parental stress, stressors in NICU, impact of stress, parents and infants in NICU, babies in NICU, neonates in NICU, preterm infants in NICU, preterm neonates in NICU, and quantitative studies with different punctuation (Appendix A).

Inclusion criteria for this literature review were quantitative full-text articles, published in English, that describe parental experience of infant admission to the NICU, parental stress, and factors that increase stress levels. The studies that were published in other languages and studies that describe the experience of parents who lost their babies after the admission to NICU were excluded. (Table 2.1).

Table 2.1 Inclusion and Exclusion Criteria for Literature Review of Quantitative Articles

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| Articles published in the English language. | Articles published in other languages. |
| Full-text articles. | Abstract only. |
| Articles relating to parental experience or perception on having infants in NICU. Parental response to admission of infants to NICU (depression, anxiety, and sleep disturbance). | Articles relating to experience of parents who lose their babies after admission to NICU. |
| Quantitative design. | Qualitative design or mixed design. |

2.1.2 Screening Process

The screening process was conducted in three stages. First, the titles of the research studies were screened and their abstracts were read before retrieving the full-text papers. Only selected articles that met the inclusion criteria (Table 2.1) were entered into the EndNote database X7.

2.1.3 Screening Results

The results of the database searches were: CINAHL EBESCO (163 articles), PubMed (94 articles), Science Direct (174 articles), Springer Link (148 articles), Psychology and Behavioural Sciences Collection (243 articles), and Web of Science (11 articles). Google Scholar was also used to find articles related to the topic of study.

Based on the titles and abstracts, 833 articles from the database search, 9 articles identified through reference lists, and 2 theses were selected for having suitable topics (Appendix B and Figure 2.1). From these 844 reviewed papers, 808 were removed due to duplicates or similar content; 8 articles were rejected for irrelevant content.

Finally, a total of 28 articles related to parental experience of infants admitted to the NICU were included in this chapter (Table 2.2). The studies covered three main subjects: the parental stress of hospitalization, factors that influence parental stress, and the impact of stress on parents.

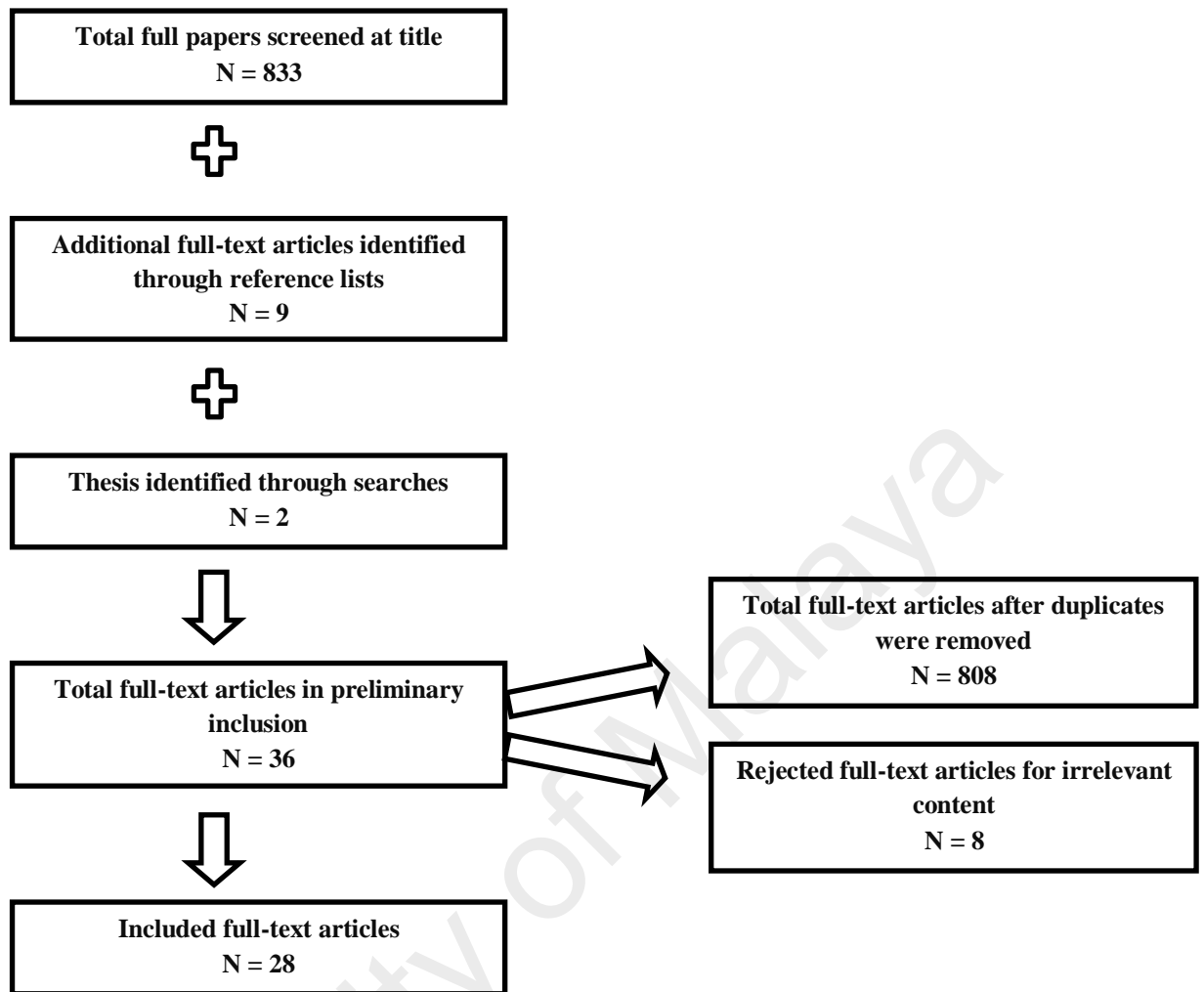


Figure 2.1 Summary of Selection and Exclusion of Quantitative Studies

Table 2.2 Summary of Selected Studies for Literature Review of Quantitative Studies

| No. | Author and Year | Design and Instruments | Sample/ Setting | Data Collection | Outcome | Limitations |
|-----|---|--|--|----------------------------|---|---|
| 1 | Chiejina et al. (2015) | Exploratory PSS: NICU Parenting Stress Index (PSI), Parental Self-report Scale | Convenience sampling 216 parents/ Nigeria | Completed self-report | Single mothers experience higher levels of stress than married mothers. | Convenience sampling limits generalizability. |
| 2 | Musabirema, Brysiewicz, and Chipps (2015) | Quantitative survey PSS: NICU | Convenience sampling 110 parents/ Kigali, Rwanda | Self-report questionnaires | The most stressful event was infant appearance and behaviour. The lowest source of parental stress was sights and sounds in the | The data was collected from a single geographical location. Convenience sampling limits generalizability. |

Table 2.2, Continue

| | | | | | | |
|---|--|---|--|------------------------|--|---|
| | | | | | NICU. ➤ Parent and infant characteristics such as parent age, educational level, infant birth weight, and gestational age affected parental stress. | Self-report questionnaires increase bias. |
| 3 | Turner, Chur-Hansen, Winefield, and Stanners (2015) | Survey PSS: NICU Parent and infant demographic sheets | Convenience sampling 73 parents/ Australia | Self-report assessment | Parents experience high levels of stress. The highest stress level was associated with alterations in parental roles. | Small sample size. Convenience sampling limits generalizability. |
| 4 | Varghese (2015) | Survey PSS: NICU | Simple random sample 343 parents/ Canada | Self-report assessment | Parents whose infants were admitted to NICU experience high stress levels associated with low gestational age and low birth weight in infants. | Self-reported questionnaires increase bias. |
| 5 | Alaradi (2014) | Cross-sectional exploratory design PPUS, PSS: NICU, SAI CES-D scales | Convenience sampling 32 pairs of parents/ Southern Indiana | Self-report assessment | Parents experienced moderate to high levels of stress, uncertainty, anxiety, and low levels of depression. | Vague inclusion and exclusion criteria. Convenience sampling limits generalizability. Self-report questionnaires increase bias. |
| 6 | Beheshtipour, Baharlu, Montaseri, and Razavinezhad Ardakani (2014) | Descriptive-analytical study PSS: NICU | Convenience sampling 42 fathers and 58 mothers/ Iran | Self-report assessment | Mothers experience higher stress levels than fathers regarding admission of infants to NICU. | Convenience sampling and small sample size limit generalizability. Self-report questionnaires increase bias. Reliability and validity of instruments not addressed. |
| 7 | Chiejina, Ebenebe, and Odira (2014) | Correlation research design PSS: NICU Parental Self-report Scale Parent-infant demographic information | Convenience sampling 216 parents/ Nigeria | Completed self-report | Significant correlations between parental stress and parent age, staff communication, sights and sounds, and infant appearance and | It was not determined if the type of data used parametric and nonparametric tests. Convenience sampling limits generalizability. |

Table 2.2, Continue

| | | | | | | |
|----|---|--|---|------------------------|--|--|
| | | | | | behaviours. | Self-report questionnaires increase bias. |
| 8 | Gönülal, Yalaz, Altun-Köroglu, and Kültürsay (2014) | Exploratory Edinburgh Postnatal Depression Scale, for mothers Beck Depression Inventory, for fathers | Convenience sampling 68 parents/ Turkey | Self-reported | Parents with infants hospitalized in the NICU experience depression. | Ethical Committee approval was not obtained. Vague inclusion and exclusion criteria. Convenience sampling limits generalizability. Small sample size. |
| 9 | Shelton et al. (2014) | Cross-sectional comparative design Edinburgh Postnatal Depression Scale PSS: NICU Lee Fatigue Scale (LFS) Sleep Disturbance Scale (GSDS) | Convenience sampling 55 mothers/United Status. | Self-reported | Mothers experience higher stress associated with depression and poor sleep. | Small sample size. Implications of the research study were not discussed. Self-report questionnaires increase bias. |
| 10 | Busse et al. (2013) | Exploratory design PSS: NICU & PROMIS | Convenience sampling 30 parents/ Spanish | Self-report assessment | Parents with infants admitted to NICU experience stress levels associated with anxiety, depression, fatigue, and sleep disruption. | Convenience sampling and small sample size limit generalizability. Self-report questionnaires increase bias. Informed consent was not obtained from participants. |
| 11 | Grosik et al. (2013) | Survey PSS: NICU | Convenience sampling 119 parents/ United Status | Self-reported | Parents experience stress from having infants hospitalized in NICU. | Convenience sampling limits generalizability. Data collection methods were not clearly described. Self-report questionnaires increase bias. |
| 12 | Kong et al. (2013) | Cross-sectional survey, Self-Rating Anxiety Scale Self-Rating Depressive Scale, Social Support Rating Scale & Perceived Stress Scale | Convenience sampling 600 parents (400 fathers and 200 mothers)/ China | Self-reported | Parents of hospitalized neonates are more prone to suffering from negative emotions than the normal population. Anxiety and depression are common emotions in parents of | Instruments were not sufficiently described. Reliability and validity of instruments were not addressed. Convenience sampling limits generalizability. Data collection methods were not clearly described. |

Table 2.2, Continue

| | | | | | | |
|----|--|--|--|---------------------------------------|---|---|
| | | | | | hospitalized infants. | Self-report questionnaires increase bias. |
| 13 | Akbarbeglo, Valizadeh, and Asadollahi (2013) | Descriptive study PSS: NICU | Convenience sampling 300 mothers/ United States. | Completed self-report | Mothers experience stress and require intervention to reduce stress. | Convenience sampling limits generalizability. Data collection methods were not clearly described. Self-report questionnaires increase bias. |
| 14 | Matricardi, Agostino, Fedeli, and Montiroso (2013) | Experimental PSS: NICU | Random sample Support group, n = 21 Interventional group, n = 21/ Italy | Completed self-report Intervention | Mothers reported more stress compared to fathers. A parental intervention was effective in reducing stress from role alteration in mothers, but not in fathers. | No literature review. Convenience sampling limits generalizability. Data collection methods were not described clearly. Self-report questionnaires increase bias. |
| 15 | Montgomery-Honger (2012) | Survey PSS: NICU Life event scale Parent demographic data | Convenience sampling 68 mothers and 68 fathers/ Florida | Self-reported | Mothers experienced higher stress levels than fathers. | Convenience sampling limits generalizability. Data collection methods were not clearly described. Self-report questionnaires increase bias. |
| 16 | Commodari (2010b) | Survey Psychological Stress Measure State Trait Anxiety Inventory (STAI) | Convenience sampling 19 men and 200 women caregivers/ Italy | Self-report assessment | Parents with infants in NICU experience high stress levels and anxiety, influenced by the length of infant hospitalization. | Convenience sampling limits generalizability. Self-report questionnaires increase bias. |
| 17 | Korja (2009) | Cross-sectional PSS: NICU & EPDS | Convenience sampling 116 mothers/ Turkey | Self-reported | Mothers experience stress related to delay in mother-infant relationships. Stress is associated with depression. | Convenience sampling and small sample size limit generalizability. Self-report questionnaires increase bias. |
| 18 | Valizadeh, Akbarbeglou, and Asad (2009) | Descriptive study PSS: NICU | Convenience sampling 300 mothers/ Iran | Completed self-report | Parents experienced high stress levels, influenced by medical procedures. | Convenience sampling and small sample size limit generalizability. Self-report questionnaires increase bias. |

Table 2.2, Continue

| | | | | | | |
|----|------------------------|---|---|--------------------------------|--|---|
| 19 | Yurdakul et al. (2009) | Case-control study Postpartum Assessment Instrument Edinburgh Postpartum Depression Scale (EPDS) Adult Attachment Scale (AAS) State-Trait Anxiety Inventory (STAI) Multidimensional Scale of Perceived Social Support (MSPSS) | Convenience sampling 100 mothers/ Turkey | Interview Self-reported | Mothers experience depression and anxiety from hospitalization of their infants in NICU. | Convenience sampling and small sample size limit generalizability. Self-report questionnaires increase bias. Limitations of the study were not identified. No recommendations for future studies. |
| 20 | Carter et al. (2007) | Descriptive PSS: NICU | 172 randomly-selected couples/ New Zealand | Completed self-report measures | Both fathers and mothers experience stress related to admission of their infants to NICU. The most common sources of stress for mothers were altered parental role and lower income. The most common sources of stress for fathers were loss of control and impaired relationship. | Insufficient information about instruments, reliability and validity. |
| 21 | Steedman (2007) | Survey PSS: NICU | Convenience sampling 182 mothers and 183 fathers/ United States | Self-reported | Mothers experience higher stress levels than fathers. Parents experience high stress related to altered parental roles, whereas they experience little stress from sights and sounds in the NICU environment. | Convenience sampling limits generalizability. Self-report questionnaires increase bias. |
| 22 | Ng (2006) | Cross-sectional PSS: NICU Edinburgh Postnatal Depression Scale (EPDS) Parental Sense of | Convenience sampling 85 parents/ Hong Kong. | Self-reported | Parents experience stress and depression with regard to admission of their infants to NICU. No significant | Insufficient information about instruments. Convenience sampling and small sample size limit |

Table 2.2, Continue

| | | | | | | |
|----|---|---|---|------------------------|---|---|
| | | Competence Scale (PSOC) Feetham Family Functioning Survey (FFFS) Nurse Support Scale (NSS) | | | relationship between nurse support and parental stress or depression. | generalizability. Self-report questionnaires increase bias. |
| 23 | Copeland and Harbaugh (2005) | Exploratory Parenting Stress Index / Short Form (PSI/SF) | Convenience sampling 22 single and 52 married first-time mothers/ United States | Completed self-report | Single new mothers experienced more stress than married new mothers. | Convenience sampling and small sample size limit generalizability. Self-report questionnaires increase bias. Strengths and weaknesses of the research study were not discussed. |
| 24 | Franck, Cox, Allen, and Winter (2005) | Descriptive PSS: NICU & Spielberg State-Trait Anxiety Scale | Consecutive samples 257 parents/ United Kingdom | Completed self-report | Mothers who had caesarian sections experienced higher stress and anxiety levels than mothers who had normal delivery. | Convenience sampling limits generalizability. Data collection methods were not described clearly. Self-report questionnaires increase bias. The process of analysis was not clear. |
| 25 | Lee, Lee, Rankin, Alkon, and Weiss (2005) | Cross-sectional, descriptive, correlation study PSS: NICU Suinn-Lew Asian Self-Identity Acculturation Scale Family Support Scale | Convenience sampling 30 Chinese-American families (30 mothers and 25 fathers)/ China | Completed self-report | The most common source of stress for parents with infants in NICU was infant appearance and behaviour . The lowest source of stress was the NICU physical environment. | Lack of a good argument for the significance of the study. Convenience sampling and small sample size limit generalizability. Data collection methods were not described clearly. Self-report questionnaires increase bias. |
| 26 | Dudek-Shriber (2004) | Survey PSS: NICU | Convenience sampling 162 parents/ New York | Self-report assessment | Parents experience high levels of stress. | Convenience sampling limits generalizability. Data collection methods were not described clearly. Self-report questionnaires increase bias. |
| 27 | Melnyk et al. (2004) | Randomized, controlled trial | Simple random sample | Interventional program | Mothers experience high | Ethical Committee |

Table 2.2, Continue

| | | | | | | |
|----|---|--|--|-----------------------|---|---|
| | | with follow-up assessments after 1, 3, 6, and 12 months PSS: NICU | 174 mothers/ United States. | | stress levels and the COPE program was effective in alleviating stress. | approval was not obtained. Informed consent was not obtained from mothers. |
| 28 | Miles, Burchinal, Holditch-Davis, Brunssen, and Wilson (2002) | Cross-sectional, descriptive study PSS: NICU | Simple random sample 69 mothers/ United States | Completed self-report | Mothers experience high stress levels associated with infant behaviours and moderate stress levels associated with altered parental role. | Small sample size. The problem was not clearly identified and stated. Ethical Committee approval and informed consent were not obtained for the study. Self-report questionnaires increase bias. |

2.1.3.1 Stressors in NICU:

There are several stressors that could contribute to differences in stress levels among parents with hospitalized infants in NICU, such as, infant behaviour and appearance, NICU physical environment, and parent characteristics (Alaradi, 2014; Chiejina et al., 2014; Chiejina et al., 2015; Jee et al., 2012; Matricardi et al., 2013; Sweet & Mannix, 2012; Varghese, 2015).

2.1.3.1.1 Infant Behaviour and Appearance

Parents with hospitalized infants in NICU are influenced by the specific characteristics of their infants. These characteristics may include infant appearance and behaviour, severity of infant's medical diagnosis, the infant's level of functioning, birth weight, gestational age, and the duration of their infant's length of hospitalization.

Turner et al. (2015) conducted a study that investigated the effect of infant characteristics on stress experience among parents with hospitalized infants in NICU. The infants who participated in this study were 61.1% (n = 99) infants born premature with gestational age of 28-36 weeks, 20.4% (n = 33) born extremely premature before 28 weeks, and 18.5% (n = 30) born full-term. In addition, infant birth weight was taken

into consideration: 28.4% (n = 46) infants were born with normal birth weight (above 2,500 grams), 27.2% (n = 44) infants had very low birth weight (1,000-1,500 grams), 24% (n = 40) infants had extremely low birth weight (below 1,000 grams), and 19.8% (n = 32) infants had low birth weight (1,500-2,500 grams). In terms of medical condition, 40.7% (n = 66) of infants suffered from prematurity with respiratory disorder and 7.4% (n = 12) of infants had gastrointestinal and/or nephrolytic disorders. Results from Turner et al. (2015) showed that gestational age was significant in relation to the stress occurrence score on the infant appearance and behaviour subscale ($F = 6.263$, $p = .002$). Parents of infants with gestational age of less than 28 weeks obtained significantly higher stress occurrence scores ($M = 3.70$, $SD = 1.75$) than parents whose infants were in the 28-36-week gestational age range ($M = 2.91$, $SD = .96$). Parents of infants with gestational age of less than 28 weeks also scored significantly higher on PSS:NICU subscale ($M = 3.27$, $SD = 2.96$) than parents of infants in the 28-36-week age range ($M = 2.36$, $SD = .86$). It should be noted that for the overall stress score on this subscale, the p-value was not significant at .01 ($F = 4.480$, $p = .013$); however, post-hoc analysis showed that parents in the two groups were significantly different in terms of stress levels ($p = .01$).

Miles et al. (2002) described the maternal perceptions about hospital-related stressors, anxiety about the infant's health, and support from health care professionals. The researcher explored differences between 31 black mothers and 38 white mothers from a larger longitudinal study. The infants in this study had serious life-threatening illnesses and a period of dependence on technology for survival. The mothers reported high stress levels (> 4 on a 5-point scale) related to the infant appearance and behaviour, and moderately high stress levels related to altered parental role (> 3.8 on a 5-point scale). Maternal perceptions of medical condition severity led to moderate stress (3 on

a 5-point scale), whereas anxiety about the child's health led to moderately high stress (> 3.7 on a 5-point scale). However, the generalizability of the results is limited due to the small sample size from only one hospital. Moreover, the study was conducted more than ten years ago.

A descriptive study conducted by Akbarbegloo, Valizadeh, and Asadollahi (2013) identified the sources of stress for 300 mothers with hospitalized infants in NICUs of three teaching hospitals in Tabriz. The researchers assessed stress using the PSS: NICU questionnaire. Results revealed many sources of stress: NICU environment stressors, infant appearance and behaviour, special treatments, unusual or abnormal breathing patterns, tubes and equipment on or near the infant, sudden changes in newborn's skin colour, and needles on the child's body. Stress was also caused by altered parental relationships and parental roles: being separated from the child (60.3%), inability to help child during hospitalization (51.7%), and inability to protect child from pain and painful procedures (44.3%). In this study, unfortunately, the problem statement was not clearly stated. Besides, the researchers did not provide sufficient information on instrument validity and reliability. No implications of the findings for clinical practice were discussed.

Franck et al. (2005) reported that an infant's physical condition contributed independently to parent-infant attachment. Parents with premature infants experience grief and anxiety because their infants may not survive, and parents of infants with technology dependency express higher stress levels. Consequently, infant appearance and the severity of the infant's medical condition (e.g. small size or being surrounded by equipment) may cause higher stress levels for parents. Parents report reduced interactions with the infant as they have to wait until the infant's medical condition stabilizes before they participate in caring for the infant.

Lee et al. (2005) described the stressful experiences of 30 Chinese-American families (30 mothers, 25 fathers) who had infants in the intensive care unit (ICU). This study used the Parental Stressor Scale: Infant Hospitalization, Suinn-Lew Asian Self-Identity Acculturation Scale, and Family Support Scale, in addition to medical reports of the infants' health conditions. It was found that parents have moderately stressful experiences during their infants' ICU hospitalization. Both mothers and fathers found infant appearance and behaviour to be the stressor with the most impact ($M = 3.3$ for mothers, $M = 3.5$ for fathers), followed by the altered parental roles ($M = 3.1$ for mothers, $M = 3.1$ for fathers) and communication with health care providers ($M = 2.8$ for mothers, $M = 2.4$ for fathers). Not only was this study dated, but the small sample size of 30 families also makes it difficult for the results to be generalized. Furthermore, the process of data analysis was not described clearly, and the researchers did not compare between the findings and that of previous research.

Franck et al. (2005) reported that parents with hospitalized infants in NICU experience feelings of helplessness and inability to provide a safe physical environment for their infants, as part of their parenting responsibilities. Added to the above, lack of support and unfamiliar medical terminology serves as another source of parental stress, because it forms a barrier for parents to understand their infant's health condition and progress. Collectively, these factors increase their sense of uncertainty and fear of the unknown, which are found to be sources of worry and concern among parents (Akbarbegloo et al., 2013)

Although all of the studies detailed above have reported important findings, with implications for nursing practice, they provide a relatively limited understanding of the complex parental experiences. This study, therefore, seeks to build upon the findings of previous research.

2.1.3.1.2 NICU Environment

The Neonatal Intensive Care Unit (NICU) has been developed to provide care for premature and unhealthy infants within the immediate transitional period after birth (Mörelus, 2006; Turner et al., 2015). The NICU is usually a busy unit in the hospital. Many infants are placed in the same room, and sometimes more than one infant are placed in the same bed; there are monitor alarms and sounds, mechanical ventilators, and complex technology all around; many staff members are needed in order to provide care to infants or to conduct medical interventions and procedures; and many parents want to be by their infants' side (Grosik et al., 2013; Mörelus, 2006).

Due to these factors, the NICU may be a source of noise pollution. As defined by the Environmental Protection Agency (EPA, 2014; Hunt, 2011), noise pollution is “unwanted or disturbing sounds”. The EPA Department of Air and Pollution’s *Noise Effects Handbook* states, “Studies have demonstrated that there is a direct link between noise and health. Problems related to noise and health includes: stress-related illness, high blood pressure, speed interference, hearing loss, and sleep deprivation” (EPA, 2014, p.153). Sudden and loud noise lead to physiological and behavioural disturbances including sleep disturbance, motor arousals such as crying, hypoxemia, tachycardia, and increased intracranial pressure (Hunt, 2011). Increased intracranial pressure can further contribute to intra-ventricular hemorrhage (Hunt, 2011).

A few studies show that the NICU physical environment and staff behaviour are the stressors with least impact on parental stress (Grosik et al., 2013; Turner, Chur-Hansen, Winefield, & Stanners, 2015). However, Turner et al. (2015) report that the physical environment of NICU may be stressful for parents for many reasons, such as dim light, infant appearance, complex technology, medical interventions, health care providers, and monitor alarms or sounds. The NICU physical environment induces

stress for the parents of premature infants, especially with regard to the malfunctioning equipment and monitor alarms or sounds. It was found that stress was evoked among parents during the infant hospitalization period. The physical environment of the NICU was more stressful for mothers than for fathers (Copeland & Harbaugh, 2005). The NICU environmental factors influence parents' unique reactions to having an infant in the NICU. Specifically, 64.3% of parents experience stress from seeing monitors and equipment, and 38.3% from seeing another infant using a respirator in the NICU (Akbarbegloo et al., 2013) .

Another descriptive study was conducted by Iranian researchers Valizadeh et al. (2009) to determine the stressors that affect mothers with hospitalized infants in the NICU. The PSS: NICU was administered to 300 mothers with premature infants in NICUs across three teaching hospitals. Results found that parents experience high stress levels associated with infant appearance and behaviour: when their infant was in distress during medical procedures and treatments, when they perceived abnormal breathing patterns in their infant, or when medical accessories and devices surrounded or were attached to the infant. They were also sensitive to the physical appearance of their infant, such as sudden changes in skin colour and facial grimaces signaling pain. This study also found that stress was related to effects of physical separation on the parent-infant relationship, in that parents were unable to help or protect their infant during painful procedures. These are important findings because the researchers collected data from a large sample size in three hospitals, and they used an appropriate scale (PSS: NICU) to assess stress. Its limitations, however, are that the researchers only collected data from mothers instead of both parents, and only from mothers with premature infants, rather than mothers of infants with various medical reasons for NICU admission.

2.1.3.1.3 Parent Characteristics

The experience of infant hospitalization is universally a stressful experience for each parent; however, the degree of stress varies among parents, according to certain parent demographic characteristics (Chiejina et al., 2014).

A recent study conducted by Turner et al. (2015) investigated the stress experience among parents with infants hospitalized in NICU and found stress to be related to parent characteristics. The study used the PSS: NICU to measure stress levels among a convenience sample of 162 parents, and examined factors such as parent gender, parent age, ethnicity, marital status, education level, and job status.

80% of participants were mothers ($n = 130$) and 20% were fathers ($n = 32$). The participants' ages ranged between 14 and 51 years; 46.3% ($n = 75$) were aged 22-32 years, 37.7% ($n = 61$) aged 33-51 years, and 16% ($n = 26$) aged 14-21 years. 80% ($n = 131$) of participants were Caucasian, 2.5% ($n = 4$) were Hispanic, 15.4% ($n = 25$) were African-American, 0.6% ($n = 1$) were Asian, and 0.6% ($n = 1$) were of other ethnicities. Married parents comprised 61.1% ($n = 99$) of participants, single parents constituted 32.7% ($n = 53$), divorcees made up 0.6% ($n = 1$) and cohabiting parents comprised 1.9% ($n = 3$). Furthermore, 15.4% ($n = 25$) of participants had primary school education, 36.4% ($n = 59$) had high school degrees, 12.3% ($n = 20$) had Associate's degrees, 24.1% ($n = 39$) had bachelor's degrees, and 2.5% ($n = 4$) had doctorates. Finally, participants were divided into three groups according to occupation: unemployed or homemakers, professionals, and non-professionals.

For the sights and sounds subscale, the results showed that four variables of parent characteristics were significant for the frequency of stress scores: gender ($t = 3.518$, $p = .001$), marital status ($F = 5.043$, $p = .008$), education level ($F = 3.399$, $p = .006$), and occupation group ($F = 5.716$, $p = .004$). Post hoc analyses revealed that males

($M = 5.00$, $SD = .00$) were more stressed than females ($M = 4.75$, $SD = .80$), and that married parents and cohabiting parents ($M = 4.92$, $SD = .34$) were more stressed than single parents ($M = 4.55$, $SD = 1.13$). Parents with a high school education ($M = 4.86$, $SD = .54$) and bachelor's degrees ($M = 4.92$, $SD = .35$) had higher stress frequency levels than parents who did not complete high school ($M = 4.28$, $SD = 1.46$). With regard to occupation, parents who were working non-professionals obtained a significantly higher frequency score ($M = 4.96$, $SD = .19$) than parents who were unemployed or homemakers ($M = 4.55$, $SD = 1.12$) (Turner, 2015).

Other studies have examined parent characteristics, as detailed below.

Parent age. The age of the parents affects stress levels regarding admission of infants to NICU and subsequent interactions with infants. Turner (2015) found that older mothers experience significantly higher levels of stress than younger mothers when their infants are hospitalized in NICU.

Parent gender. The parent's gender affects parental stress levels. Many studies report that mothers experience higher levels of stress than do fathers (Chiejina et al., 2014; Colville et al., 2009; Matricardi et al., 2013; Tooten et al., 2013).

A descriptive, cross-sectional survey was undertaken by Franck et al., (2005) on 257 parents of premature and full-term infants admitted to NICU, where 196 parents were from the United Kingdom and 61 from the United States. The study was carried out over twelve months and used the PSS: NICU to assess stress among parents whose infants were admitted to the NICU. They found that parents reported a moderate degree of overall stress, where stress levels were slightly higher for mothers than for fathers. Higher stress levels were related to sights and sounds of the NICU physical environment, and inability to perform parental roles and responsibilities (Franck et al., 2005). It should be noted, however, that this study was conducted more than ten years

ago, when the health care system and policies were different from the current system and policies. Today, family-centered care and technological advances have led to improved health care services for parents, which may influence parental experiences and stress levels for the better.

In a cross-sectional study conducted by Colville et al. (2009) to assess the parental experience of infant admission to NICU, the researcher interviewed 32 mothers and 18 fathers about their experiences and feelings regarding the hospitalization of their infants. Similarly, results of the study showed that admission of infants to NICU is a stressful experience for both fathers and mothers, but mothers experience higher levels of stress than fathers (Colville et al., 2009).

A descriptive-analytical study conducted by Beheshtipour et al. (2014) compared parental stress between fathers ($n = 42$) and mothers ($n = 58$) by using the PSS: NICU on the second day after admission of infants to the NICU. They found a significant difference in parental stress between mothers and fathers [$t(98) = 2.76, p < .001$], with mothers experiencing higher stress levels ($M = 94.63, SD = 17.24$) than fathers ($M = 84.16, SD = 20.55$). However, there is a limitation to the generalizability of these findings due to the small sample size of this study.

Carter et al. (2007) conducted a study to examine the sources of NICU stressors among parents with hospitalized infants in NICU. Randomly-selected parents ($n = 172$) were interviewed and all participants completed PSS: NICU questionnaires. The results showed that both mothers and fathers experience stress from admitting their infants to NICU, but mothers experience higher levels of stress ($M = 2.1$) than fathers ($M = 1.7$). In addition, the effects of sights and sounds, staff behaviour and communication, altered parental roles, and infant appearance and behaviours were all higher for mothers

(M = 2.1, M = 1.6, M = 2.7, and M = 2.0) than for fathers (M = 1.7, M = 1.8, M = 1.9, and M = 1.7).

Type of delivery. Among mothers whose infants are admitted to NICU, the type of delivery influences stress levels. According to Franck et al. (2005), mothers who had caesarean section deliveries did not see their infants immediately after birth and hence reported greater stress than mothers who had vaginal deliveries ($p < .01$).

Parental perception. As the neonatal units involve surgical interventions and procedures that can cause pain, researchers have explored the relationship between parental stress levels and perceptions of infant pain experience. Franck et al. (2005) found that parental stress was independently predicted by parents' estimation of their infants' worst pain, the number of worries about pain or pain management, and the degree of dissatisfaction with pain information received ($p < .001$) (Franck et al., 2005).

Education level. Chiejina et al. (2014) conducted a study among a convenience sample of 216 parents to assess the relationship between stress and parent demographic data. They reported that parents with low educational attainment experienced higher stress levels than highly-educated parents. They hypothesized that this was because the former had difficulties understanding complex medical explanations about their infant's condition. Therefore, these parents would need health care professionals to provide basic knowledge about their infant's health status, progress and treatment, using simplified explanations with minimum medical terminology and basic (Chiejina et al., 2014). There are limitations, however, to the generalizability of the study findings, due to the use of the convenience sampling technique.

Marital status. Marital status is another parent characteristic which affects stress levels among mothers with infants admitted to NICU. In the United States, Copeland and Harbaugh (2005) conducted a survey study to evaluate the differences between 22

single mothers and 52 married mothers, using the PSS: NICU questionnaire. The results indicated a significant difference between the stress levels of married and single mothers. Single mothers have higher stress levels ($p = .005$) than married mothers. That being said, the study did not provide a robust discussion as to why marital status could have an effect on stress. In addition, the small sample size may not be representative of the population, thus limiting generalization of the findings.

Two other studies have demonstrated similar effects of marital status on stress levels. An exploratory study by Copeland and Harbaugh (2005) compared the difference in parental stress between a convenience sample of 22 single and 52 married first-time mothers at 6-8 weeks after birth. The results showed a significant difference between single and married first-time mothers ($t = 2.858$, $p < .005$), demonstrating that single mothers have higher stress levels than married mothers. There are, however, a number of caveats concerning the results. The small sample size and convenience sampling technique limit generalizability of the results, and neither the validity nor reliability of the instrument is addressed by the researchers. Moreover, the study was conducted more than ten years ago, calling into question its relevance in today's health care settings. More recently, another study by Chiejina et al. (2015) evaluated parental stress among 216 parents with hospitalized infants in two NICUs in Nigeria, and found that single mothers experience more stress than married mothers.

Distance to hospital. The distance between residence and the hospital affect parental stress regarding admission of infants to NICU. Mothers who live nearer to the hospital experience lower stress levels compared to mothers who live further from the hospital (Melnik et al., 2004).

History of infertility. Chiejina et al. (2015) found that parents who have a history of infertility experience significantly higher levels of stress ($p < .001$) than parents who have no history of infertility.

Family income. Family income was also reported as a factor that influences parental stress levels among parents with infants admitted to NICU. Alaradi (2014) conducted a cross-sectional exploratory study among a convenience sample of 67 parents to assess the difference in stress levels between parents with different income ranges. The results found a significant difference ($p < .001$) between parents with annual income less than 30,000 USD and parents with annual income more than 30,000 USD. Parents whose annual income is less than 30,000 USD are found to experience higher levels of stress ($M = 10.529$, $SD = 5.245$) than those whose annual income is more than 30,000 USD ($M = 3.797$, $SD = 7.227$) (Alaradi, 2014). It was noted that this study neither addressed inclusion and exclusion criteria, nor stated the sample size. Minimal information was given regarding ethical issues and study limitations. These combined considerations make generalization of the findings difficult.

Aggregating the results of these studies, parental stress from infant hospitalization may attain different levels depending on parent characteristics (Chiejina et al., 2014; Matricardi et al., 2013; Turner et al., 2015). However, we must not neglect the fact that many studies face limitations in generalization of study results due to various reasons, including use of the convenience sampling technique, lack of information on sample selection, or absent inclusion and exclusion criteria.

2.1.3.2 Parental Stress of Infant Hospitalization

Parenting is a period of change and instability. For many individuals, it is also a period of adaptation, movement, and evolution in regard to a new role in life (Flacking et al., 2012; Roy, Schumm, & Britt, 2014). Even when parenting is regarded as a normal

and expected developmental occurrence in life, the quality of the experience depends on the health and medical conditions of the infant; for instance, becoming a parent is a great experience for those with healthy infants, but it may be extremely stressful for those with unhealthy infants (Roy et al., 2014).

Some parents, when talking about early parenting experiences, expressed that bonding between them and their babies was a gradual process, whereas many of them experienced “a rush of love”. Several parents considered the first meeting with their babies to be an amazing emotional experience, describing it as a life-changing point in their lives (Flacking et al, 2012; Stern, 2009; Vazquez & Cong, 2014).

Admission of infants to the Neonatal Intensive Care Unit (NICU) is often a stressful and unexpected experience for parents (Flacking et al., 2012; Stern, 2009). Thus, admission of infants to NICU, whether directly after birth or during the first month of life, has several stressors for parents. First, separation from infants often results in a crisis to parents because parents are not prepared emotionally, psychologically, and sometimes financially for this situation (Stern, 2009). Having an infant admitted to the NICU can lead to feelings of shock, helplessness, and powerlessness in parents.

Furthermore, having an infant admitted to the NICU may impact the parent-infant relationship. When an infant requires NICU admission, the normal parent-infant relational development process is interrupted (Stern, 2009). Many parents face difficulties in handling this stressful situation, so they may encounter further problems in interacting with their infants (Flacking et al., 2012; Stern, 2009).

Parents experience significant levels of stress (Colville & Pierce, 2012; Jee et al., 2012). A recent study conducted by Varghese (2015) on 343 parents with infants admitted to NICU used the PSS: NICU questionnaire to determine parental stress from

admitting their infants to a Level III NICU. They found that parents experience high stress levels, but mothers experience higher stress levels ($M = 3.78$) than fathers ($M = 3.65$). In this study, however, the researcher did not mention if they had obtained Human Ethical Committee approval to collect data from the hospital. The study also failed to mention if the informed consent had been obtained from the parents who participated in the study. Inclusion and exclusion criteria for sample selection were omitted as well.

Additionally, a survey study conducted by Commodari (2010a) among 219 parents of hospitalized infants found that parents experience high stress levels ($M = 103$, $p < .001$) by using the Psychology Stress Measures (PSM) scale. The high stress levels are closely related to the feelings of helplessness as parents could not care for their hospitalized newborns. Results of studies, however, may vary according to the different stress questionnaires selected by the researcher; to wit, the PSM scale was used instead of the PSS: NICU questionnaire employed by most studies. Lack of standardization may lead to different results regarding stress experience among parents whose infants are admitted to NICU. It is clear, regardless, that the hospitalization of an infant in the NICU causes significant parental stress.

2.1.4 Impact of Stress on Parents

Numerous studies report that parents with infants admitted to NICU experience high levels of stress (Alaradi, 2014; Matricardi et al., 2013; Turner, 2015; Varghese, 2015). The long-term exposure to stress may affect parents' health in terms of psychological and psychosocial health (Alaradi, 2014; Colville et al., 2009).

2.1.4.1 Impact of Stress on Psychological Health

Parents with premature infants admitted to the NICU report more psychological distress than parents with full-term infants. The literature review indicates that parents

with hospitalized infants in the NICU are able to outline numerous psychological and emotional difficulties, such as depression, anxiety, sleep disturbance, grief, and isolation (Alaradi, 2014; Busse et al., 2013; Dellenmark-Blom & Wigert, 2014).

An exploratory study conducted by Busse et al. (2013) to assess the relationships between parental stress levels and depression, anxiety, sleep disturbance, and fatigue. This study included 30 parents with hospitalized infants in NICU, who completed the PSS: NICU and PROMIS short-form instruments. Results show that there is a significant correlation between stress and anxiety ($r = .61$; $p < .001$), as well as stress and sleep disturbance ($r = .60$; $p < .001$); a moderate correlation between stress and fatigue ($r = .42$; $p < .001$); and a weak correlation between stress and depression ($r = .36$; $p < .001$). However, there is a limitation in the generalizability of the study due to its small sample size. Moreover, the researcher used a survey design which is not entirely appropriate for the sample size, as the survey design requires a large sample size to generate a better coefficient index. Furthermore, the researcher did not explain the inclusion and exclusion criteria, or how the sample size was determined. Also omitted were discussions of the strengths of the study and its implications for clinical practice.

Another cross-sectional survey undertaken by Kong et al. (2013) with a convenient sample of 600 participants (200 mothers and 400 fathers) discovered that parents with infants in the NICU are liable to suffer from symptoms of depression and anxiety when compared to parents with full-term infants. This study based its data on the Self-Rating Anxiety Scale, Self-Rating Depressive Scale, Social Support Rating Scale and Perceived Stress Scale, to research the preponderance of anxiety and depression in parents of hospitalized infants and to analyse relationships with other

factors such as stress. However, the generalizability of the results is limited due to the use of the convenience sampling technique.

In an extensive random study undertaken in New Zealand by Carter et al. (2007), a sample of 447 parents (205 fathers and 242 mothers) with infants admitted to NICU was compared to a sample of 189 parents (89 fathers and 100 mothers) with full-term infants not requiring admission to the NICU. The study took place over a 12-month period and found that the hospitalization of an infant has a psychological impingement on fathers and mothers. Parents with hospitalized infants demonstrated significantly higher anxiety scores ($p = .01$) and depression scores ($p = .034$) based on the Hospital Anxiety and Depression Rating Scale (HADS) than non-NICU parents. Factoring in the gender of parents, Carter et al. (2007) concluded that stress scores were lower among fathers in both groups. Additionally, Nievar and Luster (2006) suggest that parental psychological distress leads to parental stress, depression, anxiety, and failure to lead a normal home life.

Gönülal et al. (2014) conducted a survey among 73 parents with hospitalized infants in NICU. The researchers used the Edinburgh Postnatal Depression Scale for mothers and the Beck Depression Inventory for fathers, administered in the second and sixth weeks after delivery. They reported that parental stress in NICU contributes to depression. The results show that in the second week post-delivery, maternal depression frequency was as high as 38.3% ($M = 10.97$, $SD = 6.93$); in the sixth week, this percentage decreased to 33.3% ($M = 9.57$, $SD = 5.78$). On the other hand, paternal depression was 11.7% ($M = 7.13$, $SD = 7.35$) in the second week, and 10% ($M = 6.50$, $SD = 5.79$) in the sixth week. The frequency of maternal depression remained stable, but mean maternal depression scores decreased significantly from the second to the sixth week ($p = .023$). Paternal depression scores, however, were similar at both points

in time ($p = .428$). It should be noted that different depression scales were used for fathers and mothers, which may create error or bias in the results. In addition, the researchers used a small sample size, and did not determine sampling technique or sample size. They also provided insufficient information regarding data collection.

Furthermore, a cross-sectional comparative study was carried out by Shelton et al. (2014) to compare depression, sleep, and well-being based on the self-report of stress symptoms in mothers with hospitalized infants in NICU. The study was conducted on a convenient sample of 55 first-time mothers during the second week after admission of their infant to NICU. Results showed that approximately 62% of mothers report high stress levels. Mothers with higher stress levels reported depression and poorer well-being compared to those with lower stress levels. With regard to sleep disturbance, there was no statistically significant effect of stress; all mothers had clinically significant poor sleep. They concluded that mothers with hospitalized infants in NICU suffer from stress, with higher likelihood of depression, poor well-being, and disrupted sleep. However, this study only focused on mothers, and did not describe fathers, who may have different stress-related sleeping patterns due to the different parental roles they assume. The same sample size and convenience sampling technique may limit generalizability.

In addition, Yurdakul et al. (2009) conducted a case control study among two groups. The first is the NICU group of mothers with hospitalized infants in NICU, and the second is a control group of mothers with healthy full-term infants. The purpose of this study was to determine depression and anxiety symptoms, as well as attachment style. The researchers used the Edinburgh Postpartum Depression Scale (EPDS), Adult Attachment Scale (AAS), and State-Trait Anxiety Inventory (STAI) scale. Results showed that depression was significantly higher in the NICU group ($M = 9.6$, $SD = 5.6$)

than in the control group ($M = 4.9$, $SD = 4.9$). Mothers with infants in the NICU also had higher anxiety levels and lower parent-infant attachment, compared to mothers with healthy infants.

2.1.4.2 Impact of Stress on Psychosocial Health

Parental stress is a very important issue. Unaddressed, it may be harmful to the family system by influencing the behaviours and cognitions displayed by parents to their children (Roy et al., 2014). A premature birth with the infant hospitalized in NICU has been associated with psychological problems among parents, the most common of which is stress. High prevalence of stress among parents of premature infants compared with parents with healthy full-term infants may be attributed to interrupted psychological processes during the pregnancy period and delivery, concern for their infant's well-being, and NICU experience (Flacking et al., 2012). Separation from the infant is another factor that increases the risk of parental stress. Early separation between parents and infants, that is, within the first 24 hours after birth, contributes to an increase in parental stress (Flacking et al., 2012).

In addition, prolonged separation between parents and infants causes parental stress, which may result in many psychological problems such as depression, anxiety, and isolation. These mental states, in turn, affect parenting roles and interrupt parent-infant attachment (Flacking et al., 2012). These issues continue beyond the NICU hospitalization period. After discharge from NICU, it was found that parents' elevated stress levels and infants' low responsiveness negatively impact development of a relationship with their premature infants (Korja, 2009).

A few articles studied the relationship between parents after the admission of their infants to NICU (Manning, 2012; Tooten et al, 2013; Musabirema et al., 2015). Manning (2012) conducted a study hypothesizing that the experience of NICU

hospitalization affects the relationship between the parents, and found a positive correlation between admission of an infant to NICU and the incidence of divorce among parents

The quantitative literature review provides some useful evidence about the prevalence of stress and stressors, incidence of stress, and impact of stress on parents, but the existing body of literature fails to describe the magnitude of the issues in depth. Therefore, there is a need to explore pertinent qualitative literature to gain more meaningful insights.

2.2 Literature Review for Qualitative Studies

2.2.1 Searching in Database

The search for qualitative studies was carried out through large databases of scientific and medical research, including ScienceDirect, PubMed, CINAHL EBESCO, SpringerLink, Psychology and Behavioural Sciences Collection, Web of Science, and Google Scholar. Various combinations of keywords were used as search terms, such as parental experience, parental perception, parental stress, stressors in NICU, impact of stress, parents and infants in the NICU, babies in NICU, neonates in NICU, preterm infants in NICU, preterm neonates in NICU, and qualitative studies, accompanied by different punctuation (Appendix C).

Studies that were included in the literature review were qualitative full-text articles published in English, describing parental experience of infant admission to the NICU, parental stress, and factors that increase stress. Excluded studies were those which did not fulfill the inclusion criteria, for instance, if the study was published in any language except English, or if the study described the experience of parents whose babies did not survive after the NICU admission (Table 2.3).

Table 2.3 Inclusion and Exclusion Criteria for Literature Review of Qualitative Studies

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| Articles published in the English language. | Articles published in other languages. |
| Full-text articles. | Abstract only. |
| Articles relating to parental experience or perception on having infants in NICU. | Articles relating to experience of parents who lose their babies after admission to NICU. |
| Parent characteristics. | |
| Infant characteristics. | |
| The impact of stress: physical, psychological, and social problems. | |
| Qualitative design. | Quantitative design or mixed design. |

2.2.2 Screening Process

As part of the screening process, the titles and abstracts of the research studies were read before retrieval of the corresponding full-text papers. Journal articles that met the criteria (Table 2.3) were recorded in the EndNote database X7 for inclusion in the qualitative literature review.

2.2.3 Screening Results

The results of the database searches were: CINAHL EBESCO (24 articles), PubMed (24 articles), ScienceDirect (14 articles), SpringerLink (five articles), Psychology and Behavioural Sciences Collection (five articles), and Web of Science (four articles). Google Scholar was also used to find articles related to the topic of study.

Based on the inclusion criteria for qualitative studies, 76 articles were found through the database search, and four articles were identified through reference lists, forming a total of 80 articles. From these 80 reviewed papers, 61 were removed due to duplicates or similar content; five articles were rejected for irrelevant content (Appendix D and Figure 2.2).

Finally, a total of 14 qualitative research studies related to parental experience of infants admitted to the NICU were included for the literature review (Table 2.4).

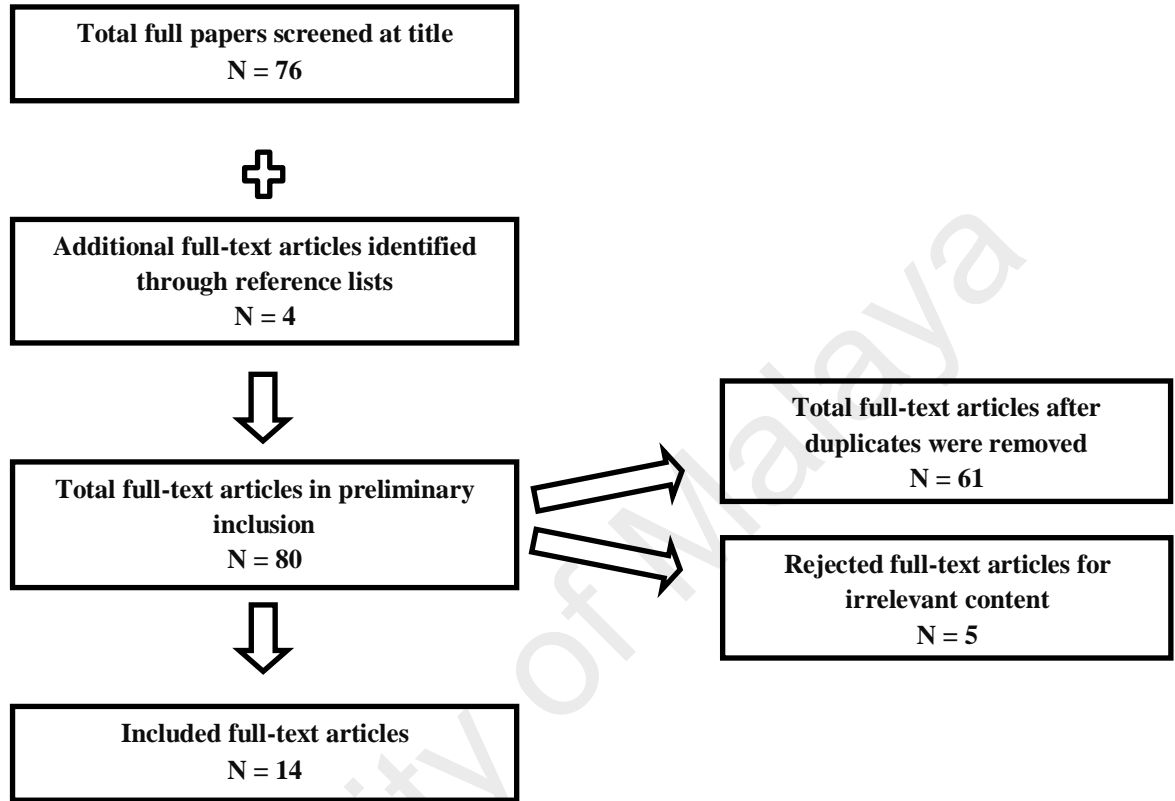


Figure 2.2 Summary of Selection and Exclusion of Qualitative Studies

Table 2.4 Summary of Selected Studies for Literature Review of Qualitative Studies

| No. | Author and Year | Design and Instruments | Sample/Setting | Data Collection | Outcome and Themes | Limitations |
|-----|--|---------------------------------------|-----------------------|-----------------|--|--|
| 1 | Abuidhail, Al-Motlaq, Mrayan, and Salameh (2016) | Qualitative study Phenomenological | 10 parents/ Jordan | Interview | Shock, worry, and anxiety experienced by parents. Influences of NICU admission on experiences of parents and families. Information and assistance required and received from health care professionals. Emotions and satisfaction of parents. | The sample selection procedures and sampling technique were not described. |
| 2 | Russell et al. | Qualitative study | 32 mothers and 7 | Interview | Parental involvement. | The sampling |

Table 2.4, Continue

| | | | | | | |
|---|---|-----------------------------|--|---------------------------|---|---|
| | (2014) | | fathers/ South East England. | | Staff competence and efficiency. Interpersonal relationships with staff. | technique and type of qualitative design were not described. |
| 3 | Whittingham, Boyd, Sanders, and Colditz (2014) | Qualitative study | 18 parents/ Australia | Focus group | Stress, grief, and isolation. Lack of preparation for parenthood, bad parenting habits, and developmental expectations. | Insufficient information about research design, data collection, and data analysis approach. |
| 4 | Aliabadi et al. (2013) | Qualitative study | 20 parents/ Iran | Semi-structured interview | Asking questions, getting help, and learning caring skills. | The sampling technique and type of qualitative design were not described. Researchers did not mention when the data reached saturation. |
| 5 | Arnold et al. (2013) | Qualitative study | 32 mothers and 7 fathers/South East England | Semi-structured interview | Parents' blurred recall of birth, and anticipation towards seeing and touching their babies. First sight and touch of their babies, impressions of NICU, and unique experiences of fathers. | The sampling technique and type of qualitative design were not described. Ethical Committee approval was not obtained. |
| 6 | Heidari, Hasanpour, and Fooladi (2013) | Qualitative inductive study | 6 fathers and 7 mothers , 5 nurses and 3 physicians/Iran | Interview | Definition of stress and parents' reactions to stress. | Insufficient information about data collection procedure, sampling technique, and interpretation of results. |
| 7 | Heinemann, Hellström-Westas, and Hedberg Nyqvist (2013) | Qualitative descriptive | 7 mothers and 6 fathers/ Sweden | Semi-structured interview | Coping with a new and unexpected situation, ways of handling the situation. Emotions and reactions. Experiences and impressions of the environment. Interaction and communication with staff. Becoming a parent, growing into the parental role, and interactions with infants. | Sampling technique was not described. Thematic analysis approach. |
| 8 | Gallegos- | Qualitative study | 20 | Interview | The NICU as a place of | The problem and |

Table 2.4, Continue

| | | | | | | |
|----|--|---|--|---------------------------|--|--|
| | Martínez, Reyes-Hernández, and Scochi (2013) | | parents/México | | suffering and waiting. Dealing with infant hospitalization. Exclusion from childcare. Inadequacies in hospital care of infants. | significance of the study were not clearly identified. Sampling technique was not mentioned. Thematic analysis approach. |
| 9 | Heidari et al. (2012) | Qualitative study (inductive and deductive) | 6 fathers and 7 mothers, 5 nurses and 3 physicians/ Iran | Semi-structured interview | Job and income loss. Shattered confidence in parental role, and challenges to family dynamics. Shame as a social stigma. Loss of control, uncertainties, and stress-induced physical and emotional problems. | Sampling technique was not mentioned. |
| 10 | Watson (2011) | Phenomenological interpretive | 20 parents , 5 senior neonatal nurses and 7 NICU nurses/Scotland | Focus group Interview | Crises and stressful events. Uncertainty, powerlessness, and properties of liminality that frame this complex early parental transition. | Sampling technique and data saturation were not mentioned. Insufficient information about thematic analysis. |
| 11 | Swift and Scholten (2010) | Qualitative phenomenological research | 9 parents/South Australia | Interview | Expected progression and feeding difficulty, feeding interventions, and expression of breast milk. Parental roles and bonding, and parenting interactions. Scheduling difficulties. Positive neonatal unit experience and support. | Sampling technique was not mentioned. Researchers did not mention ethical issues in the study. |
| 12 | Obeidat et al. (2009) | Qualitative systematic review | 14 studies (1998 – 2008) | Thematic analysis | Psychological and social problems experienced by parents. | Inclusion and selection criteria not described. Insufficient information about data analysis and selected common themes. |
| 13 | Mahamood, Reiter, and Mellish (2008) | Qualitative study | 9 parents/United Kingdom | Interview | NICU information and affective factors during NICU care. The baby's physiological circumstances. | Sampling technique and research design not described. Ethical Committee approval was not mentioned. |

Table 2.4, Continue

| | | | | | | |
|----|--------------|---------------------------|-----------------------|---------------------------|--|---|
| | | | | | | Participants did not provide informed consent. |
| 14 | Gavey (2007) | Qualitative retrospective | 20 parents/California | Semi-structured interview | Parental impressions, care delivery, impact on relationships, and parental control issues. | Sampling technique, sample size, inclusion-exclusion criteria and data saturation were not mentioned. Insufficient information about data analysis. |

2.2.3.1 Parental Stress of Infant Hospitalization

There is a general consensus in extant literature that infant hospitalization in the NICU causes extreme and untoward stress to the parents (Heidari et al., 2012; Heinemann et al., 2013; Watson, 2011; Whittingham et al., 2014).

A qualitative study conducted by Heidari et al. (2013) defines stress as a sense of pressure, tension, and nervousness resulting from new or unexpected situations. In this study, data was collected from 21 intentionally-selected participants (7 mothers, 6 fathers, 3 physicians, and 5 nurses) for the purpose of exploring parental stress and parental experience during infant hospitalization. The data was then analyzed using the content analysis method to parse out main themes from parent responses. Findings revealed many intrinsic factors that increase stress levels, including feelings such as shame, guilt, worry, fear, and restlessness. Parents tend to feel like they have lost their baby by admitting it into the NICU. Moreover, they have to deal with extrinsic stressors of social stigma, changes in family dynamics, and alteration of parental roles. Although content analysis was used to determine themes, minimal details were provided to describe how the data was analyzed. Another limitation is the omission of inclusion and

exclusion criteria for participants, thus it is difficult to determine whether the sample fits the purpose of the study.

Whittingham et al. (2014) used a qualitative approach to identify parents' perspectives when they have preterm infants hospitalized in the NICU. Data was collected from a focus group of 18 parents, and analysed using constant comparative analysis to determine main themes within the data. They discovered that parents experience stress due to loss of control or contact with their infants. The same method of analysis was used in a phenomenological study by Watson (2011) to describe the early experience among parents with preterm infants in the NICU. Semi-structured interviews were conducted with 20 parents, and their responses were analyzed to reveal that they experience many challenges and described this period of time as a stressful crisis.

A qualitative descriptive study by Heinemann et al. (2013) describes the parental experience of hospitalizing a premature infant in the NICU. 6 fathers and 7 mothers were included in the data collection process, which used semi-structured interviews. Data was analyzed using the content analysis approach, revealing that parents feel stressed from the abnormality and unreality of the hospitalization, their sense of fear, and their increased pressure and responsibilities. In addition, parents also faced additional stressful situations such as disruption of daily routines, insufficient information about their child's medical condition, hostile NICU environment, and poor communication with health care staff. The most stressful factor for mothers was being unable to breastfeed their babies. A weakness of this study, however, is that the researchers failed to provide satisfactory information about the data collection, sample size saturation, and sampling technique.

In a qualitative study interviewing 20 parents, Gallegos-Martinez et al., (2013) asserted that the physical environment of the NICU serves as a major source of stress for parents. This hospital unit is often inundated with unpleasant procedures and sights, loud sounds, and anxious visitors. Added to the above, parental stress levels increase with lack of knowledge about their baby's health status, recovery progress, or medical intervention and procedures.

Another qualitative study was conducted by Aliabadi et al. (2013) among a purposive sample of 12 parents with premature infants admitted to the NICU. Using semi-structured interviews, the researchers found that parents experience stress from lack of knowledge about their infants. They failed to manage their negative feelings because they felt worried, fearful, and stressed about their child's health. However, this study did not provide sufficient information about how the sample reached saturation and how the data was analyzed. There was no mention of ethical approval from an ethical committee, nor any mention about obtaining informed consent from participants.

2.2.3.2 Alteration of Parenting Roles

An infant hospitalization can cause devastating harm to the family system by altering parenting roles and influencing the behaviours, responsibilities, and attitudes displayed by parents towards their infants. Mothers spend long hours in postnatal recuperation or vigils at the hospital, and fathers are forced to step in to carry out the role of a mother at home (Gavey, 2007; Heidari et al., 2012; Swift & Scholten, 2010; Watson, 2011; Whittingham et al., 2014). At the same time, they are required to maintain the role of breadwinner in the family by going to work every day, bearing the psychological and emotional burdens of knowing that their child lies in the NICU.

A qualitative study was conducted by Gavey (2007) to explore parents' perceptions of infant admission to the NICU through face-to-face interviews with 20

married parents. Results showed that parents' experiences affected their parenting roles and interrupted their daily routines. Heidari et al. (2012) endorsed and supported this finding, stating that parents of hospitalized infants in the NICU experience changes in parenting roles and life routines that could be drastic, potentially involving double duties, loss of jobs, shifting responsibilities and duties, and separation of parents.

A phenomenological study by Swift and Scholten (2010) further reinforced this finding. They explored the experience of married parents with infants in the NICU, and found that these parents experience decreased ability to hold or feed their infants, in addition to altered parenting roles. Watson (2011) considers parents' fear, powerlessness, and overall stress as the factors that render them unable to fulfill their responsibilities towards their infants. Whittingham et al. (2014) also describes parents as developing poor parenting habits, such as becoming excessively obsessed with their baby's development after discharge from the hospital, and frequently looking for symptoms of medical or developmental disorders which may affect child development.

Most of the studies included in this review were implemented among Western populations, which may or may not be reflective of other cultures. There is the possibility that every culture is governed by distinct norms, and people from different cultures may have unique mindsets which would affect the results of self-report questionnaires. Furthermore, selection bias was found in most studies which only included married parents. A survey of single and married parents would most likely yield different results, as single parents have different support systems, and might be affected by infant hospitalization to a greater extent.

2.2.3.3 Impact of Infant Hospitalization on Psychological, Physical and Social Health

The literature review unequivocally reveals that parents with hospitalized infants complain of many psychological and emotional problems, such as depression, anxiety, and sleep disturbance (Gavey, 2007; Heidari et al., 2012, 2013; Heinemann et al., 2013; Watson, 2011; Whittingham et al., 2014). These are struggles unknown to parents with full-term, healthy infants.

Heidari et al. (2012) reports that parents of hospitalized premature infants in the NICU experience many psychological and emotional issues. The list includes constant crying, stress, guilt, fear, shame, anxiety, depression, restlessness, tension, and inability to care for their infants. Whittingham et al. (2014) echoes the findings of Heidari et al. (2012) and adds grief, isolation, and distress to the list of psychological problems associated with parents' responses to NICU hospitalization. This study clearly explains how the infant admission to the NICU results in physical symptoms such as postpartum hemorrhage and breast milk reduction in mothers. In a similar vein, Gavey (2007) found that parents with infants admitted to the NICU felt stressed, anxious, and depressed, to the point that they suffered from insufficient sleep due to the separation from their infants. Another study, conducted by Heinemann et al. (2013), affirmed that parents with hospitalized infants in the NICU frequently feel shocked, sad, and disillusioned. They are stunned by the unreality of the situation, and feel inept to deal with it in a constructive way. Parents also experience fragmentation of their relationships resulting from feelings of powerlessness, loss of control, and fear (Watson, 2011).

A recent phenomenological study was conducted by Abuidhail et al. (2016) to describe the lived experiences, needs, and support systems of Jordanian parents with hospitalized infants in NICU. The researchers interviewed 8 mothers and 2 fathers

whose premature infants were admitted to NICUs in government, private, and teaching hospitals in Jordan. Results showed that they experience shock, surprise, anxiety, worry, sleep disturbance, and emotional problems. However, this study did not describe the sample selection procedure or the sampling strategy. There was also lack of information on how the sample size reached saturation, or how the research design was chosen. In addition, the study did not report enough information about data analysis.

A qualitative study undertaken by Heidari et al. (2012) explored the experience of Iranian parents with premature infants in NICU. Purposive sampling was used to recruit and interview 7 mothers, 6 fathers, 5 nurses, and 3 physicians. Results showed that parents experience high levels of stress, which in turn induced physical problems. Mothers experienced stress from postpartum hemorrhage and poor lactation, whereas both parents suffered from fatigue and malnutrition. They reported in their study that many social problems, including changes to family dynamics and routine lifestyles, result from parental stress from having an infant hospitalized in the NICU. In addition, there are often changes in parenting responsibilities as fathers perform the mothers' role of caring for other children at home, and mothers spend long hours in the NICU. The admission of an infant to the NICU disrupts the family process as it separates family members and impairs the family system.

Finally, a qualitative systematic review study exploring parental experiences found parents complaining about many psychological and social problems after admitting their infants to the NICU. Psychological symptoms include stress, fatigue, irritability, anxiety, sadness, loss of appetite, suicidal thoughts, harmful thoughts towards the baby, and depression, and social issues include lack of time, lack of support, family conflicts, changes to routines, stigma and shame, and parent-infant separation (Obeidat et al., 2009). This study, however, did not use tools to evaluate the

qualitative studies included in the review. It also failed to provide enough information regarding the analysis of results.

2.3 Literature Review for Mixed Methods Design Studies

In this review, a couple of mixed methods design studies explain parental experiences of infant hospitalization in the NICU (Ahn and Kim , 2007; Sweet and Mannix, 2012).A mixed quantitative study was conducted by Ahn and Kim (2007) to examine parental perception of neonates, using the Neonatal Perception Index (NPI) to compare between parents of 26 full-term infants and parents of 22 premature infants in the NICU. This study also sought to evaluate the effect of NICU educational support on NPI and parental stress using the Parental Stress Scale (PSS) for the NICU group. Results showed that NICU mothers attained the lowest NPI scores, but no difference in direction of NPI scores was observed between parents in either the full-term or NICU group. For the NICU group, NICU education improved NPI and decreased PSS in fathers, but not in mothers. Researchers concluded that modifications to the nursery environment could improve mothers' perception of neonates, particularly targeting the distance between the nursery and the NICU. As principal caregivers, NICU mothers may suffer from culturally-grounded psycho-emotional disturbances after giving birth to a sick infant, which may not be applicable to NICU fathers. Nevertheless, fathers play significant roles in caring for mothers and infants during the hospitalization period and the subsequent transition to parenthood. Thus, educational programs should target both mothers and fathers in the acute postpartum period. On the whole, the quality of family-centered care in the NICU environment, parental role alteration, and the condition of infants need to be improved to decrease parental stress in the NICU.

Another mixed methods study was conducted by Sweet and Mannix (2012) to explore the types and levels of stress in parents with infants in a South Australian

NICU, and to identify the psychometric properties of the PSS: NICU in an Australian setting. To assess the target variables, this mixed methods study was run among 40 parents, and used a parental stress assessment tool, a maternal needs inventory, and a measure of the degree of required therapeutic interventions for the infant. Quantitative and qualitative data were collected and analyzed using descriptive statistics and thematic analysis respectively. The results demonstrated moderate stress levels in parents, predominantly related to altered parental roles, and the infant appearance and behaviour. These findings were further supported by a qualitative analysis and maternal needs inventory assessment, ultimately suggesting the need for frequent and positive communication, information sharing, and empathetic staff practices.

2.4 Conceptual Model

The design of this study is a mixed quantitative and qualitative study design. The conceptual framework of this study is based on the parental NICU stress model and the transactional model of coping.

2.4.1 Model of Stress

The parental NICU stress model was adapted from the Parental Intensive Care Unit Stress model (Miles & Carter, 1983), which was developed from theories of stress and other pertinent research. The parental NICU stress model is the only existing model designed to study parents of hospitalized infants in the NICU, and this model considers infants with different medical diagnoses. Moreover, it is a comprehensive, easily-understood, and appropriate model for the purposes of the present study.

Factors in this model thought to affect parental stress are: (1) personal characteristics of the parent, such as past experiences and concurrent life events; (2) situational factors, such as the severity of the infant's illness and uncertainty about the illness; (3) personal resources of the parent, such as family support, cognitive resources,

and financial resources; (4) environmental support, such as support from health care professionals or other parents in the NICU; and (5) environment stressors.

In the parental NICU stress model (Wereszczak, Miles, & Holditch-Davis, 1997), the NICU environment stressors directly influence the parental stress response. Four major NICU environment stressors were identified and described in detail by Miles et al. (1993). First, the factor of “sights and sounds” is specified as the physical environment in the hospital unit, including the lights, noises, infants, equipment, and staff. Second, the factor of “infant appearance and behaviour ” is described as how the infants in NICU look and behave, which is usually quite different to healthy newborn infants, due to illness and medical treatments. Third, the factor of “parent-infant relationship” is explained as alterations to normal parental roles and parent-infant relationships, due to nurses being the primary caregivers in the NICU.

2.4.2 Model of Coping

The transactional model of coping was proposed by Lazarus and Folkman (1984) and used as a basis for the present study. This model outlines key factors that mediate between a stressor and the outcomes for individuals, and has been widely used in the context of stress and coping of parents of premature infants (Lau & Morse, 2001).

According to Lazarus and Folkman (1984, p.10), psychological stress is “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being”. The relationship involves connections between cognitive appraisal and coping strategies, as well as the moderating effect of social support. Although appraisal is commonly seen to precede coping strategies, these factors regularly overlap in a continuous feedback loop, and are thus often indistinguishable from one another (Lazanis, 1999).

2.4.3 Conceptual Model of the Study

The conceptual framework of this study is a mixed quantitative and qualitative design. The first part of the model is the quantitative framework, which addresses parental stress and the impact of stress. The second part of the model is the qualitative framework, which describes the parental experience from admission of infants to NICU.

This conceptual framework presents the external variables that affect stress levels among parents. Variables may be related to parent characteristics (e.g. gender, education level, financial status, medical history, and type of delivery) or infant characteristics (e.g. gender, gestational age, birth weight, and medical condition).

Parent and infant characteristics affect parental stress to varying degrees. For instance, parents with a history of infertility experience more stress than parents without a history of infertility. Mothers experience higher stress compared to fathers, as mothers are often more emotionally invested in their child's well-being. Similarly, parents of female infants may experience more stress than those of male infants, and parents of babies with mild medical conditions would predictably experience lower stress levels than those of babies with moderate or severe medical conditions.

The framework also encompasses the three factors related to the NICU environment, such as "sights and sounds", which describes the physical environment (e.g. medical equipment, alarms, noise, lights); "infant appearance and behaviour", which describes how the baby looks and behaves, as well as how parents perceive their babies in the NICU (e.g. small baby size, wrinkled skin, restlessness, lines connected with baby's body); and "altered parental role and relationship", which describes changes in parental roles regarding their infant's needs (e.g. delayed parent-infant relationship, care giving behaviours of feeding, bathing, changing diapers, kissing, and holding). Each of these stressors influences parental stress and responses in different ways. For

example, one parent may experience high stress levels due to the infant's small physical size, but other parents may not experience the same level of distress.

The conceptual framework also describes the impact of parental stress. Stressed parents may experience many psychological problems, such as depression, anxiety, and sleep disturbance, throughout the hospitalization period. These symptoms are the most common psychological problems presented by parents with infants admitted to NICU, but they are by no means the only symptoms of stress.

In the qualitative part of the study, parents express and describe their experiences and feelings regarding the admission of their infants to the NICU, as well as the factors that increase stress levels and the coping strategies they utilize (Figure 2.3) According to the transactional model of coping, the birth of a premature infant is a stressful event that prompts parents to make a cognitive appraisal. Cognitive appraisal is “an evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful” (Lazarus & Folkman, 1984, p.19). Following the appraisal of a situation as stressful, the individual then begins to implement various ways to cope with the event (Lazarus & Folkman, 1984).

There have been conflicting findings about the relationship between coping strategies and outcomes for parents of premature infants, partly due to the different ways in which coping has been operationalized. Parents experience many emotional problems from the admission of their infants to NICU, such as feelings of stress, anxiety, fear, guilt, and hopelessness. In addition, many factors increase stress, such as NICU physical environment, infant appearance and behaviour, altered parental roles, and delayed parent-infant relationship. Coping strategies in the form of spiritual,

emotional, and social support help parents cope with infant hospitalization in positive ways.

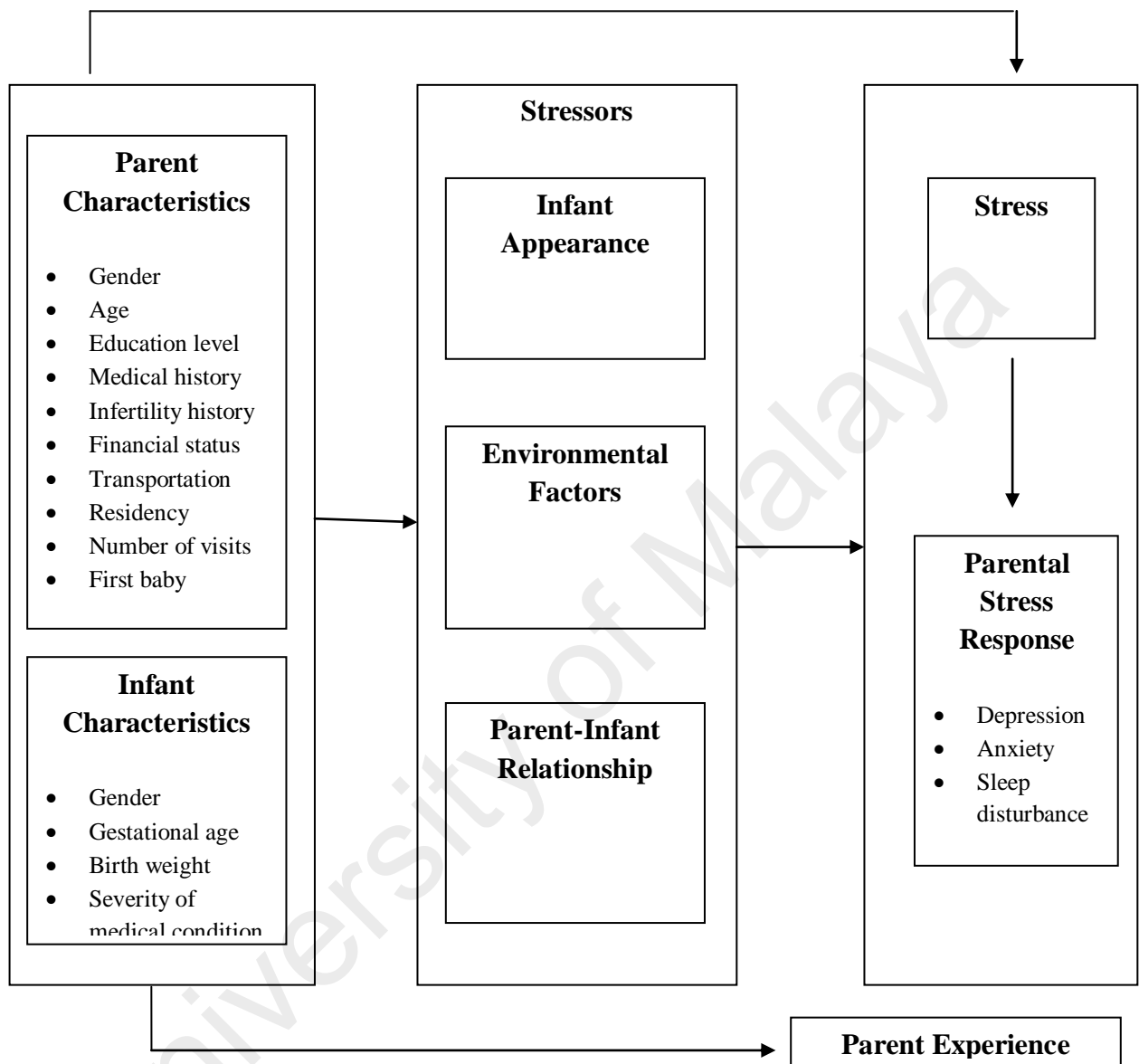


Figure 2.3 The Conceptual Framework of Quantitative and Qualitative Design Based on the Parental NICU Stress Model by Wereszczak, Miles, and Holditch-Davis (1997)

2.5 Summary

In summary, this chapter has discussed relevant quantitative, qualitative, and mixed design literature regarding infant hospitalization in the NICU and its effects on parental stress. Quantitative studies report that the hospitalization of infants in the NICU is an unexpected and stressful event for parents, resulting in prolonged exposure to multiple stressors within the NICU environment, as well as catastrophic stressors related to infant appearance and behaviour, and altered parental roles. Furthermore, parents suffer from negative psychological problems and interrupted development of healthy parent-infant relationship or attachment. Qualitative studies extend our knowledge by revealing that parents experience a range of negative feelings post-NICU admission. Collectively, existing literature shows that parents have to endure immeasurable physical, psychological, and social problems.

CHAPTER 3: METHODOLOGY

3.0 Introduction

This chapter presents the research methodology used to address the research questions of the present study. The study design, setting, data collection, and planned data analysis methods are explained. A section is allocated to describe the sample size and sampling approach used in this study. Ethical concerns are explored, and the use of a pilot study to ensure reliability and validity of the research instrument is discussed.

3.1 Study Design

3.1.1 Mixed Methods Research Design

3.1.1.1 Definition and Purpose of the Mixed Methods Research Design

A mixed methods design was used to conduct the present study. The mixed methods research design is a method for conducting research, which involves collecting, analyzing, and integrating both quantitative and qualitative data in a single study or in a longitudinal program of inquiry. The purpose of this form of research is to combine quantitative and qualitative research that provide a better understanding of a research problem or issue than either research approach alone could (Creswell, 2013; Munhall, 2012; Tashakkori & Teddlie, 2010).

3.1.1.2 Types of Mixed Methods Research Design

There are four types of mixed methods research designs: the triangulation design, the embedded design, the explanatory design, and the exploratory design. These are explained below, with considerations of the advantages and limitations of each design.

Triangulation design is the most common approach in mixed methods research. The goal of this design is " to obtain different but complementary data on the same topic to best understand the research problem " (Morse, 1991, p. 122) . Researchers use

triangulation design when they want to compare between quantitative and qualitative findings, or to expand or validate quantitative findings with qualitative findings. Triangulation design has an advantage in that it makes intuitive sense. In addition, the design effect and each data type may be controlled separately and independently, using techniques traditionally associated with each data type. On the other hand, there are some limitations facing researchers who utilize this type of mixed design, as it requires more expertise and effort (Creswell, 2013; Munhall, 2012; Tashakkori & Teddlie, 2010; Teddlie & Tashakkori, 2009).

Embedded design is a mixed approach design in which one data set serves a supportive, secondary role in a study based primarily on the other data type. Researchers use this design when they need to include quantitative or qualitative data to answer a research question within a largely quantitative or qualitative data. This design is particularly useful when a researcher needs to embed a qualitative component within a quantitative design, as in cases of experimental or correlation design. The advantages of this design are time-related: it is appropriate in a study which has insufficient resources or time, and it requires less data because only one method is required. On the other hand, the design is limited because of the difficulty in integrating quantitative and qualitative results; the researcher must justify the purpose of collecting qualitative (or quantitative) data as part of a larger quantitative (or qualitative) study (Creswell, 2013; Munhall, 2012; Teddlie & Tashakkori, 2009).

Explanatory design is a design consisting of two phases – quantitative collection and analysis, followed by qualitative data collection and analysis. The aim of this design type is to explain the initial quantitative findings (Creswell, 2013). The main advantage of this design is that it is simple to implement, as the researcher conducts two designs in separate phases and at different times, consequently making it the process of

reporting results more straightforward. This design is strongly quantitative-oriented, and allows the researcher to provide a clear delineation between the quantitative and qualitative phases. On the other hand, this design requires a long time for data collection. It is also often difficult to secure internal board approval for this design because the researcher cannot specify how participants will be selected for the second phase, at least until preliminary findings from the first phase are obtained (Creswell, 2013; Munhall, 2012; Tashakkori & Teddlie, 2010; Teddlie & Tashakkori, 2009).

Exploratory design, finally, is a design consisting of two phases – qualitative collection and analysis, followed by quantitative collection and analysis. This design is based on the premise that an exploration is needed for one of several reasons: unavailable measures or instruments, unknown variables, or lack of a guiding framework or theory. As this design is qualitative, it is best suited for exploring a phenomenon. The advantage of this design is that the separate phases make it simple to describe, implement, and report. Although this design typically emphasizes the qualitative aspect, the inclusion of a quantitative component can promote its acceptance among biased audiences. On the flipside, the implementation of this design demands a lengthy period of time; it is difficult to specify the procedures of the quantitative phase when applying for initial internal review board approval; and procedures are needed to ensure validity and reliability of scores developed on the instrument (Creswell, 2013; Munhall, 2012; Tashakkori & Teddlie, 2010; Teddlie & Tashakkori, 2009).

3.1.1.3 Mixed Methods Research Design in the Present Study

The explanatory sequential mixed methods design was used for this study. This explanatory study consisted of two phases: quantitative design, followed by qualitative design. The quantitative research design used is a descriptive, cross-sectional survey design. A quantitative approach was chosen because it allows the researcher to describe

and examine the relationship among the variables (Creswell, 2013; Munhall, 2012; Tashakkori & Teddlie, 2010; Teddlie & Tashakkori, 2009). A cross-sectional survey was selected, as self-reported data facilitates collection at one point in time. Parents who participated in the survey and experienced high stress levels were invited to attend a face-to-face interview to explore their experience, in particular their stressors and coping strategies. The qualitative design is a systematic subjective approach used to describe life experiences and give them meaning (Creswell, 2013; Tashakkori & Teddlie, 2010; Teddlie & Tashakkori, 2009). This study chose to include the qualitative design component because of its inherent goals, which are to gain insight; to explore depth, richness, and complexity of a phenomenon; and to examine the uniqueness of an individual's reality (Figure 3.1) (Creswell, 2013; Munhall, 2012; Tashakkori & Teddlie, 2010; Teddlie & Tashakkori, 2009).

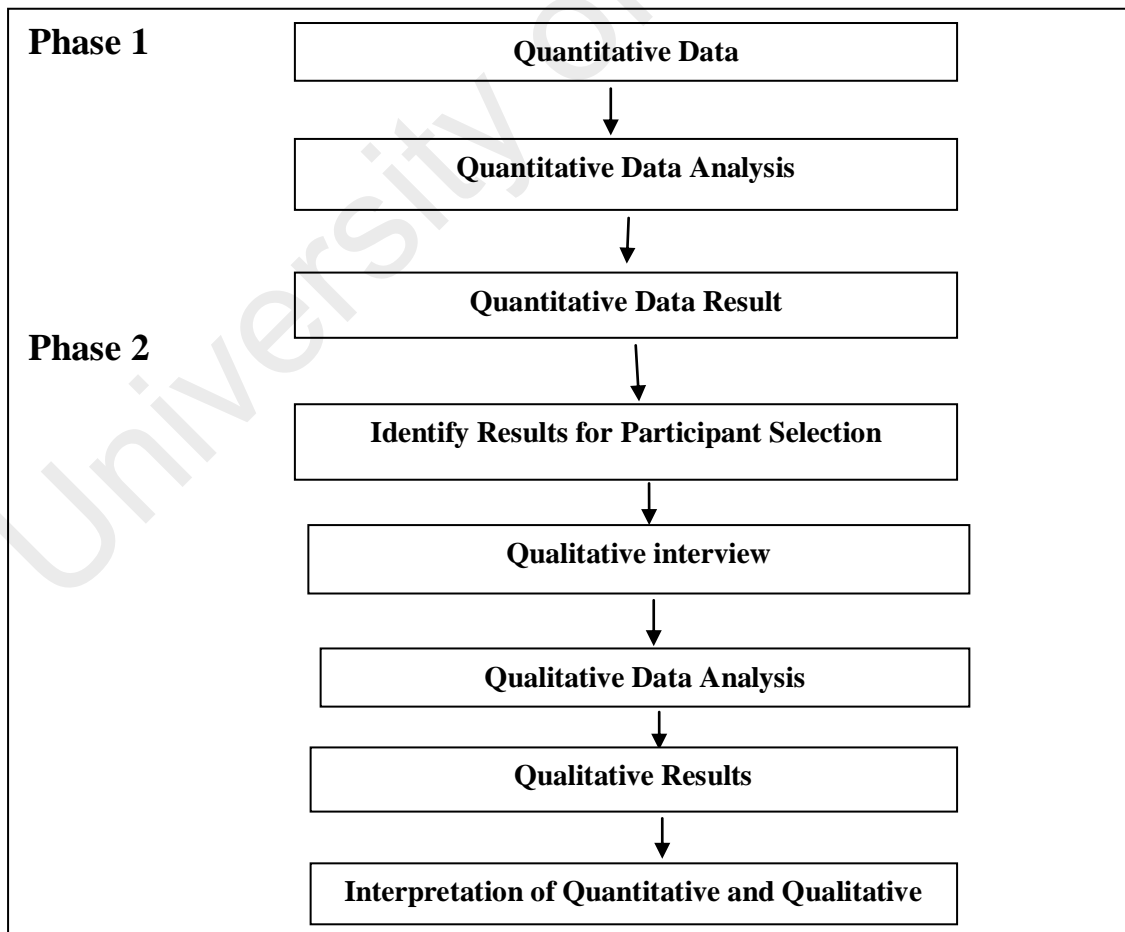


Figure 3.1 Explanatory Sequential Mixed methods Design in This Study

3.1.1.4 Steps of Study Design

The study was divided into two phases (Figure 3.2), as follows:

Step one: Instrument validation was undertaken to ensure the reliability and validity of the short-form of PROMIS scales (depression, anxiety, and sleep disturbance), as well as to assess the clarity and comprehensibility of the questionnaire. The pilot study also helps to identify potential problems that may arise during the data collection phase.

Step two: The quantitative design used a survey to identify stress levels, stressors, and the impact of parental stress on depression, anxiety, and sleep disturbance.

Step three: The qualitative design used a face-to-face in-depth interview to explore parental experience with admission of their infants to the NICU, to identify the source of parental stress, and to explore the coping strategies used by parents.

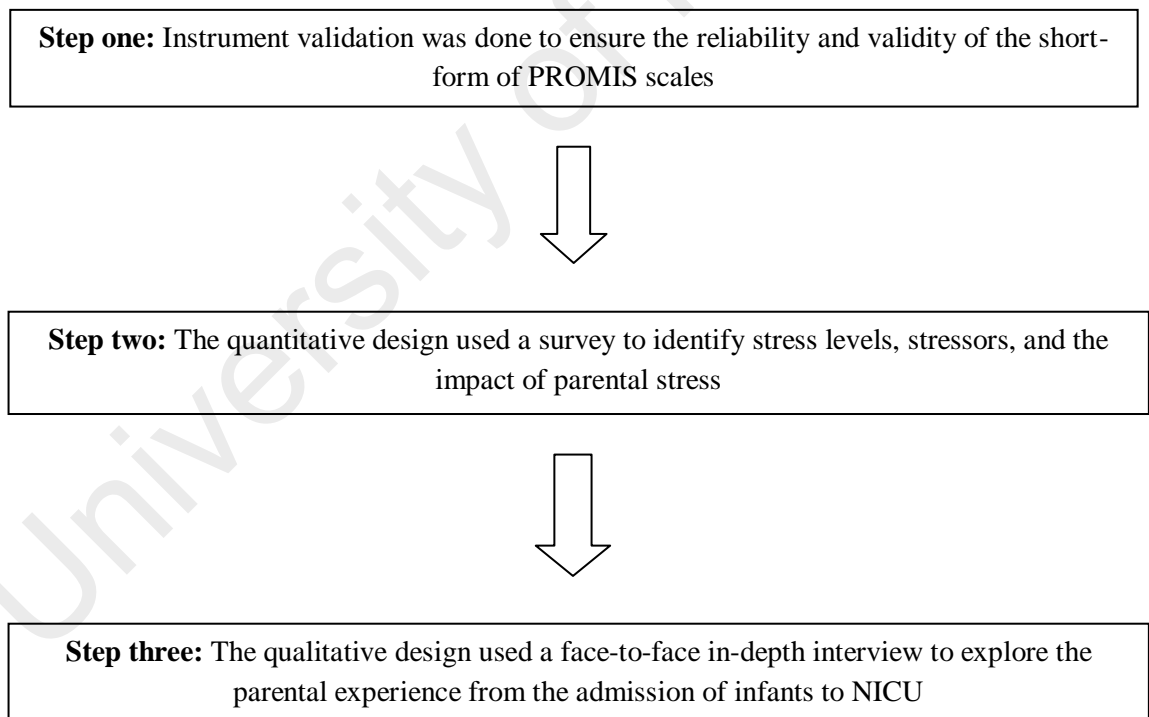


Figure 3.2 Flowchart of Steps of Study Design

3.2 Study Setting

This study was conducted in three government teaching hospitals in Jordan, selected because they are the biggest teaching hospitals in Jordan. Hospital A is located in Amman, with a capacity of 1,100 beds and NICU capacity of 65 beds. Hospital B is located in Al Mafraq, with a capacity of 120 beds and NICU capacity of 24 beds. Hospital C is located in Irbid, with a capacity of 140 beds and NICU capacity of 30 beds.

All NICUs are Level III NICUs, all provide similar medical services: advanced respiratory support and mechanical ventilator support. Table 3.1 presents the differences between the three levels of NICU (Barfield et al., 2012). The nurse-patient ratio is 1:3 to 1:5 during the day shift and 1:5 to 1:7 during the night shift, depending on the number of cases and the number of nurses on duty for each shift.

Table 3.1 Levels of neonatal care (Barfield et al., 2012)

| NICU Level | Description | Roles |
|-------------------|---|---|
| Level I | Basic Newborn Care / Special Care Baby Unit | Provide care for healthy full-term infants who need continuous monitoring and phototherapy. |
| Level II | Advanced Newborn Care / Local Neonatal Unit (LNU) | Provide basic level of care for infants requiring short-term intensive care, tube feeding, and continuous positive airway pressure (CPAP). |
| Level III | Subspecialty Newborn Care / Neonatal Intensive Care Unit (NICU) | Provide care for infants with less than 32 gestational weeks, infants born with critical conditions at all gestational ages, and infants who need to gain weight. This unit consists of advanced respiratory technology support, and includes care provided in levels I and II. |

3.3 Population and Sampling

3.3.1 Population for Quantitative Design

Population refers to all the people who could possibly be in the study; it is also a complete set of elements – person or objects – that possess some common characteristic defined by the sampling criteria established by the researcher (Yacoub, Alkharabsheh, Zaitoun, & Al-Atiat, 2013). The **target population** comprises the entire group of people or objects to which the researcher wishes to generalize the study findings (Yacoub et al., 2013).

In this study, the target population is all infants admitted to NICU in Jordan. The population for the three hospitals in Jordan is presented in Table 3.2.

Table 3.2 The Number of Infant Admissions in NICU in 2014

| Hospital / Number of beds | Male | Female | Total Admissions |
|----------------------------------|-------------|---------------|-------------------------|
| Hospital A / 65 | 2427 | 1918 | 4345 |
| Hospital B / 24 | 404 | 333 | 737 |
| Hospital C / 30 | 695 | 565 | 1260 |
| Total | 3526 | 2816 | 6342 |

3.3.2 Quantitative Study Sampling Technique

Sampling is the process involving selection of a portion of the population to represent the total population. The sampling technique selected in this study is a non-probabilistic convenience sampling technique (Parahoo, 2014).

Convenience sampling is a type of sampling where the first available primary data source is used for research, without additional requirements (Daniel, 2011; Parahoo, 2014). In other words, this sampling method involves getting participants wherever it is convenient to do so. The advantages of this technique are its simplicity of sampling and ease of research, helpfulness for pilot studies and hypothesis generation,

short duration of data collection time, and cost effectiveness (Daniel, 2011; Parahoo, 2014). On the other hand, this technique increases sampling bias, difficulty for generalizability, and sampling error (Daniel, 2011; Parahoo, 2014). For the purposes of the present study, the convenience sampling method was selected due to time constraints and limited cases.

3.3.3 Calculating Sampling Size

Sample size is calculated based on the estimation population proportion formula (Scheaffer, Mendenhall III, Ott, & Gerow, 2011). The purpose of drawing a sample is to make inferences about the population from the information collected about the sample. Scheaffer et al. (2011) clarified that the sample size of a survey is usually determined by estimating the proportion of the population.

In this study, the population is 6350 infants admitted to NICU per year. This is considered a large population; therefore the formula below, with reference to Scheaffer et al. (2011), was used to calculate the sample size. The parameters used are as follows:

- Population size (**N**) is the total number of people that a researcher could send the survey to. This is the total number of people to which the results will be generalized.
- Proportion of response distribution (**p**) is set based on findings from previous studies, where the highest value of proportion is set at 50% (.5) to obtain the highest sample size. For this study, the value for proportion was set at 50% to ensure a representative sample size, in light of wide variation of proportions from previous studies.
- Proportion of sample elements (**q**) that do not have a particular attribute, so $q = 1 - p$.
- Precision of the estimate (**D**) could either be the relative precision, or the absolute precision. Based on this formula, $D = B^2 / 4$.
- **B** units should be analogous to determining a sample size for estimating μ with a bound on the error of estimation, $B = 0.05$.

Sample size required to estimate p with a bound on the error of estimation, B :

$$n = \frac{Npq}{(N-1)D + pq}$$

$$q = 1 - p \quad \text{and} \quad D = \frac{B^2}{4}$$

Calculating sample size:

$$D = \frac{B^2}{4} = \frac{(0.05)^2}{4} = 0.625 \times 10^{-3}$$

$$n = \frac{Npq}{(N-1)D + pq} = \frac{6342 \times 0.5 \times 0.5}{6341 \times (0.625 \times 10^{-3}) + 0.5 \times 0.5} = 376.3239875$$

The sample size required to determine the correlation between stress and the impact of stressors was calculated based on single sample correlation using Arun Varman Software (Arun Varman, 2008), Table 3.3 shows that the recommended sample size for each outcome that correlate with stress, the highest samples size (376) among all outcomes was decide as sample size for this study.

Table 3.3 Sample Size Calculation for correlation ^a

| Variable | Alpha | power | Correlation coefficient (r) | N |
|------------------------------|-------|-------|-----------------------------|------------|
| Stress -depression | 0.05 | 0.8 | 0.31 ^a | 68 |
| Stress -Anxiety | 0.05 | 0.8 | 0.33 ^a | 257 |
| Stress -sleep disturbance | 0.05 | 0.8 | 0.24 ^a | 376 |
| Stress – stressors | 0.05 | 0.8 | 0.28 ^a | 343 |

^a: Rochette A. (2006)

3.3.4 Inclusion Criteria and Exclusion Criteria for Quantitative Sampling

The inclusion and exclusion criteria for the sample were based on previous studies which examined the impact of stress on parents with infants admitted to NICU

(Busse et al., 2013; Shelton et al., 2014; Yacoub et al., 2013). These criteria are summarized and listed in Table 3.4.

The inclusion criteria includes: parents who are Jordanian, consent to participate in the study, understand the Arabic language, have an infant hospitalized in the NICU for at least seven days, have an infant who is the product of a singleton pregnancy, and who visited their infant at least once throughout the hospitalization period. The exclusion criteria are non-Jordanian parents, parents with critically-ill infants in the NICU, parents with infants hospitalized in the NICU for less than seven days, parents who have never visited their infant, parents whose hospitalized infant is the product of a twin pregnancy , transfer cases from other hospitals and surgical cases.

Table 3.4 Inclusion Criteria for Quantitative Data

| Inclusion Criteria |
|--|
| Jordanian nationality only. |
| Agree to participate in the study. |
| Speaks and understand the Arabic language. |
| Infant hospitalized in the NICU for at least seven days. |
| Infant is a product of a singleton pregnancy. |
| Visited infant at least once. |
| Medical cases. |
| Parents with no previous experience in NICU. |

3.3.5 Qualitative Sampling Technique

A non-probabilistic, purposive sampling method was used to recruit participants who met the qualitative sampling criteria. Parents who were having their first experience with NICU admission and identified as having high level of stress from the survey, whereas it excluded parents who had lost their babies after NICU admission , parent with low level of stress, parents with previous experiences of NICU admission.

The aim of the qualitative study was not to obtain a statistically representative sample size for generalizability of the findings (Myles, 2015). However, it was emphasized by Baker and Edwards (2012) and Guest, Bunce, and Johnson (2006) that sample size should be adequate to allow in-depth analysis and provide deeper understanding of the topic.

The qualitative sample size is determined until the data reached a saturation point (Baker & Edwards, 2012; Guest et al., 2006). Thus, no sample size calculation is performed. For this study, having considered the depth and richness of the data obtained, a decision was made to recruit a total of 15 parents for interviews. Previous qualitative studies which have explored similar parental experiences reported a smaller sample size, usually between six and twelve participants (Fishing, Broeder, & Donze, 2016; Gale, Franck, Kools, & Lynch, 2004; Granrud, Ludvigsen, & Andershed, 2014; Hutchinson, Spillet, & Cronin, 2012; Pepper, Rempel, Austin, Ceci, & Hendson, 2012; Susan Penjvini, Hejrani, & Mansouri, 2015). In the end, the data reached saturation point after 13 interviews with married couples (13 mothers and 13 fathers) who were undergoing their first experience with admission of an infant to the NICU. Saturation was deemed achieved when the data of participants' were reviewed, scrutinize and verified by the researcher and the supervisors.

3.4 Instruments

Self-administered questionnaires were used to collect the quantitative data, including the Parent Demographic Data Questionnaire, Infant Demographic Data Questionnaire, Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU), and Patient-Reported Outcomes Measurement Information System (PROMIS).

3.4.1 Infant Demographic Data Questionnaire

Demographic data about infants were collected from medical files and the electronic medical system. Information obtained includes infants' name, gender, birth weight, gestational age, and medical diagnosis (Appendix E).

Information on infant characteristics was sorted into three classes according to the severity of the infants' medical conditions because all hospitals in Jordan follow this classification (Kliegman, Stanton, Geme, Schor, and Behrman, 2015). The "severe" class consists of infants who are fasting, depending on total parental nutrition (TPN) and intravenous fluid, or depending completely on mechanical ventilators; the "moderate" class consists of infants who need oxygen supplements by incubator or nasal cannula, phototherapy, nasogastric tube feeding, or blood transfusion; and the "mild" class consists of infants who are admitted to the NICU for feeding and weight gain (Kliegman et al., 2015) (Table 3.5) (Appendix E).

Table 3.5 Classification of Medical Conditions in NICU (Kliegman et al., 2015)

| Medical Condition in NICU | Classification |
|---|----------------|
| Infants who are admitted to NICU for feeding and weight gain | Mild |
| Infants who need oxygen supplements by incubator or nasal cannula, phototherapy, nasogastric tube feeding, or blood transfusion | Moderate |
| Infants who are fasting, depending on total parental nutrition (TPN) and intravenous fluid, or depending completely on mechanical ventilators | Severe |

3.4.2 Parent Demographic Data Questionnaire

The parent demographic data questionnaire was developed to collect information about gender, age, education level, financial status, history of infertility, history of medical disorder, distance between home and hospital, transportation, number of visits, type of delivery, number of children and number of wives (Appendix F).

3.4.3 Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU)

The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) was developed by Margaret S. Miles and her colleagues to assess stress experience by parents whose infants require admission to NICU and to measure parental experience of stressors arising from NICU hospitalization (Miles et al., 1993).

The updated instrument includes 26 items divided into three dimensions: sights and sounds of the environment (5 items), infant appearance and behaviour (14 items), and altered parental roles (7 items). These were rated on a 5-point Likert-type scale, ranging from 1 (not at all stressful) to 5 (extremely stressful). A rating of 1 means that the experience did not cause the parent to feel stressed, upset, tense, or anxious, whereas a rating of 5 means that the experience upset the parent and caused a great deal of stress or tension. Additionally, an NA (not applicable) option was offered for items not experienced by the parents (Appendix G).

This instrument was scored for Stress Occurrence Level – the level of stress produced when a situation occurs. In this case, only those who report having the experience receive a score on the item, whereas those who report that they did not experience the item had the score coded as “missing”. Scale scores were then calculated by averaging stress responses for the items on each scale and for the total scale. Using this metric provides a better understanding of the amount of stress each aspect of the environment engenders.

The PSS: NICU scale was adopted by Yacoub, Alkharabsheh, Zaitoun, & Al-Atiat (2013). The coefficients alpha for all the APSS: PICU subscales ranged from .71 to .94, which means that they share a great deal of their variance in common. The internal consistency for the entire scale (.72) was acceptable. To examine the equivalency reliability of the scale, two different forms of an instrument were

completed by the 37 bilingual parents. Pearson correlation coefficients were computed between the two versions completed by the bilingual parents. The APSS: PICU was found to be correlated significantly in each of the subscales ($r = .81$ to $.96$, $p < .001$) and total score ($r = .79$, $p < .001$) with the original PSS: PICU. Yacoub and colleagues conducted this validation APSS: PICU in Jordan. Translation of English version of PSS:PICU done by three translators who are proficient and fluent in English and Arabic languages. In addition, paired t-tests were also computed between the APSS: PICU and the original English version completed by the bilingual parents. No statistically significant differences were found among subscales in both versions.

3.4.4 Patient-Reported Outcomes Measurement Information System (PROMIS)

The Patient-Reported Outcomes Measurement Information System (PROMIS) was the second instrument used in this study. It was developed by a conglomerate of researchers who employed the instrument at 12 primary research sites across the nation to give an efficient, reliable, and valid measure of self-reported health for utilization by researchers in clinical areas. Instruments utilized by PROMIS are available online or printed as a hard copy, including short-form or computerized adaptive tests. Ranging from 4 to 10 items, the PROMIS short-form instruments cover a wide spectrum of outcomes such as emotional distress, physical function, social function, and cognition (PROMIS, 2009).

In this study, the following PROMIS short-form scales were used to quantify health outcomes: depression (8 items), anxiety (8 items), and sleep disturbance (8 items). The scales were rated on a 5-point Likert-type scale ranging from 1 (never) to 5 (always). A rating of 1 means that the experience never caused the parent to feel depression, anxiety, or sleep disturbance, whereas a rating of 5 means that the

experience always caused the parent to feel depression, anxiety, and sleep disturbance (Appendix H).

The internal consistency reliability of the depression, anxiety, and sleep disturbance scales was tested and found to be acceptable, with alpha coefficients $> .70$ for all scales. The internal consistencies for the entire scale were .83, .80, and .85 for depression, anxiety, and sleep disturbance respectively (Busse et al., 2013). Busse et al. (2013) conducted a study to examine the relationship of stress to anxiety, depression, fatigue, and sleep disruption among parents with hospitalized infants in the NICU by using the PROMIS questionnaire. They found results for the PROMIS depression test bank items ($r = 0.83$); PROMIS anxiety test bank items ($r = 0.80$); and PROMIS sleep disturbance test bank items ($r = 0.85$). Furthermore, the instrument was tested in Jordan among 310 parents with infants hospitalized in a government NICU after the pilot study. Three constructs extracted from confirmatory factor analysis were anxiety, depression, and sleep disturbance, with good fit index results ($\chi^2 = 1.398$; GFI = .963; CFI = .996; IFI = .996; RMSEA = .036). Average Variance Extracted (AVE) and Composite Reliability of the three constructs were larger than .50 and .70, respectively. Average Variance Extracted (AVE) results for anxiety, depression and sleep disturbance constructs were .83, .82, and .89; also, reliability results were .96, .95, and .96 for anxiety, depression and sleep disturbance, respectively. The PROMIS short-form instruments were tested in Jordan to assess its feasibility and validity in Jordan (refer to Chapter Four).

3.5 Pilot Study

3.5.1 Pilot Study for Quantitative Phase

There were two aims for conducting a pilot study: first, to identify any potential problems that may arise during the data collection period, and second, to test the reliability and validity of the questionnaire (refer to Chapter Four).

The pilot study was conducted with 15 parents of NICU infants to assess face validity. Participants were invited to evaluate verbally whether the items were difficult to understand, and to provide suggestions for item revisions if necessary. Since no problems were reported, no modifications were made.

3.5.2 Pilot Study for Qualitative Phase

For this study, the researcher prepared three questions, as aforementioned, which were reviewed by four nursing professionals (A, B, C, D). Professional A is an associate professor and head of the Department of Nursing Sciences in University Malaya; Professional B is a lecturer in the Department of Nursing Sciences in University Malaya; Professional C is an associate professor in the Faculty of Nursing at Irbid National University; and Professional D is a specialist in gynecology and obstetrics, the head of the gynecology and obstetrics department in a hospital, as well as a lecturer in the University of Science and Technology. Two face to face interviews were conducted to assess the interview questions and any potential problems that may arise during interview.

3.6 Validation of Qualitative Data:

Validation checking for the qualitative data means assessing whether the information obtained through qualitative data collection is accurate. It is important to recognize that the criteria for judging quality should be appropriate to the methodology

of the study (Creswell & Clark, 2007). Various procedures were used to enhance data quality, which included procedure rigor and interpretative rigor (Boeije, 2010).

3.6.1 Procedural Rigor:

Throughout the research process, a clear detailed account of various research related activities was kept in a research journal. This help to provide a justification for the researcher's lines of reasoning and thoughts during the research process (Boeije, 2010). In this study, detailed descriptions of the setting, parents involved and the data collection and analysis processes used are provided so that the reader can experience the research process. This detail has been provided so that those wishing to utilize the findings within their setting or practice can make credible and similarity judgment.

The time spent in the research setting started a few months before the actual data collection. This has allowed the opportunity to build rapport with the staff which assisted my access to the parents for the interviews.

3.6.2 Interpretative Rigor:

This is another aspect of data quality which ensures credible interpretation has been made on the basis of the obtained results.

3.6.2.1 Translation of Audio Recording:

Audio recording of the interviews of all participants were transcribed in Arabic then translated to English language by two researchers. The first one is a PhD student at University of Malaya, the second one is an associate professor and head of the Department of Nursing Sciences at Irbid National University. Next, the researchers sent the translated transcribed audio recording via an email to expert in translation to check the languages and to assure the accuracy of the translation. Rich thick detailed description was achieved by selecting quotes of the participants in their own words to report findings of major themes and subthemes. Selection of participants adds further to

transparency and trustworthiness of the findings and interpretation of the data. It is also in line of the qualitative research regarding, importance of describing the experiencing of people from own point of view (Parahoo, 2014, p. 357).

3.6.2.2 Reflexivity

Reflexivity is the consideration of whether researcher's view of value having any possible impact upon the data is accounted is one of the criteria for assessing qualitative research rigor (Kitto, Chesters, & Grbich, 2008). As emphasized by Boeije (2010) it is important for research to be aware of their own personal characteristics, experiences and feelings etc and to be able to overcome any possible bias that may be caused by them.

The process of introducing myself as coming from the university doing research with approval might have an impact on the participant's willingness to participate in the interview and the way they presented themselves. Clear information regarding the study's objectives and method of data collection, how the study findings would be used were conveyed to participants to reduce possible research effects on interviews (Kitto et al., 2008) .

3.7 Ethical Consideration

The study was approved by the Ethical Committee of the Medical Research Ethics Committee, Ministry of Health, Jordan (No. Development/plans/73221). Ethical approval was also obtained from University Malaya (MRECID. No: 20158-1590) (Appendix I). Researchers obtained approval from Margaret Miles to use the PSS: NICU scale in this study (Appendix J). An email was also sent to Dr. Howard Tenenbaum with regard to usage of the PROMIS scale, although this instrument is readily available online (Appendix K).

Finally, participants were assured of the confidentiality of the study. Anonymity was established through the use of codes, rather than participants' names. Informed

written consent was obtained from participants after clear and detailed explanations about the objectives of the study (Appendix L).

3.8 Data Collection

Data collection was conducted in two phases: quantitative data collection, and qualitative data collection. The former includes the administration of the PSS: NICU and PROMIS instruments to a convenience sample, whereas the latter includes semi-structured in-depth interviews with selected participants (Figure 3.3).

3.8.1 Quantitative Data Collection

On the first day of hospital admission, the infant's files and electric medical system records were checked, to identify those who met the inclusion criteria. The home address and phone number of eligible patients were recorded. With permission from the nurse-in-charge, the researcher then approached the parents seven days after the admission of an infant to the NICU, as specified by the rules of the PROMIS scale. The well-being of the parents was a priority throughout the process of data collection.

The researcher explained the purpose and significance of the study to all potential participants. They were informed that their participation is voluntary, and they could choose to withdraw at any time. Additionally, the participants were assured that all data will be kept confidential. Written informed consent was obtained from parents after they agreed to participate in the study (Appendix L). The PSS: NICU and PROMIS questionnaires were distributed to parents. The collected questionnaires were sealed envelope and kept it locked locker, and the only researcher has a key for this locker to provide the privacy and confidentiality of parent's information's. The researcher collected the data within 6 months from 1/3/2015 to 1/8/2015.

3.8.2 Qualitative Data Collection

In the second phase, qualitative semi-structured in-depth interviews were used to identify the themes that characterize parental experience in the NICU. The interviews were guided by three open-ended questions:

- a. How did you feel when your baby was admitted to the NICU?
- b. What are the factors that affect your stress in the NICU?
- c. How did you cope when your baby was admitted to the NICU?

3.8.2.1 Semi-Structured In-Depth Interview

The method of semi-structured, in-depth, face-to-face interview is used to discuss broad areas, develop ideas, probe information, and sustain a conversation that covers a wide range of topics (Rubin & Rubin, 2011). This type of interview also identifies a clear set of information for interviewers, and provides reliable, comparable qualitative data. More importantly, this method allows participants the freedom to express their views in their own terms (Rubin & Rubin, 2011). The duration for one interview is approximately 60 minutes.

Participants were interviewed in a closed room beside the NICU to ensure privacy and prevent interruptions during the interview. First, the researcher explained the aims and process of the interview, and assured parents that all data would be confidential. The parents were informed that they could withdraw at any time from the interview. Next, informed consent was obtained prior to the interview. During the interview, the researcher asked parents open-ended questions, encouraging parents to explain their ideas, answers, and feelings. Parents were requested to explain their responses, and the researcher did not proceed until the parents did not have any more information to share for a particular question. After asking all three questions, the researcher ended the interview and thanked the participants. Only one face to face

interview was conducted since rich and thick data was obtained. The need for more than one interview is debatable as there is no literature that supports the need for more than one interview.

3.8.2.2 Audio Recording

Written permission was obtained from parents to record the interview (Appendix F^b). The researcher recorded the interview because taking comprehensive notes in real-time would have resulted in decreased eye contact and reduced listening capacity throughout the interview. Recording is also advantageous because it helps the interviewer collect all information, prevents data loss, saves the quality of tone and voice, and allows the interviewer to listen again to the interview at a later time.

For this study, audio recording was done with a smart phone. This device was chosen because it is more reliable than other recording methods, and it has additional advantages such as small size, good sound quality, and portable power bank to recharge the mobile battery. It was also easy to upload files into a computer, by connecting the phone through a USB port (Hannawald, Marschner, & Liers, 2013).

After recording the audio data, the researcher uploaded the file into a computer by connecting the mobile phone via USB port. The researcher made many copies of the audio files and stored them in many different data storage devices (e.g. a computer, USB drive, external hard drive, and Google Drive) to prevent data loss.

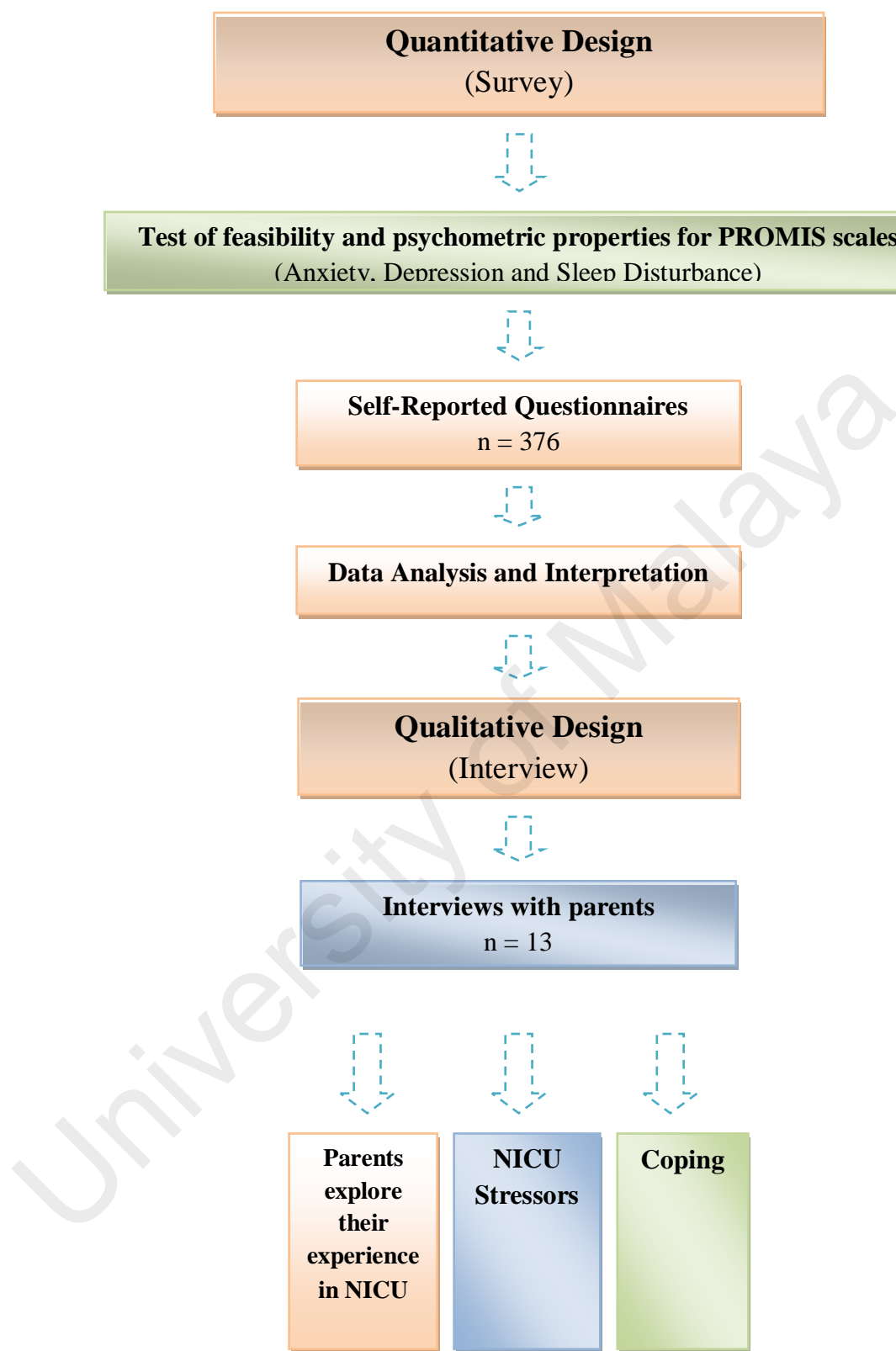


Figure 3.3 Flowchart of Data Collection

3.9 Planned Data Analysis

Data analysis was conducted separately for the quantitative and qualitative data sets. The quantitative results were analyzed using descriptive and inferential statistics, the Mann-Whitney U test, the Kruskal-Wallis test, Spearman's rank correlation coefficient, and Smart PLS. The qualitative results, on the other hand, required transcription, translation, coding, and thematic analysis.

3.9.1 Planned Data Analysis for Quantitative Design

Statistical Package for Social Sciences (SPSS) Graduate Pack 21.0 and Smart PLS were used to analyze relationships among the variables and answer the research questions. Descriptive and inferential statistics were used to describe the sociodemographic data of the sample. To determine the most stressful item among parents with infants admitted to the NICU, the researcher computed the total score for PSS: NICU subscales, and then compared the means and calculated the mean and standard deviation for each item. Also, used the Wilcoxon Signed-Rank test to compare the most stressors among fathers and mothers.

The Mann-Whitney U test was used to compare differences in overall stress levels, depression, anxiety, and sleep disturbance for parent characteristics such as gender, history of infertility, medical history, NICU experience, type of delivery, and number of wives. The same test was used for the infant characteristic of gender.

The Kruskal-Wallis test was employed to compare the differences in overall stress levels and impact of stress for parent characteristics like age, education level, distance between residence and hospital, transportation, and financial status. For infant characteristics, the same tests were used for gestational age, birth weight, and severity of medical condition.

Furthermore, Spearman's rank correlation coefficient was used to examine the relationship between stress levels and depression, anxiety, and sleep disturbance. Finally, the study used Smart PLS to develop a model and examine relationships between all variables (Table 3.6).

Table 3.6 Planned Data Analysis for Quantitative Design

| Objectives | Variables | Tests |
|--|--|---|
| To identify the stressors experienced by Jordanian parents whose infants are admitted to the NICU. | Stressors: <ul style="list-style-type: none"> • Infant appearance and behaviour • Sights and sounds in the NICU Altered parental roles | <ul style="list-style-type: none"> • Descriptive (mean, medium, frequency, proportion) and Wilcoxon Signed-Rank Test |
| To assess the difference in stress levels experienced by Jordanian parents. | <ul style="list-style-type: none"> • Stress levels • Parents (mothers and fathers) | <ul style="list-style-type: none"> • Descriptive (mean, medium, frequency, proportion) and Wilcoxon Signed-Rank Test. |
| To examine the relationship between stress levels and stressors. | <ul style="list-style-type: none"> • Stress level • Stressors: <ul style="list-style-type: none"> ✓ Infant appearance and behaviour . ✓ Sights and sounds in the NICU. ✓ Altered parental roles. | <ul style="list-style-type: none"> • Spearman Correlation • Descriptive (mean, proportion) • Smart PLS |
| To examine the relationship between stress levels and the impact of stress. | <ul style="list-style-type: none"> • Stress levels • Impact of stress : <ul style="list-style-type: none"> ✓ Depression ✓ Anxiety ✓ Sleep disturbance | <ul style="list-style-type: none"> • Spearman Correlation • Descriptive (mean, proportion) • Smart PLS |
| To compare the influence of parent and infant characteristics on stress levels and the impact of stress. | <ul style="list-style-type: none"> • Stress levels • Depression, anxiety, and sleep disturbance • Parent and infant characteristics | <ul style="list-style-type: none"> • Mann-Whitney U test • Kruskal-Wallis test |
| To Identify a model that describes the relationship between variables. | <ul style="list-style-type: none"> • Stress levels • Depression, anxiety, and sleep disturbance • Parent and infant characteristics | <ul style="list-style-type: none"> • Smart PLS |

3.9.2 Planned Data Analysis for Qualitative Design:

Step 1: *Prepare and organize data, translate for data analysis*

After each interview, audio recording files from the interview were uploaded from a mobile smart iPhone into a computer, and stored in a folder. Two copies of each recording file were saved in another computer and an external storage device.

Then, through repeated listening to the recordings, the researcher transcribed the audio recordings verbatim into textual data. The researcher also took notes of parents' behaviour and responses during the interview, to avoid loss of details due to forgetfulness. Interview transcripts and written field notes were saved as Word document. Finally, the data was translated from the Arabic language to the English language by two translators for accurate translation.

Step 2: *Read through all the data*

Transcripts were read and reread for immersion. Following that, the researcher reflected on the overall meaning about what parents were saying, and assessed the general impression of credibility and depth of the information.

Step 3: *Read and understand interviews and coding process*

After initial reading to acquire a general, preliminary sense of the content of the textual data, a thorough review of the data was carried out, beginning with the interview transcripts. Textual data was read, sentence-by-sentence and in detail, as part of the comprehensive data treatment described by Silverman (2005).

While reading through the data source, the researcher was mindful to ask related questions about the data such as, "What is this person trying to say? Which experience is represented here?" The researcher strove to be alert to participants' statements and meaningful expressions of perspectives, views, or experience. The preliminary coding process was done manually, with attempts to interpret interview responses. The

researcher made annotations of thoughts that arose regarding particular data segments. The coding process analysis was assisted by two researchers; segments of textual data were assigned different coding labels and negative cases were excluded.

Step 4: *Form themes and subthemes using the coding process*

Data analysis was done manually by two researchers to identify recurrent themes. Theme refers to “topic or information with similar content”. All information that had been coded from a single source (interview transcripts) were inspected and compared with other coded information within the data sources. During the coding process, themes were identified and analyzed from individual cases and across different cases.

Step 5: *Represent and describe themes*

Each theme was identified and described. The researchers discussed information regarding each theme and rationalized it. Parental experiences, as gathered from the interview transcripts, were categorized into relevant themes. Direct quotes served as evidence for each theme (Figure 3.4).

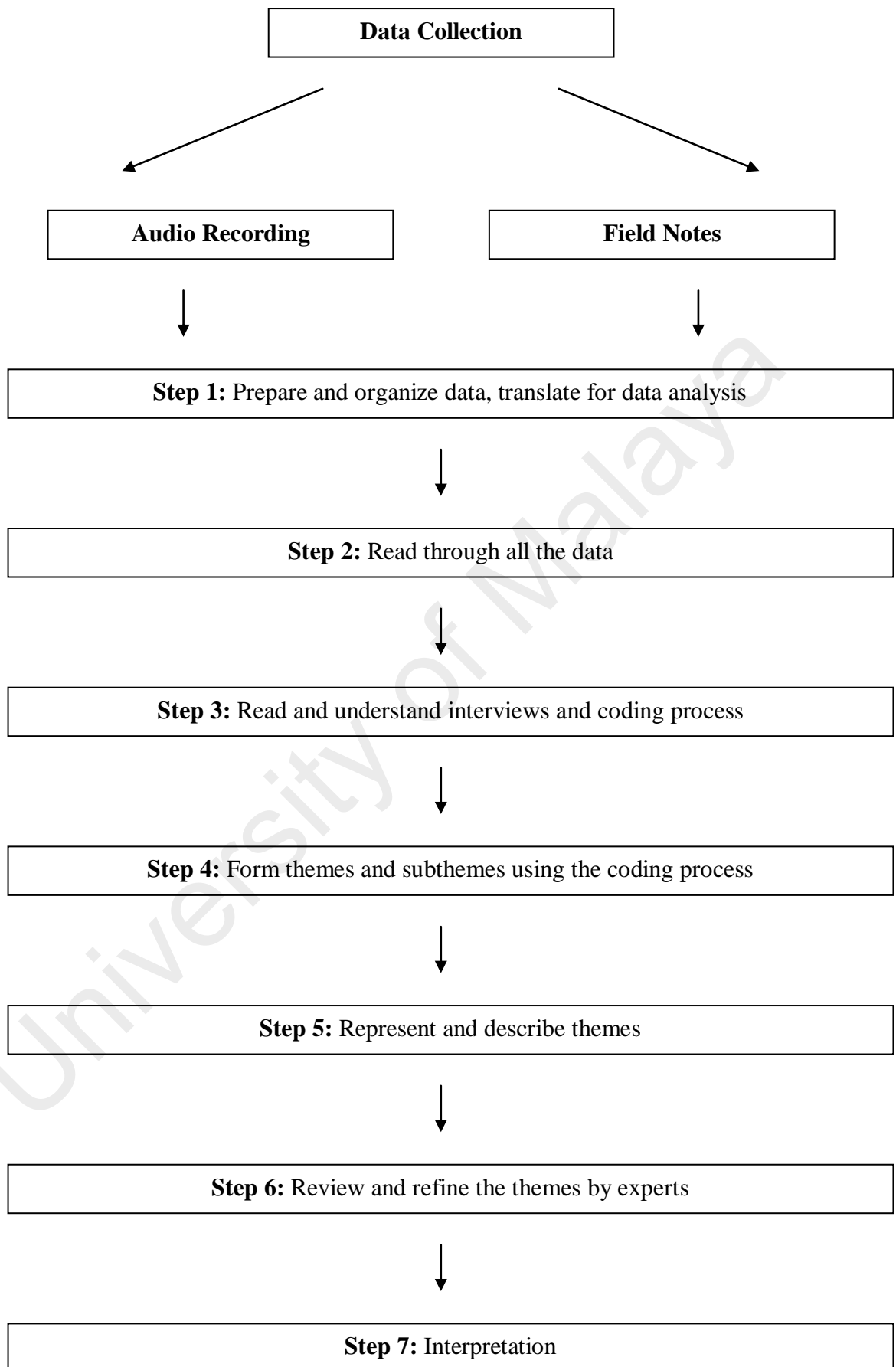


Figure 3.4 Steps of Qualitative Analysis (Myles, 2015)

3.10 Summary

The researchers first collected data from a convenience sample of 376 parents from three hospitals by administering the Parent Demographic Data Questionnaire, PSS: NICU and PROMIS. Following that, 13 pairs of parents who participated in the survey and experienced high stress levels due to infant NICU hospitalization were invited to attend the face-to-face interview to explore parental experience – particularly their stressors and strategies for coping with stress. Semi-structured in-depth interviews were used to collect information.

University of Malaysia

CHAPTER 4: VALIDATION OF INSTRUMENT

4.0 Introduction

This chapter explains the reliability and validation of questionnaires by using Structural Equation Modeling (Amos). The study used two questionnaires: the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU) and Patient-Reported Outcomes Measurement Information System (PROMIS). The PSS: NICU is valid and reliable in Jordan (Yacoub et al., 2013), but the PROMIS questionnaire was not valid in Jordan. This chapter presents validation of the Arabic version of PROMIS by using Structural Equation Modeling (Amos).

4.1 Normality Test for Data Distribution

The Kolmogorov-Smirnov test ($p > .05$) (Razali & Wah, 2011) and visual data show that depression, anxiety, and sleep disturbance scores have normal data distribution, with askewness of .301 (SE = .251), .726 (SE = .711), and .334 (SE = .226) respectively, and kurtosis of .376 (SD = .351), .322 (SD = .251), and .225 (SD = .251) respectively (Doane & Seward, 2011). Thus, parametric tests are used and Structural Equation Modeling (Amos) is an appropriate method to validate the instruments.

4.2 Validation of the PROMIS Questionnaire in Jordan

4.2.1 Participants and Setting

The convenience sampling technique was used to recruit or select participants. The sample size required for validation was based on the population size Table by Krejcie and Morgan (1970). The population size was based on the total number of infants admitted to hospitals in Jordan last year which was 1600; with CI 95% and $P \pm .05$. The sample size required was determined to be 310. The researcher distributed questionnaires to 372 parents, of which, 20 parents declined to participate and 42 were excluded from participation (four parents could not read and write; one parent was

admitted to a psychiatric hospital; two parents had infants needing surgical procedures; 35 parents did not return the questionnaires). The final number of parents included in the study was three hundred and ten (155 mothers, 155 fathers) participants, who were conveniently recruited from the two hospitals.

Parents were recruited if they met the following criteria:

- a. They were willing to participate in the study,
- b. They could speak and understand Arabic,
- c. They were Jordanian,
- d. They had had a neonate in the NICU for at least two days,
- e. The neonate was the product of a singleton pregnancy, and
- f. They had visited their neonate at least once.

Data from this sample were not used in the actual study, as the sample was used to validate the research instrument.

4.2.2 Content Validity

A panel was formed, comprising five experts: a professor and head of department at a nursing college, a psychiatrist, a psychologist working in a hospital, an associate professor and head of the department of nursing sciences, and a lecturer in the department of nursing sciences. The expert panel reported that there were no problems with the content of the questionnaire. The questionnaire was then translated.

4.2.3 Translation of Instruments

Prior to data collection, permission to translate the instrument was obtained from the developer of the instrument. Translation of the English version of PROMIS to Arabic was then performed using the standard “forward-backward” procedure (Alumran, Hou, and Hurst 2013; Abu-Shanab and Pearson 2009; Ahmed , 2015; (Dafaalla et al. , 2016 ; Koller et al. ,2007; Sperber , 2004; Brancato et al. , 2006).

The translation from English to Arabic involved three independent Jordanian translators (A, B, C) who are proficient and fluent in both languages. Translator A is an assistant professor and head of department at a nursing college; translator B is a qualified translator with no medical background (native translator); and translator C is a psychologist working in a hospital.

The translated English-to-Arabic version was then back translated from Arabic to English by three translators (D, E, F). Translator D is a psychologist and researcher in the hospital; translator E has a master's degree in nursing and a researcher at the university; and translator F is a qualified translator with no medical background.

4.2.4 Data Analysis

Descriptive statistics were used to analyse the parents' sociodemographic characteristics. Confirmatory factor analysis (CFA) was used to test whether the data fit the model of the three PROMIS constructs with 12 items (anxiety = 4 items, depression = 5 items, and sleep disturbance = 3 items). This was accomplished via Structural Equation Modeling [Analysis of Moment Structure, AMOS version 21 (IBM Corporation, Armonk, NY, USA)]. CFA was used to finalize and confirm the latent, manifest factor structure of the three constructs in PROMIS. The performance of the model can be assessed by the following model fit indices (Bentler, 1990; Bollen, 1989; MacCallum, Browne, & Sugawara, 1996; Mueller, 1996):

- $\chi^2 \Rightarrow .05$
- Root Mean Square Error of Approximation (RMSEA) with acceptance level of $< .08$
- Goodness of Fit Indices (GFI) with acceptance level of $> .90$
- Comparative Fit Indices (CFI) with acceptance level of $> .90$
- Normal Fit Indices (NFI) with acceptance level of $> .90$

The factor loading for items were assessed before assessing the model fit indices. The acceptance level of factor loading is $\geq .50$ (Byrne, 2013; Hair, Black, Babin, Anderson, & Tatham, 2006; O'Rourke et al., 2013). If the data in the model does not fit the factor loading for items, it needs to be reevaluated by deleting items from the scale that have factor loadings of less than .50; then, the fit indices will be improved (Byrne, 2013; Hair et al., 2006; O'Rourke et al., 2013).

Modification indices (MI) proposed correlations among variables. The reduction in chi-square values resulted in these correlations being added to the model, which improves model fit (Bowen & Guo, 2011). The Average Variance Extracted (AVE) for Composite Reliability (CR), based on formulas in Microsoft Excel by Fornell and Larcker (1981), was then used to evaluate the final model (Appendix M). The accepted levels of AVE and CR are $> .50$ and $> .70$ respectively (Byrne, 2013).

Discriminant validity was evaluated by ensuring that the correlation between constructs are less than .90 and that the AVE is greater than the squared correlations (Byrne, 2013; Hair et al., 2006; O'Rourke et al., 2013). Finally, convergent validity was evaluated by ensuring that the AVE is greater than .50 (Byrne, 2013; Hair et al., 2006; O'Rourke et al., 2013).

4.2.5 Results

4.2.5.1 Parent Characteristics

The sample consisted of 310 Jordanian parents (155 mothers and 155 fathers). The demographic data of the participants are shown in Table 4.1. Ages of parents ranged from 17 to 59 years (mean = 31.09, SD = 7.19), whereas the number of parents was evenly split between male and female. Slightly more than half of the participants (52.9%, $n = 164$) had bachelor's degrees, 19.7% ($n = 61$) had diplomas, and 8.4% ($n = 26$) had postgraduate degrees. In terms of financial status, 73.2% ($n = 227$) earned more

than 714 USD per month, 26.1% (n = 81) earned between 358 and 714 USD per month, and 0.6% (n = 2) had a monthly income of less than 357 USD.

Infant characteristics were also taken into consideration, with gestational age averaging at 35.46 weeks (SD = 2.207). 65.8% (n = 204) of infants were male, whereas 34.2% (n = 106) were female. Nearly half (49%, n = 152) of the infants had severe medical conditions, 28.4% (n = 88) had moderate conditions, and 22.6% (n = 70) had mild conditions.

For half (50%, n = 155) of the parents in the study, this was their first parenting experience, whereas the other half (50%, n = 155) had other children previously. 31.3% (n = 97) of mothers had normal vaginal deliveries, whereas 18.7% (n = 58) delivered via caesarean section. Among the 310 parents, 26.8% (n = 83) of parents had a history of infertility, whereas 73.2% (n = 227) did not.

The distance between place of residence and hospital was 15 kilometers or nearer for 45.2% (n = 140) of parents, 16-30 kilometers for 49% (n = 152), and more than 30 kilometers for 5.8% (n = 18). Participants mostly took public transport to the hospital (47.1%, n = 146) or drove their own cars (47.7%, n = 148), whereas a small minority walked to the hospital (5.2%, n = 16). Within seven days after the hospital admission, 76.5% (n = 237) of parents had visited the hospital 1-3 times, 15.5% (n = 48) had visited 4-6 times, and 8.1% (n = 25) had visited their infants more than 6 times.

Table 4.1 Parent and Infant Characteristics

| Variables | Participant Characteristics (N=310) n (%) |
|---|--|
| Parent Age [M (SD)] | 31.09 (7.190) |
| Infant Gestational Age (Weeks) [M (SD)] | 35.46 (2.207) |
| Parent Gender [n (%)] | |
| Male | 155 (50) |
| Female | 155 (50) |
| Infant Gender [N (%)] | |
| Male | 204 (65.8) |
| Female | 106 (34.2) |
| Financial Status (Monthly Income) (USD) [N (%)] | |
| ≤ 357 | 2 (0.6) |
| 358-714 | 81 (26.1) |
| > 714 | 227 (73.2) |
| Classification of Medical Condition [N (%)] | |
| Mild | 70 (22.6) |
| Moderate | 88 (28.4) |
| Severe | 152 (49.0) |
| First Baby [N (%)] | |
| Yes | 155 (50.0) |
| No | 155 (50.0) |
| Type of Delivery [N (%)] | |
| Normal Vaginal Delivery (NVD) | 97 (31.3) |
| Caesarean Section (CS) | 58 (18.7) |
| History of Infertility [N (%)] | |
| Yes | 83 (26.8) |
| No | 227 (73.2) |
| Distance between Residence and Hospital (km) [N (%)] | |
| ≤ 15 | 140 (45.2) |
| 16-30 | 152 (49.0) |
| 31-45 | 14 (4.5) |
| > 45 | 4 (1.3) |
| Transportation [N (%)] | |
| Walk | 16 (5.2) |
| Public transport | 146 (47.1) |
| Own car | 148 (47.7) |
| Number of Visits [N (%)] | |
| 1-3 | 237 (76.5) |
| 4-6 | 48 (15.5) |
| > 6 | 25 (8.1) |

SD: Standard Deviation; M: Mean

4.2.5.2 Validity of the Arabic Version for Depression, Anxiety and Sleep

Disturbance Subscales in PROMIS

Anxiety Subscale in PROMIS

Factor loading for each construct was initially evaluated to test the model fit of anxiety. The modification indices result was subsequently checked and applied if the result was not accepted. Table 4.2 displays each item's factor loading within the anxiety subscale, which is above .5 with fit indices at $\chi^2 = 8.378$; GFI = .866; CFI = .965; IFI = .965; and RMSEA = .155. These were not accepted. Thus, a series of modification was performed to improve model fit.

Based on the modification indices, items PA2 ("I found it hard to focus on anything other than my anxiety."), PA5 ("I felt nervous."), PA6 ("I felt like I needed help for my anxiety."), and PA8 ("I felt tense.") were deleted from the subscale. After deletion and modification, the fit indices resulted in a better model fit ($\chi^2 = 2.246$; GFI = .993; CFI = .998; IFI = .998; RMSEA = .064). The final anxiety scale consists of four items.

Depression Subscale in PROMIS

Results for the depression subscale showed that each item had factor loading above .5. However, the fit indices for items in the subscale ($\chi^2 = 6.300$; CFI = .969; GFI = .900; IFI = .969; RMSEA = .131) were not accepted. A series of modifications was performed to improve fit.

Based on the modification indices, three items were deleted: PD1 ("I felt worthless."), PD2 ("I felt helpless."), and PD7 ("I felt that I had nothing to look forward to."), leaving five items intact for the depression scale. The result had indices which indicated a better fit ($\chi^2 = 2.177$; GFI = .986; IFI = .997; CFI = .997; RMSEA = .062).

Sleep Disturbance Subscale in PROMIS

The result for the sleep disturbance scale showed that for all items, factor loading was above .5, except for items PS1 ("My sleep quality was affected") and PS2 ("My sleep was refreshing") (Table 4.2). These two items were thus deleted from the scale. After deleting these items, the fit indices for sleep disturbance items were still not acceptable ($\chi^2 = 3.613$; GFI = .968; CFI = .990; IFI = .990; RMSEA = .092). After a review of the modification indices, AMOS indicated that three more items needed to be deleted to improve model fit: items PS6 ("I tried hard to get to sleep"), PS7 ("I worried about not being able to fall asleep"), and PS8 ("I was satisfied with my sleep").

The fit was improved after the additional deletions ($\chi^2 = 3.053$; GFI = .995; CFI = .999; IFI = .999; RMSEA = .041) and the final sleep disturbance scale consisted of three items in total.

Table 4.2 Factor Loadings for Anxiety, Depression, and Sleep Disturbance Items in the PROMIS Questionnaire

| No. | Items | Factor Loading |
|-------------------|---|----------------|
| <i>Anxiety</i> | | |
| PA1 | I felt fearful. | .92 |
| PA2 | I found it hard to focus on anything other than my anxiety. | .94 |
| PA3 | My worries overwhelmed me. | .94 |
| PA4 | I felt uneasy. | .95 |
| PA5 | I felt nervous. | .95 |
| PA6 | I felt like I needed help for my anxiety. | .94 |
| PA7 | I felt anxious. | .95 |
| PA8 | I felt tense. | .93 |
| <i>Depression</i> | | |
| PD1 | I felt worthless. | .94 |
| PD2 | I felt helpless. | .93 |
| PD3 | I felt depressed. | .93 |
| PD4 | I felt hopeless. | .94 |
| PD5 | I felt like a failure. | .91 |
| PD6 | I felt unhappy. | .89 |
| PD7 | I felt that I had nothing to look forward to. | .88 |

Table 4.2, Continue

| | | |
|--------------------------|--|-----|
| PD8 | I felt nothing could cheer me up. | .86 |
| <i>Sleep Disturbance</i> | | |
| PS1 | My sleep quality was affected. | .11 |
| PS2 | My sleep was refreshing. | .26 |
| PS3 | I had a problem with my sleep. | .93 |
| PS4 | I had difficulty falling asleep. | .95 |
| PS5 | My sleep was restless. | .94 |
| PS6 | I tried hard to get to sleep. | .96 |
| PS7 | I worried about not being able to fall asleep. | .93 |
| PS8 | I was satisfied with my sleep. | .63 |

4.2.5.3 Confirmatory Factor Analysis (CFA) for Anxiety, Depression and Sleep

Disturbance Items in PROMIS

CFA was conducted on each dimension of the depression, anxiety, and sleep disturbance scales to evaluate the factor loading of each construct. As a general rule, the factor loading of items should be more than .50 ($\geq .50$) (Hair et al., 2006). The CFA result indicates that the factor loadings of all items are acceptable. Furthermore, the fit is improved ($\chi^2 = 1.398$; GFI = .963; CFI = .996; IFI = .996; RMSEA = .036) (Figure 4.1).

Chi-square (df) = 71.319 (51); df = 51 ; P value = .032
 ;Relative Chi-Sq = 1.398; AGFI = .944
 ;GFI = .963; CFI = .996; IFI= .996
 ;RMSEA = .036; RMR (<=0.08) = .023
 (Standardized estimates)

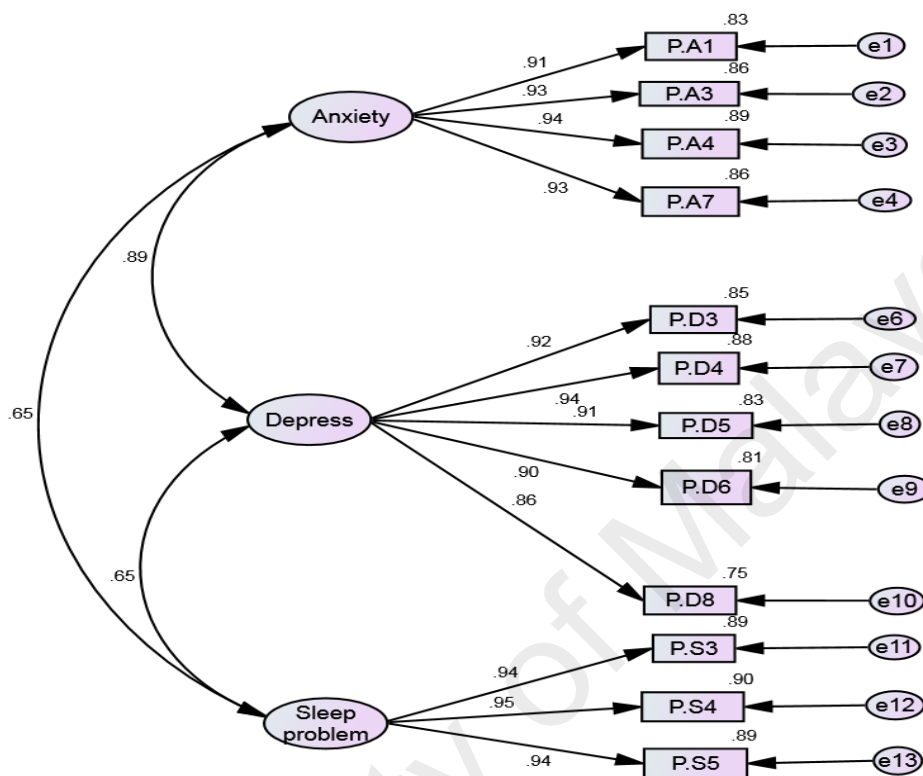


Figure 4.1 Confirmatory Factor Analysis (CFA) for anxiety, depression and sleep disturbance items

4.3 Assessment of Measure Validity

Convergent validity and discriminant validity of the constructs were assessed to ensure that the test measures are valid and acceptable for the purposes of this study. Convergent validity looks at the Composite Reliability (CR) and Average Variance Extracted (AVE), whereas discriminant validity compares AVE and squared correlation coefficients of the constructs.

4.3.1 Convergent Validity

Convergent validity is evaluated using Average Variance Extracted (AVE). The result of AVE is greater than .50, indicating high convergent validity for latent variables

(Fornell & Larcker, 1981; Hair et al., 2006). Consequently, all items in these scales have good convergence (Table 4.3).

Table 4.3. Composite Reliability and Convergent Validity

| Latent Construct | CR | AVE |
|-------------------------|-----------|------------|
| Anxiety | .96 | .83 |
| Depression | .95 | .82 |
| Sleep disturbance | .96 | .89 |

CR: Composite Reliability; AVE: Average Variance Extracted

4.3.2 Discriminant Validity

Discriminant validity is evaluated by comparing the results of AVE for each construct if it is more than the squared correlation coefficient between the construct and all other constructs in the model (Fornell & Larcker, 1981; Hair et al., 2006). To obtain better discriminant validity, the AVE result for each construct should be more than the result of squared correlations.

The AVE for anxiety (.83) is found to be greater than squared correlations of anxiety with depression (.79), whereas the AVE for sleep disturbance (.89) is greater than squared correlations of sleep disturbance and anxiety (.42). Similarly, the AVE for depression (.82) is greater than squared correlations of depression and sleep disturbance (.42). Based on the results, there is adequate discriminant validity between items (Table 4.4).

Table 4.4. Estimation of Squared Correlation Coefficients

| Constructs | Correlation Coefficient | Squared Correlation Coefficient |
|--------------------------------|--------------------------------|--|
| Anxiety ↔ Depression | .89 | .79 |
| Depression ↔ Sleep disturbance | .65 | .42 |
| Sleep disturbance ↔ Anxiety | .65 | .42 |

4.4 Reliability of the Arabic Version for Depression, Anxiety and Sleep Disturbance Subscales in PROMIS

Composite reliability (CR) is used to assess the internal consistency for latent constructs (Hair et al., 2006; O'Rourke et al., 2013). All items in the scale yielded CR between .95 and .96, indicating good CR (Table 4.4) since $CR \geq .70$ is considered a good composite reliability (Hair et al., 2006; O'Rourke et al., 2013).

4.5 Summary

The original PROMIS was translated into an Arabic version of the 4-item anxiety scale, 5-item depression scale, and 3-item sleep disturbance scale. It has been examined for psychometric qualities, and the results were supported by CFA. In summary, the depression, anxiety, and sleep disturbance items in the PROMIS questionnaire constitute an effective instrument to assess symptoms in parents with hospitalized infants in NICU in Jordan. However, continued evaluation is necessary to verify if the instrument is applicable in other Arab-speaking countries.

CHAPTER 5: PHASE 1 RESULTS (QUANTITATIVE RESULTS)

5.0 Introduction

This chapter presents the quantitative results. It begins by providing descriptive results of the demographic characteristics of mothers and fathers whose infants are admitted to the NICU. Following that is an exposition of the most stressful NICU factors among mothers and fathers, and correlations between stress levels. Stress levels among parents are determined, and scores computed for depression, anxiety, and sleep disturbance. The results are then compared for differences between mothers and fathers, and related to parent and infant characteristics. Finally, the chapter presents the model that describes the relationships between the variables, by using Structural Equation Modeling analysis with Smart PLS.

5.1 Normality Test for the Data Distribution

A Kolmogorov-Smirnov test ($p < .5$) (Razail & Wah, 2011) and a visual inspection of the histograms, normal Q-Q plots, and box plots show that stress level scores do not follow a normal distribution, with space a askewness of -0.865 (SE = .126) and kurtosis of .021 (SE = .251) (Doane & Seward, 2011). Anxiety, depression and sleep disturbance scores also do not have normal data distribution; askewness was -0.726 (SE = .126), -0.301 (SE = .251), and -0.334 (SE = .126) for anxiety, depression, and sleep disturbance respectively, and kurtosis was -0.322 (SD = .251), -0.976 (SD = .251), and .025 (SD = .251) respectively. Thus, nonparametric tests are used.

5.2 Parents' Demographic Data

A total of 376 Jordanian parents (188 mothers and 188 fathers) with infants admitted to the NICU participated in this study. Parents' ages ranged between 17 and 59 years, and the mean age for parents was 30.93 ± 7.079 . All parents were married couples and Muslims. Slightly more than half of the participants (55.1%, $n = 206$) had

bachelor's degrees, 18.1% (n = 68) had diplomas, 10.5% (n = 40) had postgraduate degrees, 15.2% (n = 27) had secondary education, and 1.1% (n = 4) had primary education. The other parent characteristics taken into consideration are financial status, number of wives, first baby, type of delivery, history of infertility and medical disorders, distance between residence and hospital, transportation, and number of visits. Table 5.1 represents the demographic characteristics of participating parents.

Table 5.1 Parents' Demographic Data

| Variables | Participant Characteristics N = 376 n (%) |
|--|--|
| Hospital [N (%)] | |
| Hospital A (Al Mafrq) | 80 (21.3) |
| Hospital B (Rahmah) | 124 (33.0) |
| Hospital C (Al Basher) | 172 (45.7) |
| Parent Age [M (SD)] | 30.93 (7.079) |
| Parent Gender | |
| Male | 188 (50) |
| Female | 188 (50) |
| Education Level | |
| Primary | 4 (1.1) |
| Secondary | 58 (15.2) |
| Diploma | 68 (18.1) |
| Bachelor's | 206 (55.1) |
| Postgraduate | 40 (10.5) |
| Financial Status (Monthly Income) (USD) | |
| ≤ 357 | 38 (10.1) |
| 358-714 | 206 (54.5) |
| > 714 | 132 (35.4) |
| Number of Wives | |
| One | 184 (97.8) |
| More than one | 4 (2.2) |
| First Baby | |
| Yes | 192 (51.1) |
| No | 184 (48.9) |

Table 5.1, Continue

| | | |
|---|--|------------|
| Type of Delivery | | |
| Normal Vaginal Delivery (NVD) | | 108 (57.4) |
| Caesarean Section (CS) | | 80 (42.6) |
| History of Infertility | | |
| Yes | | 108 (28.5) |
| No | | 268 (71.5) |
| History of Medical Disorders | | |
| Yes | | 80 (21.3) |
| No | | 296 (78.7) |
| Distance between Residence and Hospital (km) | | |
| ≤ 10 | | 178 (47.6) |
| 11-22 | | 174 (46.0) |
| 23-34 | | 20 (5.3) |
| > 35 | | 4 (1.1) |
| Transportation | | |
| Walk | | 32 (8.5) |
| Public transport | | 178 (47.3) |
| Own car | | 166 (44.2) |
| Number of Visits | | |
| 1-3 | | 288 (76.9) |
| 4-6 | | 62 (15.5) |
| > 6 | | 26 (6.6) |

5.3 Infants' Demographic Data

In this study, there were a total of 188 infants admitted to NICUs across three hospitals. 105 infants were male (55.9%) and 83 (44.1%) were female. More than half of the sample (58.5%, n = 110) consisted of premature infants aged between 28 and 36 weeks, 35.6% (n = 66) were full-term babies aged between 37 and 42 weeks, and 5.9% (n = 12) were very premature infants aged less than 28 weeks. Other infant characteristics recorded are birth weight and classification of medical condition. Table 5.2 represents the demographic characteristics of infants.

Table 5.2 Infants' Demographic Data

| Variables | Participant Characteristics N=188 n (%) |
|---|--|
| Infant Gestational Age | |
| Very premature (< 28 weeks) | 12 (5.9) |
| Premature (28-36 weeks) | 110 (58.5) |
| Full-term (37-42 weeks) | 66 (35.6) |
| Infant Gender | |
| Male | 105 (55.9) |
| Female | 83 (44.1) |
| Infant Birth Weight | |
| Very low (< 1500 grams) | 70 (37.5) |
| Low (1500-2500 grams) | 96 (47.3) |
| Normal (> 2500 grams) | 22 (15.2) |
| Classification of Medical Condition* | |
| Mild | 36 (19.1) |
| Moderate | 52 (27.7) |
| Severe | 100 (53.2) |

*Source: Classification of medical condition in NICU (Kliegman et al., 2015).

5.4 Similarity Between Three Hospitals

A Kruskal-Wallis test showed no statistically significant differences in terms of parent characteristics between hospitals A, B, and C (Table 5.3). We may thus conclude that the parents in the three hospitals were homogenous.

Table 5.3 Similarity of Parent Characteristics Between Three Hospitals

| Characteristics | N | Mean Rank | χ^2 | <i>p</i> -value | df |
|---------------------------------|-----|-----------|----------|-----------------|----|
| Parent Age | | | | | |
| Hospital A | 100 | 198.75 | 1.227 | .541 | 2 |
| Hospital B | 130 | 184.06 | | | |
| Hospital C | 146 | 185.43 | | | |
| Education Level | | | | | |
| Hospital A | 100 | 152.20 | 2.473 | .616 | 2 |
| Hospital B | 130 | 162.77 | | | |
| Hospital C | 146 | 192.57 | | | |
| Financial Status | | | | | |
| Hospital A | 100 | 183.64 | .590 | .745 | 2 |
| Hospital B | 130 | 188.53 | | | |
| Hospital C | 146 | 191.80 | | | |
| First Baby [N (%)] | | | | | |
| Hospital A | 100 | 198.02 | 1.683 | .431 | 3 |
| Hospital B | 130 | 181.82 | | | |
| Hospital C | 146 | 187.92 | | | |
| History of Infertility | | | | | |
| Hospital A | 100 | 185.60 | 2.136 | .344 | 2 |
| Hospital B | 130 | 197.17 | | | |
| Hospital C | 146 | 182.77 | | | |
| Medical Disorder History | | | | | |
| Hospital A | 100 | 191.49 | 1.091 | .579 | 2 |
| Hospital B | 130 | 182.79 | | | |
| Hospital C | 146 | 191.54 | | | |
| Transportation | | | | | |
| Hospital A | 100 | 214.38 | 8.752 | .086 | 2 |
| Hospital B | 130 | 185.90 | | | |
| Hospital C | 146 | 173.09 | | | |
| Number of Visits | | | | | |
| Hospital A | 100 | 187.98 | 1.063 | .588 | 2 |
| Hospital B | 130 | 183.45 | | | |
| Hospital C | 146 | 193.36 | | | |

* *P* value < .05

Similarly, a Kruskal-Wallis test showed no statistically significant differences in terms of infant gestational age ($\chi^2 = 6.498$, $df = 2$, $p = .093$), infant gender ($\chi^2 = 2.969$, $df = 2$, $p = .227$), birth weight ($\chi^2 = 3.983$, $df = 2$, $p = .136$), or classification of medical condition ($\chi^2 = 11.082$, $df = 2$, $p = .017$) (Table 5.4).

Table 5.4 Similarity of Infant Characteristics Between Three Hospitals

| Characteristics | N | Mean Rank | χ^2 | <i>p</i> -value | df |
|-------------------------------|----|-----------|----------|-----------------|----|
| Infant Gestational Age | | | | | |
| Hospital A | 50 | 93.92 | 6.498 | .093 | 2 |
| Hospital B | 65 | 83.88 | | | |
| Hospital C | 73 | 104.36 | | | |
| Infant Gender | | | | | |
| Hospital A | 50 | 84.96 | 2.969 | .227 | 2 |
| Hospital B | 65 | 96.38 | | | |
| Hospital C | 73 | 99.36 | | | |
| Infant Birth Weight | | | | | |
| Hospital A | 50 | 98.04 | 3.983 | .136 | 2 |
| Hospital B | 65 | 84.76 | | | |
| Hospital C | 73 | 100.75 | | | |
| Medical Condition | | | | | |
| Hospital A | 50 | 102.16 | 11.082 | .017 | 2 |
| Hospital B | 65 | 107.86 | | | |
| Hospital C | 73 | 78.55 | | | |

* *P* value < .05

5.5 Factors Influencing Parental Stress

To answer the first objective in this study, " To identify the stressors experienced by Jordanian parents whose infants are admitted to the NICU.", the total scores for PSS: NICU subscales were computed and the means were compared. The most stressful item was determined by calculating the mean and standard deviation for each item. Results show that the most common NICU stressor for parents is infant appearance and behaviour ($M = 3.76$, $SD = .914$) whereas the lowest source of stress is sights and sounds ($M = 3.56$, $SD = .918$) (Table 5.5).

Looking at each stressor in greater detail, the first domain, "NICU sights and sounds" causes higher stress levels among parents related to "the presence of monitors and equipment" (M = 3.65, SD = 1.027), whereas parents experience the least stress with regard to "the sudden noises of monitor alarms" (M = 3.50, SD = 1.128). For the second domain, "infant appearance and behaviour ", parents experience higher stress due to "the small size of my baby" (M = 3.89, SD = 1.062), "the bruises, cuts, or incisions on my baby" (M = 3.88, SD = 1.041), and "the wrinkled appearance of my baby" (M = 3.87, SD = 1.005). In the third domain of "altered parental role," parents experience more stress with regard to "being separated from my baby" (M = 3.82, SD = 1.049), and least stress for "not being able to care for my baby myself (e.g. changing nappies, bathing)" (M = 3.32, SD = 1.383). Table 5.5 lists the means and standard deviations in stress levels for all three PSS: NICU subscales. The items within each stressor domain are arranged in decreasing order of stressfulness.

Table 5.5 Means and Standard Deviations in Stress Levels for PSS: NICU Subscales

| Descriptive Statistics | Mean | SD |
|---|-------------|-------------|
| <i>Sights and Sounds</i> | | |
| The large number of people working in the unit | 3.70 | 1.110 |
| The presence of monitors and equipment | 3.65 | 1.027 |
| The constant noises of monitors and equipment | 3.56 | 1.056 |
| The other sick babies in the room | 3.52 | 1.084 |
| The sudden noises of monitor alarms | 3.50 | 1.128 |
| Total Score | 3.56 | .918 |
| <i>Infant Appearance and Behaviour</i> | | |
| The small size of my baby | 3.89 | 1.062 |
| The bruises, cuts, or incisions on my baby | 3.88 | 1.041 |
| The wrinkled appearance of my baby | 3.87 | 1.005 |
| The unusual color of my baby (e.g. pale or jaundiced) | 3.85 | 1.028 |
| Seeing tubes and equipment on or near my baby | 3.80 | 1.052 |
| My baby looked sad | 3.78 | 1.075 |
| My baby seemed to be in pain | 3.78 | 1.110 |
| The limp and weak appearance of my baby | 3.78 | 1.062 |
| The jerky or restless movements of my baby | 3.77 | 1.017 |

Table 5.5, Continue

| | | |
|---|-------------|-------------|
| My baby not being able to cry like other babies | 3.71 | 1.074 |
| My baby's unusual or abnormal breathing patterns | 3.67 | 1.269 |
| My baby fed by an intravenous line or tube | 3.60 | 1.267 |
| Seeing needles and tubes put in my baby | 3.58 | 1.278 |
| Having a respirator breathe for my baby | 3.56 | 1.305 |
| Total Score | 3.76 | .914 |
| <i>Altered Parental Roles</i> | | |
| Being separated from my baby | 3.82 | 1.049 |
| Not having time alone with my baby | 3.80 | 1.110 |
| Feeling helpless about how to help my baby | 3.78 | 1.068 |
| Not being able to hold my baby whenever I want to | 3.73 | 1.079 |
| Not being able to protect my baby from pain or painful procedures | 3.71 | 1.038 |
| Not feeding my baby myself | 3.35 | 1.337 |
| Not being able to care for my baby myself (e.g. changing nappies, bathing) | 3.32 | 1.383 |
| Total Score | 3.68 | .967 |
| Total Overall Stress Score | 3.82 | .852 |

Out of the 188 parents (mothers and fathers) tested, 147 recorded mother experience high stress than father in regarding to exposure to Infant appearance and behavior stressor (mother stress-father stress negative ranks). 33 recorded father experience high stress than mother in regarding to exposure to Infant appearance and behavior (father stress-mother stress positive ranks), 8 mothers and fathers experience same stress level in regarding to exposure to Infant appearance and behavior stressor (mother and father same in strength). The results showed ($t = 97.50$; $z = -9.019$; $p < 0.5$). Hence there is a significant difference in stress level after exposure to Infant appearance and behavior stressor between mothers and fathers (Table 5.6).

Table 5.6 Difference in Infant Appearance and Behaviour Stressors Among Fathers and Mothers

| | | N | Mean Rank | Sum of Rank | Z | P | Mother Mean (SD) | Father Mean (SD) |
|---------------------------------------|-----------------------|------------------|-----------|-------------|--------|------|------------------|------------------|
| Father stress-mother stress | Negative Ranks | 147 ^a | 98.34 | 97.50 | | | | |
| Infant appearance and behavior | Positive Ranks | 33 ^b | 55.58 | 56.50 | -9.019 | .001 | 4.06 (.810) | 2.99 (.896) |
| | Ties | 8 ^c | | | | | | |
| | Total | 188 | | | | | | |

^aFather stress < Mother stress; ^b Father stress > Mother stress; ^c Father stress = Mother stress

Out of the 188 parents (mothers and fathers) tested, 105 recorded mother experience high stress than father in regarding to exposure to sight and sound stressor (mother stress-father stress negative ranks). 70 recorded father experience high stress than mother in regarding to exposure to sight and sound (father stress-mother stress positive ranks), 13 mothers and fathers experience same stress level in regarding to exposure to sight and sound stressor (mother and father same in strength). The results showed ($t = 30.5$; $z = - 3.088$; $p < 0.5$). Hence there is a difference in stress level after exposure to sight and sound stressor between mothers and fathers (Table 5.7).

Table 5.7 Differences in Sight and Sound Stressors Among Fathers and Mothers

| | | N | Mean Rank | Sum of Rank | Z | P | Mother Mean (SD) | Father Mean (SD) |
|---|-----------------------|------------------|-----------|-------------|--------|------|------------------|------------------|
| Father stress- mother stress Sight and Sound | Negative Ranks | 105 ^a | 93.03 | 30.5 | | | | |
| | Positive Ranks | 70 ^b | 80.45 | 52.25 | -3.088 | .002 | 3.20 (.822) | 3.62 (.952) |
| | Ties | 13 ^c | | | | | | |
| | Total | 188 | | | | | | |

^aFather stress < Mother stress; ^bFather stress > Mother stress; ^cFather stress = Mother stress

Out of the 188 parents (mothers and fathers) tested, 105 recorded mother experience high stress than father in regarding to exposure to altered parent role stressor (mother stress-father stress negative ranks). 70 recorded father experience high stress than mother in regarding to exposure to altered parent role (father stress-mother stress positive ranks), 13 mothers and fathers experience same stress level in regarding to exposure to altered parent role stressor (mother and father same in strength). The results showed ($t = 120.50$; $z = - 5.905$; $p < 0.5$). Hence there is a difference in stress level after exposure to altered parent role stressor between mothers and fathers (Table 5.8)

Table 5.8 Difference in Altered Parent Role Stressors Among Fathers and Mothers

| | | N | Mean Rank | Sum of Rank | Z | P | Mother Mean (SD) | Father Mean (SD) |
|------------------------------------|---------------------------------|------------------|------------------|--------------------|----------|----------|-------------------------|-------------------------|
| Father stress-mother stress | Negative Ranks | 126 ^a | 95.45 | 120.50 | | | | |
| | Positive Ranks | 52 ^b | 75.09 | 39.50 | -5.905 | .001 | 3.64 (1.098) | 3.09 (.894) |
| | Altered parent role Ties | 10 ^c | | | | | | |
| | Total | 188 | | | | | | |

^a Father stress < Mother stress; ^b Father stress > Mother stress; ^c Father stress = Mother stress

In conclusion, the most stressor for mothers with hospitalized infant in NICU is infant behaviour and appearance followed by altered parent role, then sight and sound. In addition, the mother experience more stress than fathers in regarding to exposure to stressors in NICU.

5.6 Parental Stress of Infant Hospitalization in NICU

To answer the second objective in this study, "to assess the difference in stress levels experienced by Jordanian parents", results show that parents with infants admitted to NICU experience stress with a mean of 3.82 and median of 4.04. Results showed more than half of parents experience high stress levels whereas 11.2% experience mild stress levels, with mothers (n = 131) generally experiencing greater stress than fathers (n = 89) (Table 5.9).

Table 5.9 Stress Levels Among Jordanian Parents with Hospitalized Infants in NICU

| Stress Level | Mothers (%) (n = 188) | Fathers (%) (n = 188) | Total (%) (n = 376) |
|---------------------|----------------------------------|----------------------------------|--------------------------------|
| High | 131 (59.5) | 89 (40.5) | 220 (58.5) |
| Moderate | 49 (42.9) | 65 (57.1) | 114 (30.3) |
| Mild | 8 (19) | 34 (81) | 42 (11.2) |

5.7 Correlation Between Stress and Stressors

The third objective of the study was "to examine the relationship between stress levels and stressors"; in other words, the relationship between overall stress (as measured by PSS: NICU) and subscales (sights and sounds, infant appearance and behaviours, altered parental roles) among mothers with hospitalized infant in NICU. This was investigated using Spearman's rank correlation coefficient (Spearman's rho). It was found that there is a strong positive correlation between overall stress and "infant appearance and behaviour" ($r = .910, n=376, p < .05$) and "altered parental role" ($r = .820, n = 376, p < .05$), such that higher levels of parental stress are associated with higher scores on the stressors. There was a moderately positive correlation between overall stress and "sights and sounds" ($r = .660, n = 376, p < .05$) (Table.5.10)

Table 5.10 Correlation Between Stress and Stressors among mothers

| Spearman's rho | Sight and sound | Infant behavior and appearance | Altered in parent role | Stress |
|---------------------------------------|------------------------|---------------------------------------|-------------------------------|---------------|
| Sight and sound | 1.000 | | | |
| Infant behavior and appearance | .380** | 1.000 | | |
| Altered in parent role | .422** | .710** | 1.000 | |
| Stress | .660** | .910** | .820** | 1.000 |

*Correlation is significant at the 0.01 level (2-tailed)

In regarding to the relationship between overall stress (as measured by PSS: NICU) and subscales (sights and sounds, infant appearance and behaviours, altered parental roles) among fathers with hospitalized infant in NICU. It was found that there is a strong positive correlation between overall stress and "sight and sounds" ($r = .923$, $n=376$ $p < .05$) and "infant behaviour and appearance" ($r = .750$, $n = 376$, $p < .05$), such that higher levels of parental stress are associated with higher scores on the stressors. There was a moderately positive correlation between overall stress and " Altered in parent role" ($r = .521$, $n = 376$, $p < .05$) (Table 5.11).

Table 5.11 Correlation Between Stress and Stressors among fathers

| Spearman's rho | Sight and sound | Infant behavior | Altered in parent role | Stress |
|----------------|-----------------|-----------------|------------------------|--------|
| | 1.000 | | | |
| | .333** | 1.000 | | |
| | .433** | .625** | 1.000 | |
| | .923** | .750** | .521** | 1.000 |

*Correlation is significant at the 0.01 level (2-tailed)

5.8 Correlations between Depression, Anxiety, Sleep Disturbance, and Stress

Spearman's rho was used to address the fourth objective, "to examine the relationship between stress levels and the impact of stress", including the association between depression, anxiety, sleep disturbance, and stress among mothers with hospitalized infant in NICU. The r of depression, anxiety, and sleep disturbance are .584, .664, and .425 respectively, with p -values for all variables less than .001. Thus, there are strong positive associations between depression, anxiety and stress, on the other hand moderate positive association between sleep disturbance, and stress among mothers with hospitalized infant in NICU (Table 5.12).

Table 5.12: Correlations Between Depression, Anxiety, Sleep disturbance, and Stress among mothers with hospitalized infant in NICU

| | Stress | Depression | Sleep disturbance | Anxiety |
|--------------------------|---------------|-------------------|--------------------------|----------------|
| Stress | 1.000 | - | - | - |
| Depression | .584* | 1.000 | - | - |
| Sleep disturbance | .425* | .525* | 1.000 | - |
| Anxiety | .664* | .840* | .424* | 1.000 |

*Correlation is significant at the 0.01 level (2-tailed)

In regarding to examine the relationship between stress levels and the impact of stress among fathers with hospitalized infant in NICU", including the association between depression, anxiety, sleep disturbance, and stress among fathers with hospitalized infant in NICU. The *r* of depression, anxiety, and sleep disturbance are .523, .615, and .210 respectively, with *p*-values for all variables less than .001. Thus, there are strong positive associations between depression, anxiety and stress, on the other hand mild positive association between sleep disturbance, and stress among fathers with hospitalized infant in NICU (Table 5.13).

Table 5.13. Correlations between Depression, Anxiety, Sleep disturbance, and Stress among fathers with hospitalized infant in NICU

| | Stress | Depression | Sleep disturbance | Anxiety |
|--------------------------|---------------|-------------------|--------------------------|----------------|
| Stress | 1.000 | - | - | - |
| Depression | .523* | 1.000 | - | - |
| Sleep disturbance | .210* | .425* | 1.000 | - |
| Anxiety | .615* | .627* | .236* | 1.000 |

*Correlation is significant at the 0.01 level (2-tailed)

5.9 Parental Stress related to Parent Characteristics

Nonparametric tests were used to answer the fifth objective, "to compare the influence of parent and infant characteristics on stress levels and the impact of stress". This section examines the parent characteristics of gender, first baby, type of delivery, history of infertility, history of medical disorders, and number of wives.

Results showed statistically significant differences in stress (Mann-Whitney = 3014, $p < .05$) between mothers ($M = 216.64$) and fathers ($M = 160.36$), indicating that mothers experience higher stress than fathers. First-time parents ($M = 221.62$) experience more stress than parents with more than one child ($M = 153.94$) (Mann-Whitney = 1130, $p < .05$). Furthermore, there were significant differences for stress related to type of delivery (Mann-Whitney = 3177, $p < .05$), such that mothers who had normal vaginal deliveries ($M = 105.08$) experience more stress than mothers who gave birth by Caesarian section ($M = 80.21$).

Parents with a history of medical disorders also led to significant stress (Mann-Whitney = 1004, $p < .05$), such that parents with a history of medical disorders ($M = 208.85$) suffer more stress than those parents without ($M = 182.43$). Similarly, parents with a history of infertility ($M = 242.33$) are significantly more stressed than parents who were fertile ($M = 167.09$) (Mann-Whitney = 8632, $p < .05$). Finally, there was no statistically significant difference in stress (Mann-Whitney = 95.5, $p > .05$) between fathers who married one wife ($M = 137.75$) and those who had more than one wife ($M = 93.02$). Table 5.14 displays the differences in parental stress related to parent characteristics.

Table 5.14 Differences in Parental Stress Related to Parent Characteristics

| Parent Characteristics | N | Mean Rank | Mann-Whitney | p-value |
|---------------------------------|----------|------------------|---------------------|----------------|
| Parent Gender | | | | |
| Male | 188 | 160.36 | 3014 | .001 |
| Female | 188 | 216.64 | | |
| First Baby | | | | |
| Yes | 192 | 221.62 | 1130 | .001 |
| No | 184 | 153.94 | | |
| Type of Delivery | | | | |
| Normal vaginal delivery | 108 | 105.08 | 3177 | .001 |
| Caesarean section | 80 | 80.21 | | |
| History of Infertility | | | | |
| Yes | 108 | 242.33 | 8632 | .001 |
| No | 268 | 167.09 | | |
| Medical Disorder History | | | | |
| Yes | 80 | 208.85 | 1004 | .001 |
| No | 296 | 182.43 | | |
| Number of Wives | | | | |
| One wife | 185 | 137.75 | 95.5 | .242 |
| More than one Wife | 3 | 93.02 | | |

The Kruskal-Wallis test also showed no statistically significant differences in terms of financial status ($\chi^2 = .816$, $df = 2$, $p = .665$), but results show a difference in stress among parents with different financial statuses (low income = 233.75, moderate income = 194.94, high income = 186.05). This means that parents with low income experience higher stress than parents with moderate and high income.

Education level resulted in a non-significant difference in stress levels ($\chi^2 = 8.118$, $df = 4$, $p = .087$). Among five groups, parents who had postgraduate degrees experienced the most stress. Results also indicate that the distance between residence and hospital cause a non-significant difference ($\chi^2 = 1.089$, $df = 3$, $p = .087$). Among the four groups, highest stress levels were seen in parents who lived 35 kilometers or more away from the hospital. Transportation and number of visit resulted in a non-significant

difference in stress levels ($\chi^2 = 9.431$, $df = 4$, $p = .099$; $\chi^2 = 9.039$, $df = 4$, $p = .061$) respectively (Table 5.15).

Table 5.15 Differences in Parental Stress Related to Parent Characteristics

| Parent Characteristics | N | Mean Rank | χ^2 | p-value | df |
|--|-----|-----------|----------|---------|----|
| Education Level | | | | | |
| Primary | 4 | 88.00 | | | |
| Secondary | 58 | 182.14 | | | |
| Diploma | 68 | 185.77 | 8.118 | .087 | 4 |
| Bachelor's | 206 | 186.95 | | | |
| Postgraduate | 40 | 224.36 | | | |
| Financial Status (USD) | | | | | |
| ≤ 357 | 38 | 233.75 | | | |
| 358-714 | 206 | 194.94 | .816 | .665 | 2 |
| > 714 | 132 | 186.05 | | | |
| Distance between Residence and Hospital | | | | | |
| ≤ 10 | 178 | 184.83 | | | |
| 11-22 | 174 | 189.27 | | | |
| 23-34 | 20 | 205.00 | 1.059 | .087 | 3 |
| ≥ 35 | 4 | 210.10 | | | |
| Transportation | | | | | |
| Walk | 32 | 244.00 | | | |
| Public transport | 178 | 184.57 | 9.431 | .099 | 2 |
| Own car | 166 | 181.87 | | | |
| Number of Visits | | | | | |
| 1-3 | 288 | 165.42 | | | |
| 4-6 | 62 | 182.63 | 9.039 | .061 | 2 |
| > 6 | 26 | 225.19 | | | |

5.10 Parental Stress related to Infant Characteristics

In service of the second part of the fifth objective, nonparametric tests (Mann-Whitney and Kruskal-Wallis tests) were used to compare the influence of infant characteristics on stress levels and the impact of stress. The four infant characteristics considered are gender, gestational age, birth weight, and classification of medical condition. Gestational age and birth weight were recorded upon admission to the NICU, and the severity of medical condition reflects medical complications and dependency on technology to recover or survive. The mean rank was 92.76 for stress among parents

with male infants ($n = 105$), whereas it was 96.76 for parents with female infants ($n = 83$). Based on the Mann-Whitney U test of 4175, this difference was not statistically significant ($p = .622$). Significant results were found for the other three infant characteristics in terms of their impact on parental stress levels: gestational age ($\chi^2 = 28.8632$, $df = 2$, $p = .001$), birth weight ($\chi^2 = 29.951$, $df = 2$, $p = .001$), and severe medical conditions ($\chi^2 = 67.607$, $df = 2$, $p = .001$). Higher stress levels were evident in parents of infants with low gestational age (< 28 weeks), very low birth weight (< 1500 grams), and severe medical conditions (Table 5.16).

Table 5.16 Differences in Parental Stress Related to Infant Characteristics

| Infant Characteristics | N | Mean Rank | χ^2 | <i>p</i>-value | <i>df</i> |
|--------------------------------|----------|------------------|----------------------------|-----------------------|------------------|
| Gestational Age (weeks) | | | | | |
| Very premature (> 28) | 12 | 112.06 | | | |
| Premature (28-36) | 110 | 71.16 | 28.863 | .001 | 2 |
| Full-term (37-42) | 66 | 57.32 | | | |
| Birth Weight (grams) | | | | | |
| Very low (< 1500) | 71 | 167.83 | | | |
| Low (1500-2500) | 96 | 70.60 | 29.951 | .001 | 2 |
| Normal > 2500 | 21 | 64.27 | | | |
| Medical Condition | | | | | |
| Mild | 36 | 40.93 | | | |
| Moderate | 52 | 75.57 | 67.607 | .001 | 2 |
| Severe | 100 | 122.81 | | | |

5.11 The Influence of Parent Characteristics on Impact of Stress (Depression, Anxiety, and Sleep Disturbance)

5.11.1 The Influence of Parent Characteristics on Depression

The nonparametric Mann-Whitney U test was used to compare the influence of parent characteristics on depression, and to investigate whether differences between groups were significant. Statistically significant differences in depression scores were found for gender, first baby and history of fertility, whereas other characteristics (history of medical disorders and type of delivery) were non-significant.

Mothers ($M = 205.69$) have statistically significant higher scores of depression than fathers ($M = 171.31$) (Mann-Whitney = 144.4, $p < .05$). First-time parents had higher scores ($M = 223.73$) than parents with more than one child ($M = 151.37$) (Mann-Whitney = 108.9, $p < .05$). Parents with history of infertility expressed statistically significantly higher depression levels than those who did not (Mann-Whitney = 98.23, $p < .05$), but there was no significant difference for those who had history of medical disorders and those who had not (Mann-Whitney = 971.10, $p > .05$). Differences from type of delivery were also non-significant according to the Mann-Whitney U test (Mann-Whitney = 345.80, $p > .05$) (Table 5.17)

Table 5.17 The Influence of Parent Characteristics on Depression

| Parent Characteristics | N | Mean Rank | Mann-Whitney | <i>p</i> -value |
|---------------------------------|-----|-----------|--------------|-----------------|
| Parent Gender | | | | |
| Male | 188 | 205.69 | 144.40 | .001 |
| Female | 188 | 171.31 | | |
| First Baby | | | | |
| Yes | 192 | 223.73 | 108.90 | .001 |
| No | 184 | 151.37 | | |
| Type of Delivery | | | | |
| Normal vaginal delivery | 108 | 102.48 | | |
| Caesarean section | 80 | 83.73 | 345.80 | .099 |
| History of Infertility | | | | |
| Yes | 108 | 231.20 | 98.23 | .001 |
| No | 268 | 171.52 | | |
| Medical Disorder History | | | | |
| Yes | 80 | 213.08 | | |
| No | 296 | 181.31 | 971.10 | .081 |

According to the Kruskal-Wallis test, education levels show no statistically significant influence on depression ($\chi^2 = 7.305$, $df = 4$, $p = .121$). Similarly, non-significant relationships were found between stress and transportation ($\chi^2 = 3.687$, $df =$

2, $p = .158$), distance between residence and hospital ($\chi^2 = 7.067$, $df = 3$, $p = .070$), and number of visits ($\chi^2 = 2.639$, $df = 2$, $p = .267$). Lastly, there was a significant influence of financial status on differences in depression levels ($\chi^2 = 1.919$, $df = 2$, $p = .001$), with higher depression found among low-income parents who receive less than 357 USD per month ($M = 191.27$), compared to parents with medium-income ($M = 181.03$) and high-income ($M = 146.75$). Table 5.18 shows the results of the Kruskal-Wallis test.

Table 5.18 The Influence of Parent Characteristics on Depression

| Parent Characteristics | N | Mean Rank | χ^2 | p-value | df |
|--|-----|-----------|----------|---------|----|
| Education Level | | | | | |
| Primary | 4 | 161.38 | | | |
| Secondary | 58 | 181.77 | | | |
| Diploma | 68 | 170.29 | 7.305 | .121 | 4 |
| Bachelor's | 206 | 189.51 | | | |
| Postgraduate | 40 | 226.54 | | | |
| Financial Status (USD) | | | | | |
| ≤ 357 | 38 | 191.27 | | | |
| 358-714 | 206 | 181.03 | 1.919 | .001 | 2 |
| > 714 | 132 | 146.75 | | | |
| Distance between Residence and Hospital | | | | | |
| ≤ 10 | 178 | 181.99 | | | |
| 11-22 | 174 | 189.16 | | | |
| 23-34 | 20 | 216.60 | 7.067 | .070 | 3 |
| ≥ 35 | 4 | 310.88 | | | |
| Transportation | | | | | |
| Walk | 32 | 216.58 | | | |
| Public transport | 178 | 192.93 | 3.687 | .158 | 2 |
| Own car | 166 | 179.32 | | | |
| Number of Visits | | | | | |
| 1-3 | 288 | 183.53 | | | |
| 4-6 | 62 | 206.08 | 2.639 | .267 | 2 |
| > 6 | 26 | 202.38 | | | |

5.11.2 The Influence of Parent Characteristics on Anxiety

The Mann-Whitney U test was used to compare the different influences of parent characteristics on anxiety. Significant parent characteristics were gender, first

baby and a history of infertility. Results show a significant difference in anxiety between mothers and fathers (Mann-Whitney = 139.88, $p < .05$), where mothers ($M = 208.10$) were more anxious than fathers ($M = 168.90$). First-time parents also experienced significantly higher levels of anxiety compared to parents who had more than one child (Mann-Whitney = 109.8, $p < .05$). History of infertility was found to be an important contributing factor. Statistically significant results were also found when comparing parents with and without a history of infertility (Mann-Whitney = 98.23, $p < .05$). Higher scores of anxiety were found in parents with a history of fertility ($M = 237.17$) than in those without ($M = 222.71$).

Finally, Medical history and the type of delivery, whether normal delivery or caesarean section, did not have a strong influence on anxiety (Mann-Whitney = 101.05, $p > .05$; Mann-Whitney = 33.02., $p > .05$) respectively. Table 5.19 displays all the results of the Mann-Whitney U test.

Table 5.19 The Influence of Parent Characteristics on Anxiety

| Parent Characteristics | N | Mean Rank | Mann-Whitney | <i>p</i> -value |
|---------------------------------|-----|-----------|--------------|-----------------|
| Parent Gender | | | | |
| Male | 188 | 208.10 | 139.88 | .001 |
| Female | 188 | 168.90 | | |
| First Baby | | | | |
| Yes | 192 | 223.28 | 109.80 | .001 |
| No | 184 | 152.21 | | |
| Type of Delivery | | | | |
| Normal vaginal delivery | 108 | 81.78 | 33.02 | .066 |
| Caesarean section | 80 | 103.92 | | |
| History of Infertility | | | | |
| Yes | 108 | 237.17 | 98.23 | .001 |
| No | 268 | 222.71 | | |
| Medical Disorder History | | | | |
| Yes | 80 | 208.08 | 101.05 | .063 |
| No | 296 | 182.64 | | |

The Kruskal-Wallis test showed no statistically significant difference in anxiety for parent characteristics such as education level ($\chi^2 = 8.628$, $df = 4$, $p = .071$), transportation ($\chi^2 = 1.520$, $df = 2$, $p = .460$), distance between residence and hospital ($\chi^2 = 8.950$, $df = 3$, $p = .030$), and number of NICU visits ($\chi^2 = 2.459$, $df = 2$, $p = .292$). The only significant difference was found among parents with different financial status ($\chi^2 = 1.164$, $df = 2$, $p = .001$), whereupon higher anxiety is found in low-income parents who earn less than 357 USD a month ($M = 211.25$), compared to medium- and high-income groups of parents with infants hospitalized in the NICU ($M = 189.27$ and $M = 185.76$ respectively) (Table 5.20).

Table 5.20 The Influence of Parent Characteristics on Anxiety

| Parent Characteristics | N | Mean Rank | χ^2 | <i>p</i> -value | df |
|--|-----|-----------|----------|-----------------|----|
| Education Level | | | | | |
| Primary | 4 | 144.13 | 8.628 | .071 | 4 |
| Secondary | 58 | 183.68 | | | |
| Diploma | 68 | 175.24 | | | |
| Bachelor's | 206 | 186.42 | | | |
| Postgraduate | 40 | 233.11 | | | |
| Financial Status (USD) | | | | | |
| ≤ 357 | 38 | 211.25 | 1.164 | .001 | 2 |
| 358-714 | 206 | 189.27 | | | |
| > 714 | 132 | 185.76 | | | |
| Distance between Residence and Hospital | | | | | |
| ≤ 10 | 178 | 179.81 | 8.950 | .030 | 3 |
| 11-22 | 174 | 189.73 | | | |
| 23-34 | 20 | 232.73 | | | |
| ≥ 35 | 4 | 303.13 | | | |
| Transportation | | | | | |
| Walk | 32 | 196.22 | 1.520 | .460 | 2 |
| Public transport | 178 | 182.81 | | | |
| Own car | 166 | 180.11 | | | |
| Number of Visits | | | | | |
| 1-3 | 288 | 183.94 | 2.459 | .292 | 2 |
| 4-6 | 62 | 207.36 | | | |
| > 6 | 26 | 194.48 | | | |

5.11.3 The Influence of Parent Characteristics on Sleep Disturbance

The results show no statistically significant differences in sleep disturbance between male and female parents (Mann-Whitney = 157.3, $p > .05$), between parents with and without history of medical disorders (Mann-Whitney = 101.43, $p > .05$) and between types of delivery (Mann-Whitney = 378, $p > .05$).

On the other hand, certain parent characteristics result in statistically significant differences in sleep disturbance. For instance, Sleep disturbance was significantly higher (Mann-Whitney = 1269, $p < .05$) for first-time parents (M = 214.40) than for parents with many children (M = 161.48). Parents with a history of infertility (M = 222.71) experienced more sleep disturbance than those without (M = 174.89) (Mann-Whitney = 107.31, $p < .05$) (Table 5.21).

Table 5.21 The Influence of Parent Characteristics on Sleep Disturbance

| Parent Characteristics | N | Mean Rank | Mann-Whitney | <i>p</i> -value |
|---------------------------------|-----|-----------|--------------|-----------------|
| Parent Gender | | | | |
| Male | 188 | 198.82 | 157.30 | .065 |
| Female | 188 | 178.18 | | |
| First Baby | | | | |
| Yes | 192 | 214.40 | 126.90 | .001 |
| No | 184 | 161.48 | | |
| Type of Delivery | | | | |
| Normal vaginal delivery | 108 | 87.75 | 378.00 | .142 |
| Caesarean section | 80 | 99.50 | | |
| History of Infertility | | | | |
| Yes | 108 | 222.71 | 107.31 | .001 |
| No | 268 | 174.89 | | |
| Medical Disorder History | | | | |
| Yes | 80 | 207.60 | 101.43 | .070 |
| No | 296 | 182.77 | | |

Results indicate that education levels do not have a significant influence on sleep disturbance ($\chi^2 = 2.210$, $df = 4$, $p = .697$) among the five groups, although parents

with postgraduate degrees ($M = 189.59$) had higher sleep disturbance levels than those with only primary education ($M = 172.50$). The Kruskal-Wallis test showed that differences between transportation modes on sleep disturbance are not statistically significant ($\chi^2 = 8.011$, $df = 4$, $p = .088$). Parents who visited the hospital by car experienced less sleep disturbance ($M = 172.38$) than parents who took public transportation ($M = 200.52$) or who walked ($M = 215.86$). Other non-significant parent characteristics are financial status ($\chi^2 = 2.505$, $df = 2$, $p = .069$), distance between residence and hospital ($\chi^2 = 6.176$, $df = 3$, $p = .103$), number of visits to NICU ($\chi^2 = 3.504$, $df = 2$, $p = .173$) (Table 5.22).

Table 5.22 The Influence of Parent Characteristics on Sleep Disturbance

| Parent Characteristics | N | Mean Rank | χ^2 | <i>p</i> -value | df |
|--|-----|-----------|----------|-----------------|----|
| Education Level | | | | | |
| Primary | 4 | 172.50 | 2.210 | .697 | 4 |
| Secondary | 58 | 179.64 | | | |
| Diploma | 68 | 175.66 | | | |
| Bachelor's | 206 | 193.52 | | | |
| Postgraduate | 40 | 189.59 | | | |
| Financial Status (USD) | | | | | |
| ≤ 357 | 38 | 193.65 | 2.505 | .069 | 2 |
| 358-714 | 206 | 174.25 | | | |
| > 714 | 132 | 173.26 | | | |
| Distance between Residence and Hospital | | | | | |
| ≤ 10 | 178 | 184.05 | 6.176 | .103 | 3 |
| 11-22 | 174 | 187.15 | | | |
| 23-34 | 20 | 215.83 | | | |
| ≥ 35 | 4 | 304.63 | | | |
| Transportation | | | | | |
| Walk | 32 | 215.86 | 8.011 | .088 | 2 |
| Public transport | 178 | 200.52 | | | |
| Own car | 166 | 172.38 | | | |
| Number of Visits | | | | | |
| 1-3 | 288 | 183.01 | 3.504 | .173 | 2 |
| 4-6 | 62 | 210.81 | | | |
| > 6 | 26 | 196.58 | | | |

5.12 The Influence of Infant Characteristics on Impact of Stress (Depression, Anxiety, and Sleep Disturbance)

Nonparametric tests (Mann-Whitney U and Kruskal-Wallis tests) were used to compare the influence of infant characteristics on the impact of stress levels (depression, anxiety, and sleep disturbance). The infant characteristics considered are gender, gestational age, birth weight, and classification of medical conditions.

5.12.1 The Influence of Infant Characteristics on Depression

Based on the Mann-Whitney U test of 391.9 ($p = .237$), the mean rank for depression among parents with male infants ($n = 105$) was 90.33, whereas it was 99.78 among parents with female infants ($n = 83$). Thus, gender is not a statistically significant contributing infant characteristic to depression. Gestational age was also found to be a significant factor of depression ($\chi^2 = 25.44$, $df = 2$, $p = .001$), such that there was a significant difference between parents of infants with varying gestational ages. Lower gestational ages result in higher levels of depression ($M = 111.12$) than higher gestational ages ($M = 65.50$).

Parental depression is significantly related to infant birth weight ($\chi^2 = 29.737$, $df = 2$, $p = .001$). Parents of infants with very low birth weight (< 1500) ($M = 107.31$) experience higher depression than those of infants with low and normal birth weight ($M = 78.78$, 62.40). Depression is also significantly related to the severity of the infant's medical condition ($\chi^2 = 53.372$, $df = 2$, $p = .001$). Parents of infants with severe conditions ($n = 100$, $M = 117.32$) experience more depression than those with moderate conditions ($n = 52$, $M = 86.48$) and those with mild conditions ($n = 36$, $M = 40.57$) (Table 5.23).

Table 5.23 The Influence of Infant Characteristics on Depression

| Infant Characteristics | N | Mean Rank | χ^2 | <i>p</i> -value | df |
|--------------------------------|-----|-----------|----------|-----------------|----|
| Gestational Age (weeks) | | | | | |
| Very premature (>28) | 12 | 111.12 | 25.44 | .001 | 2 |
| Premature (28-36) | 110 | 71.38 | | | |
| Full-term (37-42) | 66 | 65.50 | | | |
| Medical Condition | | | | | |
| Mild | 36 | 40.57 | 53.372 | .001 | 2 |
| Moderate | 52 | 86.48 | | | |
| Severe | 100 | 117.32 | | | |

5.12.2 The Influence of Infant Characteristics on Anxiety

The infant's gender, gestational age, birth weight, and medical condition were examined for impact on parental stress levels. Based on the Mann-Whitney U test of 489.9 ($p = .237$), the mean rank for anxiety among parents with male infants ($n = 105$) was 89.14, whereas the mean rank for anxiety among parents with female infants ($n = 83$) was 100.39. Thus, gender is not a statistically significant contributing infant characteristic to anxiety.

Differences in anxiety related to gestational age ($\chi^2 = 25.85$, $df = 2$, $p = .001$) were found to be significant. Parents of infants with lower gestational age (< 28 weeks) ($M = 111.23$) have higher anxiety levels than parents of infants with higher gestational age ($M = 64.68$). Birth weight has a significant impact on anxiety in parents ($\chi^2 = 30.108$, $df = 2$, $p = .001$), whereby parents of infants with very low birth weight of less than 1500 grams ($M = 106.66$) experience higher levels of anxiety than parents of infants with low ($M = 60.90$) or normal ($M = 86.40$) birth weight. The severity of an infant's medical condition is determined by the gestational age, birth weight, medical complications, and dependency on technology to recover or survive. This is divided into three classes: mild, moderate, and severe, and found to be significant related to anxiety ($\chi^2 = 49.226$, $df = 2$, $p = .001$). Parents of infants with severe conditions ($n = 100$, $M =$

116.94) experience more anxiety than those with moderate (n = 52, M = 84.99) or mild (n = 36, M = 43.87) infants (Table 5.24).

Table 5.24 The Influence of Infant Characteristics on Anxiety

| Infant Characteristics | N | Mean Rank | χ^2 | p-value | df |
|--------------------------------|----------|------------------|----------------------------|----------------|-----------|
| Gestational Age (weeks) | | | | | |
| Very premature (> 28) | 12 | 111.23 | 25.85 | .001 | 2 |
| Premature (28-36) | 110 | 71.33 | | | |
| Full-term (37-42) | 66 | 64.68 | | | |
| Birth Weight (grams) | | | | | |
| Very low (< 1500) | 71 | 106.66 | 30.108 | .001 | 2 |
| Low (1500-2500) | 96 | 60.90 | | | |
| Normal > 2500 | 21 | 86.40 | | | |
| Medical Condition | | | | | |
| Mild | 36 | 43.87 | 49.226 | .001 | 2 |
| Moderate | 52 | 84.99 | | | |
| Severe | 100 | 116.94 | | | |

5.12.3 The Influence of Infant Characteristics on Sleep Disturbance

The gender of the infant was not statistically significant in terms of effects on sleep disturbance, such that parents with male and female infants experience more or less the same amount of sleep disturbance (Mann-Whitney = 355.5, $p = .30$). The mean rank for sleep disturbance among parents with male infants (n = 105) was 86.86, whereas the mean rank among parents with female infants (n = 83) was 104.16.

There were, on the other hand, significant differences in sleep disturbance due to gestational age ($\chi^2 = 16.102$, $df = 2$, $p = .001$), birth weight ($\chi^2 = 8.066$, $df = 2$, $p = .001$), and medical condition ($\chi^2 = 18.163$, $df = 2$, $p = .001$). Parents of infants with lower gestational age experienced more sleep disturbance (M = 107.59) than those with higher gestational age (M = 67.09). Parents of infants with very low birth weight (< 1500 grams) experienced more sleep disturbance (M = 98.49) than those with low or normal birth weight (M = 74.28, 77.60). Furthermore, infants with severe medical

conditions (n = 100, M = 107.63) caused higher parental stress levels than infants with moderate (n = 52, M = 90.32) or mild (n = 36, M = 62.81) conditions (Table 5.25).

Table 5.25 The Influence of Infant Characteristics on Sleep Disturbance

| Infant Characteristics | N | Mean Rank | χ^2 | p-value | df |
|--------------------------------|----------|------------------|----------------------------|----------------|-----------|
| Gestational Age (weeks) | | | | | |
| Very premature (> 28) | 12 | 107.59 | 16.102 | .001 | 2 |
| Premature (28-36) | 110 | 77.05 | | | |
| Full-term (37-42) | 66 | 67.09 | | | |
| Birth Weight (grams) | | | | | |
| Very low (< 1500) | 71 | 98.49 | 8.066 | .001 | 2 |
| Low (1500-2500) | 96 | 74.28 | | | |
| Normal > 2500 | 21 | 77.60 | | | |
| Medical Condition | | | | | |
| Mild | 36 | 62.81 | 18.163 | .001 | 2 |
| Moderate | 52 | 90.32 | | | |
| Severe | 100 | 107.63 | | | |

5.13 Established a model to describe the relationships between Stress and Impact of Stress, Stress and Parent Characteristics, and Stress and Infant Characteristics

This study used Structural Equation Modeling PLS. Smart PLS is one of the prominent software applications for Partial Least Squares Structural Equation Modeling (PLS-SEM). The researcher selected this software to develop a model describing the relationships among dependent and independent latent variables, and to show the relationship among the latent variables and their observed indicators.

Variables in SEM are endogenous and exogenous. The endogenous variables have at least one path leading to it and represent the effects of other variables, whereas an exogenous variable has path arrows pointing outwards and away from it. To assess the PLS-SEM model, some basic elements are covered in this study. First, the coefficient of determination (R_2) is assessed to explain target endogenous variable variance. R_2 is determined such that a value of above or equal to .70 is strong, between

.70 and .50 is moderate, and less than .50 is weak. Subsequently, the model assessed the inner model path coefficient sizes and significance by examining the significance of relationships between independent and dependent variables. Its standardized path coefficient is more than .50. After that, the outer model loadings were assessed by two sub-models: the structural model, otherwise known as the inner model, and the measurement model, which is the outer model. The inner model is the part of the model that has to do with relationships between latent variables. Following that, the model assessed internal consistency reliability for latent variables, convergent validity, and discriminant validity. Finally, bootstrapping was used to check structural path significance.

5.13.1 Factor Loading for Items

The factor loading for items were assessed. The acceptance level of factor loading is $\geq .50$ (Byrne, 2013; Hair et al., 2006; O'Rourke et al., 2013). The fit factor loading of items in the model needs to be evaluated by deleting items from the scale if they have factor loadings of less than .50. All items for depression, anxiety, and sleep disturbance passed the acceptance level. With regard to the stress variable, two items were deleted from the "sights and sounds" domain: item 4 ("The other sick babies in the room") and item 5 ("The large number of people working in the unit."). All items in the domains of "infant appearance and behaviour" and "altered parental roles" were accepted.

5.13.2 Explanation of Target Endogenous Variable Variance

The coefficient of determination, R^2 , is .396 for the endogenous latent variable of stress. This means that the three latent variables (depression, anxiety, and sleep disturbance) moderately explain 39.6% of the variance in stress.

5.13.3 Inner Model Path Coefficient Sizes and Significance

The inner model suggests that stress has the strongest effect on anxiety (.748), followed by depression (.651), and sleep disturbance (.577). The hypothesized path relationship between stress and impact of stress (depression, anxiety, and sleep disturbance) is statistically significant. This is because its standardized path coefficient is more than .50. Thus, we can conclude that depression, anxiety, and sleep disturbance are all strong predictors of stress.

5.13.4 Outer Model Loading and Significance

There was no outer loading for this model; the estimation for this model is good because the maximum number of iterations has been reached. To obtain a stable estimation, the algorithm was converged before reaching the maximum number of iterations.

5.14 Indicator Reliability

After squaring each of the outer loadings for indicators, the results show that all the indicators have reliability values above the minimum acceptable level of .4 (Wong, 2013) (Table 5.26).

Table 5.26 Results for Reflective Outer Models

| Latent Variable | Indicators | Outer loadings numbers | Indicator Reliability |
|-----------------|------------|------------------------|-----------------------|
| Stress | S1 | .7332 | .537 |
| | S2 | .7455 | .555 |
| | S3 | .7238 | .523 |
| | BL1 | .7609 | .579 |
| | BL2 | .7962 | .634 |
| | BL3 | .7887 | .622 |
| | BL4 | .7740 | .599 |
| | BL5 | .8280 | .686 |
| BL6 | .8169 | .667 | |

Table 5.26 , Continue

| | | | |
|--------------------------|------|-------|------|
| | BL7 | .6745 | .455 |
| | BL8 | .6661 | .444 |
| | BL9 | .7057 | .498 |
| | BL10 | .8325 | .693 |
| | BL11 | .8793 | .773 |
| | BL12 | .8670 | .752 |
| | BL13 | .8321 | .692 |
| | BL14 | .8464 | .716 |
| | PR1 | .8425 | .709 |
| | PR2 | .7172 | .514 |
| | PR3 | .7562 | .571 |
| | PR4 | .7772 | .604 |
| | PR5 | .8133 | .661 |
| | PR6 | .8126 | .660 |
| | PR7 | .8133 | .661 |
| Anxiety | A1 | .9041 | .851 |
| | A3 | .9432 | .889 |
| | A4 | .9380 | .879 |
| | A7 | .9283 | .862 |
| Depression | D3 | .9235 | .853 |
| | D4 | .9410 | .885 |
| | D5 | .9256 | .857 |
| | D6 | .9194 | .845 |
| | D8 | .8709 | .756 |
| Sleep Disturbance | S3 | .9494 | .901 |
| | S4 | .9452 | .893 |
| | S5 | .9513 | .905 |

5.15 Internal Consistency Reliability

Composite reliability (CR) is used to assess the internal consistency for latent constructs (Hair et al., 2006; O'Rourke et al., 2013). All items in the scale yielded CR

between .93 and .95, indicating good composite reliability (Table 5.23) since $CR \geq .60$ is considered a better composite reliability (Hair et al., 2006; O'Rourke et al., 2013).

5.16 Convergent Validity

Convergent validity was evaluated using Average Variance Extracted (AVE). The result of AVE is greater than .50, indicating high convergent validity for latent variables (Fornell & Larcker, 1981; Hair et al., 2006). Consequently, all items in these scales have good convergence (Table 5.27).

Table 5.27 Composite Reliability and Convergent Validity

| Latent Construct | CR | AVE |
|-------------------------|-----------|------------|
| Anxiety | .94 | .81 |
| Depression | .95 | .82 |
| Sleep disturbance | .93 | .83 |
| Stress | .95 | .86 |

CR: Composite Reliability; AVE: Average Variance Extracted

5.17 Discriminant Validity

Discriminant validity is evaluated by comparing the AVE (Table 5.27) and squared correlation coefficients of variables (Table 5.28). The AVE for anxiety (.81) is greater than the squared correlation of anxiety and depression (.71), the AVE for depression (.82) is greater than the squared correlation of anxiety and sleep disturbance (.40), and the AVE for sleep disturbance (.83) is greater than the squared correlation of sleep disturbance and anxiety (.38). Furthermore, the AVE for stress (.86) is greater than the squared correlations of stress with depression (.44), stress with anxiety (.56), and stress with sleep disturbance (.41). Based on these results, there is adequate discriminant validity between items (Table 5.28).

Table 5.28 Estimation of Squared Correlation Coefficient

| Constructs | Correlation Coefficient | Squared Correlation Coefficient |
|--------------------------------|--------------------------------|--|
| Anxiety ↔ Depression | .84 | .71 |
| Depression ↔ Sleep disturbance | .62 | .38 |
| Sleep disturbance ↔ Anxiety | .63 | .40 |
| Stress ↔ Depression | .66 | .44 |
| Stress ↔ Anxiety | .75 | .56 |
| Stress ↔ Sleep disturbance | .64 | .41 |

5.18 Checking Structural Path Significance in Bootstrapping

Smart PLS generates T-statistics for significance testing between independent and dependent latent variables. As presented in Table 5.25, all the T-statistics are larger than 1.96, thus the outer model loadings are highly significant. For the correlation between stress and depression, anxiety, and sleep disturbance, the results show that stress is a significant factor, with T-statistics larger than 1.96 (Table 5.29).

Table 5.29 T-Statistics of Path Coefficients

| Stress → Impact of Stress | T-statistics |
|-----------------------------------|---------------------|
| Stress → Depression | 18.494* |
| Stress → Anxiety | 20.844* |
| Stress → Sleep disturbance | 9.154* |

*Significant at $p < .05$

As a result of Structural Equation Modeling analysis with Smart PLS, there were some parent characteristics that were significant factors of stress, showing T-statistics larger than 1.96. Significant factors are gender, age, first baby experience, history of infertility, and medical history. On the other hand, non-significant factors were education level, financial status, distance between residence and hospital, transportation, and number of visits (Table 5.30 and Figure 5.1).

Table 5.30 T-Statistics of Path Coefficients for Stress and Parent Characteristics

| Parent characteristics | → Stress | T-statistics |
|------------------------|----------|--------------|
| Gender | → Stress | 4.678* |
| Financial status | → Stress | .089 |
| Infertility | → Stress | 6.929* |
| Medical history | → Stress | .535 |
| Visits | → Stress | 1.804 |
| Transportation | → Stress | 1.078 |
| Education level | → Stress | .433 |
| Age | → Stress | 3.378* |
| First baby | → Stress | 17.679* |
| Distance | → Stress | .301 |

*Significant at $p < .05$

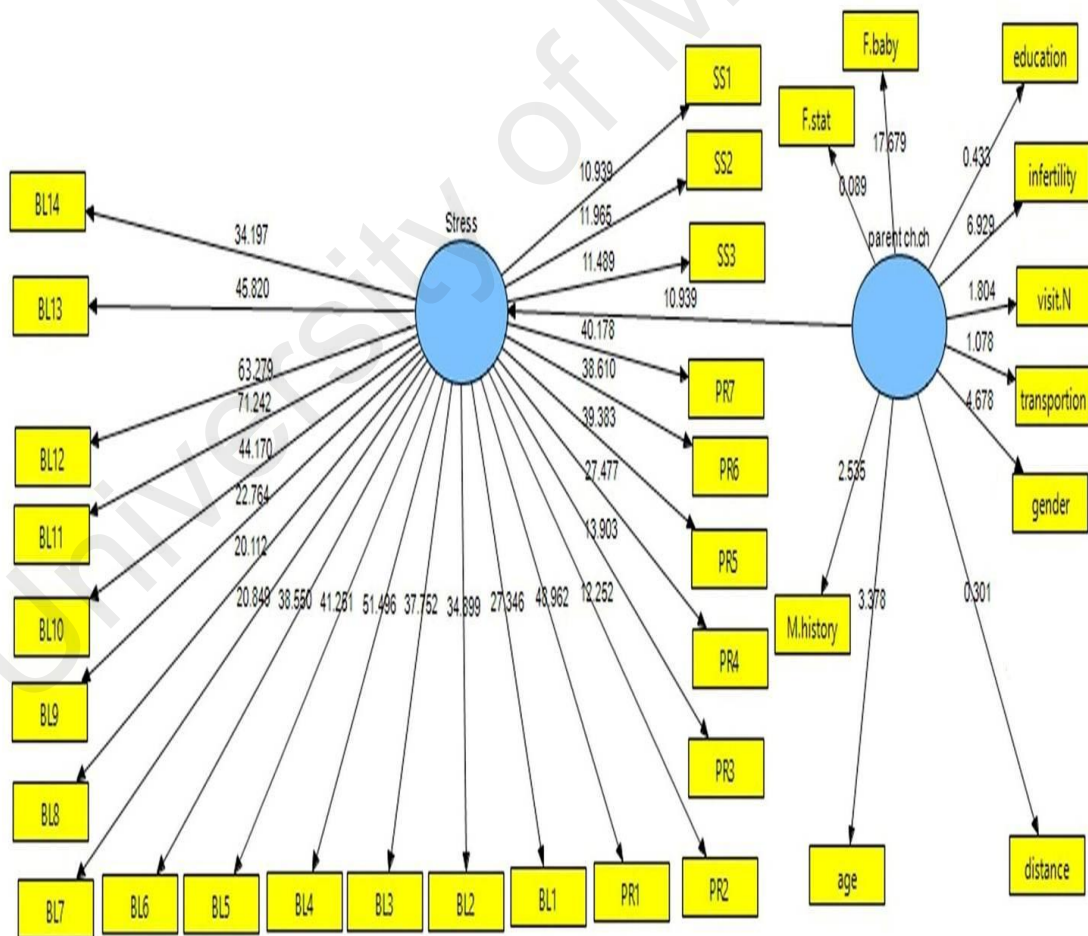


Figure 5.1 T-statistics of Path Coefficients for Stress and Parent Characteristics

Furthermore, infant characteristics such as gestational age, birth weight, and classification of medical condition were significant factors affecting stress, with T-statistics larger than 1.96. On the other hand, the gender of the infant did not significantly affect stress levels among parents (Table 5.31).

Table 5.31 T-Statistics of Path Coefficients for Stress and Infant Characteristics

| Infant characteristics | → Stress | T-statistics |
|------------------------|----------|--------------|
| BW | → Stress | 27.152* |
| CMC | → Stress | 61.260* |
| GI | → Stress | 11.227* |
| Gender | → Stress | 1.864 |

*Significant at $p < .05$

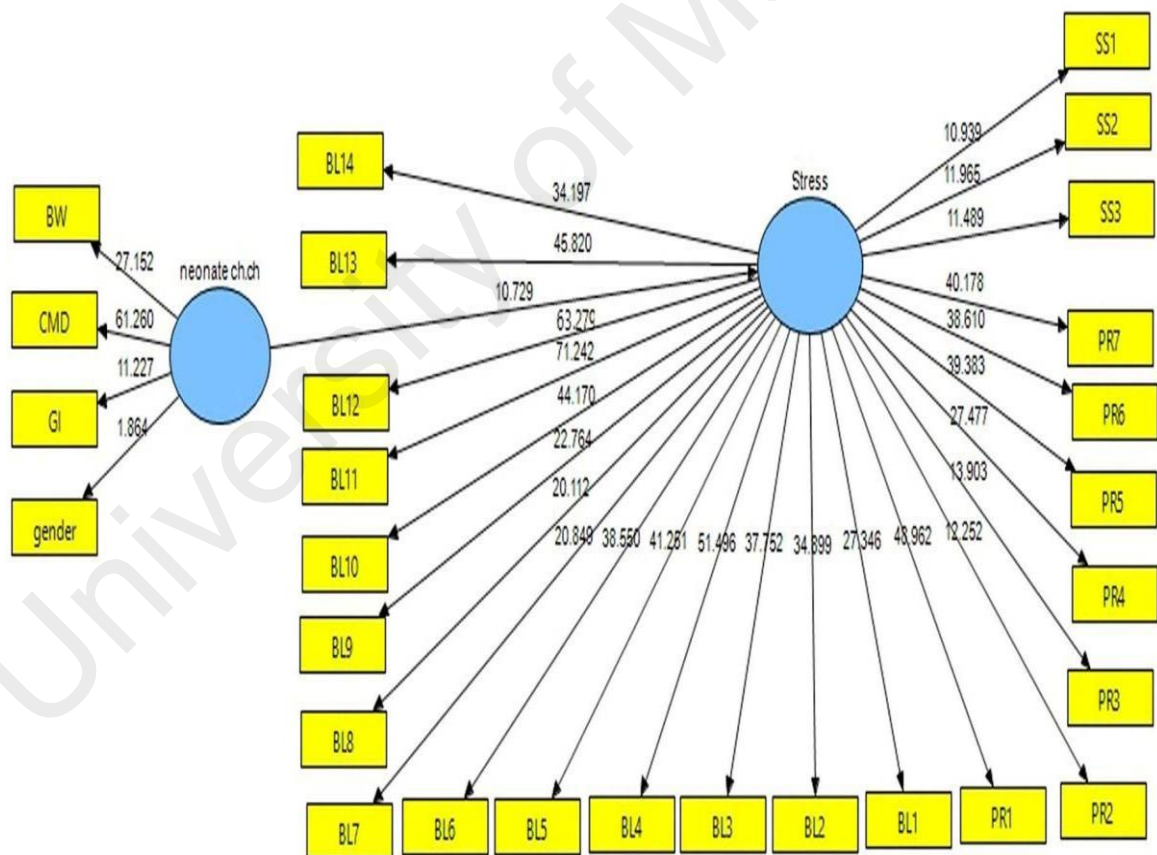


Figure 5.2 T-Statistics of Path Coefficients For Stress and Infant Characteristics

With regard to the differences of parent characteristics on anxiety, the results of Structural Equation Modeling analysis with Smart PLS showed that gender, financial

status, first baby and infertility history were significant contributing factors to anxiety, with T-statistics greater than 1.96. Parents' education level, medical history, transportation, and number of NICU visits were not significant factors (Table 5.32 and Figure 5.3).

Table 5.32 T-Statistics of Path Coefficients for Anxiety and Parent Characteristics

| Parent characteristics | → Anxiety | T-statistics |
|-------------------------------|------------------|---------------------|
| Gender | → Anxiety | 3.297* |
| Financial status | → Anxiety | 2.002* |
| Infertility | → Anxiety | 4.511* |
| Medical history | → Anxiety | .698 |
| Visits | → Anxiety | 1.011 |
| Transportation | → Anxiety | .698 |
| Education level | → Anxiety | 1.189 |
| Age | → Anxiety | 2.452* |
| First baby | → Anxiety | 5.562* |
| Distance | → Anxiety | 1.320 |

*Significant at $p < .05$

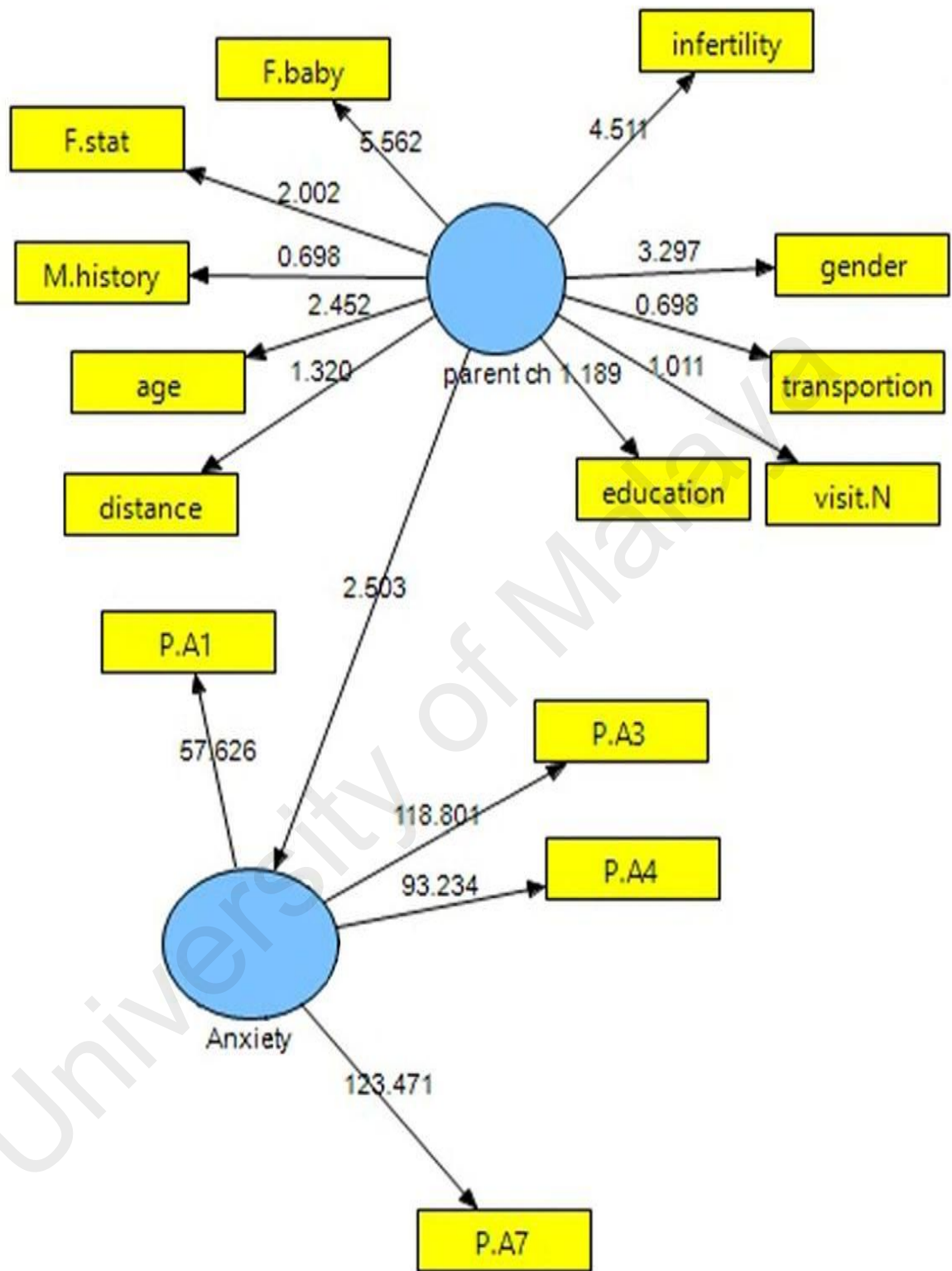


Figure 5.3 T-Statistics of Path Coefficients for Anxiety and Parent Characteristics

Analysis of infant characteristics showed that infant gender did not significantly contribute to anxiety. On the other hand, gestational age, birth weight, and classification of medical condition were significant factors of anxiety (Table 5.33 and Figure 5.4).

Table 5.33 T-Statistics of Path Coefficients for Anxiety and Infant Characteristics

| Infant characteristics | → Anxiety | T-statistics |
|------------------------|-----------|--------------|
| BW | → Anxiety | 18.802* |
| CMC | → Anxiety | 44.177* |
| GI | → Anxiety | 9.015* |
| Gender | → Anxiety | 1.045* |

*Significant at $p < .05$

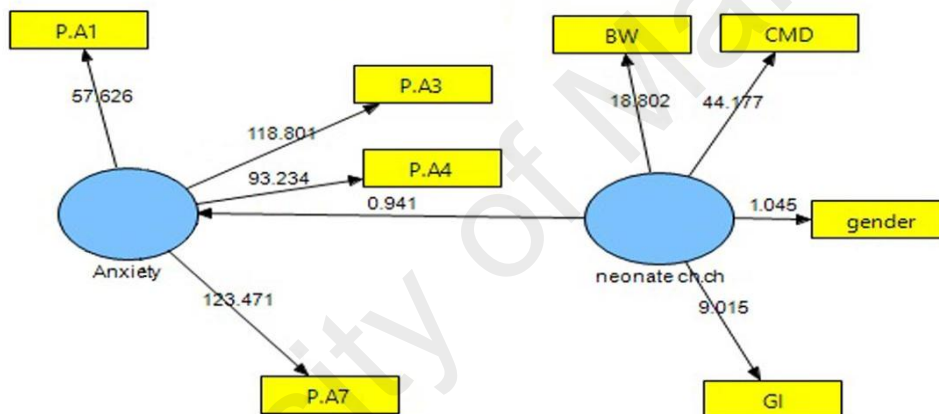


Figure 5.4 T-Statistics of Path Coefficients for Anxiety and Infant Characteristics

Moreover, Structural Equation Modeling analysis with Smart PLS shows that some parent characteristics are significant factors on depression, such as financial status, first baby, and history of infertility, with T-statistics larger than 1.96. Other parent characteristics were not significant factors on depression, namely age, education level, medical history, distance between residence and hospital, transportation, and number of visits (Table 5.34 and Figure 5.5).

Table 5.34 T-Statistics of Path Coefficients for Depression and Parent Characteristics

| Parent characteristics | → Depression | T-statistics |
|------------------------|--------------|--------------|
| Gender | → Depression | 1.456 |
| Financial status | → Depression | 2.935* |
| Infertility | → Depression | 2.438* |
| Medical history | → Depression | .896 |
| Visits | → Depression | 1.095 |
| Transportation | → Depression | .396 |
| Education level | → Depression | 1.008 |
| Age | → Depression | 1.089 |
| First baby | → Depression | 2.479* |
| Distance | → Depression | .912 |

*Significant at $p < .05$

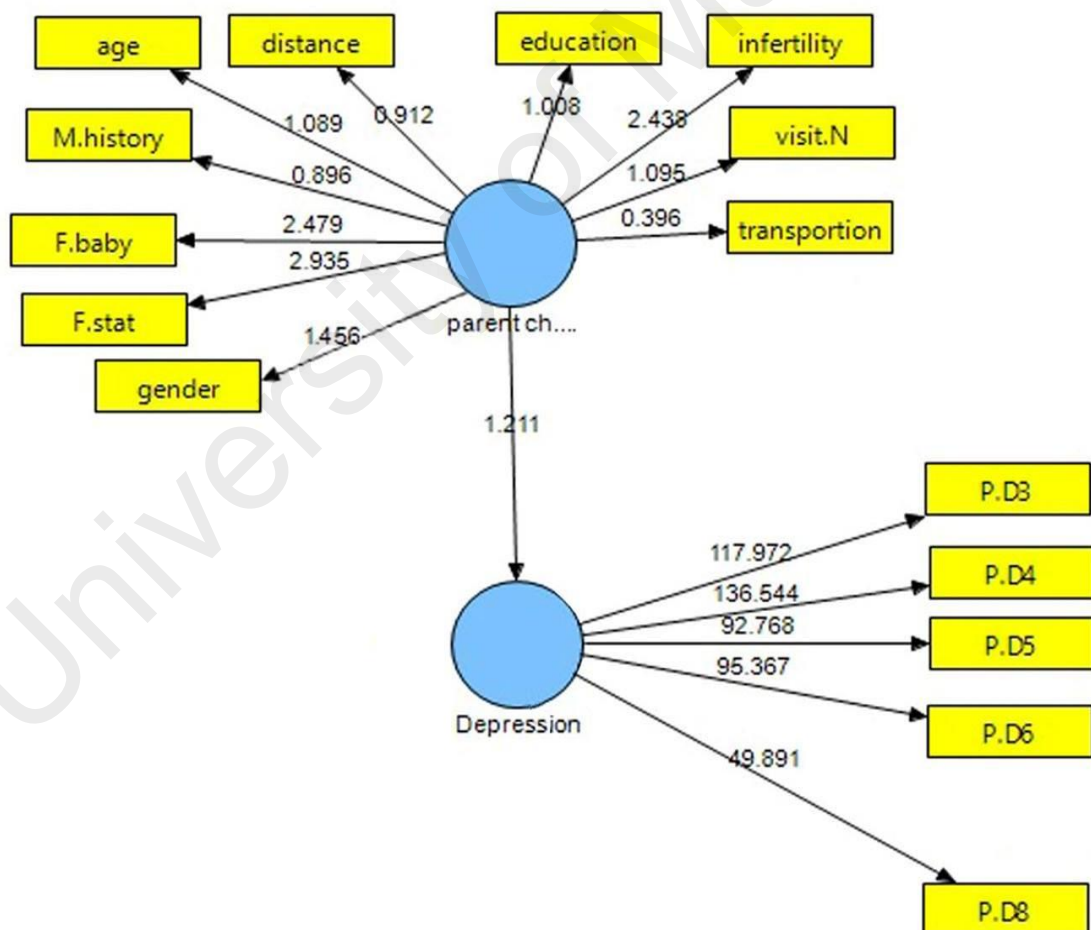


Figure 5.5 T-Statistics of Path Coefficients for Depression and Parent Characteristics

With regard to the effect of infant characteristics on depression levels among parents, gender was not a significant consideration, whereas gestational age, birth weight, and medical condition were significant factors (Table 5.35 and Figure 5.6).

Table 5.35 T-statistics of path coefficients for depression and infant characteristics

| Infant characteristics | → Depression | T-statistics |
|------------------------|--------------|--------------|
| BW | → Depression | 22.845* |
| CMC | → Depression | 49.868* |
| GI | → Depression | 10.973* |
| Gender | → Depression | 1.756 |

*Significant at $p < .05$

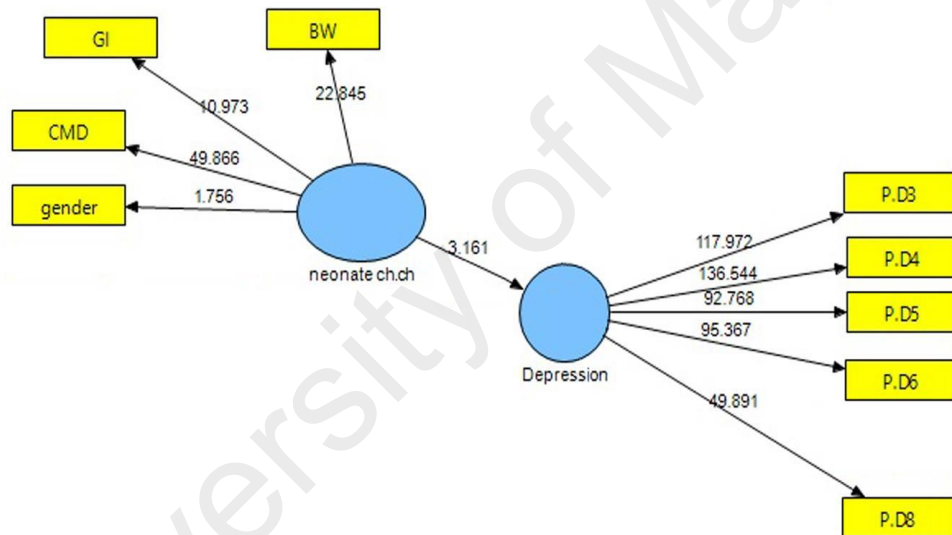


Figure 5.6 T-Statistics of Path Coefficients for Depression and Infant Characteristics

Moreover, Structural Equation Modeling analysis with Smart PLS showed certain parent characteristics having a significant effect on sleep disturbance (T-statistics > 1.96), such as first baby, and history of infertility. Other parent characteristics were not significant factors, namely age, gender, education level, financial status, medical history, distance between residence and hospital, transportation, and number of visits. Table 5.36 and Figure 5.7 depict these results.

Table 5.36 T-Statistics of Path Coefficients for Sleep Disturbance and Parent Characteristics

| Parent characteristics | → Sleep disturbance | T-statistics |
|------------------------|---------------------|--------------|
| Gender | → Sleep disturbance | 1.881 |
| Financial status | → Sleep disturbance | 1.317 |
| Infertility | → Sleep disturbance | 2.151* |
| Medical history | → Sleep disturbance | 1.317 |
| Visits | → Sleep disturbance | 1.685 |
| Transportation | → Sleep disturbance | 1.109 |
| Education level | → Sleep disturbance | 1.083 |
| Age | → Sleep disturbance | 1.532 |
| First baby | → Sleep disturbance | 2.293* |
| Distance | → Sleep disturbance | 1.101 |

*Significant at $p < .05$

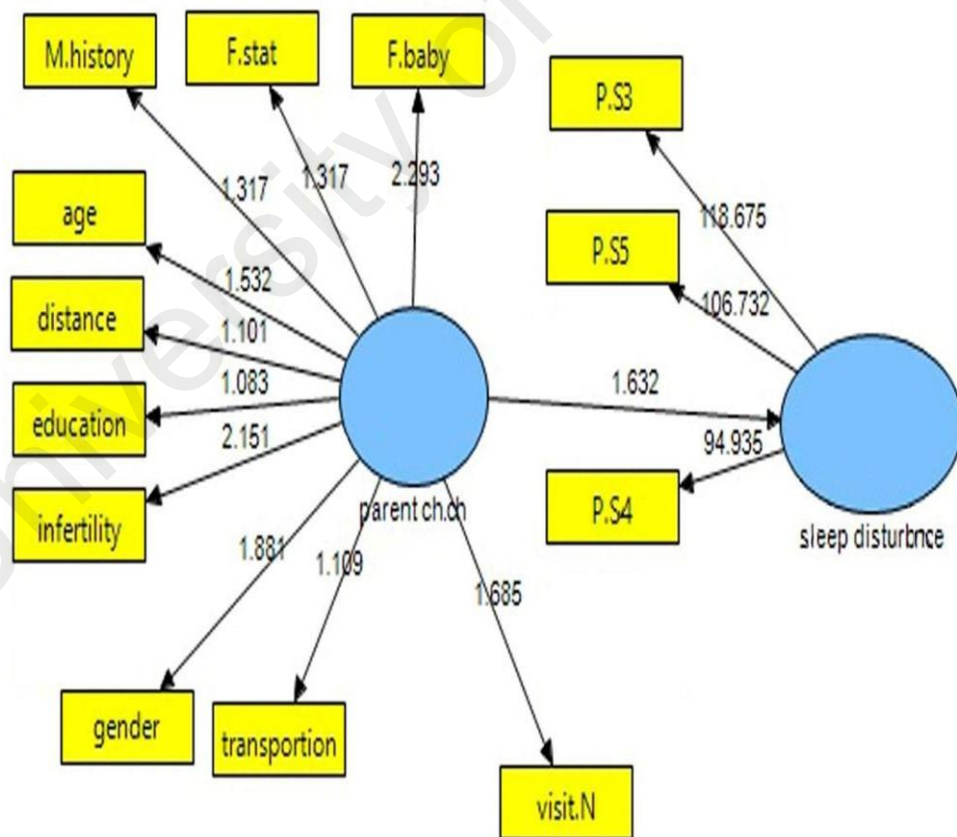


Figure 5.7 T-Statistics of Path Coefficients for Sleep Disturbance and Parent Characteristics

Among four infant characteristics considered, infant gender was not a significant factor on sleep disturbance levels. Gestational age, birth weight, and medical condition, however, were found to significantly affect sleep disturbance (Table 5.37 and Figure 5.8).

Table 5.37 T-Statistics of Path coefficients for Sleep Disturbance and Infant Characteristics

| Infant characteristics | → Sleep disturbance | T-statistics |
|------------------------|---------------------|--------------|
| BW | → Sleep disturbance | 8.592* |
| CMC | → Sleep disturbance | 12.076* |
| GI | → Sleep disturbance | 6.513* |
| Gender | → Sleep disturbance | 1.098 |

*Significant at $p < .05$

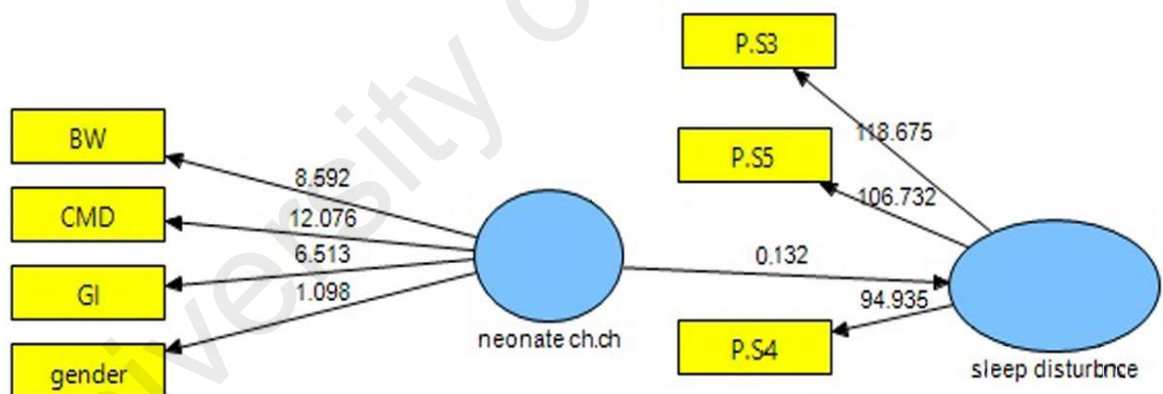


Figure 5.8 T-Statistics of Path Coefficients for Sleep Disturbance and Infant Characteristics

5.19 Relationships between All Independent and Dependent Variables

The model provides new insight into the dimensions of the model of stress and the impact of stress (depression, anxiety, and sleep disturbance). The discriminant validity, convergent validity, and reliability for the model are good. Consequently, this model can be used to determine the relationships between stress and impact of stress, as

well as to evaluate the effect of parent and infant characteristics on stress and impact of stress (Figure 5.9 and Figure 5.10).

The model shows that there are large effects of stress on anxiety ($\beta = .730$, $t = 20.844$, $p < .001$), depression ($\beta = .653$, $t = 18.494$, $p < .001$) and sleep disturbance ($\beta = .558$, $t = 9.154$, $p < .001$). Based on the benchmark by Cohen (1988) the effect is large when the standardized regression weight (β) is $\geq .50$. The three large and positive regression weights further ascertain that stress is a significant factor of anxiety, depression, and sleep disturbance for Jordanian parents (Figure 5.9 and Figure 5.10).

Stress. According to the model, there are large effects of certain parent characteristics on stress. The scores were, respectively, age ($\beta = .518$, $t = 3.378$, $p < .001$), gender ($\beta = .517$, $t = 4.678$, $p < .001$), first baby ($\beta = .760$, $t = 17.622$, $p < .001$), history of infertility ($\beta = .533$, $t = 6.929$, $p < .001$), and medical history ($\beta = .588$, $t = 2.535$, $p < .001$). On the other hand, other parental characteristics do not have significant effect on stress, for which the scores were: education level ($\beta = .054$, $t = .433$, $p > .001$), financial status ($\beta = .011$, $t = 0.089$, $p > .001$) the distance between residence and hospital ($\beta = .029$, $t = .301$, $p > .001$), transportation ($\beta = .127$, $t = 1.078$, $p > .001$), and number of visits ($\beta = .186$, $t = 1.801$, $p > .001$) (Figure 5.9 and Figure 5.10).

Furthermore, the model shows large effects of infant characteristics on stress levels among parents with hospitalized infants in NICU, such as gestational age ($\beta = .685$, $t = 11.227$, $p < .001$), birth weight ($\beta = .803$, $t = 27.152$, $p < .001$), and classification of medical condition ($\beta = .907$, $t = 61.260$, $p < .001$). On the other hand, gender of the baby does not have significant effects on stress levels among parents ($\beta = .182$, $t = 1.864$, $p > .001$) (Figure 5.9 and Figure 5.10).

Depression. There are large effects of certain parent characteristics on depression, namely financial status ($\beta = .574, t = 2.935, p < .001$), first baby ($\beta = .774, t = 2.479, p < .001$) and history of infertility ($\beta = .527, t = 2.438, p < .001$). Depression, on the other hand, is not significantly affected by other parent characteristics such as age ($\beta = .266, t = 1.089, p > .001$), gender ($\beta = .289, t = 1.456, p > .001$), education level ($\beta = .180, t = 1.008, p > .001$), medical history ($\beta = .142, t = .896, p > .001$), distance between residence and hospital ($\beta = .128, t = .912, p > .001$), transportation ($\beta = .046, t = .396, p > .001$), and number of visits ($\beta = .232, t = 1.095, p > .001$).

With regard to the effect of infant characteristics on depression levels among parents, the infant gender does not significantly affect depression ($\beta = .253, t = 1.765, p > .001$). On the other hand, significant effects on depression are found for gestational age ($\beta = .687, t = 10.973, p < .001$), birth weight ($\beta = .788, t = 22.845, p < .001$), and classification of medical condition ($\beta = .906, t = 49.866, p < .001$) (Figure 5.9 and Figure 5.10).

Anxiety. With regard to the effect of parent and infant characteristics on anxiety among parents with infants in the NICU, the model shows that there are large effects of some parent characteristics, namely age ($\beta = .594, t = 2.452, p < .001$), gender ($\beta = .548, t = 3.297, p < .001$), financial status ($\beta = .535, t = 2.002, p < .001$), first baby ($\beta = .742, t = 5.562, p < .001$) and history of infertility ($\beta = .555, t = 4.511, p < .001$). However, other parent characteristics are not significant, including education level ($\beta = .168, t = 1.189, p > .001$), medical history ($\beta = .208, t = 0.698, p > .001$), transportation ($\beta = .090, t = .698, p > .001$), distance between residence and hospital ($\beta = .144, t = 1.320, p > .001$), and number of NICU visits ($\beta = .219, t = 1.011, p > .001$).

For infant characteristics, gender do not have significant effects on anxiety levels among parents ($\beta = .307, t = 1.045, p > .001$). On the other hand, gestational age

($\beta = .664$, $t = 9.015$, $p < .001$), birth weight ($\beta = .768$, $t = 18.802$, $p < .001$), and classification of medical condition ($\beta = .911$, $t = 44.177$, $p < .001$) affect anxiety levels to a significant degree. (Figure 5.9 and Figure 5.10).

Sleep disturbance. Sleep disturbance is significantly affected by parent characteristics such as first baby ($\beta = .739$, $t = 2.293$, $p < .001$) and history of infertility ($\beta = .540$, $t = 2.151$, $p < .001$). On the other hand, non-significant effects are found for parents' age ($\beta = .223$, $t = 1.532$, $p > .001$), gender ($\beta = .267$, $t = 1.881$, $p > .001$), education level ($\beta = .216$, $t = 1.083$, $p > .001$), financial status ($\beta = .276$, $t = 1.317$, $p > .001$), medical history ($\beta = .224$, $t = 1.317$, $p > .001$), distance between residence and hospital ($\beta = .150$, $t = 1.101$, $p > .001$), transportation ($\beta = .204$, $t = 1.109$, $p > .001$), and number of visits ($\beta = .341$, $t = 1.685$, $p > .001$).

Infant characteristics that contributed significantly to sleep disturbance levels among parents are gestational age ($\beta = .705$, $t = 6.513$, $p < .001$), birth weight ($\beta = .787$, $t = 8.592$, $p < .001$), and medical condition classification ($\beta = .910$, $t = 12.076$, $p < .001$), whereas gender does not have significant effects on sleep disturbance levels ($\beta = .161$, $t = 1.098$, $p > .001$) (Figure 5.9 and Figure 5.10).

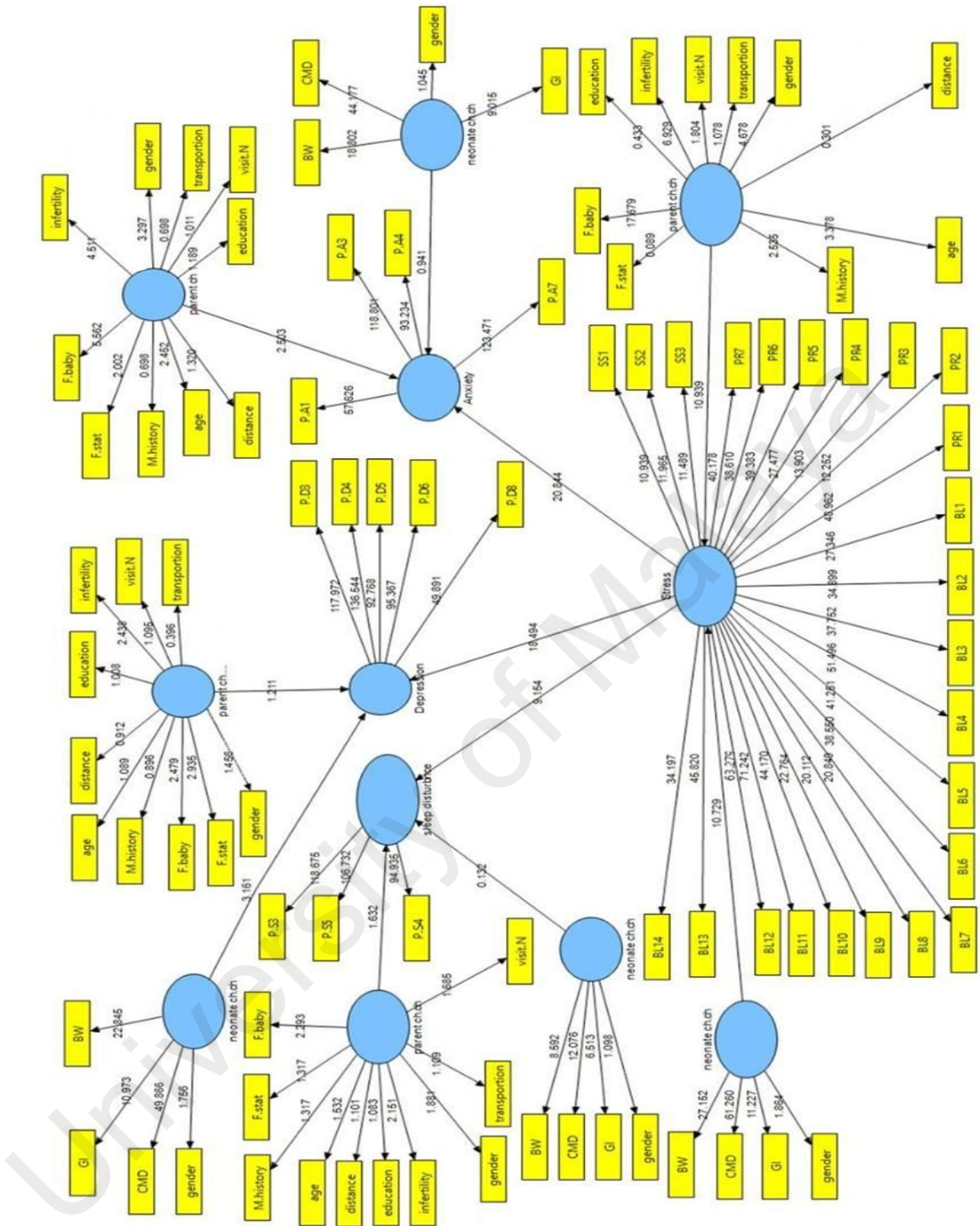


Figure 5.10 T-statistics of Path Coefficients for All Variables

After reviewing all relationships between variables, all variables with regression weights less than .5 were removed. Latent variables with coefficient of determination, R^2 , equivalent to 0.000 were also removed. The final model applied among Jordanian parents is presented in Figures 5.11 and Figure 5.12.

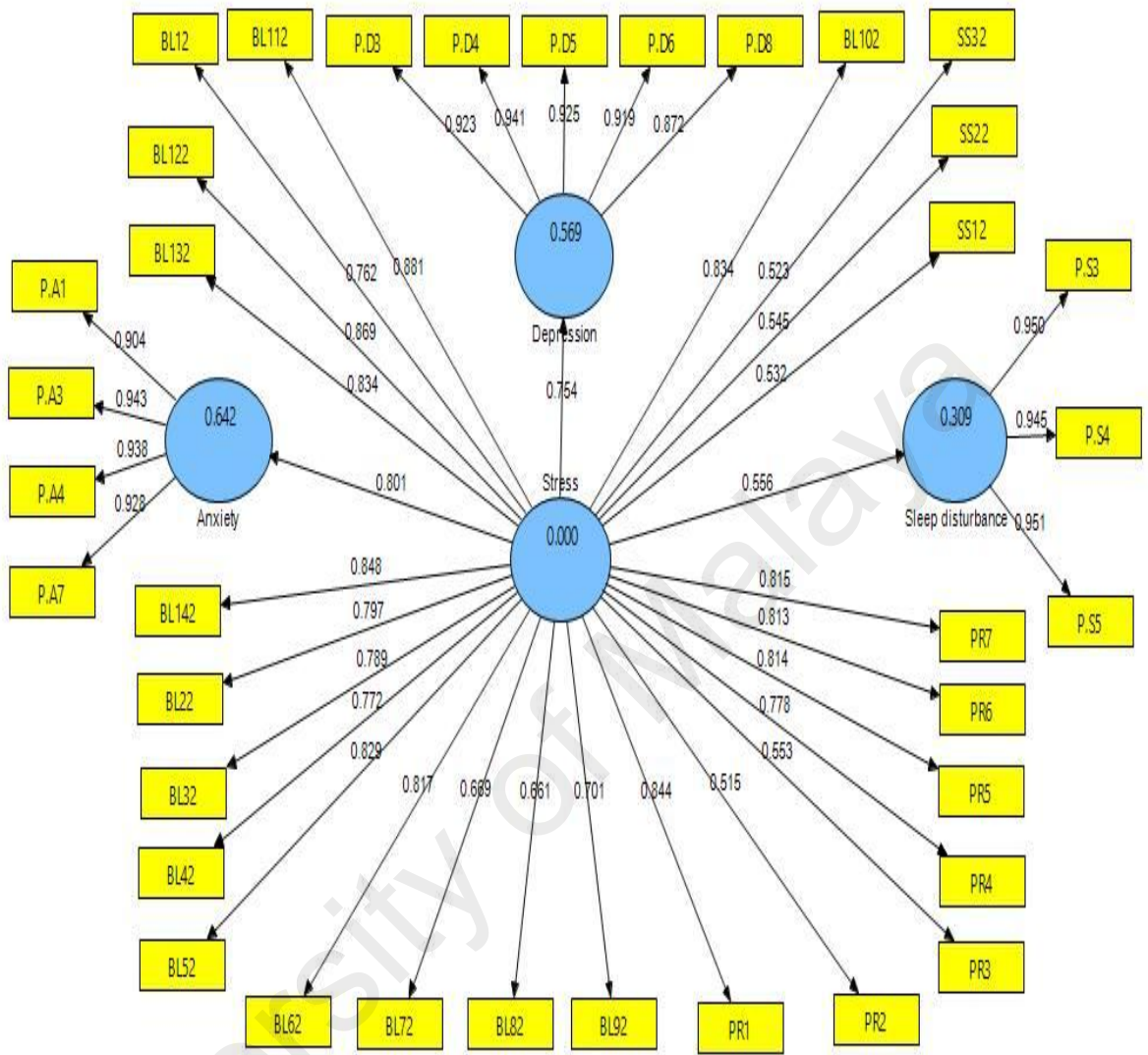


Figure 5.11 Final Model (Regression Weights of Relationships Between all Variables)

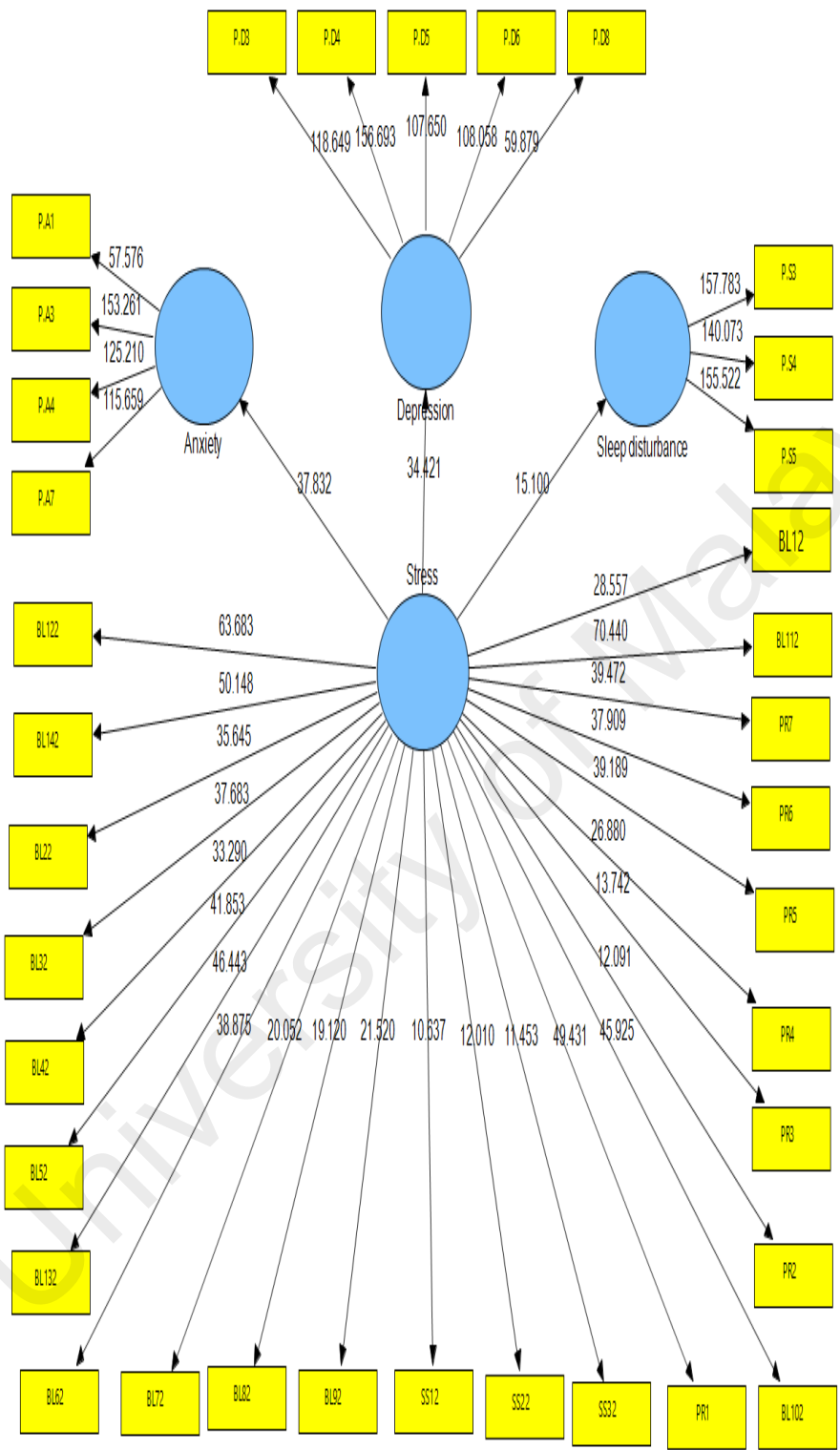


Figure 5.12 Final Model (t-Statistics of Path Coefficients)

5.20 Summary

The chapter presented the results for quantitative data. Nonparametric tests were used to analyze the data, the results of which showed that the most common stressor for parents with hospitalized infants in NICU is infant appearance and behaviour ($M = 3.76$, $SD = .914$), whereas the lowest source of stress to parents is sights and sounds ($M = 3.56$, $SD = .918$). There are strong positive associations between stress levels and depression, anxiety, and sleep disturbance. In addition, parent characteristics such as parent gender, parent age, first parenting experience, history of infertility, and medical history are found to have significant impacts on parental stress levels. On the other hand, other parent characteristics such as education level, distance between residency and hospital, transportation, number of visits, and financial status are not significant contributors to stress levels. Furthermore, results show that there are certain infant characteristics, such as gestational age, medical condition classification, and infant birth weight, which had significant influences on stress levels among parents with hospitalized infants in NICU, whereas infant gender does not significantly affect parental stress. Results also show the difference of parent and infant characteristics on the impact of stress. Finally, the chapter presents the model that shows the relationships between variables.

CHAPTER 6: PHASE 2 RESULTS (QUALITATIVE RESULTS)

6.0 Introduction

This chapter presents the qualitative component of the study. A brief description of the background characteristics is provided to facilitate understanding. The subsequent section presents various findings from the thematic analysis of the interview transcripts and field notes. These findings are organized into main themes and subthemes. From the analysis, major themes underlying parental experiences are intense emotional responses, sources of stress in the NICU, physical and psychological impacts of stress, and coping strategies. To illustrate the themes and subthemes, this chapter presents selected quotes from interviews with parents.

6.1 Parent Characteristics

The background characteristics of 13 mothers and 13 fathers are outlined in Table 6.1 to provide context and facilitate deeper understanding of parental experience from the admission of infants to NICU.

Table 6.1 Parents characteristics

| | Mothers Characteristics | Fathers Characteristics |
|--|------------------------------------|------------------------------------|
| | No. | |
| Hospital | | |
| Hospital A (Al Mafraq) | 3 | 3 |
| Hospital B (Rahmah) | 5 | 5 |
| Hospital C (Al Basher) | 5 | 5 |
| Education Level | | |
| Primary | 1 | 0 |
| Secondary | 3 | 2 |
| Diploma | 4 | 4 |
| Bachelor | 4 | 5 |
| Postgraduate | 1 | 2 |
| Financial Status (USD) /per month | | |
| ≤ 357 | 4 | 4 |
| 358-714 | 7 | 7 |
| > 714 | 2 | 2 |

Table 6.1, Continue

| | |
|--------------------------------|----|
| Type of Delivery | |
| Caesarian Section (CS) | 6 |
| Normal Vaginal Delivery | 7 |
| (NVD) | |
| Age (Year) | |
| Mean Age for father | 35 |
| Mean Age for Mother | 26 |

6.2 Experiences of Parents with Hospitalized Infants in NICU

Thematic analysis of textual data from interview transcripts and field notes yielded four major themes with fourteen subthemes, as outlined in Table 6.2.

Table 6.2 Outline of major themes and subthemes of parental experience

| Themes and Subthemes |
|--|
| Intense Emotional Responses |
| • Shock and Surprise |
| • Sadness |
| • Hopelessness and Self-Hatred |
| • Shame and Guilt |
| Sources of Stressors in NICU |
| • NICU Physical Environment |
| • Infant Appearance and Behaviour |
| • Parental Role, Relationship and Attachment |
| • Health Care Professionals' Communication and Behaviour |
| • Lack of Knowledge |
| Impact of Stress |
| • Physical Impact |
| • Psychological Impact |
| Coping Strategies |
| • Spiritual Support |
| • Social Support |
| ➤ Family Support |
| ➤ Peer Support |
| ➤ Health Care Professional Support |
| ➤ Friend support |
| • Physical Activities Support |

6.2.1 Intense Emotional Responses

This section provides details of parents' experience of intense emotional responses within themselves and their family members, as a direct result of having a baby admitted to the NICU. These various intense emotions are divided into the subthemes of:

- Shock and Surprise
- Sadness
- Hopelessness and Self-Hatred
- Shame and Guilt

All parents were inundated with intense emotions such as sadness, guilt, anxiety, fear, shock, and disappointment. A few recounted feelings of shock and surprise when informed of their infants' admission to NICU. They described this situation as a sudden, unexpected, and unbelievable crisis, leading to hopelessness and powerlessness. Most parents had not prepared themselves to face NICU admission, because their pregnancy experience had been normal. At the same time, several parents expressed irrational feelings of hatred towards themselves, their babies, or their lives.

6.2.1.1 Shock and Surprise

Most parents expressed shock and surprise upon being informed that their infants had been admitted to the NICU, and described this situation as a sudden, unexpected, and unbelievable crisis. Most of them were unprepared to face this situation as their pregnancy experience appeared to be normal.

One of the parents recounted his experience as below:

“I was surprised, shocked, and my feet could not hold my weight; I felt like I would fall from this news, because this was an unexpected and unbelievable situation for me. I don’t know. What can I do for my baby...? It really is a crisis.” (Fayiz, 3/6/2015)

Another parent, a mother, related her own experience:

“It was a premature delivery, and my daughter was admitted to the NICU. It is a sudden and unexpected situation for me, I had not prepared myself for situation because there were no complications during the pregnancy period.” (Rula, 4/6/2015)

6.2.1.2 Sadness

A number of parents described an overwhelming feeling of sadness that affected not only them, but also their entire family.

“After admitting my daughter to NICU, my family became very sad and there was no laughter in our home. There was just a sad feeling, spreading throughout our home. My home became gloomy.” ... “I saw my wife crying, which made me feel sad... I don’t like to see her sad.” (Hani, 8/6/2015)

“My feelings are like any mother’s feelings, when she has a sick infant... I feel fear, sadness, tiredness, stress, guilt... I had a nervous breakdown and felt very stressed when I saw the nursing taking my baby to the NICU... I fear for my baby daughter. I am afraid that something bad is happening to my daughter.” (Rufaid, 8/6/2015)

“I felt sad when I saw the nurse carrying my baby and putting her in the incubator, the doctor putting the machines on my daughter, when I saw the machine around my baby, and many machines attached to her body...” (Jamal, 4/6/2015)

6.2.1.3 Hopelessness and Self-Hatred

For a few parents, the initial period of NICU admission was a time a struggling with feelings of hopelessness and powerlessness. For others, the hopelessness of the situation caused feelings of hatred towards themselves, the babies, and their lives.

Illustrative quotes as below:

“I hate my life. Why is my baby admitted to the NICU?” (Esra’a, 3/6/2015)

“I feel hopeless with my baby admitted to the NICU... I hate my life... I hate myself... I hate my baby... I can’t do anything for my baby... I feel powerless...” (Tariq, 9/6/2015)

“I don’t love my life, I don’t love anybody. I hate all things and all people. What is the point of living? I hate my baby, I don’t want my baby even when my husband brings her to me. I don’t want to come to the hospital to see my son. I wish my baby were

dead. I hate everything in life, I hate my husband, I hate my family, I hate myself.” (Aya’a, 6/6/2015)

6.2.1.4 Shame and Guilt

For most of the parents, the initial period after they were informed of their baby’s admission to the NICU was a time of struggling with shame, guilt, and self-blame. These were common expressions among parents as they feared their babies might be perceived as having some genetic disorder.

Parents expressed their feelings of shame as below:

“I feel shame when anyone asks me about my daughter... I am ashamed to tell anyone, ‘My daughter has been admitted to the NICU’. I sense sympathy in the eyes of some people.” (Anas, 9/6/2015)

“I am ashamed that I have a baby girl admitted to the NICU. I fear for her future... maybe people will say this family has a genetic disorder and nobody will want to marry someone from my family.” (Shrooq, 10/6/2015)

“I feel ashamed because our community does not accept any abnormal babies... maybe in the future, people will call my son an abnormal boy... so I feel ashamed when I tell anyone my son is admitted to the NICU.” (Aya’a, 6/6/2015)

Among the parents, there were those who attributed their guilt to various causes, which were indirectly related to their obligations and responsibilities as parents. They feel that they have failed as parents because they are powerless to help their infants. As below, parents express their guilt stemming from not being there for their babies:

“I felt distraught... mixed emotions of upset and guilt. I don’t know why I felt this way... maybe because I don’t know what I can do for my daughter. My feelings of guilt increase when I’m not there at home, because I feel that I should be there... but when I’m at home I feel guilty because I should be here with my daughter.” (Esra’a, 3/6/2015)

“I feel guilty because I can’t help my baby... I can’t carry out the role of a father for my baby... I feel guilty when I see my sick baby in the incubator and I can’t do anything to help him.” (Ahmad, 2/6/2015)

6.2.2 Sources of Stressors in NICU

Parents identified many sources of stress during the period in which their infants received NICU hospitalization, namely, the NICU physical environment, infant appearance and behaviour, altered parental roles, occupational or financial difficulties, history of infertility, social norms and stigma, and health care professionals' communication and behaviour. To various degrees, these factors contribute to increasing parental stress during the hospitalization period.

6.2.2.1 NICU Physical Environment

The physical environment in the NICU is a major stressor for parents, for a number of reasons. Parents experience stress, for instance, when they see a lot of advanced technology or medical equipment, due to the intimidating appearance and complexity of the machines, and on occasion the sounds emitted by these machines.

“I saw the incubator and mechanical ventilator, babies with frightening shapes, and babies with mental or physical disabilities. I felt like I was in a ghost room.” (Fayiz, 3/6/2015)

“It is a busy environment, with small or abnormal babies, alarms, the smell of alcohol, mechanical ventilators, incubators, and dim light... all of these made me feel stressed.” (Esra'a, 3/6/2015)

As one of the parents described, she experienced stress from odors present in the NICU. Many parents dislike the smell of alcohol and medication that is typically present in the units, feeling stressed when they visit their infants because many precautions are required before they enter the sterile environment. Parents also experienced uneasiness from the busyness and crowdedness of the NICU, caused by the presence of other parents and visitors.

“I experience feelings of choking and dyspnea when I enter the NICU because it always seems dark, with dim lights, monitor sounds, many beds next to one another, sick babies, many equipments... all of these things make me stressed, to the point of feeling like choking or suffocating.” (Rufaid, 8/6/2015)

Parents also lamented the lack of hospital facilities, such as waiting rooms and incubators. The lack of waiting rooms prevents parents from resting when they visit their infants, and contributes to the parents crowding around the NICU. Chairs where visitors can sit and rest are often too far from the NICU.

“There is no place to take a rest or sit, no waiting room. We remain standing in front of the NICU. Sometimes we stand for more than three hours.” (Ahmad, 2/6/2015)

6.2.2.2 Infant Appearance and Behaviour

During the pregnancy, parents await the delivery of their infant with a sense of anticipation, no doubt imagining the appearance and behaviour of their infant. But when infants are born premature and require NICU admission, their appearance and behaviour would differ vastly from that of full-term, healthy infants, thereby increasing parental stress. Indeed, the results of this study show that all parents experience stress related to infant appearance and behaviour, such as small baby size and abnormal skin color.

“I feel stressed about the unusual color of my baby and its restless, abnormal movements...” (Rana, 9/6/2015)

“I was very stressed when I saw the nurse taking my baby... she was small with blue skin, and she looked dead and wrinkled.” (Fayiz, 3/6/2015)

Parental stress also rises as a consequence of seeing needles, machines, and equipment around infants; and stress levels increase further among parents when they see their infants connected to machines or when nurses carry out medical interventions that appear painful.

“When I saw my baby in the NICU, she needed a respirator to breathe... there were needles ;and tubes inserted into her body. My feelings of stress increased because these frightening images are saved in my mind... I mean, when I saw my baby having a machine breathe for her, having many needles in her arms, and sleeping motionlessly in the bed... she looked tired.” (Fayiz, 3/6/2015)

"Today in the morning when I saw the nurse collect a blood sample from my baby, I started to cry... also when I saw other babies in the incubators or when the nurses performed CPR for other babies or when one of the babies died... these caused me to be very stressed, anxious, tense, and sad."(Rana, 9/6/2015)

"I saw the incubator, mechanical ventilator, babies with frightening shapes and other babies with mental or physical disabilities..." (Rula, 4/6/2015)

Furthermore, the most stressful factor for parents is their infant's ongoing health status and recovery progress. Parents were highly invested in following developments of their infant's health status throughout the hospitalization period. All parents became less stressed when their infants' medical condition improved, but their stress levels worsened when their babies' medical conditions deteriorated.

"When I don't have any information and knowledge about my baby's status, many bad ideas start to race through my mind. But I feel comforted when there is good news regarding my baby's health status." (Ahmad, 2/6/2015)

6.2.2.3 Parental Role, Relationship and Attachment

Infant hospitalization in the NICU holds many stressors for parents, many of which are evoked by the crisis of parent-infant separation early on in the child's life. Many parents, separated from their infants, report an interruption in the development of a healthy parent-infant relationship. Normal transition to parenthood is delayed, so parents cannot carry out their role of parenting.

For these parents, the primary stressor is the inability to carry out their roles and responsibilities as parents, which is to feed, clothe, and hold their infants. Mothers are unable to breastfeed their babies. Rather than bringing their infants home, they are separated from their infants by a pane of glass, from where physical touch and personal interaction is difficult, if not impossible. Parents also explained that being merely a visitor to the NICU is extremely difficult, leading to feelings of helplessness, powerlessness and instability.

“The nurses don’t allow me to enter the NICU and carry my baby and call ‘Adan’ in his ear, the way I did with his siblings... it’s hard when I can’t touch my baby in the NICU and when I can’t do anything to help my baby... I can’t carry out my motherly role with my infant... this is a very difficult factor that increases stress for a mother, making her feel helpless because she can’t do anything... I can’t help my baby, can’t take care of my baby. I fear in future the relationship with my baby will be disrupted because he stayed in the NICU.” (Rana, 9/6/2015)

Moreover, infant hospitalization impacts parents’ normal functioning in their day-to-day lives. Fathers may be forced to perform double duties and play the role of the mother in the mother’s absence, besides maintaining the role of breadwinner in the family. Parents thus experience alterations in parental roles, in daily routines, and in domestic responsibilities. Fathers face problems in their jobs, staying late at work or risking recurrent absence.

“I did many things in the same day... I cooked food, cleaned my home, took care of my wife, came to the hospital, did shopping... some days I can’t go to work because I don’t have time. I can say to you, my life is turning upside down.” (Zaid, 6/6/2015)

6.2.2.4 Health Care Professionals’ Communication and Behaviour

Continuous communication between parents and health care professionals is a vital part of reducing parental stress and worry, and supporting parents in coping with stress. Poor communication with staff leads to increased parental stress levels. Parents in this study described nurses in the NICU as impolite, nervous, disinterested, careless, and negligent. Furthermore, nurses were perpetually busy and did not have time to discuss the health status of infants with their parents. When they did communicate, they barely used eye contact; some nurses even shouted at parents or argued with them.

“I tried to request permission from nurses to enter the NICU and see my baby, but the nurse shouted rudely, ‘NO! You can’t enter!’ I felt inferior, like a servant. The nurses talk impolitely and don’t use eye contact when speaking to me... why do the nurses treat parents this way? We are humans. They should speak politely to parents.” (Aya’a, 6/6/2015)

“The nurses prevent me from being motherly to my infant. The staff here is not good... the nurses are usually nervous, fighting with me and other parents, shouting when I talk to them... they don’t respect the parents and visitors.” (Rana, 9/6/2015)

“Today when my wife was tired and started to cry, the nurse’s response was just, ‘don’t cry, or if you want to cry, leave the unit,’ without any other comment or concern for why she was crying. My baby is very ill. I think the nurse’s behaviour was wrong because it affects my wife and me psychologically. I don’t think the nurses and doctors are interested in understanding how we feel.” (Esra’a, 3/6/2015)

6.2.2.5 Lack of Knowledge

Lack of knowledge is a major stressor among parents with hospitalized infants, whether it is regarding infant health status, recovery progress, medications, medical interventions, medical jargon, or how to care for the infant in the future. Parents had many questions about the duration of hospitalization, appropriate treatments and interventions, and the impact of NICU admission on the physical and mental development of their infants.

It is often the case that parents have misconceptions about premature babies or babies admitted to the NICU, mistakenly believing that their babies are abnormal or different from other infants. In addition, parents’ fears are aggravated by the medical jargon used among health care professionals; they assume the worst about their infants’ health status as they do not fully understand the medical terms used. Once more, this is related to the way health care professionals communicate information about the baby’s health and progress to the concerned parents.

“The most stressful factor for me is when the doctors use too many medical terms and give too many different answers to the same questions... it makes you think they don’t really know what they’re talking about. Moreover, they throw terminology at you that you don’t understand, and they are sometimes totally insensitive to the fact that it feels like a death sentence for your child when they come in and explain test results, and then rush out again before the information has sunk in.” (Ahmad, 2/6/2015)

“I feel stressed when I hear the doctors talking with nurses in medical jargon because I don’t understand what he is saying... I want to know all information about my

baby's health... I want to know when my baby will be discharged from the hospital... what will happen in the future? What are the medical interventions for my baby?" (Rahaf, 11/6/2015)

"I'm worried about my daughter. There are many questions in my mind, such as: why can't I take her home? What if she dies (God forbid)? Why does she need to be in the NICU? When will she be discharged? What about her health?" (Fayiz, 3/6/2015)

"All parents worry for the health status of their children, especially if they are admitted to the hospital. When they are admitted, we want to know their health status and when they will be discharged. How long do they have to stay in the hospital? Here, the doctors do not explain in detail about the baby's health status. Maybe it's very difficult for doctors to provide us with a lot of information, because the medical condition of our daughter is very complex, and it changes all the time. I think." (Esra'a, 3/6/2015)

6.2.3 Impact of Stress

The majority of parents with hospitalized infants in NICU indicate that the episode leads to physical and psychological issues.

6.2.3.1 Physical Impact

The results show that parents suffer from many physical problems after admission of their infants to NICU, such as fatigue, dizziness, headache, nausea, dyspnea, weakness, poor concentration, and frustration. Mothers also suffer from breast engorgement, reduction in breast milk, and severe hemorrhage because they do not breastfeed their infants. Jordanian Muslim mothers consider breastfeeding and providing nutrition to their infants an important maternal duty.

"I feel tired because my daily life has changed... I don't have adequate rest... sometimes I feel dizzy, weak, and severe headaches." (Qais, 8/6/2015)

"When I saw my baby like this, I felt dyspnea and severe headache... I found it hard to focus on anything, my concentration decreased, and many problems occurred in my workplace due to my poor performance. I feel frustrated." (Tariq, 9/6/2015)

"I feel more stressed and worried because the bleeding wouldn't stop, but increased daily instead. I used nearly three packets of sanitary pads, or more than three... I'm very worried about my case and I feel embarrassed for having to go many times to the

bathroom at home and in the hospital. I have such severe bleeding that sometimes I feel the blood flowing down my legs. I also feel pain in my breasts and the milk accumulates because I'm not feeding my baby.” (Asma, 2/6/2015)

“Nearly six days after admitting my baby to NICU, I felt sad related to decreased milk in my breasts because I didn't breastfeed my baby... now I can't breastfeed my baby because there is no milk. I also have nausea, headache, and general weakness throughout my body.” (Aseel, 7/8/2015)

6.2.3.2 Psychological Impact

With regard to psychological problems, nearly all parents complained of symptoms such as depression, anxiety, sleep disturbance, postpartum depression, loss of pleasure, nervousness, anorexia, nightmares, and continuous thinking. These problems arise due to lack of rest and stress faced by parents from the admission of their infants to NICU, coupled with increased responsibilities and duties which burden them psychologically.

“I can't sleep at night because I have many nightmares and I'm continuously thinking about my baby, and I prefer sitting alone and crying because I fear losing my baby.” (Aya'a, 6/6/2015)

“I cried a lot of times... I felt nervous, sad, anxious, helpless... I was worried about my daughter's health status, I had anorexia, I couldn't sleep, I had symptoms of depression... always thinking about my daughter and her future... I lost pleasure or interest in doing anything...” (Shrooq, 10/6/2015)

“After admitting my baby to NICU, I became nervous... I had anorexia... I lost nearly 5kg within a week... I preferred to be alone... I was stressed...” (Ihsan, 30/7/2015)

6.2.4 Coping Strategies

Parents who are affected by stress use many coping strategies to help them face stressful situations. The results show that the most common coping strategies are spiritual support, social support, and physical support.

6.2.4.1 Spiritual Support

The parents interviewed for this study expressed that their religious inclinations and convictions were helpful. Although they might not be able to fully accept the situation, they report that praying helps them to cope with the situation.

“I want to tell you that, until now, I still cannot accept this situation, but I have tried to cope with it. In the first few days, I cried... I didn’t do anything except cry. Now, I doa’a to my God. I cannot pray or read the Quran, but I doa’a that my God will help me to deal with and to cope with this situation.” (Hadeel, 8/6/2015)

“I pray every day in the mosque and doa’a for my daughter to heal and be discharged from the hospital as soon as possible.” (Qais, 8/6/2015)

6.2.4.2 Social Support

Another coping strategy described was seeking social support from parents, spouses, siblings, relatives, friends, and other parents in similar situations.

6.2.4.2.1 Family Support

Parents share their experience with supportive family members, obtaining advice from them and confiding negative feelings. This process reduces stress levels and alleviates the effect of psychological stress among parents.

“I express my emotions to my mother and my wife. It helps me to relax and cope with my problems, because they give me supportive words that help change negative feelings into positive feelings.” (Fayiz, 3/6/2015)

“I feel comforted when I express my feelings to my mother, my sister, and my husband. I feel comforted because I tell them everything in my heart and on my mind, and they give me support to help me face this situation.” (Esra’a, 3/6/2015)

6.2.4.2.2 Peer Support

Sharing experience among parents with similar experiences also helps parents to gain new perspectives; parents know they are not alone in this world as they can obtain support from other parents whose infants are admitted to NICU.

“Talking with other parents who have a baby in NICU... we talked about the NICU, their babies, how they cope with the situation, how they take care of their babies, etc.” (Hani, 8/6/2015)

“My stress decreased when I talked with other parents who had infants admitted to NICU. We were sharing our experience, and when I was talking with them, I felt that I was not the only mother in the world with an infant in the NICU.” (Inam, 30/7/2015)

6.2.4.2.3 Healthcare Professional Support

Support from health care professionals is important because parents felt comforted and optimistic when they are provided with positive information regarding their infant’s health status. On the other hand, parents become stressed and worried when they do not have any information regarding their child’s health progress.

“I felt comforted when I talked to the health care providers such as nurses or doctors. In our family, we have many relatives working in the hospital. I asked them questions and talked with them about the health of my baby, complications, medical interventions, progress, and medications.” (Hadeel, 8/6/2015)

“I feel comforted when I express my feelings to the doctors or nurses, and discuss with them regarding the health status of my baby...” (Taleb, 29/7/2015)

6.2.4.2.4 Friend support:

Added to the above, the results showed that friend support is a vital coping strategy for parents during this stressful situation. The parent reported that when they express their feeling to their friend they feel comfortable and their friend support them to face this stressful situation and their friend provide them advice and some of their friend provide the parent financial support. This is illustrated by one parent:

When I feel stress I prefer to set with my friend and express my feeling to her.....she supports me Advice mecomfort mehelp me My stress decrease when I talked with my friend....my friend is helping me in stressful situation also help me in financial problems (Rana, 9/6/2015).

"I prefer to talk and express my feeling to my friend instead of my wife or my family "(Qais, 8/6/2015)

6.2.4.3 Physical Activities Support

Some parents cope with stress by eating chocolate, relaxing, running or jogging; others by crying, shouting, breaking things, not eating, smoking, sitting alone, or taking photos for their infants.

“When I feel very stressed or encounter a bad event, I smoke many times in one day, sometimes up to three packs a day... I don’t know why. I feel like cigarettes are ‘magical sticks’ that minimize my stress and help me to deal with stressful situations. I know that smoking affects my life negatively, but I can’t stop. I can’t... I can’t eat or sleep, and I’m so nervous that I smoke to deal with these problems.” (Hani, 8/6/2015)

“I tried many ways to deal with my stress. I cried to express my sadness, I took photos daily with my daughter, I brought her clothes and asked the nurse to put the clothes on her, and I took photos of her in the new clothes. I put her pictures in my house and I pray daily to God to heal her... I eat more... I eat chocolate, fruit, rice, bread... I eat more than seven meals daily, and I eat between meals... I can’t stop eating... I always feel hungry... I don’t know what I can do to stop eating... I’ve gained weight, but I feel relaxed when I eat. I’m constantly nervous... I shout at any one who talks to me. (Rufaid, 8/6/2015)

6.3 Integration of Themes

The qualitative results in this study resulted in many themes, namely intense emotional responses, sources of stress in NICU, physical and psychological impact, and coping strategies. In the first theme, admission of an infant to the NICU is a stressful experience for parents, and many parents describe initial negative emotional responses as a result. These feelings include sadness, guilt, nervous breakdown, irritability, anxiety, restlessness, fear, shock, upset, and disappointment.

Many sources in the NICU contribute to a negative experience for parents, such as the physical environment, infant appearance and behaviour, health care professionals’ communication and behaviour, and social norms and stigma. These sources impact parents and increase stress during the hospitalization period of their infants. Results show that parental stress stems partially from the presence of complex medical equipment, alarms, lack of hospital facilities (such as waiting room and incubators),

medical interventions for infants, and progress in infant health. Another source of stress is infant appearance and behaviour, such as small baby size. Parents feel stressed when their infants looked tired, sick, or in pain. Separation from their infants also causes a delay in normal transition to parenthood, such that there is disruption in the development of healthy parent-infant relationships and attachment; understandably, parents experience emotional distress and guilt from the inability to carry out their parental roles. Furthermore, parental stress increases with poor communication and behaviour demonstrated by health care providers, such as shouting, arguing with parents, lack of knowledge, impolite behaviour, nervousness, disinterest, carelessness, perpetual busyness, negligence, and overuse of medical jargon.

Added to the above, parents are physically and psychologically impacted by the admission of their infants to NICU. Prolonged exposure to stressors lead parents to experience physical discomfort, such as fatigue, perspiration, dizziness, headaches, nausea, dyspnea, weakness, poor concentration, and frustration. Mothers additionally suffered from breast engorgement, reduction in breast milk, and severe hemorrhage. Psychological problems also surface, including depression, anxiety, sleep disturbance, postpartum depression, loss of pleasure, self-hatred, guilt, hopelessness, sadness, anorexia, nightmares, and even rejection of the infant.

Finally, parents employed many coping strategies to manage their experience. As 95% of Jordanian parents are Muslims, spiritual support is a primary coping strategy used by parents to deal with exposure to stressors. Spiritual support comes in the form of spiritual behaviours, such as prayer, reading the Quran, Doa'a, Sunni practices, and seeking patience and pardon. In times of difficulties, Muslims depend on Allah to help them deal with the stressors of their reality. Turning to religion provides understanding of the purpose and meaning underlying the hospitalization experience. Spiritual support

is also a powerful source of happiness, optimism, and hope, especially as it decreases incidence of psychological problems such as depression, anxiety, and sleep disturbance (Koenig et al., 2001). The value of religion is that it helps parents to change their mindsets and perceptions regarding illnesses, and promotes their acceptance of infants' medical condition. Much evidence in Sunni and the Holy Quran enables Muslims to use spiritual behaviours to cope with stress.

Other social coping strategies available to parents include sharing their feelings with their fathers, mothers, spouses, siblings, relatives, friends, or other parents. Community support also comes from other parents who share the same experience of infant hospitalization. In addition, parents engage in physical activities such as writing in a diary, relaxing, exercising, eating chocolate, crying, shouting, breaking things, smoking, or isolating themselves. By actively engaging in another activity, parents are able to take their mind off the stressful situation and channel their energy in productive ways. All of these are coping strategies that help minimize the negative effects of prolonged exposure to stress (Figure 6.1).

It would appear that for parents the admission their infant in NICU cause them to experience intense emotions due to exposure to many sources of stress. Prolonged exposure to these stressors and feeling of intense emotion cause a physical and psychological problem. To face these problems the parents used many coping strategies (Figure 6.1).

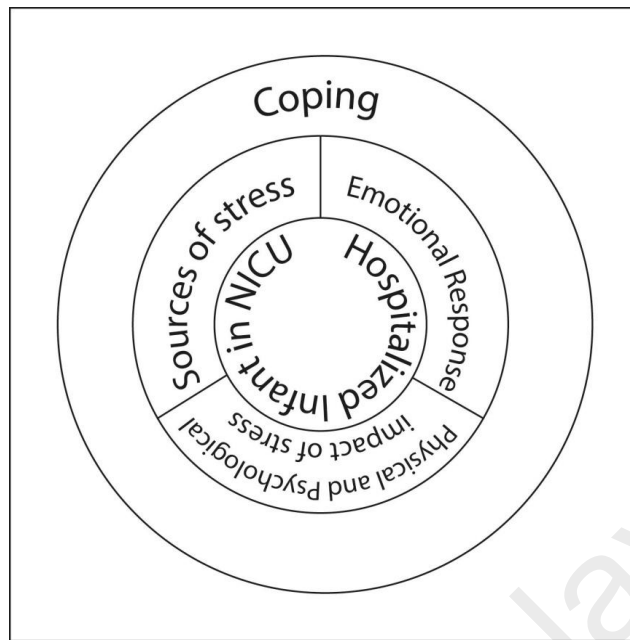


Figure 6.1 Framework of Integration of Themes

6.4 Summary

Having an infant hospitalized in the NICU constitutes a stressful experience for parents. Parents react with a range of intense emotional feelings to the situation, and confront many different stressors related to the hospitalization episode – including but not limited to NICU environment and staff, physical and psychological impact, and altered parental roles. Consequently, parents of hospitalized infants employ various coping strategies to alleviate stress.

CHAPTER 7: DISCUSSION

7.0 Introduction

The aim of this chapter is to discuss the findings of this study and to compare the findings with previous studies. This chapter also provides rationalizations for the results, and explains how the results add new knowledge to the nursing field.

7.1 Parental Stress of Infant Hospitalization in NICU

The findings of this study showed that both parents experience high stress levels due to the admission of their infants to NICU. Both parents experience high stress levels after the hospitalization of their infants, but Jordanian mothers had higher levels of stress than fathers. Other research studies have also found that mothers with infants in the NICU encounter higher levels of stress than fathers (Beheshtipour et al., 2014; Buuse et al., 2013; Chiejina et al., 2015; Dudek-Shriber, 2004; Matricardi et al., 2013). To our knowledge, no journal articles report fathers experiencing higher stress levels than mothers. These findings could be due to mothers' elevated anticipation of their role as the primary caregiver (Heidari, Hasanpour, & Fooladi, 2012a; Penjvini, Hejrani, & Mansouri, 2015). Upon the hospitalization, mothers feel that they have lost their role and identity due to the inadequacy of their baby. In Jordan, females are culturally expected to be the caregivers (Abuidhail, 2014; Baker & Dwairy, 2003).

The literature reports that elevated parental stress from admission of infants to NICU results in negative impact on normal parenting roles and parent-infant relationship (Busse, Stromgren, Thorngate, & Thomas, 2013; Heidari, Hasanpour, & Fooladi, 2014; Vazquez & Cong, 2014). Parental stress, furthermore, leads to many psychological problems such as depression, anxiety, and sleep disturbance.

7.2 Stressors in NICU

There are many stressors in the NICU that elevate parental stress. Based on the literature review, the most common stressors are sights and sounds, infant appearance and behaviour, and altered parental roles (Miles et al., 1993).

The findings of this study also indicate that the most common stressor associated with mother stress is infant appearance and behaviour ($M = 4.06$, $SD = .810$), whereas the lowest source of stress is sights and sounds ($M = 3.20$, $SD = .822$); while the most common stressor associated with father stress is sight and sounds ($M = 3.62$, $SD = .952$), whereas the lowest source of stress is infant appearance and behaviour ($M = 3.20$, $SD = .822$). This supports the findings of Varghese (2015) that infant appearance and behaviour is the greatest source of stress, followed by altered parental roles, and lastly, sights and sounds for mothers and sights and sounds is the greatest source of stress, followed by altered parental roles, and lastly infant appearance and behaviour for fathers. Similar results regarding infant appearance and behaviour were also found by Dudek-Shriber (2004), and Musabirema et al. (2015) found that infant appearance and behaviour ($M = 4.02$) caused highest parental stress levels, whereas sights and sounds ($M = 2.51$) was the lowest source of stress. This might be explained by the Jordanian society's expectations of infants to be chubby, pink, and healthy.

Busse et al. (2013) reported, on the other hand, that alterations in parental roles was rated as the highest stressor for parents with infants in the NICU ($M = 3.25$, $SD = .99$), whereas sights and sounds in the NICU was rated as the lowest source of stress ($M = 2.37$, $SD = .81$). Also, Carter et al. (2007) found that the most stressful factor for parents was altered parenting role, followed by sights and sounds, and lastly, infant appearance and behaviour.

Moreover, findings of the current study showed that parents experience the most stress in terms of NICU sights and sounds due to the presence of monitors and equipment ($M = 3.65$, $SD = 1.027$), and the least stress due to the sudden noises of monitor alarms ($M = 3.50$, $SD = 1.128$). Miles et al. (1993) supports this aspect of the results. This finding may be related to the parental perception that complex machines and equipment surrounding their infants may be a sign of the severity of their infant's health condition. Parents feel stressed and worried because they are unfamiliar with the machines and equipment.

Related to infant appearance and behaviour, parents experience higher stress when they see the small size of the baby ($M = 3.89$, $SD = 1.128$), bruises, cuts or incisions on their baby ($M = 3.88$, $SD = 1.041$), and the wrinkled appearance of their baby ($M = 3.87$, $SD = 1.005$). It stresses parents out to see the fragility and size of their baby, and to compare their babies with normal babies. Small size may indicate a baby's critical health condition, and parents cannot help but fear delay in their baby's physical and mental development. Miles et al. (1993) also reported that parents experience more stress regarding the small size and wrinkled appearance of the baby. On the other hand, Al-Hamad (2007) reported that parental stress originates from seeing their infants on respirators.

In terms of altered parental roles, parents experience higher stress levels because they are separated from their babies ($M = 3.82$, $SD = 1.049$), whereas they experience less stress with regard to not being able to care for their babies ($M = 3.32$, $SD = 1.383$). As infants are hospitalized in the NICU, there are delays in the relationship and attachment between parents and infants. Al-Hamad (2007) supports this finding that parents experience more stress from the separation with their child.

In comparing the effect of NICU stressors between fathers and mothers, this study found that fathers experience less stress regarding infant appearance and behaviour, sights and sounds, and altered parental roles, compared to mothers. A possible explanation is that mothers play the role of the main caregivers, and the close association to their child leads them to be most affected by the appearance and behaviour of their infants. The findings also show that the most significant difference in stress between mothers and fathers are with regard to altered parental roles and sights and sounds. Miles et al. (1993) support this finding, reporting that mothers experience higher stress levels than fathers regarding altered parental roles. Likewise, Seideman et al. (1997) reported that the altered parental roles ($n = 31$, $M = 3.29$, $SD = .90$) had highest mean scores on the PSS: NICU scale, followed by the infant appearance and behaviour ($M = 3.15$, $SD = .96$). They also found that mothers experienced more stress related to these stressors, compared to fathers. Moreover, there were significant correlations between overall stress levels and PSS: NICU subscales (sights and sounds, infant appearance and behaviour, and altered parental roles) ($r = .699$, $r = .960$, and $r = .869$ respectively). This finding is congruent with previous studies (Miles et al., 2002; Seideman et al., 1997).

7.3 Impact of Parental Stress

The present study found a positive association between stress and depression, anxiety, and sleep disturbance among parents with infants admitted to the NICU. These results are supported by Busse et al. (2013), Carter et al. (2005), Holditch-Davis et al. (2009), Lee, Lee, Rankin, Weiss, and Alkon (2007), and Shelton, Meanery-Delman, Hunter, and Lee (2014).

Upon comparison of anxiety and depression levels among Jordanian fathers and mothers with infants admitted to the NICU, the current study found lower levels of

anxiety in fathers. Likewise, Carter et al. (2005) reported that the anxiety level among fathers was 11%, whereas it was 18% among mothers. Additional recent studies support the finding, indicating that 20% of fathers and 24% of mothers report anxiety (Kong et al., 2013). Kong et al. (2013) found a similar trend for depression, where fathers experience lower levels of depression compared to mothers. Using the Self-Rating Depressive Scale (SDS) to measure depression levels in 600 parents of hospitalized infants, a recent study demonstrated that 35% of mothers and 31% of fathers had depressive symptoms. Carter et al. (2005) on the other hand, reported no significant differences in levels of depression between fathers and mothers with infants in the NICU. Deeney, Lohan, Spence, and Parkes (2012) theorized that mothers experience more depression because females are more expressive and emotional.

The current study reported that mothers and fathers did not experience significantly different levels of sleep disturbance. This contrasts with the study by Lee et al. (2007), which found that a staggering 93% of mothers reported sleep disturbance, compared to 60% of fathers. Meanwhile, Gay, Lee, and Lee (2004) revealed that, in the postpartum period, mothers encounter sleep changes similar to those of fathers, meaning that both parents suffered equal amounts of reduced sleeping hours. A logical interpretation of this result could be due to the differing roles and anticipations of mothers and fathers in different nations. Mothers in Jordan are normally in charge of caring for their children; they are expected to care for their infant (Abuidhail, 2014). When infants are admitted to the NICU, mothers may feel that the NICU staff members have become the primary caregivers, thus rendering their own role and identity insignificant. This insecurity may be the main cause of stress, anxiety, depression, and sleep disturbance (Abuidhail, 2014).

The findings of this study illustrate the ubiquitous experience of depression, anxiety, and sleep disturbance among fathers and mothers, thereby reinforcing the research that admitting an infant to the NICU can be a difficult experience for parents. The correlation tests demonstrate that stress plays a fundamental role in psychological problems among parents. One study has illustrated a high correlation between stress and depression, anxiety, and sleep disturbance for the general population (Ohayon & Roth, 2003). Sleep is vital for mothers and fathers in neonatal intensive care, as it affects their physical, emotional, and psychological health, as well as the capability to address the situation and take control regarding the infant (Edéll-Gustafsson, Angelhoff, Johnsson, Karlsson, & Mörelius, 2015).

Generally, parents visit their infants in the NICU daily, spending their time in a dimly-lit NICU environment designed to provide little stimulation and promote the health and development of preterm or sick infants. As a result, parents have dramatically decreased exposure to light, which can impact their sleep in a negative way (Edéll-Gustafsson et al., 2015; Hunt, 2011). Daytime fatigue, inhibition of mental clarity, and cognitive functioning may be increased due to lack of recuperative sleep (Edéll-Gustafsson et al., 2015; Hunt, 2011). Being the culturally-designated major caregivers, it is understandable that mothers in this study indicated more sleep disturbance than fathers. In the long-run, parents' health or mental state can become an issue and jeopardize marital relations, family dynamics, and parent-infant relationships.

7.4 The Influence of Parent and Infant Characteristics on Parental Stress

When infants are admitted to the NICU, the most significant contributors to parental stress levels can be related to parent or infant characteristics. The findings of the present study showed significant differences in stress levels of mothers and fathers, indicating that parent gender is a contributing factor. Mothers experienced higher stress

levels than fathers, a finding which is congruent with other previous studies (Beheshtipour et al., 2014; Busse et al., 2013; Gallegos-Martinez et al., 2013; (Akbarbegloo et al., 2013). This may be due to the natural vulnerability and emotional reactions of mothers. Mothers may also feel more pressure than fathers to give birth to a healthy infant, so they experience overwhelming sadness and guilt when their infants are admitted to the NICU. They feel personally responsible for the unhealthy state of their infants.

The study found insignificant differences between stress and education levels. The study found that parents with postgraduate degrees experience higher stress levels than other parents. This is because such parents have better basic knowledge regarding their infant health status, and they are more able to access information regarding diseases, recovery progress, and medical complications from an intellectual standpoint. Musabirema et al. (2015) and Al-Hamad (2007) also found similar results; parents with lower education levels have the additional challenge of not being able to understand explanations regarding their infant's health status. However, in this study, only a small group of 40 parents (out of 376 parents) possessed postgraduate qualifications, which may affect the overall findings; thus, this finding should be treated with caution.

In addition, there are insignificant effects of financial stress on overall stress levels for parents with hospitalized infants in NICU. However, Jordanian parents with low income reported higher stress levels than those with moderate or high incomes. This could be due to their financial constraints, meeting payment at discharge time, fees for special care in the future, or extra payments because of transportation used to visit their infants during the hospitalization period. This finding is supported by other studies (Grosik et al., 2013; (Akbarbegloo et al., 2013; Al-Hamad, 2007).

There are also statistically significant differences in stress levels for type of delivery, whether normal vaginal delivery (NVD) or caesarean section (CS). Al-Hamad (2007) supports the finding that mothers who give birth by NVD experience higher stress levels than those who give birth by CS. In contrast, Franck, Cox, Allen, & Winter (2004) found opposite results. This may be explained by the number of admission days after delivery. In Jordan, the hospital policy dictates that mothers who give birth by NVD can be discharged within 24 hours, whereas those who give birth by CS will be discharged only after 72 hours, contributing to keep mothers and infants in close proximity (Melnik et al., 2004). Mothers who gave birth by CS took analgesic, possibly contributing to lower stress levels than mothers who gave birth by NVD (Abrantes et al., 2007).

The study finding showed that parents with a history of infertility and medical disorders experience higher levels of stress than those without such histories. Parents who suffer from infertility issues live the intensifying stressful experience of not being able to give birth. Some parents seek treatment options for many years, and mothers who are finally able to conceive may require special care during their pregnancy and delivery. All of this contributes to elevating parental stress levels when their first-born infant is admitted to the NICU. To our knowledge, no studies compared these variables.

Finally, the findings show no significant differences in stress for the factor of distance between residence and hospital. Transportation and number of visits to the NICU were also taken into consideration and integrated with the distance factor. Parents who live far from the hospital travel mainly by their own cars, which requires additional resources, thus reducing the number of their visits to the hospital, reducing contact with their infants, and increasing their stress. Parents who live close to the hospital

experience less stress because they are able to visit and spend time with their infants more frequently.

In terms of the influence of infant characteristics on parental stress, the present study found no significant effect of infant gender. Other studies, on the other hand, have found that parents of female infants experience more stress than parents of male infants (Akbarbegloo et al., 2013); Montgomery-Honger, 2012; Wormald et al., 2015). In this study, Jordanian social concepts about gender could explain the findings of slightly higher stress levels in parents of female infants; most people in Arabic cultures feel stigmatized and ashamed from giving birth to unhealthy girls, who may find it difficult to get married in the future.

The medical condition of the infant exerts a significant influence on parental stress, taking into consideration the infant's gestational age, birth weight, diagnosis, and dependency on survival technology. Parents with infants of severe medical conditions experienced higher stress levels than those with moderate or mild conditions. These results were also congruent with Akbarbegloo et al. (2013) , Montgomery-Honger (2012, and Wormald et al. (2015). Parents worry about their infants' survival, growth and development when infants are severely ill, very premature, and dependent on technology to survive (Wormald et al., 2015).

7.5 The Influence of Parent and Infant Characteristics on Depression, Anxiety and Sleep Disturbance

To our knowledge, there are no studies comparing between the influence of parent and infant characteristics on depression, anxiety, and sleep disturbance. According to our results, as a result of admission of their infants to NICU, mothers experience more depression and anxiety compared to fathers, but no more sleep disturbance than fathers. This may be due to the fact that mothers have closer bonding

with their infants throughout their pregnancy and elevated anticipation of their roles as primary caregivers. When infants are admitted to the NICU, Jordanian mothers feel like they have lost their role and identity. In addition, females are usually more expressive and emotional than males. Low-income parents also experienced higher scores on these subscales, compared to those with moderate and high income. Parents with their first baby experience higher depression, anxiety, and sleep disturbance than parents with many children.

On the other hand, some parent characteristics are not significantly related to increased depression, anxiety, and sleep disturbance. For instance, education level resulted in non-significantly higher scores on all three subscales in parents with postgraduate degrees. A history of medical disorders caused parents to experience non-significant slight increases in depression, anxiety, and sleep disturbance. In addition, there were no significant differences of depression, anxiety, and sleep disturbance for parent characteristics related to distance between residence and hospital, transportation, and number of visits. Those who lived farther from the hospital experienced higher depression, anxiety, and sleep disturbance than those who lived closer to the hospital, but this was not significant.

Turning to infant characteristics, the gender of the infant results in a significant difference in depression, anxiety, and sleep disturbance; parents with female infants experience higher scores on all three subscales than those with male infants. Infant gestational age of less than 28 weeks resulted in higher stress scores in parents. Lastly, parents of infants with severe medical conditions experienced higher depression, anxiety, and sleep disturbance than parents of infants with moderate or mild conditions.

Additionally, quantitative results showed that stressor associated with the highest stress levels is infant appearance and behaviour, followed by altered parental

roles, then sights and sounds in the NICU. An explanation for this is that parents feel stressed when they see their fragile or small babies, and when they compare their babies to healthy infants. They associate the appearance of their infants with its health condition, and they inevitably feel concerned about possible delays in physical and mental development. In summary, the NICU stressors faced by parents increase parental stress and the impact of stress, and the level of parental stress or the impact of stress is correlated with parent and infant characteristics.

7.6 Emotional Responses

This study shows that parents experience many emotional problems such as surprise, shock, sadness, hopelessness, self-hatred, shame, and guilt after the admission of their infants to the NICU. Some parents experienced emotional pain that was nearly as paralyzing as physical injury, and some expressed loathing towards themselves, their lives and circumstances, as well as their own babies. Other parents were speechless, not being able to find the words to describe their situation. Moreover, parents felt shocked and surprised when their infants needed admission to the NICU. They described this situation as a crisis or disaster, as most of them had not been mentally prepared to face this challenge. Many parents expressed that their pregnancy experience had been normal and they were expecting a normal transition into parenthood, as well as a normal first encounter with their infants. The infant hospitalization in the NICU places parents in a complicated emotional situation which results in nervous breakdowns, irritability, anxiety, restlessness, powerlessness, fear, and shock.

The hospitalization of an infant, either directly after birth or within the first two weeks of life, causes a number of stressors for parents; many of which are evoked by the experience of separation and interrupted parent-infant attachment (Arnold et al., 2013, Heidari et al., 2012, 2013; Heinemann et al., 2013; Watson, 2011; Whittingham et

al., 2014). Moreover, a hospitalized infant takes a toll on the parents' emotions and peace of mind; they descend into despair and disappointment. Heidari et al. (2013) found that parents experience emotional problems such as frequent crying, anxiety, fear, restlessness, worry, insomnia, guilt, and sadness. The negative feelings and stress were the main reasons for delaying the mothers' normal transition to parenthood and carrying out their parenting roles. They feel like an outsider because of the NICU environment and they do not know what to do in the unfamiliar situation (Heidari et al., 2012, 2013; Watson, 2011).

7.7 Sources of Stress in NICU

The findings of this study identified many sources of parental stress during the hospitalization period, such as the NICU physical environment, infant appearance and behaviour, altered parental roles, occupation and financial difficulties, and social stigma. These stressors add to the burdens that parents already have to face with the hospitalization of their infant.

The physical environment in the NICU is a major stressor for parents, in part due to the presence of advanced technology and complex machines. Parents are unfamiliar with medical equipment and procedures, and fearful of long, sharp needles inserted into their babies' bodies. The dim light, sterile odors and beeping sounds add to parental stress by stimulating their senses. The results show that another source of stress is infant appearance and behaviour. Parents feel stressed upon seeing the small size of their infants, the equipment and needles connected to their infants, and the medication. This could be explained by the parents' mounting anticipation during the pregnancy period; they imagine cradling and feeding their child, their own flesh and blood, who bears a close physical resemblance to them. Premature infants, however, might not have the same appearance and behaviour as full-term infants, thus inducing parental stress.

Parents compare between their infant and other infants, and feel stressed and worried about the health and development of their infant. Parents are afraid that their infants' lives will be fraught with developmental delay or health problems, or that their infants might not survive at all.

Another source of stress is altered parental roles and attachment. Parents fear separation from their infants, as well as interruption in the parent-infant relationship. The greatest stressor is that parents are unable to carry out their role of feeding, clothing, and diapering their sick infant. As their babies are hospitalized behind a pane of glass, parents often cannot carry, hold or touch their infants. In the absence of physical contact with their infants, parents – who have longed for months to kiss and care for their infants – feel stressed, guilty, and helpless. It is fundamentally an interruption in the transition to parenthood. Instead of stepping into the role of being loving parents, they are left feeling like outsiders because of the NICU environment, where they do not know what to do as a parent in a stressful situation (Heidari et al., 2012, 2013; Russell, et al., 2014; Watson, 2011).

Results showed that parents experience guilt, shame, self-blaming, and stigma from the admission of their infants to the NICU. This result is due to Jordanian socio-culture glorifying perfect infant appearances and behaviour, and finding ways to criticize or judge anything less than perfect. Parents with hospitalized infants in the NICU have had their hopes dashed. They do not have a perfect, healthy, normal baby, and to add to that, they need to provide explanations to their relatives and friends. They need to defend themselves from accusations of genetic or hereditary diseases in their family, so that they do not carry the burdens of that stigma for the rest of their lives. Parents of female infants fear that rumours about their babies' possible disease or deformities may prevent her from getting married in the future.

Finally, the communication and behaviour of health care professionals are a source of parental stress. Parents report poor experiences with staff communication and behaviour. In their busyness, nurses in the NICU can be harsh or brusque, seeming impolite, disinterested, careless, and negligent. Parents interpret their behaviours such as lack of eye contact and excessive use of medical jargon as hostile behaviour. Unfortunately, however, there are also staff members who engage in unhealthy communication behaviour such as shouting or fighting with parents. A qualitative study conducted by Heidari et al. (2012) supported these findings, reporting that parents encounter many sources of stress in the NICU, such as social stigma and shame, poor staff communication, and interrupted parent-infant relationships. Sweet & Mannix (2012), on the other hand, found that the physical environment, infant appearance and behaviour, and altered parental roles were sources of stress for parents with hospitalized infants in the NICU.

7.8 Impact of Stress

The results show that parents present with many psychological problems, such as stress, depression, anxiety, and sleep disturbance. Besides that, they experience loss of interest in normal activities, pessimism, constant crying, nightmares, and continuous thinking. Some of these problems were due to lack of sufficient rest, inability to care for their infants, and increased responsibilities or duties, which are caused by stress and stressors as a result of admitting their infants to the NICU.

Heineman et al. (2013) affirmed that parents with hospitalized infants feel shocked, sad, and disillusioned, whereas Abuidhail et al. (2016) reported that they experience shock, surprise, anxiety, and worry. Watson (2011) added that parents feel powerless and fearful, and that they experience loss of control that can impact on their relationships. Whittingham et al. (2014) reported parents' grief, isolation, distress,

anxiety, and depressive symptoms. In addition, Heidari et al. (2012) found that parents experience guilt, fear, frequent crying, restlessness, anxiety, and physical problems caused by stress and tension. Gavey (2007) asserts that many negative mood states are caused by the separation between parents and infants.

Besides affecting parents' psychological and emotional stability, the admission of an infant to the NICU also results in physical problems. Parents with hospitalized infants complained of headaches, nausea, dyspnea, and dizziness. They were also constantly feeling tired, weak, sick, and distracted. Mothers, in addition, suffered from breast engorgement, reduced breast milk, and severe hemorrhage. Breast engorgement occurs because of accumulation of breast milk, as mothers do not have the opportunity to breastfeed their hospitalized infants. Toussaint, Shields, Dorn, and Slavich (2014) supported findings of dizziness, headache, nausea, dyspnea, and physical weakness, whereas Vohr et al. (2007) supports findings of breast engorgement due to accumulation of milk in the breast. Heidari, Hasanpour, and Fooladi (2012) also found that mothers experience postpartum hemorrhage and reduction of breast milk as a direct result of stress.

7.9 Coping Strategies

Parents with hospitalized infants in the NICU use many coping strategies, most commonly spiritual support, social support, and physical support. Results demonstrated the reliance of parents on spiritual practices such as praising Allah, praying or doa'a, cultivating patience and pardon to deal with stressful situations. Jordanian parents are mostly Muslims, and it is common in Islamic practice to ask Allah to help one deal with stressful life circumstances. Blumberg et al. (2003) supports this finding, reporting that religion is the primary source of stress relief for fathers of children with special needs; reliance on spiritual support also alleviates symptoms of depression. Biesinger and

Arikawa (2008) also found that parents of children with special needs who depend on spiritual support and religious values experience more happiness than those who did not.

Another coping strategy employed by many parents is social support, obtaining encouragement from family members and friends. Parents express their feelings to supportive members of their support system, and obtain advice to reduce stress levels and psychological burdens. Sharing experiences in this way allows parents to gain new perspectives to face their fears; it also gives them the assurance that they are not isolated from their community. In addition, professional support from health care staff becomes extremely important in the case of NICU admission. Professionals who work with parents of admitted infants play a key role in comforting parents and providing them with information. Parents become optimistic and hopeful when they gain positive updates about their infant's health status, whereas lack of knowledge or information increases their fears and worries. Many parents also cope with stress through physical activities such as writing in a diary, sitting alone in peace, eating chocolate, running or jogging, and relaxing in a manner of their choosing. Admittedly, some engaged in destructive or negative activities such as crying, shouting, breaking things, skipping meals, or smoking.

To our knowledge, there are no qualitative studies describing the coping strategies of spiritual support and physical activities elaborated upon in the present study, although there are general studies on stress which mention similar coping strategies (Aung, 2014; Davis, Eshelman, & McKay, 2008; Greenway, Phelan, Turnbull, & Milne, 2007; Saad & de Medeiros, 2012). As for social support, Smith, Steelfisher, Salhi, and Shen (2012) identified many coping strategies similar to those found in the present study, such as expressing feelings to family members, friends, staff,

and other parents. However, Smith et al. (2012) also identified other coping strategies that could be implemented by hospital staff, namely facilitating parents to be involved in caring, and arranging volunteer activities or programs in which parents whose infants have similar medical conditions can interact. Yoon (2013) and Respler-Herman, Mowder, Yasik, and Shamah (2012) also found that parents of children with special needs experience reduced stress when they use social support as a coping strategy. Respler-Herman et al. (2012)'s findings concerned the alleviation of stress specifically when parents communicate and share experiences with other parents with infants in the NICU.

7.10 Integration of Quantitative and Qualitative Results

In this mixed methods design study, qualitative results provide useful information that explain and support quantitative results. The quantitative results show that both parents experience high stress levels ($M = 3.70$, $SD = .822$) after the admission of their infant to NICU, although fathers have lower stress levels than mothers in general. The biggest stressor is infant appearance and behaviour, whereas the lowest source of stress is sights and sounds in the NICU. Positive associations were found between stress levels and the depression, anxiety, and sleep disturbance subscales. However, fathers were found to have lower levels than mothers on all three subscales.

Qualitative results were presented to develop a deeper understanding of the feelings, experiences, stressors, and impact of stress related to the admission of an infant to the NICU. The qualitative component also proved instrumental in adding crucial information about coping strategies. Parents experience many intense and negative emotions in response to the NICU admission and associated stressors such as infant's size and condition, medical interventions, machines and equipments, and the appearance of the baby. The social stigma and shame only adds to parents' stress.

Altered parental roles and routines also inflicted stress upon parents as they had to make adjustments in their home life, workplace, and family relationships. Communication with health care providers forms another source of stress through convoluted medical jargon, insufficient health updates, or lack of appropriate communication skills.

With regard to the impact of stress, quantitative results found positive correlations between stress and depression, anxiety, and sleep disturbance. Qualitative results, on the other hand, showed that prolonged exposure to stress causes many psychological problems besides depression, anxiety, and sleep disturbance. These side effects include eating disorders, loss of interest in activities, self-loathing, poor concentration, frequent crying, nightmares, and continuous thinking. Physical problems are fatigue, sweating, dizziness, headache, nausea, dyspnea, and weakness; mothers also suffer from breast engorgement, reduced breast milk, and severe hemorrhage. Fortunately, a range of coping strategies are available for use among Jordanian parents.

To our knowledge, there are no mixed design studies which support these findings, save for Sweet and Mannix (2012)'s exploration of parental stress levels in a South Australian NICU. The study identifies the psychometric properties of the PSS: NICU, and shows that moderate stress levels in parents ($n = 40$) are predominantly related to infant appearance and behaviour and altered parental role. These quantitative results were further elaborated upon by a qualitative analysis and a maternal needs inventory assessment, and the collective evidence suggests the need for positive communication, information sharing, and consistent and empathetic staff practices (Figure 7.1).

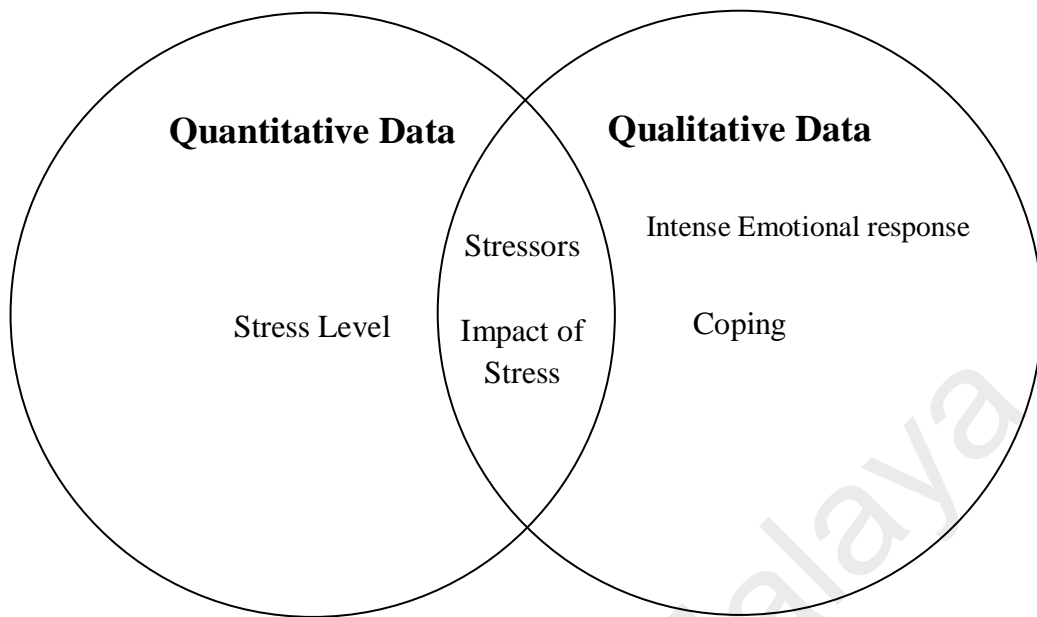


Figure 7.1 Integration of quantitative and qualitative results

7.11 Summary

In summary, the qualitative study results show that parents experience many emotional problems such as sadness, guilt, nervous breakdown, irritability, anxiety, restlessness, fear, gloom, shock, disappointment, pessimism, and incapacity regarding the admission of their infants to NICU. The results also show that parents experience mixed feelings, strange emotions, pain, difficulty, and powerlessness. Some parents described the hospitalization episode as “a knife cutting through my life”, “pain in my heart” and “a rock on my chest”; others expressed hatred towards themselves, their babies, and their lives.

These results can be explained by the relationships developed between mother and infant during pregnancy. Prior to the birth of the infant, parents prepare themselves for parenthood and imagine the first encounter with their infants. This may be why parents feel unprepared to face the challenge of their infants requiring NICU admission.

The findings of this study show many sources of stress identified by parents during their infants’ hospitalization period, such as the NICU physical environment,

infant appearance and behaviour , altered parental roles, occupation or financial problems, history of infertility, social norms and stigma, increased responsibilities and duties, and health care professionals' communication and behaviour . These impact and increase parental stress when their infants are hospitalized in the NICU. The key stressor is the unfamiliar NICU physical environment, due to alarms, sounds, odors, needles, and the presence of advanced technology, complex machines, and medical equipment. Many parents feel frightened and intimidated by the sights and sounds in the NICU.

Results show that parents suffer from a range of physical and psychological health problems, for example, stress, depression, anxiety, sleep disturbance, loss of pleasure, negativity, anorexia, nightmares, continuous thinking, constant crying, and even rejection of their own babies. These problems surface as a result of the stressors from the admission of infants to NICU.

Parents respond to this stressful situation by using many coping strategies, which can be categorized into spiritual, social, and physical support. As the majority of Jordanians are Muslims, spiritual support encompasses practices that adhere to the Islamic religion, such as reading the Quran, praying or doa'a, and cultivating patience.

CHAPTER 8: CONCLUSION

8.0 Introduction

The admission of an infant to the NICU is a stressful event for Jordanian parents. This study aimed to identify the impact of stressors on Jordanian parents with infants in NICU. The study used mixed methods design (explanatory design) and was conducted in three hospitals in Jordan. PSS: NICU and PROMIS were used to survey 376 parents with infants in the NICU. Quantitative results show that the most common NICU stressor among parents with hospitalized infants in NICU is infant shape and behaviour whereas the lowest source of parental stress is sights and sounds. There are strong positive associations between depression, anxiety and stress, on the other hand moderate positive association between sleep disturbance, and stress among mothers with hospitalized infant in NICU. Moreover, there are strong positive associations between depression, anxiety and stress, on the other hand mild positive association between sleep disturbance, and stress among fathers with hospitalized infant in NICU.

Parent characteristics affect stress levels among parents with hospitalized infants in NICU. Results show that parents having their first parenting experience suffer from higher stress levels than parents with previous parenting experience. Higher stress levels were also seen in parents with a history of infertility or medical disorders, as compared to parents without history of infertility or medical disorders. In addition, the results indicate that stress levels are not significantly affected by other parent characteristics such as transportation, number of hospital visits, financial status, distance between residency and hospital, and number of wives (for fathers).

With regard to influence of parent and infant characteristics on parental stress levels, results found no statistically significant differences in stress levels between parents of male and female infants, whereas there were significant differences based on

gestational age, birth weight, and classification of medical condition. Parent characteristics such as first parenting experience and history of infertility had significant effects on the impact of stress, in terms of increasing depression, anxiety, and sleep disturbance. On the other hand, transportation, financial status, distance between residence and hospital, and number of visits did not significantly increase the impact of stress. The qualitative component of the study resulted in many themes: intense emotional responses, sources of stress, physical and psychological impact of stress, and coping strategies. These qualitative results provided good elaborations for the quantitative results. Finally, a model was established to show the relationship between variables.

8.1 Strengths and Limitations

Strengths. This study uses a large sample size to achieve the purpose of assessing stress levels and the impact of stress among parents with hospitalized infants in NICU. Data collection was conducted in three major hospitals in Jordan, where participants came from different socioeconomic and education backgrounds, different geographical regions, and different age groups.

In addition, this study validates the PROMIS questionnaires in Jordan, presents a model of the relationships between variables for application among Jordanian parents, and explores the parental coping process during the hospitalization period of infants. To our knowledge, this is the first study in Jordan that used a mixed methods design. Thus, the study provides an in-depth understanding of the quantitative results through the corroboration of qualitative data, and presents evidence through convergence of both data types. This approach adds new knowledge to the existing body of literature. Finally, the equal representations of mothers and fathers were decrease bias and provide depth understanding of the sources and impact of parental stress.

Limitations. On the other hand, this study used the convenient sampling technique, which can limit generalizability and increase bias. It is hoped that the large sample size and diverse backgrounds of the participants will offset this limitation. There is also a risk of bias error due to the use of self-report questionnaires for data collection. In addition, the results of this study will help nurses to identify the coping strategies which can minimize parent stress. A final factor is that nonparametric tests were used to analyze the data as it did not have a normal distribution.

8.2 Implications for Nursing

The findings of this study are useful and may be implemented in many areas of the nursing field, such as nursing education, nursing administration, and nursing practice.

8.2.1 Nursing Education

Nursing education should be based on best practices and evidence-based case to help support the staff in their important role. Moreover, nursing education should focus on best practices in supporting families and benefits of appropriate family-centered care for NICU infants at every stage of development. For health care professionals, these findings contribute to the development of support and educational programs for new parents or high-risk parents with infants admitted to NICU. Professionals may use these findings to assess the stress levels and symptoms of negative psychological states, and subsequently develop ways to support parents during their baby's time in the NICU – such as providing a parenting guide, a NICU guide, and a keepsake booklet for parents. Moreover, educational programs for parents should use a variety of teaching methods, such as verbal instruction, demonstration and interactive hands-on practice, written instruction, and/or audiovisual materials. For strongest potential influences on parenting and infant outcomes, nurses ought to take into consideration each parent or caregiver's

learning style, collaborate closely with the parent, and choose the educational method that best meets their needs.

These findings may help NICU nurses to increase awareness of parental needs and try to fulfill them within their parameters, for example, by providing facilities for parents to participate in caring for their infants. Parental stress can be alleviated if parents had a care area designed to provide privacy and minimize disturbance, e.g. rooms with six or fewer cots, space between cots, screening facilities, overnight rooms with en suite facilities, and a pantry for snacks and drinks. At the very least, hospitals should allocate a sitting room adjacent to the neonatal unit for parents or a short distance away.

Furthermore, nurses need to be educated on the importance of communicating information and updates to parents on a timely basis. Nursing staff should allocate time for meetings between staff and parents, in order that parents' questions regarding their infants' health status may be addressed. Additionally, information should be individualized and tailored according to the parents' specific needs. Communication skills should be made a compulsory module in nursing curricula to ensure nurses are taught how to communicate with stressed parents. Collectively, these improvements to nursing education and considerations for parent education will greatly aid infant development, encourage parent-infant relationships, teach parents typical developmental trends, and help parents identify delays in child development.

8.2.2 Nursing Administration

The findings of this study indicate that sights and sounds in the NICU are a major stressor for parents, thus the hospital administration should act strategically to modify the physical environment of the NICU. Possible modifications to minimize stressful stimuli in the unit include adjusting the alarms, grouping infants with similar

health conditions or treatments, and reducing parental exposure to technological equipment.

Taking it a step further, the administration could establish a family center where parents can receive advice regarding strategies and measures to cope with the hospitalization of their infants to NICU. Such a center could also serve as a place that provides educational programs for nurses, to enable them to identify parental stress, high-risk parents, NICU stressors, negative psychological symptoms, and coping strategies. In addition, nurses must be educated on how to help parents with infants hospitalized in the NICU.

8.2.3 Nursing Practice

It is hoped that the results of this study will promote more supportive nursing practices for parents with hospitalized infants in the NICU. The findings of this study identified the high-risk groups of parents, such as those who have a history of infertility, as well as parents of infants with severe medical conditions, low birth weight, and low gestational age. Effective nursing practice trains nurses to support parents and help them to deal with stressful situations.

The findings of this study will help nurses to identify the coping strategies which can minimize parent stress and increase negative psychological problems, and subsequently provide identification programs for all NICU health care providers, thereby increasing awareness regarding stressors in the NICU. Lastly, the findings from this study aim to provide nurses with a good understanding of the factors that increase stress, depression, anxiety, and sleep disturbance among parents, which will guide nurses to plan nursing care accordingly.

8.3 Recommendations for Future Research

As the present study still encounters limitations related to sample size, there is a need for future studies to use a large random sample size that is representative of all Jordan. Moreover, further studies are needed to develop effective interventions or educational programs that alleviate symptoms of stress, depression, anxiety, and sleep disturbance among new parents. The nursing field would additionally benefit from studies that explore the long-term effects of parental stress, such as assessing its impact on job performance and psychosocial functioning.

8.4 Summary

In summary, mothers experience higher levels of stress, depression, anxiety, and sleep disturbance compared to fathers. There are significant positive correlations between depression, anxiety, sleep disturbance, and stress. The most common stressor in NICU that causes parental stress is infant appearance and behaviour, followed by altered parental roles, then sights and sounds. The themes identified through this study are emotional responses, sources of stress, physical and psychological problems, and coping strategies. Several implications can be drawn from this study: first, it encourages strategies to modify the physical environment in the NICU; and second, it provides nurses with a solid understanding of the stress, depression, anxiety, and patterns of sleep disturbance among parents, as well as the stressors which aggravate the mental state of parents. It is hoped that this knowledge will guide nurses in planning nursing care accordingly to alleviate the stress of parents with infants in NICU.

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List of Publication

Conference Publication

15th July 2015

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Re: LETTER OF ACCEPTANCE FOR ORAL PRESENTATION AT 1ST IPGNC

Dear Duaa Fayiz Al Magaireh,

On behalf of the Conference Scientific Committee, I am pleased to inform you that your abstract entitled: **Validation of the Arabic Version of Patient-Reported Outcomes Measurement Information System (PROMIS) Questionnaire in Jordan** has been accepted for oral presentation for the 1st INTERNATIONAL POST GRADUATE NURSING CONFERENCE 2015. The official language for oral presentation is in English. The format of abstract and speaker guideline is attached with this email.

You are required to revise your abstract according to the format given (sample attached) and re-send to us through email. Please provide us a 'brief' biographical note for introductory purpose for your session. More details and instructions will be announced closer to the event.

Please note that everyone who participates in the conference must register at our website umconference.um.edu.my/1stIPGNC. Payment must be made within days after the

REVIEW

Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit

Dua'a Fayiz Al Maghaireh, Khatijah Lim Abdullah, Chong Mei Chan, Chua Yan Piaw and Mariam Mofleh Al Kawafha

Aims and objectives. To determine the feasibility and utility of a thematic analysis approach to synthesising qualitative evidence about parental experiences in the neonatal intensive care unit.

Background. Admission of infants to the neonatal intensive care unit is usually an unexpected event for parents who can cause them to experience psychosocial difficulties. A qualitative systematic review is the best method for exploring these parents' experiences regarding this type of admission.

Design. Systematic review.

Methods. Qualitative studies in peer-reviewed journals aimed at understanding parental experiences regarding infant neonatal intensive care unit admission were identified in six electronic databases. Three reviewers selected relevant articles and assessed the quality of the methodological studies using the Critical Appraisal Skills Programme. A thematic analysis approach was used to identify the most common themes in the studies describing parental experiences in the neonatal intensive care unit.

Results. A total of eighty articles were identified; nine studies were included in this review. Four studies used semistructured interviews, three used interviews, one used self-reporting and one used both focus group and interview methodologies. Common themes across parents' experiences were the stress of hospitalisation, alteration in parenting roles and the impact of infant hospitalisation on psychological health.

Conclusion. Having an infant hospitalised in the neonatal intensive care unit is a stressful experience for parents. This experience is the result of exposure to different stressors related to the infant's condition, an alteration in parenting roles or the neonatal intensive care unit environment and staffing. These parents suffered negative psychological effects, experienced an interrupted development of a healthy parent–infant attachment and/or felt parental role alteration.

Relevance to clinical practice. The study's findings are crucial for neonatal intensive care unit nurses to develop intervention strategies and programmes that help parents to decrease the stress of their experience and to support them in facing this stressful situation.

What does this article contribute to the wider global clinical community?

- The findings from this article will provide nurses with a better understanding of mothers' and fathers' experiences regarding their infant's admission to the NICU.
- This review is important for NICU nurses to develop intervention strategies that decrease levels of stress among parents.
- This review highlights the potential use of thematic analysis in systematic reviews of qualitative studies.

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