

The Experiences of Parents after having a Preterm Child

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Abstract

The purpose of this dissertation was to investigate the experiences of parents of premature children in the Neonatal Intensive Care Unit (NICU). This study aims to provide up to date information which focuses primarily on parent's perceptions and experiences following a preterm birth and how nurses can help them during their hospitalisation in the NICU. In order to conduct this study, researcher has used qualitative research approach. The research design of this study was exploratory. Researcher strategy was systematic review of literature. The secondary data in this study was collected through a systematic key word search of electronic data bases. Overall eight studies were short listed for the analysis.

Using PICO three themes were generated and selected studies were grouped in different theme. AGREE II tool was used to for the analysis of selected studies. The review of literature divulged that due to lack of information, NICU environment and in absence of any support or guidance majority of patient experience stress and fearwhile theirpreterm child is under treatment in NICU. This study has also identified that patient in this scenario has emotional needs such as information and updates about the environment of NICU and other process of treatment and overall health and wellbeing of their child. Besides, parents also feel to be included in the care of their preterm child. This dissertation has also discovered that nursed can play an effective role in enabling patient to avoid and mangle distress while their preterm child is under treatment in NICU.

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Chapter Introduction

1.1 Background

Premature birth interrupts the process of psychobiological nesting of parents and newborn, as both need time for the nine months of gestation. At first, to create a physical and psychological place for that new family member, this leads to a reorganisation and maturation throughout the months of pregnancy that allows them to prepare for the birth (Holditch-Davis, et al., 2009).

According to the World Health Organisation (WHO) preterm may be defined as babies born before 37 weeks of gestational age. A broad description of preterm birth includes those who are born extremely preterm (<28 weeks), those born very preterm (28 to <32) and those born moderate to late preterm (32 to 37 weeks) (WHO, 2014). In the UK there is a proportion of women who have preterm deliveries. Rate of preterm births vary according to countries. In UK prevalence of having a preterm baby has risen and about 15 million babies are born before the gestational age every year (WHO, 2014).

Basically, at the birth of a premature babe time, a convergence of events generate a degree of stress among parents which increases the likelihood of psychosomatic diseases; this only adds to the fact that the of birth a new member in the presence of family illness, making room for other events such as changes in financial condition, considering the monetary costs involved specialised care; changes recreation, wholesale dedication to the child; changes in social activities; and changes in sleep patterns, feeding, hygiene or grooming (Lasiuk, et al., 2013). Parents also might present physical symptoms of stress as a result of the presence of some factors, namely: health status of the new-born, the environmental characteristics of where child is hospitalised, and separation of parent-child binomial (Miles, et al., 2007).

The child also needs nine biologically months to mature and be able to survive outside the womb. Therefore, being born before this period, found both parents and the baby and unprepared state of somatic and psychological vulnerability of the child, the mother and father created. This may worsen the situation of the child in a hospital intensive care unit of high complexity.

Shah, et al., (2013), shows that admission to the NICU it causes various reactions in parents generally intense and disturbing. Stress and depression of parents are some of the most frequently observed aspects and may interfere in the organisation of interaction between them and their child, as well as communication with the professionals who attend the child. Besides, there are other negative effects of preterm birth. Some of these negative effects include morbidity and mortality. Mathews and MacDorman (2012) show that 70% of death in neonatal and infant death can be related to preterm birth complications.

1.2 Aim

The present study investigates the experiences of parents of premature children in the Neonatal Intensive Care Unit (NICU). This study aims to provide up to date information which focuses primarily on parent's perceptions and experiences following a preterm birth and how nurses can help them during their hospitalisation in the NICU.

1.3 Objectives

To evaluate the overall impact of having a preterm baby

To analyse the emotional distress among parents of preterm baby in NICU

To evaluate the causes and impact of stress among parents of preterm baby in NICU

To evaluate the role of nurses in helping parent for coping with stress during hospitalisation of their preterm baby in the NICU

1.4 Rational

The environment of the NICU can be very overwhelming, especially for parents who are already under stress due to their baby's unexpected admission; equipment monitors and bleeping alarms can disorientated them (Yeo, 1998). Advances in the care of premature infants have meant a remarkable progress in modern neonatology. The units of increasingly NICU play an important role in reducing infant and child mortality. However, as expected, these encouraging results of the NICU have caused some unwanted effects, especially on parents.

According to the World Health Organisation (WHO, 2014) Preterm may be defined as babies born before 37 weeks of gestational age. A broad description of preterm birth includes those who are born extremely preterm (<28 weeks), those born very preterm (28 to <32) and those born moderate to late preterm (32 to 37weeks) (WHO, 2014) .In the United Kingdom (UK) there is a proportion of women who have preterm deliveries.

The population is exposed to stressors at the Neonatal Intensive Care Unit (NICU) is large, considering that UK, the average prevalence of stress among parents of premature babes is 76% on the first day and between 30% to 40 % on second day of new-borns . It is equally important to note that the average stay of these neonates approaches to twelve days, during which time parents change their daily activities: employment, type and time of meals, home care, relationships with family and friends, to go to visit and provide care relationship and their children (WHO, 2014).

Nursing care in NICU is a considered as crucial element in providing proper care to premature babes as Marlow, et al., (2015), in a study has claimed that due to more skilled and dedicated staff, more and more premature babes are surviving. There are other negative effects of preterm birth. Some of these negative effects include morbidity and mortality. Mathews and MacDorman (2012) show that 70% of neonatal and infant death can be related to preterm birth complications. According to Lissauer et al (2014) due to enhanced nursing skills and more focus on parental support the huge improvement in stress management us reported in NICU setting, and survival rate of premature babes has also enhanced. However, Young (2007) said that, despite the improvement in neonatal care and even if those born at shorter gestation survival. However, these infants are still at increased risk for poor health and depression among their parents and lack of counselling for stress management affect their health as well.

The above data forms the rationale of the study and the different reasons why women have preterm babies and the ways in which preterm birth can be dealt with will be identified and discussed. The Recommendations will be made on ways in which preterm deliveries can be reduced. The negative health and social effect of preterm deliveries will be identified and

addressed. Overall the significant role of the nurse in the Special care Baby Unit will be discussed.

II. Methodology

2.1 Introduction

In this chapter, all of the strides taken to lead the research are talked about. The researcher characterises the methodology of the research, the research design and how this research was led.

2.2 Research Approach

It is an experimental research with the intends to give up and coming data which concentrates essentially on guardian's discernments and encounters following a preterm conception and how medical attendants can help them amid their hospitalisation in the NICU. Considering the way of the research study, it appears to be fitting to utilise Systematic Review (SR) way to carry out this study.

A SR is a kind of research whereby science is investigated the logical literature on a point beginning from an unmistakable and target inquiry, utilising orderly methods and unequivocal to find and discriminatingly assess research important to this inquiry and applying efficient data collection conventions and data from such research with the point of coming to legitimate and target decisions about what are the proof accessible on this subject (LoBiondo-Wood, Haber, 2014). Therefore, a SR is the execution of methodologies restricting the commission of predisposition to coordinate and dissect basically and orchestrate all important studies on a specific theme(s) (Smith, et al., 2011).

2.3 Search Strategy

The search of the literature can be performed basically in different sorts of sources. There are diverse groupings of the sorts of archives that we handle in this search of literature:

Primary: Original, straightforwardly transmit data (unique papers, propositions);

Secondary: They give depictions of the primary reports (indexes, databases, SRs, rundowns);

Tertiary: They integrate secondary and primary studies (directories)

The databases are a secondary source of recoverable homogeneous data through Internet.

Records containing references or complete, organised in fields that cover all aspects of the information (title, author, summary, etc.). One of the most frequently used databases in Health Sciences is Medline (Fink, 2013).

The National Library Medicine (NLM) developed MEDLINE database in the United States of America (USA), more than 4,000 bibliographic references and abstracts are available in this database, most of the biomedical journals published in the UK, USA and 70 other countries. It is including the International Nursing Index (INI) that containing around 270 international journals nursing articles. Medline has approximately 11 million records on biomedical literature since 1966. It contains the fields of medicine, nursing, dentistry and veterinary medicine (Fink, 2013). The updating of the database is monthly and contains a thesaurus (dictionary controlled terms) called Medical Subject Headings (MeSH), a system tree that using different terminology for the same aspects, provides a steady way to search for information,.

The chosen research style to implement was a systematic literature review. This style helps to track down all available research on a topic (LoBiondo-Wood, 2013). Fink (2013) have defined a systematic review has follow; “is a concise summaries of the best available evidence that address sharply defined clinical questions “

2.3.1 Keywords

Subsequent to selecting databases, descriptors or keywords will be chosen. Keywords are the real ideas or variables of the issue or issue of examination. These words will be the way to begin the search. In the vast majority of the databases, keywords may be utilised as just words in

addition to expresses. At the point when recognise pertinent studies, the researcher can check for different terms that can be utilised as keywords. Option terms (equivalent words) for ideas or variables can likewise be utilised as keywords. Most databases have a thesaurus that can be utilised to recognise key search words. In this specific study the keywords, for example, premature birth, parents, Stress, NICU are utilised with Boolean administrators of "Or" "And" to locate the greatest number of researches.

The search process begins performing a different search in each database, for each keyword is recognised. Search gadgets not forget spelling slip-ups and, accordingly, it is important to painstakingly screen. Most databases permit show quickly what a piece of the database records is planned search for the term (in the titles of the articles, diary names, keywords, headers formal issues or full messages of articles).

While searching for my relevant articles, search terms were included to ensure that the research was not oversaturated with literature (Fink, 2013). (See Table)

First attempt of combinations of terms	Prem* OR parents AND experiences
	Prematurity OR parents OR attitudes
	Parents experiences AND preterm-baby
	Parents OR perceptions AND prematurity
Final search terms	Experiences AND parents AND prem*
	Parental experiences AND early birth

Table. Search Terms

Most databases give synopses of the articles in which it refers to the term, giving some data about its substance, so the researcher can judge whether the term is helpful in connection to its chose point. On the off chance that he finds any imperative reference, he ought to spare it in a

record. Then again, the quantity of references (or "discoveries") that were discovered ought to be noted. Now and again, the quantity of discoveries may be too high for them to be analysed in its total. Contingent upon the search method and mix of keywords, results will be pretty much precise and will get high number of results. At the point when records coordinate the search themes, it permits recognising what their descriptors and in this manner utilising as a part of new searches for more exact data.

2.3 Selection Criteria

The determination criteria are dictated by the targets of the audit, i.e. the unmistakable inquiry for research. Another perspective that decides the determination of things is methodological quality and in the event that they meet the criteria looked for investigative quality. In a first stage the angles that the researcher considers should be: the authors, title, and results and the abstract.

At the beginning I had planned on investigating the role of the nurse in SCBU, however as the role of the nurse is broad and focusing only on one specific role could have reduce the amount of primary research. After reflection I decided to investigate parents' experiences after having a preterm baby and how this can have an impact on their lives and this leads to my research question "What are the lived experiences of parents having a preterm-baby".

As to title, the researcher can check whether it is helpful and significant to the research subject, the researcher's involvement in the field will be distinguished and the rundown ought to break down whether it is right and if the outcomes are appropriate to the subject of study. The second stage will continue to the discriminating perusing of records. Discriminating perusing project is a strategy that offers the chance to build the adequacy of the perusing, gaining aptitudes important to reject as fast as scholarly articles and terrible acknowledge those

sufficiently other investigative quality to help the researcher in choice making. Along these lines, the papers must be assessed in three regions:

1. Can we believe the outcomes? As such: would they say they are substantial? That is to say, arraign the methodological legitimacy of the article. The criteria of legitimacy things are diverse for distinctive inquiries;

2. What are the outcomes? Case in point, would it be able to be contrasted with the test intercession with control an extraordinary impact and so forth? What's more, how they aren't that right?

3. Are these outcomes important or material in my surroundings? (Supino, Borer, 2012)

2.5 Inclusion / Exclusion Criteria

The inclusion/Exclusion criteria are utilised to channel the search. In the wake of utilising legitimate keywords with fitting Boolean administrators, and also manual search on search motors, will give countless on the given theme. To minimise this number, the researcher needs to apply some particular criteria so the quantity of studies gets to be diminished and all the resultant studies are exceptionally important to the theme.

In order to ensure that only literature that were relevant and applicable to the research question were used, a managing strategy was developed. Literature that was relevant to my topic was saved directly in my folder and those that were not were discarded. Also to enable to articulate the attention of my research and limited time frame it was important to have an inclusion and exclusion. See Table below:

Inclusion criteria	Rationale
Primary Research relating to parents	To ensure that all results were relevant to my

experiences after having a preterm baby	research question
English and French languages only	All articles had to be published either in English or French; as French been my first language no need of translation needed.
Published literature only	According to Parahoo, 1998 to Ensure credibility it is better to use only published literature due to the nature of this literature review. However, Aveyard (2010) has argued that using only published literature could bias the view of the research and also that good information can be finds in unpublished literature.
Time frame 2010 onwards	In order to Limit my research to more recent literature, a time frame was important, also in order to ensure that the literatures were up-to date.

Table. **Inclusion and rationale**

The following table gives the specific Inclusion / Exclusion criteria used in this systematic review:

Inclusion	Exclusion
The studies discuss the risks associated with smoking	Studies talking about other things in addition to experiences of parents of premature children in the NICU or role of nursing in helping such parents during hospitalisation
Studies available in English language	Studies available in other languages
Published studies only	Studies which are not published
Studies conducted and published between 2000 to 2015	Studies conducted and published prior to 2000

2.6 Data Extraction

The fundamental point of data extraction is to collect however much studies as could be expected and to evaluate them legitimately. This appraisal is taking into account the reason or the essential inquiry of the SR on which the entire building of research is built up. This may choose the significance of the chose studies. It is exhorted that this data ought to be recorded in a different database (Schüttpelz-Brauns, et al., 2015).

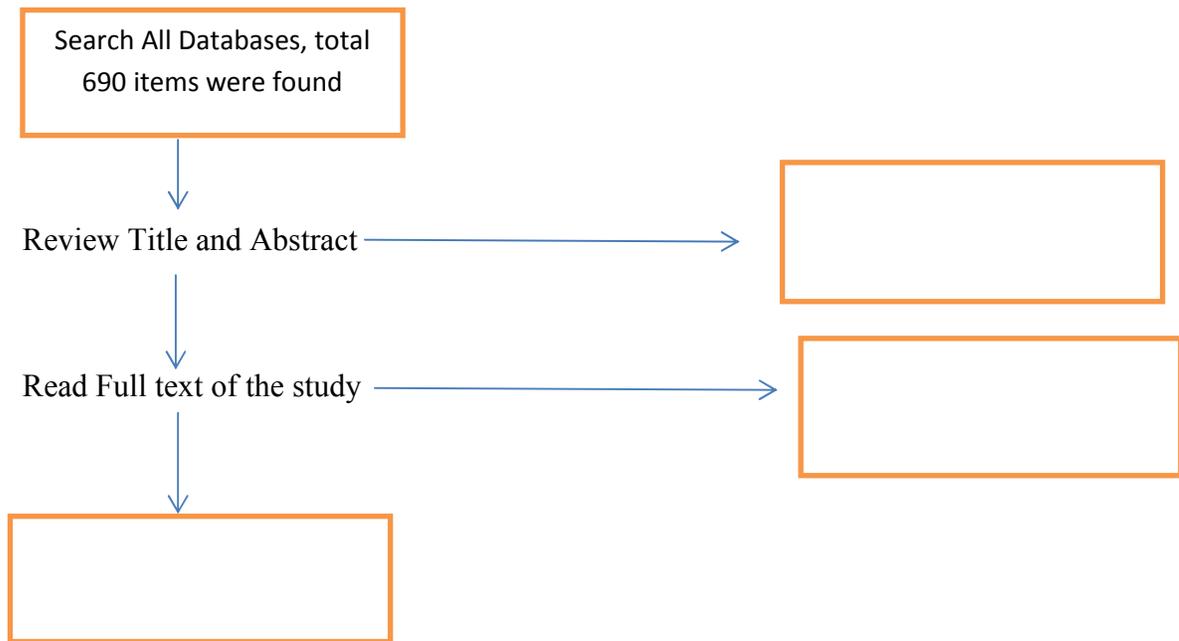
One of the real difficulties of directing SR is to discover most extreme number of pertinent studies. This should be possible by receiving an exhaustive and powerful searching technique which can minimise all the recovery inclinations. In this way, it is critical to join manual searching likewise into the search study.

For this study, data extraction was performed by an evaluator and accepted by the researcher. The extraction was in light of the PICO where P remains for Population of the Study, I is for Intervention, C is for Comparison and O is Outcome. For this study:

- Target population: Parents of premature babes in NICU;
- Intervention: - Any nursing intervention for supporting parents rehabilitation;
- Comparison: this is not the focus of this SR.
- Outcomes: Improving parents skill for coping stress in such situation and role of nurse in stress management

2.7 Results of the Literature Search

From the start clear up that an exploratory narrative research ought to concentrate on the folks who have brought forth an untimely angel in NICU. As talked about in the past section, this search is taking into account distinctive keywords has distinguished 390 things (Not avoided copies) in the logical literature.



At the second stage, the title and unique of the chose things were looked into and 623 things were rejected in light of the fact that they either did not satisfy the inclusion criteria or copy. In the following stage, the reviewing so as to remain things was checked all in all content of the study. This has further separated the search and 62 things were rejected from the rundown of chose studies. In this way, toward the end there stay seven studies which are most important to the research inquiry and which will be investigated in this research study.

2.7.1 Identified Themes

For the analysis of data the following themes were generated for this study

- Emotional distress
- Parental needs
- The roles of Nurses in the NICU

Being a novice researcher and by identified my own themes, I understand that I may have introduced bias as to ensure ability; articles will be review by many others research and this is not the case (Aveyard. 2010).

2.8 Data Analysis

The determination of records recognised amid the literature search was completed and accepted by the researcher in view of the criteria specified in the past section. After determination, the quality of studies was surveyed by utilising the network and appraisal criteria gave by Appraisal of Guidelines to Research & Evaluation II (AGREE II) (Polit, Beck, 2013).

2.8.1 Tool for Analysis

The researcher has decided to survey the methodological quality of these archives as an element of the most using so as to astound standard, or the Appraisal of Guidelines for Research and Evaluation (AGREE II). This framework incorporates 23 criteria surveyed each on a scale from 1 (unequivocally disagree) to 7 (emphatically agree). This grid is an apparatus to survey the methodological straightforwardness and thoroughness of the rule improvement process. Various criteria inquiries are gathered into six particular evaluating ranges which include: topics and aims, participation of influenced gatherings, create suggestions for clarity, Clinical Practice Rigor, relevance, presentation and editorial autonomy. It closes with an issue of general appraisal (Polit, Beck, 2013).

The researcher of this instrument prescribes least of 2 analysts and ideally four as this will expand the dependability of the appraisal. Every evaluator portrays each of the things of the AGREE II taking after the Likert scale. Scores of things in every area are summed to get a general score for spaces. However, these can't be added to acquire a "quality esteem" index, yet permits correlation between a few aides in every specific zone. Toward the end of the assessment

additionally incorporates two things of complete assessment, albeit subjective, should as of now be considered the logical meticulousness of the procedure, as well as the down to earth contemplations of execution.

Once in a while, a portion of the AGREE II things may not be relevant to any direction to survey. For instance, the aides with a little target can't give all the full scope of alternatives for dealing with the condition. AGREE II does exclude a standard message "not material" in scale. There are distinctive methodologies to deal with this circumstance including one who assesses skirt that thing in the appraisal process or rate this thing as 1 (nonattendance of data) and giving remarks on the score. Despite the picked procedure, choices must be made ahead of time, depicted in an unequivocal way, and if the things are overlooked, ought to be taken to appropriately alter the computation of the score of the area. On a fundamental level, it is not fitting to reject things in the appraisal procedure (Polit, Beck, 2013).

2.8.2 Studies Identified

Researcher has chosen specific electronic databases for which I could have access easily through my Brighton University Library account. Some articles appeared in more than one database. However, the electronic databases that researcher has included are: British Nursing Index (BNI), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, Embase, PsycInfo, NHS Evidence Wiley Online. The following table shows the studies which have been selected for this systematic review:

BNI	Covers full text articles relating to British-based nursing and midwifery (Aveyard.2010)
CINAHL	Holds relevant primary research articles for nursing and allied health literature (Aveyard.2010)
Cochrane Library	Evidence-based that contains systematic reviews for health and social care (Cochrane.2013)
Embase	An excellent database for and drugs pharmaceuticals (NICE 2013)
PsycInfo	A good database of psychological literature (Aveyard.2010)

NHS Evidence	Provides health care professionals and helps the public to have an easy access to current health research (NICE.2013).
Wiley Online	Holds highly relevant reviewed journals (Wiley 2011)

Table. Databases searched

Author(s), Title	Population	Intervention	Results	Limitation
Skene, C., Franck, L., Curtis, P., & Gerrish, K. (2012). Parental involvement in neonatal comfort care.	Eleven families (10 mothers, 8 fathers) with infants residing in the NICU participated in the study.	Interview	“Five stages of learning to parent in the NICU were identified. Although the length and duration of each stage differed for individual parents, movement along the learning trajectory was facilitated when parents were involved in comforting their infants. Transfer of responsibility from nurse to parents for specific aspects of care was also aided by parental involvement in pain care. Nurses’ encouragement of parental involvement in comfort care facilitated parental proximity, parent/infant reciprocity, and parental sense of responsibility”.	“In this study the major limitation was in data collection, as the challenge comes to a head against the experienced commitment of meeting varied resistance and fear in parents to hold the preterm newborn skin to skin when the infant is considered ready for it with both current and developmental purposes and prospects at stake”.
Pohlman, S. (2005). The primacy of work and fathering preterm infants: findings from an interpretive	The sample included 9 white fathers between the ages of 22 and 40 years, who had	Interview	“Fathers' narratives revealed the primacy of work in their lives; work remained a pivotal focus even after an early birth. Fathers returned to	This study has made no mention of any limitations.

phenomenological study.	infants born between 25 and 32 weeks gestation.		work quickly after their infant's birth. They approached their work with a renewed sense of fervor in order to provide financially for their families. They found comfort in their work because in the work setting they felt that they were the experts, as opposed to feeling like novices in the NICU. The most stressful aspect of the experience was juggling their time between work and the outside world.	
Lindberg, B., Axelsson, K., & Öhrling, K. (2008). Adjusting to being a father to an infant born prematurely: experiences from Swedish fathers. <i>Scandinavian Journal of Caring Sciences</i> , 22(1), 79-85.	The sample in this study contained Eight fathers of prematurely born children	Interview	“Father in this study felt better educated by professionals who helped them take care of their infant”.	“The main limitation of this study is generalizability as the study designed focused on particular Swedish population. However, this is not unique in medical researchers”.
Russell, G., Sawyer, A., Rabe, H., Bliss, J. A., Gyte, G., Duley, L., & Ayers, S. (2014). Parents' views on care of their very premature babies in neonatal intensive care	The sample population in this study was 39, 7 fathers and 32 mothers	Interview	“Overall, parents were satisfied with the care on the neonatal unit. Three major themes determining satisfaction with neonatal care emerged: 1) parents' involvement, 2) staff competence and	“The major limitation of this study is that parents' evaluation of care in the NICU was not the aim of these interviews. Therefore

units			efficiency and 3) interpersonal relationships with staff”.	parents’ views on this topic might not have been explored fully”.
Sweet, L., & Mannix, T. (2012). Identification of parental stressors in an Australian neonatal intensive care unit.	The sample population of this study comprised of 24 parents	Survey	“Moderate stress levels in parents (n=40), predominantly related to alteration of their parental role, and the appearance and behaviours of their infant was demonstrated”.	The major limitation of this study is very low number of participant, which shaken its reliability to some extent. However, the application of the PSS: NICU subscales with high reliability address the limitation to some extent.
Tooten, A., Hoffenkamp, H. N., Hall, R. A., Braeken, J., Vingerhoets, A. J., & Bakel, H. J. (2013). Parental perceptions and experiences after childbirth: a comparison between mothers and fathers of term and preterm infants.	The sample in this study comprised of 202 infants with both parents, divided into three groups.	Interview	“The lower the gestational age of the infant, the more negative parental experiences and perceptions were on the following five areas: infant's current condition, pregnancy course, labor and delivery, relationship with the infant, and discharge and beyond. No differences were found between maternal and paternal perceptions on any of the eight CLIP areas”.	“The major limitation of this study is that it has explored too many (8) areas of parental perception and experience, this in broader analysis restricted the research to focus on a single area”.
Woodward, L. J., Bora, S., Clark, C. A. C., Montgomery-Hönger, A.,	133 mothers of VPT infants participated in this study.	Interview and Parental Stressor Scale	“Mothers reported moderate to low stress, with parental role alteration considered most	

<p>Pritchard, V. E., Spencer, C., & Austin, N. C. (2014). Very preterm birth: maternal experiences of the neonatal intensive care.</p>			<p>stressful and parent–staff communications least stressful. Predictors of overall stress included maternal educational underachievement, stressful life events, postnatal depression and infant unsettled-irregular behaviour”.</p>	
<p>Turner, M., Chur-Hansen, A., & Winefield, H. (2014). The neonatal nurses' view of their role in emotional support of parents and its complexities</p>	<p>The sample in this study comprised of nine neonatal nurses from a single neonatal intensive care unit</p>	<p>Interview</p>	<p>Nurses in this study provided support to parents by listening, communicating, providing individualised support and by encouraging parental involvement with their baby. Constructive elements that contributed to the provision of support included a positive neonatal intensive care unit environment and providing a parent support group.</p>	<p>This study has relied on interview and due to the association of researcher to the nursing profession the main limitation of this study is the potential elements of biasness in the interpretation of findings. Though, this is a usual limitation of qualitative inquiries. Use of NVIVO version 10 in the data analysis serves to address this limitation</p>

Table Studies Identified

Chapter 4 Findings and Discussion

4.1 Theme 1: Emotional Distress

This chapter presents the critical analysis of studies selected on the particular themes. This chapter is divided in free subsections each analysing a particular theme. Beside, this chapter also presents discussion on the selected themes with the help of other studies to further elaborate and critique the selected studies. This chapter review research papers that directly explore parental experiences of Neonatal Intensive Care Unit (NICU) environment after the birth of a preterm baby. Besides, this chapter has reviewed the broad needs of parents in the Neonatal Intensive Care Unit Lastly (NICU) environment after having a preterm infant. Lastly this chapter has critically reviewed and discussed the selected research on the third theme, i.e. role of nurses in helping parents for managing stress and experiences in the NICU.

Research shown that the birth of a preterm baby has a long term impact on the lives of parents as there are exposed to many different clinical procedures Woodward et al (2014). It is also recognised that preterm infant face a significant risk of long term neurodevelopmental disability which is associated to parental level of stress Sweet (2012). The most obvious way to identify parental experiences of the NICU after the birth of a preterm infant is by studying lived experience. So the appropriate research method to explore will be qualitative research as the research topic is studies from the point of view of the lived experiences of the research participant (Giorgi 2000). From this dissertation this is the most significant impact identified are

4.1.1 Emotional Impact

Woodward et al (2014) states that the psychological distress of parents of very preterm infant is related to their infant health and survival, physical and emotional features as well as the risk of disability. In their study (Woodward et al 2014) they examined the psychological distress

of maternal experience in the NICU after giving birth to a very preterm infant with a specific focus on the source of stress in the NICU setting. By measuring the proportion of responses made by mothers, taking into account the time spent during the interview; findings showed that mothers of preterm infant were more likely to experience stress than mother of full term infants. An interview was used with 133 participants in New Zealand, whose babies were born very preterm. Although the study Methodology is not well stated, it appears to be using a phenomenology theory approach as parent's experiences are described. Loss of parental role, infant appearances and behaviours were the source of the stress in the NICU

There is one criticism that can be applied to the study the larger sample size. Aveyard (2010) comment that with a very large sample size, it can appear that the researchers have not developed an in-depth understanding on the topic as this suggests that the data has not been so insightful. In the study the results given shown only the number of times each attribution was mentioned by all participant. It would have been even more interesting if the researchers could have identified personal experiences in order to explore if there is any link between certain attributes. However, the researchers have highlighted some interesting point such as mothers of preterm infant tend to experience severe distress compare to mothers of term infant. This is upheld by a study done by Tooten et al (2013) who undertook a qualitative semi-structured interview using a longitudinal study focusing on parental perceptions and experience after child birth on a purposive sample of participants in the Netherlands

With the exceptions of attributions related to parents experiences of birth and all the negative effects of the NICU, some attributions were quite the same as reported in the study done by Woodward (2014) one is comparing parents of term baby to parents of preterm infant. This suggests that there is a reason mentioned in both studies such as parental stress of preterm infant.

One of the limitations which the authors identify is about the lack of investigating coping strategies for parents as this may be highly relevant for proper psychological care giving. Although it was found that mothers and fathers have equals level of stress and worries, each single person tries to cope differently .furthermore the way men cope with stress is completely different with the way woman cope with it. Further focus on how to cope with stress will be beneficial and evidence based practice needs to consider strategies and help tools to deal and manage stress. This results show interesting comparisons to the study by Sweet et al (2012), who undertook a qualitative research on a purposive sample of parents whose infants had been admitted to the NICU, in Australia.

Sweet et al 2012 study identified parent's source of stress when coping with caring for their child in the NICU, they have recognised that separation from their child, poor communication, and not knowing what was happening and staff behaviour were the source of parents stress in the NICU. This study described the demands of constant communication between health professional, nursing staff and parents as well as engaging parents in the daily care of their child as an important strategy of coping with stress. Parents want an explanation for the information that they receive as well as guidance and empathy from people around them (Sweet et al., 2012).

One mother while describing how important is sharing accurate information to parent said: It is highly significant for nurses to be as positive about the course of treatment of child. However, they must not pass any false ideas or hope in the process. As per Sweet et al.,(2012) negativity in behaviour or in decisions about the care of preterm child in NICU can be very hurtful and distressing for parents. One of the strength of this study recognises the source of stress and implanting strategies on how to cope with this. However, the small sample size can be

seems as a limitation to this study and the possibility of participants view been influenced by the current situation as the research did not follow up parents.

Sweet et al (2012) in their discussion of their results, suggest that it is very important for nursing staff to be able to understand parents experiences and been able to support them.

Believing in parents and listening to their experiences and their feeling as well as allowing them to take part in the daily care of their child were shown to be an important attribute of neonate nurses. All the studies in this chapter rely on parent's experiences in the NCUI after giving birth to a preterm baby. Therefore parental needs in the NICU will be the focus of the next chapter.

4.2 Them 2: Parental Needs in the NICU

4.2.1 Need of Parental Involvement in Neonatal Comfort Care

From the moment the child is born, parents want to be informed of everything that is happening with their child, want to be treated with respect as well want to participate in the daily care of their infants (Heidari, 2012). Heidari (2012) went on to say that nurses can reduce any barriers that arise. In the same vain, Sken et al (2012) conducted this study to discover the interaction of parents with nurses and withtheir infants regarding the comfort care provision in a NICU. This study has clearly stated its aim and objective. Sken et al (2012) interviewed eleven families (8 fathers and 10 mothers) in the NICU setting. For this study 24 semi structured interviews and 25 observation periods were carried out, which appears to be a comprehensive method for this inquiry.

This study has provided a clear and concise background and the rational of research, a separate section of literature review serves well to establish the contemporary evidence regarding the research problem. From the methodological point of view, this is a qualitative inquiry, Sken et al (2012) has briefly stated the data collection strategy. The study has utilised primary data and

observations, data was collected through interview, and research tap recorded the interviews. A major weakness of this study appears that it has described process the data analysis very briefly which could have been elaborated. Overall it's an important study, involving sufficient sample population.

Beside, this study has very explicitly divulged that in involvement of parental in comfort care can enhance the learning process of parent, which usually is hard in the settings like NICU. This participation and involvement of parents may also provisos the responsibility transfer to parent from nurse and may simplify antecedents to infant/parent attachment. These findings appear quite valid as they are consistent to previous researches on the parental involvement.

Parohoo (2006), suggest that majority of parents agree that experiencing stress is combined with the fear of not knowing what was happening with the child; it has been recognised that there is a need for neonatal and children nurses to establish good communication skill and good rapport with parents of preterm infant as well as parent of sick infant by listening and understanding what they are going through. Parohoo (2006) also suggests that cultural differences might impact the way parents respond to the birth of a preterm infant and the needs this might require. However, one can also argued that parent's experiences were not different from western countries

Cleveland (2008) has identified that better parental learning and better access to information and about health and treatment of their child reduces parental stress in NICU. Cleveland (2008) basically has discovered six parental needs in premature birth cases when child is admitted in NICU who had an infant in the neonatal intensive care unit: (a) inclusion in the care of infant and need of accurate information. It's also identified that due to parental involvement, they are perceived more positively by nursing staff. Besides; parental involvement

in learning provides nurses an opportunity to apply and examine new concepts and strategies (Cleveland (2008).Hence, Sken et al (2012) also recommended that nursing staff should empower and help parents to learn how to interact and relate with their infant as well how to provide excellent care routine (Sken et al 2012).

4.2.2 Parents' Perspective

Russell et al (2014) provided an interesting contrast to the study of Cleveland (2008), in terms of the importance of communication between nursing staff and parents in the NICU settings. Regarding the use of adequate communication skill, Russell et al (2014), explored how communication between nursing staff and parents, help those parents to cope during the stay in the NICU. They interviewed 39 parents in the South of England about their experiences after the birth a preterm delivery and implanted nursing strategies to help those parents. The study was undertaken by an interviewer; all the interviews were tape-recorded and transcribed. However, all participants in this study were parents of preterm infants and were ranging between 25 to 44 years old. They identified that the majority of parents mentioned the lack of communication as a significant factor of distress. As per Parahoo (2006) parents in hospital setting face communication problem due to low understanding of technical aspects of treatment, discouraging attitudes of nursing and support staff and lack of information to present their specific queries.

This study can be criticised for been being limited only to a certain area of the South of England (Kent); the experiences reported by parents in this study may not be applicable and the same for all parents who face the crucial impact of having a preterm infant. One can suggest that a possible bias was introduced as the sample comprised a great number of white population, married and education people only. Furthermore this could have also affected the way parents

responded to questions they must may have been reluctant to express critical comments regarding the way nurses provided care, if parents were critical they could have had been label has been difficult.

4.2.3 Experience can be Satisfying

In confirmation to the findings of (Sken et al 2012), its divulged by Russell et all (2014) that parents can also experience positive experiences in the NICU and according to Russell et all (2014) this these positive experiences can be met only by building solid relationship with nursing staff, by communication, empowering parents to participate in the daily care of their child as well as been transparent with them regarding the medical condition of their child. The first discovery of Russell et al (2014) is that many parents experience distress and fear even before the delivery of premature child, hence they need counselling and support right from their arrivalin hospital.

Secondly Russell et al., (2014) has indicated that few patients in their research felt more positive and confident when as a result of clear and good communication with hospital staff regarding expected the premature delivery of their child. Due to good communication between parents and nurse as this help parents to feel reassured and confident about knowing what is happening in their child life.

4.3 Theme 3: Role of Nurse

The physical environment of hospital and particularly NICU's environment i.e. incubators, monitors and other equipment's which emit sounds and lights that will inevitably become foreign elements for parents, all of these element presents a sense of risk and worry to parents of preterm child. Also in this environment parents are surrounded by strangers, as staff area and other infants with their parents, who somehow represent a significant risk to the

environment under which occupy expected to enter difference and at home, where they presumed he would be his son with them and other family members such as siblings and grandparents. All of these factors create a need of more information and clarity in parents (Cleveland. 2008).

On the other hand as per Macdonald et al., (2012) parents in the NICU felt like there were not taken seriously regarding their concerns and taking part in the daily care of their infant (Macdonald et al., 2012). The role of nurses in this context pivotal to help parents not only regarding the health and treatment of their child but also in managing their own emotion and conduct (Tuner et al 2014).Tuner et al (2014) in this context conducted a research to explore perspective of nurses regarding their role in emotional support of those parents who has their preterm children admitted in NICU. This studyendeavoured to identifying elements and components of nurses' role within NICU which encourage or obstruct this role.

In order to carry out this inquiry the research method chosen by Tuner et al., (2014) was qualitative. Researchers relied on the primary data in this study;primary data was collected through interviews. From a single NICU 9 neonatal nurses were interviewed in Australia, ranging from 35-58 years of age.The interviews were recorded on a tape recorded and transcribed latter according to particular themes.This interview asked about nurse's experiences in the NICU and how they approach and deal with parents. They discussed the nurse's view of the role as an emotional support for parents facing difficult moment in the NICU.

Besides, a phenomenological hermeneutic approach was used as this approach interprets and expresses life experiences of subjects (Parohoo, 2006). Besides, in order to element the element of biasness, Tuner et al., (2014) used NVIVO version 10 in the data analysis. The application of this tool enhanced the credibility and reliability of the findings.

This study has divulged that neonatal nurses provided support to parents by listening; communicating, encouraging and facilitating involvement of parents with their child and by giving individualised support effectively manage emotional distress of parents in NICU setting. Tuner et al., (2014) has also stated that as per the perspective of neonatal nurses in this study that lack of adequate number of nurses and changes in staff shift is not only a challenge for nursing management in delivering quality care but this also produces few difficulties among parents. Because few parents feel reluctant or less confident to communicate with a new nurse after staff shift change.

Concluding the study Tuner et al., (2014) suggested that as per their findings the neonatal nurse's role in providing emotional support is crucial and has positive outcomes but this role due to various complexities demands a high quality education and persistent support to nurses. These findings are very significant to the context of this dissertation where after have establishing the prevalence of stress among patients of preterm child (admitted in NICU) and also after the identification of various emotional and education needs of the parents in this scenario, the next logical step is to discover the venue for helping such parents. Tuner et al., (2014) findings and recommendation for enhancing skills and capacity of nurses appears to be a very effective tool for helping parents to cop up with stress while their child is under care in NICU. In this vain this study is highly significant for the fact that it recommends NICU nurses ought to be provided educating and training in counselling and emotional support.

Overall this study has shown that every nurse can play a fundamental part in supporting parents and reduces reducing their level of stress by the application of knowledge, communicating efficacy efficiently as well as engaging parents in the daily care of the child. In comparison to others departments, the NICU seems to be overwhelming for parents and their

families. With a nurse supporting them perhaps teaching them how to engage in the care of their infant can make a great difference

Chapter 5 Discussion

Few fundamental aspects from the review of literature are established. First of all, I feel it is important to recognise a major criticism of these studies. Many studies looked at what mothers experience and it felt like fathers experiences were most of the time not important. In the future parental experiences after a birth of a preterm infant research would benefit from fathers experiences. However, it's evident that father's emotions stress even on setting the bench is very high as of mother (Lindberg, et al., 2008). The reviewed literature people may encourage more research on parents (father particularly) experiences and perhaps reduce the misconception held that fathers are they strongest and do not go through emotional distress. Arising issues identifying that causes high level of stress in parents were separation from their infant , poor communication between staff and parents, not been understood as well not knowing what was happening with the child were the issues that many studies highlighted (Skene, et al., Gerrish, 2012).

The review of literature has established that most parents do not have emotional manifestations caused by stress, preventing them cope with your child's health and establish optimal relationships with persons responsible for providing care to their children (Pohlman 2005). These results differ to very limited degree in the contemporary literature, where its mentioned that the birth of a premature or sick product are unexpected and overwhelming facts, which are not prepared the person or the family, in the psychological sphere, and that often they are known them as situational stressors or accidental, therefore it is logical that such events become present (Russell, et al., 2014). However, it is important to consider that the results obtained higher percentages are observed in some events related to the modification of the desired paternity during pregnancy and actual facing when your child is admitted at the NICU. Indeed, the

psychological processes that parents experience after the birth of an infant at high risk, including cited: grief for the loss of the perfect child of course, grief by the inability to procreate a perfect infant and pre affliction by the loss of the child, causing disruption in the parents because they fail to control his feelings and accept what happened (Sweet, Mannix, 2012).

In this regard, it is important to mention that if a person is not well nourished, their ability to withstand stress will actually decreased, so it is necessary to improve eating habits so that the person feels physically better and stronger to cope with stress (Tooten, et al., 2013). In fact, the resources which a person has to deal with stressful events or situations are very different, and among them are called vital basically related to health and energy=.

Moreover, although the results demonstrate a high frequency of physical reactions product parental stress it is evident that the answers given by parents on this category are distributed always significantly alternatives, often and sometimes. However, parents at the NICU might present physical symptoms of stress as a result of the presence of some factors, such as: the status of new-born health, environmental characteristics of the place where it is entered and the separation of the binomial parent-child relationship (Woodward, et la., 2014). In this perspective it is worth noting the indicator that presented the highest percentage of appearance in this category was insomnia, which is a product of stress and symptoms that may occur as a result of the interruption of the role, as parents of preterm babies often they feel deprived of the satisfaction of their expectations of the birth experience and develop a grieving the loss of her baby fantasy.

Under the results, the nurse should assess the risk among parents of preterm child admitted at the NICU to suffer, since they are exposed to the emotional impact caused by the hospitalization of their child hence nurses must provide guidelines that allow parents to analyse, recognize and

assume the development of stress that arise, and in turn provide techniques that allow them to use their social skills to operatively adapt to the situation experienced, based on human care as a focus of professional practice (Turner, et al., , 2014).

Chapter 6 Conclusion Recommendations

To conclude the study it can be stated that this literatures have revealed that giving birth to a preterm infant can have a significant impact on the life of parents and this can cause significant distress. The reason for this can be sometimes attributed to child neurodevelopmental disability, the child gestational age and lack of communication between parents and healthcare professionals. Sweet et al (2012) proposed that neonatal nurses working in the NICU settings should be able to understand what parents go through as well as understanding the common causes of stress by developing good communication skills and implementing support groups and assisting those parent's spiritual, psychological as well emotional needs.

This reviewed literature has therefore identified many sources of parental stress in the NICU, as well as highlighted areas that need improvement. By analysing this it is possible to suggest recommendation that could improve parent's experiences in the NICU. It's also evident from the analysis of selected studies that the frustration of parents had when health professionals did not communicate effectively and when decisions were taking without talking to them at the first time. This lack of communication can be attitude to the cause of emotional distress. Parents also felt that, they staff did not trust them enough to involve them in the daily care of their child. In many occasions they states that sometimes staff made them feel inadequate to enough feed their enough and also in many situations they really felt that staff were very busy and did not have enough time for them

Besides, in context of nursing it's also found in this dissertation that nursing staff are encouraged parents to engage in the daily care of their child and reduce the barriers than can rise between and parents. This is because it eases parents and there is a sense of trustiness among parent and feeling that influence parent's behaviour. Parents can therefore play a significant role

in delivering daily care such as bath, nappies changing, feeding (Tuner, 2012). Nursing staff should therefore encourage parents to take part in teaching sessions and educational programs.

However, this should not be another source of stress but rather an enjoyable time for parents and nurses should make it available for parents (Tuner, et al 2012)

Depending on how busy the NICU can be, it is ideal to have a neonatal nurse in place for each child to be a consistent help to parents. This prevents parents feeling inadequate or even more having different information from different people and improves the relationship between parents and staff. It's also evident from the review of literature in this dissertation that though, parents cannot address their psychological issues with nurses, and nurses can promote activities that can enhance parents to feel comfortable to share with them.

This review of literature has also shown that parents expressing negative feelings when invited to participate in different training sessions for example the resuscitation's one. This increased their stress feeling and anxiety levels. It is clear that parents needed more information and much more explanation on why the training was important rather than parents believing that the reason the training was offered was because something bad will happen to their child. And again that's why communication is important as this helps to build trust relationships between parents and health professionals.

Area of development

1. Communication between nursing staff and parent

- Ensure that parents are involved in the daily plan of care for their child
- Information is passed on to parents regarding any changes of nursing procedures, nursing rota as well as changes in their child's condition
- Parents to be aware of any investigation that will take place

- Professional relationships are built between parents and healthcare professionals
- Nursing staff should know the family and the child
- Parents to be offered different kind of treatment

2. Further training in education skills for parents

- Keep parents up to date with new practice
- Up to date training are offered

3. Support for parents

- Effective nursing support for parents during the stay in the NICU
- Discharge from the NICU
- Emotional support with parents learn something new regarding their child condition
- Nursing staff to ensure that parents receive adequate information and personalise support

Lastly there is a need for further study on fathers experiences as most study are done on mothers experiences alone.

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