IRAETC Journal of Nursing and Health Care
ISSN (e): 3005-3838; ISSN (p): 3078-3089
Volume: 2 (2024), Issue: 5 (Sep-Oct)
OPEN ACCESS
iraetcjournals.com

Experiences of Parents with Neonates in the Neonatal Intensive Care Unit at the University Teaching Hospital, Women and Newborn's Hospital, Lusaka, Zambia: A Case Study of the University Teaching Hospital in Lusaka District

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Review Article **DOI:** 10.62469/ijnhc.v02i05.001

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Citation:
Hankombo Wanda; *et al* (2024); Vegetarian Diets with Life Style and Nutritional Problems with Nutritional Quality of Foods. iraetc j. nur. health care; 2(5) 72-84.

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Abstract: ***Introduction:*** Neonatal health is a major concern globally and in Zambia, until lately there has been little effort to tackle the specific health problems of newborns and most of the deaths which are 24/1000 live births, remain unrecorded. Most of these deaths are caused by infections, prematurity, low birth weight, asphyxia, and birth trauma. Parents of a hospitalized neonate are anxious about their neonate's condition and do not receive adequate emotional care during the time of hospitalization. They are also prone to lose their jobs, have no confidence in the parental roles and display shame as a social stigma of having an imperfect infant. ***Method:*** This study aimed at exploring the experiences of parents whose neonates have been admitted to the University Teaching Hospital, in Lusaka, Zambia. A qualitative approach was used. The study setting was The University Teaching Hospital, Neonatal Intensive Care Unit, Lusaka. The sample consisted of 4 male and 11 female biological parents to the neonates admitted to NICU. Interviews were recorded, transcribed and analyzed through thematic analysis and N-vivo version 10 software. And semi- structured observations of parents, neonates and health workers were conducted. ***Results:*** Caregivers of neonates in NICU do not communicate adequately to the parents of neonates in NICU. This lack of information about the condition of the child causes stress and anxiety in the parents because they are not allowed to have access to the hospital files of their own children. Parents lack emotional support from the caregivers because the caregivers would shout at them. Parents also complained about the bad attitude of the caregivers towards the mothers. Mothers that just had a Caesarian section are not provided with wheel chairs to move to the NICU to breast feed their neonates. ***Conclusion:*** Parents of neonates need emotional support and information about the child. Care givers must provide this information concerning the welfare of their own child. Policy makers should introduce day rooms for parents near the NICU to make it easy for the parents. The NICU supervisors should supervise the nurses on every shift to ensure that neonates and parents are cared for accordingly.

Keywords: Neonates, Intensive Care Unit, Experiences, Parents, Neonat.

|| IRAETC Publisher || **Publication History** - Received: 25.09.2024 || Accepted: 20.10.2024 || Published: 23.10.2024 ||

INTRODUCTION AND BACKGROUND

Neonates are often admitted to NICU for conditions such as respiratory distress syndrome, prematurity, and sepsis. These situations cause significant emotional distress to parents, as they are separated from their infants during a critical period of bonding and must rely on caregivers for updates and care. Studies have shown that the physical and emotional separation between parents and neonates can lead to adverse outcomes for both parties, including parental anxiety, guilt, and postpartum depression.

The postpartum period is a time when the woman recovers fully from the trauma of the birthing experience, especially women who have had an assisted birth or a caesarian section. The mothers are deprived of the privilege to have their neonates at their bedside during the first few days of motherhood. A study done by Flacking et al., (2012) highlighted the need for parents to be in the same room as their neonate to facilitate bonding and both physical and emotional closeness. Allowing parents and babies to remain in the same room could promote better outcomes for the infant and the mother, such as reducing the hospital stay for the infant and decreasing the potential guilt of the mothers separated from their neonates and subsequent postpartum depression. It is difficult for a new mother to be discharged from postpartum care directly into a 'visitor' status in the NICU as she has to put up with the extremely strange role of parenting and the strange environment in the NICU.

This could be the case for mothers with chronic illnesses, multiple births, caesarian sections and other complications such as hypertensive disorders (Källén, 2010). However, to achieve optimum health of neonates in low resource settings, there is need to scale up training programs for staff dealing with neonates, development of infrastructure in health settings, and increased attention in maternal and neonatal services (Molyneux, 2016; Gurmesa et al., 2015).

In Zambia, neonatal health has remained a critical issue, with limited attention given to the specific needs of neonates and their parents. This study seeks to explore the experiences of parents with neonates admitted to NICU, focusing on communication, emotional support, and access to their infants during hospitalization.

Neonatal health is a major concern globally and in Zambia, until recently there has been little effort to tackle the specific health problems of newborns and most of the deaths remain unrecorded (WHO, 2015).Globally, the number of neonatal deaths has declined by 53% from 5.1 million in 1990 to 2.7 million in 2015 (Molyneux, 2016). However, the decline in neonatal mortality from 1990 to 2015 has been slower compared to the post neonatal under-five mortality (1-59 months): 47% as compared to 57% globally, 75% of all neonatal deaths occur in the first week of life, and deaths between 25% and 45% occur within 24 hours (WHO, 2015). Most of these deaths are caused by infections (36%), prematurity and low birth weight (28%), asphyxia (23%) and birth trauma. Neonatal health and child survival is an unfinished agenda and among the unachieved Millennium Development Goal (MDG) targets identified for the post 2015 priorities in the Sustainable Development Goals (SDGs) (Lawn et al., 2014). Most of the neonates that are unable to cope with normal adaptation after birth are admitted to the Neonatal Intensive Care Unit (NICU).

In a study done by Nthala (2011), in Zambia at the University Teaching Hospital (UTH) mothers' shelter, on experiences of mothers with premature babies, revealed that women were anxious about their neonates' conditions and did not receive adequate emotional care during the time of their neonates' hospitalization. In another study done by Heidari et al., (2012), the study showed that parents of a hospitalized infant in the NICU are prone to lose their jobs because of the long stay in hospital of their infant, have no confidence in the parental roles, and display shame as a social stigma of having an imperfect infant and physical and emotional stress. Socio- economic strains can be felt by parents nursing these neonates. Parents that care for their sick neonates in NICU can sometimes experience a loss of employment due to the length of stay in hospital which is prolonged. With the loss of employment comes stress as a result of financial constrains that may be experienced and some of the women have no partners thereby lacking financial backing. Furthermore, the technical advances are not available in most delivery settings in Zambia which puts the health of most neonates in danger causing the high levels of morbidity and mortality. The NICU where the neonates are admitted is understaffed, putting them at risk. The American Academy of Pediatrics advises the staffing ratios of more than one nurse to 1 critical neonate and 1 nurse to 3 stable neonates.

Statement of the Problem

The University Teaching Hospital NICU provides tertiary care to the newborns needing expert care. After delivery the mother and baby are supposed to bond and be together in the same room. However, neonates admitted in NICU are separated from their mothers during the time of their hospitalization.

Their mothers are discharged from the postnatal ward and are accommodated in the mothers' shelter which is about 5 minutes' walk from the NICU. This means that the mothers are separated from their newborns and have to walk this distance every 2-3 hours to check on their neonates. Mothers need to be with their neonates all the time in order to promote bonding and also facilitate good neonatal outcomes and attachment. On the other hand their husbands or partners have no access to visit or handle their sick neonate as they only see the baby once from the ward on the day of admission thereafter they have to view the neonate through a small window during visiting hours. Ideally, the father should not have any restrictions in seeing their baby. This situation leads to stress and anxiety among both parents during the period of hospitalization of their neonate. During their hospitalization in the NICU, the neonates are cared for by the nurses and midwives. They are only allowed to be with the babies for 1 hour which is limited time for the mother and baby to bond. When mothers visit the unit they are encouraged to express breast milk in a container and hand it over to the nurse who later feeds the baby. The mother is not sure whether the baby is fed or not and this adds more stress to the mother. Figure 1 shows the number of admissions, discharges and deaths which translates to the number of neonates separated from their parents from January to December, 2015. In January there were 313 admissions, of which 137 neonates died and 177 were discharged. In December 310 neonates were admitted, of which 139 were discharged and 171 died.

Objectives

The primary objectives of this study are as follows:

1. Assess the parents' interactions with their neonates during admission to the NICU.
2. Investigate the involvement of parents in the care of the neonate during hospitalization to the NICU.

3. Investigate the barriers created by visitation restrictions in NICU and how the parents feel about it.
4. Identify types of support which can help parents during their neonates' hospitalization.

Research Questions

To achieve these objectives, the study will address the following research questions:
1. How is the parents' interactions with their neonates during admission to the NICU.
2. How is the involvement of parents in the care of the neonate during hospitalization to the NICU.
3. What are the barriers created by visitation restrictions in NICU and how the parents feel about it.
3. What types of support which can help parents during their neonates' hospitalization.

Significance of the Study

The importance of this study is that it may improve the services offered to the neonates in the NICU at the University Teaching Hospital. It may bring out forms of support to the mothers during NICU visit which can help in attachment of mothers and their babies in NICU at the University Teaching Hospital. Guidelines may be derived from this study and if applied well they may consequently improve the relationship between health professionals and parents whose neonates are admitted in NICU at UTH, Lusaka.

LITERATURE REVIEW

Literature included in the study was from 2010 to 2016 unless in instances where subject matter had no recent literature backing. The search strategy was not limited to Zambia and Africa alone, instead it was broadened globally. The literature review in this study was arranged according to research objectives.

Parents' interactions with their neonates during admission to the NICU

A Study done by Flacking et al (2012), highlighted the need for physical and emotional closeness between the preterm infant and the parent in the NICU. In their study they outlined the need for culturally sensitive care practices, procedures being done on the infants and the physical environment to be considered to facilitate closeness of the neonates and the parents through early and prolonged skin-skin contact, family- centered care, increasing the visiting hours, family rooms and optimizing of the space of the units. The cultural aspect has been overlooked in the neonatal unit so far as family involvement is concerned. Zambia, like any other African country has a close knit community and family centered support for new mothers. Culture is known to help in the support of mothers psychologically and otherwise, even though this support may contribute to maternal stress (Gulamani et al., 2013).

The involvement of parents in the care of the neonate during hospitalization to the NICU

Several studies, for example by Bialoskurski et al., 2002: Jacon et al., 1990: Ward, 2001, have been done which highlight the needs of parents in the NICU. From these studies, the needs of nurses differed from those of parents in that parents needed to be involved in the care of their neonates. Similarly, a qualitative study done by Russell et al., (2014), described the experiences of satisfaction of mothers in NICU as being complete when they participated in the care of their neonates. Mothers feel connected to their neonates when they are involved in parental duties such as changing nappies, feeding and also holding the baby. According to Russell et al., (2014), the review looked at the involvement of parents in the care of their neonates in NICU. The study brought out complaints from women who felt that they were only involved in the expression of breast milk for their neonates. This study had some limitations in the time frame; the mothers were interviewed a month or year after the birth. It may not be possible that these interviews brought out the emotional aspect from the parent's memories. On the other hand, it is an important thing to note that communication with the nurses/ doctors or carers is an important factor that can affect the satisfaction of mothers in the NICU. Some researchers state that neonatal care is a three-way interactional process involving the mother, neonate and the nurse, and nursing both the parent and the neonate can foster connection of mother and baby (Fenwick et al, 2008 & Kenner, C., 1990 cited in Russell et. al, 2014).

Emotional aspect of parents created by the barriers related to restricted visitation to NICU

Parents can display different emotional patterns when faced with a NICU admission. In a study done by Heidari et.al (2011), the parents of admitted infants to NICU behaved in an irrational manner and showed several emotional reactions such as crying, restlessness, physical discomforts and mental instability. While the women displayed their feelings, it was common for men to hide their feelings. Similarly, a study that was done in Iran by Valizade et al., (2009) used a descriptive method to find the effects of stress on parents with premature infants in NICU. Other stressful factors included the parent–infant relation such as separation of the baby from the mother during times of hospitalization, a sense of not being able to help the infant and not being able to protect the infant during painful procedures. Parents identified noise from monitors and special devices and placing two infants in one isolated room very stressful. Parents experienced high stress levels when their infants were in distress during medical procedures and treatments as they watched abnormal breathing pattern, medical accessories and devices surrounding and attached to infants, sudden skin color changes, and the helplessness of a tiny infant

making facial grimaces indicating pain. Other stressful factors included the parent–infant relation such as separation of the baby from the mother during times of hospitalization, a sense of not being able to help the infant and not being able to protect the infant during painful procedure. Obeidat et.al (2009) conducted a systematic review that explored and described experiences of white, middle- class families. The study revealed that parents of infants admitted to NICU experienced stress, depression, anxiety, feelings of powerlessness and alienation.

Support given to parents during their neonates' hospitalization

Support offered to parents during their neonates' hospitalization can increase their confidence in the parental roles exhibited in NICU. In a study conducted in Malawi by Ngaiyeya (2016), nurses demonstrated how to care for the neonates in NICU to the mothers as a form of support. They encouraged mothers to breast feed and also to conduct kangaroo mother care method. The mothers in this study were also offered psychological support in form of counselling and guidance. The support the mothers received not only gave them confidence to bond effectively with their neonates but it also built a trusting relationship with the nurses. Some of the studies that have been conducted look at communication between the staff and the parents (Yee & Ross, 2006). It can be argued that the mothers who are separated from their newborns, during the time the newborns are sick and admitted to the NICU, can be stressed and display symptoms of psychological instability and need psychological support from the healthcare staff (Brandon et al., 2011). It cannot be ruled out that the relationships that exist between the mothers and the healthcare staff are very important in establishing close bonds of mothers and their neonates (Fleury et al, 2014). Understanding parents' experience of having an infant in NICU will prepare the nurses to meet parental needs and provide holistic, family centered developmentally supportive care and open communication with parents.

In conclusion, the literature globally has demonstrated some of the experiences of parents whose neonates are admitted to NICU. There still remains a gap in current literature to fully understand the experiences of parents as they nurse the neonates in the neonatal intensive care unit. Most of the studies discuss the stress levels of parents with neonates in NICU. Family centered care helps the mothers to take up the role of parenting and feel connected to their newborn (Cockcroft, 2011). The NICU is understaffed making it difficult to achieve the 1:1 ratio of critically ill babies to staff. Additional workload to the staff means that there is a compromise in the technical aspects of nursing and worse still family support is not a priority (Shaw, 2008)

METHODOLOGY

Study Design

This was a qualitative study design and employed the phenomenological approach. This was done because the study focused on lived experiences of parents in NICU. It was important to understand individual experiences with a phenomenon to a description of the universal essence. This made the approach particularly relevant to experiences of parents whose neonates are admitted in NICU at UTH, Lusaka, Zambia, where there is a scarcity of literature and poor understanding of lived experiences of parents in NICU.

Study Setting

The study took place at the University Teaching Hospital in Lusaka (UTH), Zambia, in the Neonatal Intensive Care Unit. UTH is the largest tertiary hospital in Zambia, which is in Zambia's capital city, Lusaka. It is a teaching hospital with a bed capacity of 1655. Premature infants and other babies with high risk conditions who are born in Zambia and require highly mechanical and expert care are nursed at the facility where they are born or referred to The University Teaching Hospital (UTH) and referred to the Neonatal Intensive Care Unit (NICU). The study site was selected because of its expert and specialized care to neonates and an established neonatal unit which would give the study a real picture of the day-to-day activities of NICU.

Study Population

The study population included the parents of neonates admitted to NICU at UTH

Sample Selection

Participants in qualitative research are sampled based on their relevance to the study topic rather than randomly. Initially, the participants were chosen using a non-probability sampling method called purposive sampling method. The participants were recruited after the ward Sister-in- charge approached parents of neonates who satisfied the inclusion criteria. After the initial data collection, theoretical sampling was used. This meant that the selection of study participants was informed by the initial responses of participants and subsequent interpretation. This is in keeping with phenomenology. In phenomenology, the sample size is determined by data saturation. This meant that data continued to be collected until no new themes had emerged. The initial purposive sample of participants for the interview included 2 mothers.

Eligibility Criteria

Inclusion Criteria

Criteria for inclusion in the study was as follows;
Parents whose neonates were admitted to the NICU at UTH.
Parents who were able to communicate without any difficulties or discomfort in the local Zambian language or English.
Parents who were between the ages of 18 and 45 years of age because of the diversity of views.
Consented to be included in the study

Exclusion Criteria

Criteria for exclusion was as follows;
Parents whose neonates were not admitted in the NICU.
Parents with very critically ill neonates.
Parents whose neonates had congenital malformations.
Guardians who were not biological parents to the neonates.

Sample size

A total of 15 respondents were selected to participate in the study. The recruited sample size was 15 which according to Creswel (2007) is recommended that researchers interview from 5 to 25 individuals who have all experienced the phenomenon.

Data Collection Tool

3.8.1 Semi-structured interviews

The semi-structured interviews were used in this research, since it assisted to explore the participants' beliefs and experiences. It also provided the opportunity to explore the participant's own views about maternity care during pregnancy and childbirth. The interview topic guide (appendix iii and iv) was used in order to cover all the relevant topics and to meet the aim and objectives in a logical structure. During the interview, the participants were not restricted to the guide and were allowed to talk freely about any issues they thought were relevant to them. Every interview was audio-recorded using a tape recorder. Participants were informed about the importance of recording the interview in order to ensure the accuracy of their opinions. This allowed the researcher to focus on the interview questions and subsequent responses, rather than taking notes during the interview. Some interviews were conducted in chi Chewa, a local language mostly used in Lusaka, some in English. The data was translated into English

Non-Participant observations

The observations in the neonatal unit were conducted in order to observe the interaction occurring amongst parents, neonates and health workers. The observation was scheduled to take place in the NICU. Being non-participant observations, the researcher was sitting in the room, away from the people being observed, in order to provide less interference during the observation. The observations lasted for approximately 30 minutes. 7 parents were willing to participate in the observation. The researcher was taking notes during the observations and field notes were also taken.

Validity of the Data Collection Tool

To ensure validity, the research was informed by the theoretical framework. The questions were made simple for the respondents to understand. Open- ended questions were asked to gather more information concerning the subject matter. Furthermore, the participants were observed from the same environment and by the same person. The content of the research instrument was compared to similar studies. Before commencement of data collection, the research proposal was presented at different fora where constructive feedback was given.

Data Collection Technique

Once ethical clearance was granted from the University of Zambia Biomedical Research Ethics Committee (UNZABREC) and permission to conduct the study was granted by University Teaching Hospital:
The researcher introduced herself in order to make the participants feel easy.
The purpose, benefits and risks of the study were explained to the participants to enable them participate in a study they are aware of.
Confidentiality was assured to the participants to enable them participate without fear.
Participants were informed that data collection would involve face to face interviews in a private room as well as non-participant observations in the unit Obtained consent from the participants to participate in the study.

The participants were interviewed and observed after signing an informed consent. The interviews were conducted in a clinic room. They were tape recorded and lasted approximately 20 minutes. The observations took place in the neonatal

unit. Considerations of mothers need to rest before the next feeding session were made. Refreshments were provided to the participants considering the length of time of the interviews and observations. The researcher communicated skills such as reflection, nodding, questioning, clarification and maintaining eye contact in order to facilitate and encourage participants to talk until there would be no more themes emerging from the participants. The interview started with an open ended question "Why was your baby admitted to NICU?" and followed by probing questions in the course of the interview. Field notes were taken by the researcher to record unstructured observations or occurrences in the setting that seemed of vital interest (Polit & Beck, 2008). The researcher also recorded the observations and expressions that were noted.

Ethical and cultural considerations

Before commencing the research, ethical approval was obtained from UNZABREC.

Permission was sought from The University Teaching Hospital management, Heads of Department for Obstetrics and Neonatology. The nature and purpose of the study was explained to the participants through the information sheet before commencing the study. The Participants then signed an informed consent form before enrolling in the study. Participants were free to decline participation and withdraw at any time during the study without being answerable to anyone. They were given time to think about before enrolling in the study.

RESULTS

Introduction

In this chapter, data processing and analysis are described. The findings have been presented in a meaningful way thus giving easy understanding.

Data Analysis

In phenomenological theory practice, data collection and data analysis often occur at the same time. The researcher used the theoretical sampling method in order to inform the next data collection process. At the beginning of the data analysis process, the researcher incorporated the data management system 'computer-aided qualitative data analysis' (CAQDAS) software of NVivo version 10 in order to support this process. CAQDAS offers an effective way of conducting qualitative research undertaken within a well-defined time and where the resources are limited. It is very useful in data management as it supports the form of complicated procedures and lengthy analytical techniques, combined with the need for rigorous and valid findings. Each day after collecting the data, the researcher listened to the tapes to assess whether the data was complete or there was a need to go back to the participant for more data. The tape was replayed to make sense out of the data. As the researcher listened to the information, it was also transcribed verbatim in the computer, which was only accessible to the researcher. As data was collected by the researcher, repeated ideas, concepts became apparent, and were tagged with codes which had been extracted from the data.

Coding Process

The researcher went through the transcriptions of the participants and highlighted the important quotes that provide an understanding of how the participants experienced the phenomenon. This step is called horizonalization. In the next step, the researcher developed clusters of meaning from these important quotes into themes. These important quotes and themes were used to write a description of what the participants experienced. They were also used to write a description of the setting that influenced how the participants experienced the phenomenon, called imaginative disparity. From the structural and textural descriptions, the researcher wrote a combined description that presents the essence of the phenomenon, called the essence (Creswel, 2007).

Results

Fifteen participants consented to participate in the study. The study included 4 fathers and 11 mothers. All the participants were married and between the ages of 20 and 42.

Table 1: Major and sub-themes

Major Themes	Sub-Themes
Reason for admission	
Quality of care	
Communication	
Access to NICU	Visitation time
	Duration of visits
	Restrictions of the visits
	Distance to the NICU from residence

Reason for admission

Participants were asked why their babies were admitted to the NICU, the study revealed that most of the mothers in the study had their babies admitted after being born prematurely due to conditions such as pre eclampsia raised blood pressure and antepartum hemorrhage. The following were their responses below;

'*I had pre eclampsia and my baby was born at 7 months that's how she ended up* here.'(Respondent 4).

'I was bleeding heavily from 'mmm' underneath, and that's how my baby was born at 6 to 7months.They said she was premature and needed incubator care. She started fitting badly and was brought here for admission.'(Respondent 1).

Quality of care

When the study participants were asked if they felt cared for by the nurses and doctors while their babies were admitted to NICU, the following were their responses below;

'*Honestly I don't think they care because they are supposed to tell the parents what they are doing to the babies……'* (Respondent 6)

'*Others do care and others don't because sometimes even when you call them they don't come……'* (Respondent 4).

The study revealed that the mothers in the study had a lot to complain about the attitude of the health workers. The study revealed that they felt cared for when the care givers showed concern in the way they handled the neonates and the way they spoke to the parents and responded to situations as they handled the neonates.

Communication system

The participants in this study were asked how their experience was in terms of communication with the nurses and doctors, these were their responses below;

'*My experience hasn't been good because there's little communication to the parents on exactly what is happening to our children. Doctors who work here seem to also be restricted with….you know ahhh giving information to the mothers making the mothers worry even more. I don't know if that's the policy here.' Respondent 15.*

'*Sometimes you are told you have to feed the baby starting at 5mls then when they increase the feed they don't tell you until late afternoon. Like today I should have started feeding my baby 20mls but no one told me until afternoon*.'(Respondent 10.)

The study found that the participants expressed concern that important information was not availed to parents including concerns of feeding quantities of milk to their babies. The study also revealed that parents wanted to be availed their baby's' files so that they knew what was going on with the baby's health.

Access to NICU

Visitation time

The study participants were asked how often they came to visit their babies, the following were their responses below;

*'I usually come every 2 hours to visit my baby……' (*Respondent 9*.)*

'I come every 3 hours since I have triplets…….' (Respondent 3.)

The study revealed that mothers were expected to be in NICU every 2-3 hourly depending on the baby's condition. Due to the distance of the mothers' shelter to NICU, the mothers normally do not go back to the mothers' shelter but stick around in the NICU changing room until the next feeding session.

Duration of visits

The participants were asked how much time they spent with their babies. The following were their precepts below;

'Sometimes they just send you out saying time' yasila' (time up) because we are only given 30 minutes to be in NICU……' (Respondent 3).

'I think 30 minutes is not enough because in that 30 minutes you must feed the baby until its full, start changing the baby or sometimes they say we do the kangaroo. Sometimes they say its time up when you haven't even changed the baby.' (Respondent 5).

'The mother feeds the baby for some time, and is only in NICU for 30 minutes…' (Observation 4).

The study showed that the mothers only stayed 30 minutes in NICU to feed their baby. The participants stated that this was not enough time to be with their babies.

Restriction of visitors

When participants were asked who else came into the NICU to visit the baby apart from the mother. The following were the excepts from the participants;

'*Fathers are not allowed in here. I was allowed in here because my wife is at Chipata clinic. They say we should check the babies through the window…..' Respondent 2.*

'…they don't allow other people coming inside here apart from mothers as a result the father has never seen the baby, unless they give him a paper allowing him to come and see the baby, his relatives have never seen the baby……..' (Respondent 14).

The study participants discussed that only the mother was allowed to visit the baby freely. The father was allowed to visit if they had some documentation from the ward. The other relatives were not allowed to come in NICU.

Distance to the NICU from the residence

When participants were asked how far their residence was from the NICU. These were the excepts below;

'*I think the mothers shelter is very far, maybe they should move us nearby where we can manage to walk*….' (Respondent 5)

'…it takes me about 10 minutes to walk here, I think it's far…..(Respondent 7)

'..it's far from the ward…*It is not safe for us to move at night from the mother's shelter so we just sit in the changing room'*.

The study participants expressed concern about the distance of NICU from their residence at mothers' shelter. They stated that because of the distance they did not go back to mothers' shelter in the night.

OBSERVATION OF THE NICU

In addition to the interviews, semi- structured, non- participant observations were also conducted for this study. After interviewing the participants, selected participants were observed from within the neonatal unit and a total of 7 participants were observed.

The NICU is an open ward with incubators and cribs for the neonates that are admitted. It has cubicles where neonates are admitted with different health needs. It is an area of high sterility, meaning one does not enter with the clothes they wore outside the unit. The nurses and doctors provide care for the neonates who are admitted to NICU. Within the unit there is a changing room for the mothers where they change into gowns before entering the neonatal unit. In the change room women also wash their hands and breasts before breastfeeding their neonates or expressing breast milk.

The researcher used a semi structured guide which guided her observation pattern. The researcher wanted to observe the interaction that took place between parents and their neonates in NICU and the healthcare staff.

'…***Holding the baby'.***

In most cases the mothers were able to hold the baby freely, only with difficulties for those whose babies were in the incubator. When the mothers had a challenge holding the baby who was in the incubator, there was no healthcare staff seen to provide assistance and the mothers did not report that they needed help. Most of the mothers were able to change the baby's nappy without assistance from the healthcare staff.

'…Feeding the baby'

In some observations the mother fed the baby the whole time and in the other the health worker fed the baby every 2 hours, mother only put the milk in the cup and put it on top of the incubator. When the health worker fed the baby in the absence of the mother, mother didn't know who had fed the baby. Most of the mothers were able to feed the baby without any difficulties.

'..Visitation'

During visiting times, the father and other relatives were allowed to see the baby through the window, only a few fathers were seen around the unit. Fathers who came in the unit did not stay as long as the mothers did. In some cases, no relatives were seen to be checking on the baby and the mother was alone near the baby.

'….Communication and body language'

The health workers fed the babies but didn't tell the mothers they had fed the baby. These were cases were the mothers were asked to express breast milk and leave it on the incubator for the next feed. The mothers didn't ask any questions concerning who had fed their baby.

When getting information concerning the wellbeing of the neonate, the healthcare staff were seen to provide valid information in a respectful manner to the father. When the father was seen around the unit, the mother was not in the unit.

When talking to the mothers some of the health workers explained in harsh tones. Dialogue took place at the bed side sometimes and away from the bed side. When spoken to in harsh tones, the mothers did not look happy, others were seen fighting back tears when they got back to the bedside. No one was seen talking to them when they were in that sad moment.

During discharge, it was not easy to tell how the healthcare staff were informing the mothers, the researcher couldn't see any nurse talking or giving instructions to the mothers.

DISCUSSION

This chapter will discuss the findings of the study with regards to the major themes that were generated from the study. The themes to be discussed will include; Reasons for admission, quality of care, communication system, and access to NICU. The study aimed at exploring the experiences of parents whose neonates were admitted to the NICU at UTH.

Reasons for Admission

Neonatal period is the most vulnerable period of life due to different diseases which can be preventable but are also life threatening. Neonates are faced with different threats to their health in low economic countries like Zambia. In order to save the neonates lives, they are admitted to NICU as referrals sometimes from other health facilities within Zambia and also from within the University Teaching Hospital. The common causes of admission to the NICU are prematurity and low birth weight, Respiratory distress syndrome, sepsis, asphyxia and congenital malformations. In our study, it was revealed that prematurity was one common cause of admission to NICU. Parents of admitted neonates revealed that their neonates were mostly admitted as a result of prematurity. Similar findings in a study done by Patil et. al., (2014) indicate that low birth weight and prematurity are important contributors for NICU admissions.

Other studies for example (Gauchan et al, 2011: Vasudevan et al, 2006) indicated that jaundice, sepsis and perinatal asphyxia were the commonest indication for admission in the neonatal intensive care unit. In another study done in South Africa by Hoque et al., (2011), the common causes of admission were birth asphyxia, prematurity, low birth weight and neonatal infections. Maternal conditions can also contribute towards neonatal admission and mortality, the common causes are hypertension, abruption placentae, vaginal bleeding, diabetes and HIV infections (Hoque et, al. 2011). In the current study, the maternal conditions that contributed towards neonatal admissions as reported by the mothers were vaginal bleeding and pre-eclampsia.

Quality of Care

In this study, mothers discussed that they felt cared for when the health workers communicated to them about their baby's health and the way in which they attended to their babies. This was captured from one of the respondents who said:

'Honestly I don't think they care because they are supposed to tell the parents what they are doing to the babies'.

Similar studies done by (Fawcett et al, 1992; Hall, 2008; Smith, 1987) have explored the concept of care, the provision of care and the process of parenting in the NICU. These studies have highlighted that the healthcare providers need to provide care to the parents during their neonates' hospitalization which findings are similar to our study. Parents should be given support during their neonates stay in hospital in form of lessons on breastfeeding, changing of nappies, bathing, kangaroo care and also counseling sessions and guidance to help them cope with the environment in NICU (Ngaiyeya, 2016). Parents battle with negative emotions when their neonates are admitted to the NICU. Our study revealed that some mothers were seen talking to themselves during the time they were visiting their sick neonates, others were sad and others would shed tears. This shows that parents in this state need emotional care in form of counselling services. The healthcare staff need to recognize the fear and pain that the parents go through having a sick neonate in NICU and not being able to do anything about it. In the current study it was revealed that nurses rendered care to the neonates by feeding them and this was also confirmed by the observations which the researcher did in addition to the interviews.

In another study conducted in Canada by Lee (2014), the nurses shared responsibilities of care with the parents in NICU such as giving oral medication, measuring of temperature and also keeping track of their neonates' progress so that they can actively participate in daily decision making. Parents in the current study highlighted the need to view their baby's files so that they could be involved in the care of their neonates and know the health status of the babies. This is very important to parents as it would help them track the health of their neonates and alley their anxiety. In a study conducted by De Bernado (2017), attending ward rounds was revealed as one way of involving parents in the health care of their neonates. When parents are involved in the care of their neonates they feel accepted and thus cared for by the healthcare staff.

Parents have expectations of the NICU that they feel are not being met by the healthcare staff, and this could be because the healthcare staff do not understand the needs of parents and relate them to their sick neonates.

Communication System

Communication and provision of updates is an important element in NICU between the healthcare staff and the parents in NICU. In this study it was found that there was inadequate communication between the healthcare staff and the parents in NICU. This was consistent with a study done by (Yee & Ross, 2006) which found parental satisfaction to be based on quality and amount of communication in the NICU. The parents in the our study complained of a lack of consistent communication from the healthcare staff which increased their anxiety and agitation. In a study done in Malawi by Ngiayeya (2016), mothers reported that the updates they received from the nurses and midwives regarding the health of their newborn were helpful in alleviating their fears and equally allowing them to be connected to their babies. Parents feel satisfied when the health workers offer adequate information concerning their neonates' health. Conflicting advice from

doctors and nurses concerning the care of the neonate can cause anxiety to the parents during the course of their neonates stay in hospital. It is therefore important for the healthcare staff to be consistent with the information given to the parents to avoid raising their fears. It could be this lack of communication and proper information that left most parents thinking that the fathers were not allowed in NICU to visit their babies on first day of admission. The parents were not availed with information pertaining to the feeds as seen in one of the excepts below:

'….Sometimes you are told you have to feed the baby starting at 5mls then when they increase the feed they don't tell you until late afternoon. Like today I should have started feeding my baby 20mls but no one told me until afternoon….' (Respondent 14).

Information which can improve the neonates wellbeing if well delivered to the parents is withheld from them meaning they are not told what is happening. Increasing of feeds is a very important aspect which can improve the health of neonates in NICU and if parents who feed the babies are not told when changes are made, then the neonates will not benefit. The ability to recognize parents as co-workers in NICU for the healthcare staff is a very important aspect which should not be overlooked, because parents help in the care of the neonates (Hedeira, 2014).

Therefore, whatever decision is made concerning the neonates wellbeing, the parents should be informed so that there is continuity of care. Our study also found that parents especially the mothers were answered harshly whenever they wanted to enquire anything concerning their neonates in NICU. They also displayed gestures such as talking to themselves, crying and showing sadness on their faces, which would have meant that they were not happy with what was pertaining in NICU. The staff in NICU would have noticed the pain through these gestures had they been more attentive to the parents and trained in psychosocial counselling. Attentive communication offers the parents relief in their difficult circumstances. What the parents would want is someone to listen to them because a lack of communication aggravates the feelings of loneliness, rejection and unwanted responsibility (Wigert et al, 2014). It is important to note that the NICU staff do not meet the needs of parents and may not experience communication problems in the same way as do the parents (Turner et al, 2014).

Access to NICU

The parents who participated in this study revealed that they wanted to have access to their neonates and this would include spending longer hours in NICU. The study revealed that spending adequate time in NICU, and having access to see their babies for both parents made them happy. This was consistent with a study done by (De Bernado et al., 2017) which supported parent's unrestricted presence in the NICU and parental involvement in the care of neonates including attending ward rounds and having access to medical files. In our study the parents complained about the long distance from their residence to the NICU, they expressed the need to stay near the NICU for easy access to their babies. The parents also complained of the danger they faced in the night when moving from the mothers' shelter to NICU. They had no one to escort them and offer them protection during the night as it was very dangerous. Our study revealed that when mothers came to feed their neonates especially in the night, they did not go back to the mothers' shelter to rest, instead they rested in the changing room where there was no space and the place was not conducive for long hours of stay. Flacking et al., (2012) in their study highlighted the need for physical and emotional closeness between the preterm infant and the parent in the NICU. In their study they highlighted the need for culturally sensitive care practices, procedures and the physical environment to be considered to facilitate closeness of both the neonates and the parents. This can be achieved through early and prolonged skin-skin contact, increasing the visiting hours, having family rooms within NICU and improving of the space on the units. It can also be achieved by educating the parents on infection prevention practices (IPP) in NICU which can prevent transfer of infection to the neonates and promote good health. Family members including the husband or partner are not automatically allowed in NICU for visits as shown in our study. Our study showed that husbands or partners were only allowed to visit the neonate on the first day of admission, there after they had to view the baby through a window. The cultural aspect could have been overlooked in the NICU at UTH so far as family centered care is concerned. Zambia supports community and family centered support for mothers, like any other African country and this helps the mother to cope with the new role of motherhood. According to Gulamani et al., (2013), culture is known to help in the support of mothers psychologically and otherwise.

Application of the Compassionate Care Framework (CCF) to the study

This study has shown that the compassionate care framework plays a role in bettering the care of the neonates in NICU. The study findings revealed that communication was a major aspect of the NICU that was lacking between the healthcare staff and the parents to the neonates, it also revealed that there was limited time for bonding between the neonates and their mothers.

Affiliative Relationships

The Affiliative relationships between parents and infants are based on attachment and bonding principles as opposed to what is happening in the NICU at UTH. Our study concluded that the mothers and babies in NICU were not bonding adequately.

The mothers had limited time to be with their babies and it was observed that they only spent 30 minutes with the baby, which was not enough. The fathers were not allowed to see their babies from inside unless on the first day of admission, there after he had to view through a window.

Bidirectional Communication

This study found that there was inefficient communication between the healthcare staff and the parents to the neonates in NICU. Communication should be given priority in NICU because this aspect is important in as giving information is concerned. According to CCF Bidirectional communication addresses both interpersonal and informational communication. Interpersonal communication which is both verbal and non-verbal, involves two- way communication based on respect. The study found that there was a lack of two-way communication between the healthcare staff and the parents to the neonates in NICU. Most of the time the parents wanted to communicate to the staff but did not get good feedback concerning the health of their neonates. The parents in our study related good care to good communication system. CCF has demonstrated that parents are a rich source of information and experiences and also value sharing information and perspectives concerning their baby and welfare. Bilateral communication is not a one-way flow of information from the care givers to the parents, it involves getting feedback from parents to ensure that the parents understand what is being communicated to them. Our study found that the parents did not get as much information as they wanted with regards to their neonates' health. This meant the progress of the disease not being communicated, the increase in feeds or with holding of the feeds not communicated to the parents, who had fed their baby in their absence and how long ago that was done and also what kind of investigations were done on the baby. Parents felt the healthcare staff were not concerned with the way they felt with this kind of communication pattern.

Compassionate Partnerships

The results in the study revealed that the parents were not incorporated in the care of their neonates from admission apart from changing nappies and breastfeeding. The parents complained of a lack of involvement in the care of their neonates. The CC framework suggests that the parents should be involved in the care of their neonates and this can only happen if they are shown sympathy and empathy by the healthcare providers in the NICU. It is important for the healthcare staff to create rapport with the parents.

Implication to Nursing

This section discusses the implication of the study to nursing. The implications will be discussed under the following headings: nursing practice, nursing administration, nursing education and nursing research.

Nursing Practice

Our study has provided information on the experiences of parents with neonates admitted in NICU at UTH. The parents in NICU revealed that communication was a missing element in the NICU because the healthcare staff did not give the parents as much information and updates as they would need concerning their neonates. Nurses should act as advocates for the parents and give them information to help them understand their neonates' health status. The study also discovered that parents in NICU needed care in form of support. Nurses should therefore provide support to the parents by offering lessons on breastfeeding, cup feeding, bathing, kangaroo mother care, and also measuring temperature of their neonates once they are oriented. Nurses also provide care for neonates in NICU and therefore can provide care for their parents as well.

Nursing Administration

The nurse managers should influence development of guidelines which will help in the relationship of nurses and parents in the NICU. The nurse administrators should supervise nurses on every shift to ensure that parents are also given care in NICU and treated with love and respect. They need to assign nurses to give information, education and communication on the care of the sick neonates in NICU. The nurse administrators should also organize literature for nurses which gives information on the care of parents with sick neonates in NICU.

Nursing Education

As much as neonatal health has gained ground in Zambia, there is little attention paid to the parents who help in the nursing of the neonates admitted in NICU.

There is need to emphasize on care for parents in the NICU, bonding and attachment of neonates and mothers in the nursing curriculum in order to provide nurses with knowledge and consequently care to parents in NICU. In-service training programs should equally be provided to nurses not only on the care for neonates in NICU but also on the care for parents in NICU. All the nursing staff in NICU should be trained in psychosocial counselling in order to offer support to the NICU parents. Nurses should be equipped with knowledge to conduct mini workshops for parents on the care of the neonates. This can be done by incorporating peer support from parents with past experience of NICU admissions.

Nursing Research

Literature reviewed has shown that research on experiences of parents with neonates in NICU has only been done in developed countries. Nurse researchers should take keen interest and concentrate their research projects in areas such as NICU where there is scanty literature in Zambia. The nurse researchers should be encouraged to conduct research on experiences of clients in a health setting so that they get the real picture of clients' perceptions and how they can be helped.

CONCLUSION

The study shows that parents in NICU need more information with regards to the health of the neonates during hospitalization as this would calm them and alley their anxiety. The parents also need access to their neonates without restrictions in terms of time and duration of visits. There's need for support to be offered to parents to help them adjust to the new and unfamiliar environment of NICU.

Limitations of the study

The study had some limitations being the first of its kind in the study setting.

1. The non- participant observations may have created social desirability bias. The presence of the researcher may have influenced the participants' actions during the observations. Participants may change their behaviour if they know they are being observed and this could have happened to the study participants in this study.
2. The use of observations may not capture everything that happens in a study unless it is done over a period of time, this could have happened in this study.
3. Being a qualitative study generalizability of findings is not possible unlike a quantitative study. Therefore findings for this study cannot be generalized to other settings.

Acknowledgment

I want to thank you my God for being the source of all my aspirations and desires, for making this a dream come true.
I wish to express my gratitude to the Superintendent of Kalulushi General Hospital and staff for supporting me during the time I was pursuing the Masters of Science in nursing Programme at the University of Zambia.
Many thanks go to the University of Zambia and in Particular the School of Nursing Sciences for providing the necessary learning materials and facilities.
My innermost gratitude goes to my research supervisors Professor M.C Maimbolwa and Ms Mutinke Zulu who helped me during my research study, reading through my numerous scripts and helped me make sense out of the confusion.
I am very grateful to my entire family members for their encouragement, support and love.
Most of all I want to thank the participants for accepting to be in my study.

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