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The Needs of Mothers of Preterm Neonate(s) Admitted at the New-Born Intensive Care Unit of Mother Baby, Riley of MoI Teaching and Referral Hospital

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Abstract: Background: Expecting a healthy baby and then being confronted with a preterm neonate admitted to a new born unit requires adaptation to a frightening and stressful situation. The experience for most mothers of premature babies is like a roller coaster ride; feelings of sadness, regret, anger, powerlessness, guilt and anxiety. Apart from these experiences, are the needs of mothers that are not addressed by healthcare professionals. Significance of the study: Mothers with preterm neonates in the NICU encounter a wide variety of experiences and needs due to the unfolding events. Unmet needs may precipitate psychological, social, physical and financial strain in the family. Identifying the experiences and needs of mothers with premature neonates will help improve the quality of health care. Objective: To assess the needs of mothers with preterm neonate(s) in the new born intensive care unit of Mother Riley of Moi Teaching and Referral Hospital (MTRH). Study area: The study was conducted at the NICU (Riley Mother and Baby Hospital) of MTRH, Eldoret, Kenya. Methodology: A qualitative approach was utilized. Participants were selected by use of purposive sampling. The sample size was determined when saturation of the data was obtained. The inclusion criteria were mothers of premature babies born before 37 weeks gestation and admitted to the NBU. The exclusion criteria were mothers of neonates with congenital anomalies and mothers with severe mental illness. The study utilized thematic analysis based on a template design for qualitative data. The interview guide served as a template for this and was helpful in the extraction of categories and themes from data. Results: The findings demonstrated the existence of most crucial needs that mothers require when their baby is admitted at the NICU. Themes that made up category of informational needs included the need for information on progress of the baby, explanation of alarm and monitors, understanding charts and discharge information. Supportive care needs comprised of lack of support from staff, assistance with ambulation, abandonment, bonding with baby and assistance of mothers with multiple neonates. Conclusion: The study revealed that despite the aggressive care that focused only on the preterm baby, mothers had their concerns too which needed to be addressed. Recommendation: Mothers should be involved in the basic care of their babies and get information on neonate's treatment plan, procedures and progress. Healthcare professionals should follow a multi-disciplinary team approach in addressing the needs of mothers. Adjustment should be made in NBU training courses to increase awareness of parental experiences and their needs. An additional discharge guide should be designed and handed to the mothers upon discharge.

1. Introduction

1.1 Background

Every mother has a birth story to tell. For a few, their story follows the script they had imagined during pregnancy. But for most mothers, their story doesn't follow the script, instead veering off in unexpected directions with disappointing and at times with devastating surprise (Deborah, Davis, Mara &Tesler, 2002).

The early delivery occurs at a time when taking on the attitudes and expectations of pregnancy. This results in lost opportunities to prepare mentally for motherhood and the mother is thrust into a developmental crisis when the neonate is born prematurely (Younger, Kendell, & Pickler, 1997). During this crisis, mothers find it difficult to cope with intense and confusing emotions stemming from an unexpected delivery, concern about a sick neonate, admission of the neonate to NBU, appearance of the sick or premature neonate, grief from the loss of an ideal pregnancy and birth experience. According to Welma (2003), the reality of caring for a premature baby plus its appearance can be an enormous and unexpected shock for both parents.

A variety of emotional responses including sadness, regret, anger, powerlessness, detachment, anxiety, vigilance,

depression and guilt can feel overwhelmingly intense (Deborah et al, 2002). According toMcHaffie&Fowlie, 2004, the dreams of cuddling a healthy baby and showing off to admiring friends and relatives all dissolve into a nightmare of a critically ill newborn that has to be kept away from the mother and in the care of strangers and machines in order to survive. The NBU environment is also described as a traumatic experience. Accordingto (Peebles-Kleiger 2000), the technical surroundings among them; the noisy machines, tubes attached all over the neonate, heat, and lights are a stressor to mothers.

Above and beyond NBU encounter, mothers need discharge information regarding illness, development, therapy, feeding, growth, interaction and possible disabilities of their preterm baby as they plan to take their baby home (Welma, 2003).

McGrath, (2001), Miles, (1996) and Prudhoe & Peters, (1995), found that many mothers yearn for support and information about their painful, confusing and overwhelming experiences of delivering too early and having a baby in the neonatal unit.

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1.2 Problem Statement

During my clinical practice as a midwife and a neonatal nurse, I observed fluctuating emotions and unmet needs in mothers with neonates in the NBU. Due to lack of knowledge regarding the care of their neonates, these mothers were not empowered to manage the needs of their babies or their own needs while the neonate was still admitted and even after discharge from the hospital. In Moi Teaching and Referral Hospital, and many other hospitals in the country, much attention and care is directed towards the preterm baby. However, very little is known concerning the experiences and needs of mothers who have their neonates admitted to the NBU.

As noted earlier, the NBU environment can also be described as high stress environment. Mothers rarely know the neonatal unitstaffs before their baby is admitted. The language (i.e. the medical jargon and behavioursthey encounter) can contribute to an overwhelming feeling ofisolation.

The needs of the mothers are normally seen as inferior to the neonate's condition (Deborah et al 2002). Parental needs are neglected and mothers are not involved in the decision making of their infant's care. Learning the experiences and needs of mothers following the birth of a preterm neonate in NBU has not been comprehensively studied (Welma, 2003).

1.3 Justification

Parents with preterm neonates in NBU encounter a wide variety of experiences and needs, due to the unfolding events following the birth of a premature baby. Unmet parental needs may precipitate stress and cause clinical depression or mental illness. According to Gardner & Stewart, as cited by Ward & Hayes, (2001), inappropriate responses to these needs may lead family members to experience heightened levels of anxiety, fear, and misunderstanding. It is therefore important to identify the common experiences and needs that parents with premature neonates have and address them while their baby is admitted at the NBU.

Identifying these needs and experiences of parents with premature neonates will provide opportunity to set standards for nursing practice that optimizes maternal and neonatal care. It also helps mentor students and incorporate the information into the teaching curriculum of medical training institutions.

Knowing the experiences and needs of mothers will impact on the care that the mother will give to her baby. Helping parents with their emotional reactions to hospitalization of their baby can increase physical healing, decrease psychopathological sequelae, and be cost efficient by decreasing the number of post-discharge emergency room visits and days of hospitalization (Peebles-Kleiger, 2000).

1.4 Objective of the Study

To describe the needs mothers with preterm neonate(s) at the new born intensive care unit (NICU) of Mother and Baby, Riley of MTRH.

2. Research Methodology

2.1 Research Design

The study utilized qualitative research design using descriptive and exploratory techniques. "Qualitative design and analysis involves the collection, integration and synthesis of nonnumeric narrative data" (Burns & Grove, 2001). In this study, the focus of the qualitative research method was on qualitative aspects such as meaning, experience and understanding of needs that mothers required during the admission of their preterm baby in the NBU. The research process was inductive in its approach; resulting in the generation of new theories as mothers narrated their experiences and needs while their babies were admitted at the newborn unit.

2.2 Study Area

The study was conducted at the Moi Teaching and Referral Hospital (MTRH). The hospital is located in the western part of the country and offers specialized healthcare, covering the wider region of Kenya. It is a parastatal institution that runs almost autonomously and is classified as the second largest national referral hospital after Kenyatta National Hospital in Nairobi.

The facility is situated in Eldoret town 320 kilometres northwest of Nairobi, Kenya. From Eldoret International Airport, the hospital lies on the northern part, about 5 kilometres away. The New Born Unit is situated in the ground floor of Riley Mother and Baby Hospital adjacent to MTRH. Mothers of preterm neonates stay in the hostels situated in the 3rd floor, about 200 meters away from the nursery with no lifts.

2.3 Study Population

In this study the target population were all the mothers with preterm neonate(s) in NBU of MTRH. The sample size was purposively determined when saturation of the data was reached.

According to Babbie and Mouton (2002), an indication for a study in the interpretive (qualitative) paradigm is between 5 and 20 or 25 respondents, depending on the nature of the study and the number of times data-gathering techniques will be repeated with each respondent.

In this study, a total of 24 mothers were interviewed whereby 18 mothers were placed in three groups each comprising of 6 mothers. To assist in checking saturation of data, individual interviews were conducted and the researcher stopped at the sixth mother because data had become repetitive. The first group constituted of mothers with neonates who were newly admitted and had not stayed more than five days in the unit. The second group was characterized by mothers who had stayed for a while (>5days<2weeks) and were not yet ready for discharge. The last group comprised of mothers who were ready for discharge and had stayed in the ward for more that 2 weeks. The length of stay of all the neonates was derived from the

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admission register. Pseudo names were used to describe individual mothers.

2.4 Sampling Technique

All mothers who delivered premature babies from the month of April to May 2010 and got admitted at the NBU were asked to participate in the study.

Purposive sampling methodology was used to derive cases of premature births. This method uses the researcher's knowledge about a population and uses subjects who are experts on the subject (Polit&Hungler (1999). The experts in this study were the mothers with preterm neonates confined to neonates born before 37 weeks gestation and born at/or admitted to NBU of MTRH. An admission register was used to purposely get participants who fitted in the eligibility criteria. and to pick the new admissions, mothers who had stayed for more than 5 days but not ready for discharge and finally mothers whose neonates were ready for discharge. It was however difficult to determine which mothers were ready for discharge because most of them were not given information on when they would be discharged. I therefore had to get this information from the matron regarding the neonates who were ready for discharge.

Mothers were informed about the study by the researcher and written consent requested. Since some respondents had primary level, they did not have the capacity to understand the consent form and the interview guide and the researcher translated the two forms in Swahili.

The neonates with severe congenital malformations and mothers diagnosed with a psychological condition were excluded. The reason for excluding neonates with severe congenital anomalies was because the mother's reactions would be different to that of a mother having a normal but premature baby. Mothers diagnosed with psychological condition would not be in stable condition hence their interpretation to their experiences and needs would not be a true representation.

2.5 Data Collection

As indicated, the researcher was the primary instrument in collecting data. The researcher took an inductive approach and begun with the emersion in the natural setting. The research activities included focused group discussions, individual interviews and field notes. A private room was used for the interviews to ensure privacy and confidential purposes. After permission was given by the participants all sessions were tape recorded.

2.5.1 Focused Group Discussion

The use of group interaction was deployed to produce data and insights that would be less accessible without the interaction found in a group. Participants were encouraged to express their needs directly without the constraints of rigid, predetermined questions. Saturation of data was arrived at after conducting three FGDs each comprising of 6 participants. Each session was considered complete after thick description of data was achieved thus the length of time taken to conduct each session were all different. The

main function of the researcher was to encourage the participants to talk freely about the topic and to record the responses on a tape recorder. In order to obtain maximum information from the participants during the process, the researcher employed the following interactive skills: probing, reflecting, clarifying, paraphrasing, and summarising (Uys& Middleton, 2004).

2.5.2 In-depth Interviews

A relaxed and comfortable setting was used to enable participants talk freely about their experiences and needs so as to generate rich empirical data. To ensure privacy and confidentiality, a private room was availed. All the interview sessions were tape recorded to capture the dialogue between the interviewer and interviewee for purposes of analysing data. Facilitative skills mentioned above were used. In this study, six in-depth interviews were held to check saturation of data. There were no definite characteristics of the respondents as long as they met the eligibility criteria.

2.5.3 Field Notes

The researcher made observational, theoretical and personal field notes as a validation of observation and taped comments during interview sessions. The observational notes described events experienced through watching and listening. Theoretical notes were used to derive meaning from observational notes. Personal notes contained the researcher's reaction and experiences.

2.6 Measures to Ensure Trustworthiness of Data

To ensure trustworthiness of data the researcher used Guba's Model of trustworthiness (Lincoln & Guba, 1985). The model consisted of credibility, researcher credibility, dependability, transferability, and confirmability.

1) Credibility

Credibility establishes how confident the researcher is with the truth of the findings and it involves two aspects;

a) Prolonged Engagement.

The researcher established a good rapport and trust with the participants. A considerable time (1 month) was spent with the participants during the interviews.

b) Persistent observation.

The study was considered credible after it presented such accurate descriptions that people, who also shared that experience, would immediately recognize the description. This was determined by reaching a thick description in the data collection.

2) Researcher Credibility

In this study the researcher served as the instrument and an analytic process. The researcher's knowledge was important in establishing confidence in the data because she underwent a rigorous research & methodology coursework. The input from the researcher's qualified supervisors was very important in establishing trust in the research.

3) Member Check

The researcher did all transcriptions immediately after the interviews and went back to confirm statements that were unclear.

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4) Transferability

This refers to the extent to which the findings can be applied in other contexts or with other respondents. Within the qualitative paradigm, generalization of results was not done. The aim of this study was to provide an understanding of the experiences and unmet needs of mothers with preterm neonate in NBU.

5) Dependability

In the study if an inquiry were to be done it would provide its audience with evidence that if it were to be repeated with the same or similar respondents in a similar context, its findings would be similar. The stability of data was attained by use of an independent coder (a qualified psychosocial counsellor) who read through the researcher's transcribed findings and replicated it.

2.7 Data Analysis

The recorded discussions were transcribed verbatim. The study utilized thematic analysis based on a template design for qualitative data (Brink, 2001). The interview guide (Appendix 3) served as a template for this and was helpful in the extraction of themes from the data. Data from both individual and focused group discussions were analysed using the same method. The researcher read all transcriptions carefully and wrote down some ideas as they came to mind. When the task had been completed for several respondents, the researcher made a list of all topics, and formed these topics into columns that were arranged as major themes. The researcher then found the most descriptive wording and converted the themes into categories, and reduced the total list of categories by grouping related themes together. Moreover, the researcher reviewed the observational and personal field notes made during the discussion sessions and developed themes that were converted into categories.

Data was repeatedly exposed to analysis until the themes and categories that emerged were regarded as satisfactory. Tesch's method of data analysis as applied in the study involved eight steps:

- 1) Getting a sense of the whole by reading through all transcriptions of the interviews.
- 2) Selecting the shortest most interesting interview and perusing it, asking what its about, bearing in mind its underlying meaning. Writing thoughts in the margin.
- 3) Making a list of topics from all the interviews, clustering together similar topics. Arranging these topics into major themes, unique themes and left over topics.
- 4) Abbreviating the topics as codes, this had to be written next to the relative segment of the text. Checking if new categories or themes emerged.
- 5) Changing the topics into descriptive categories. Reducing the categories by clustering together similar topics.
- 6) Deciding on the final abbreviations for each category and placing these codes in alphabetical order.
- 7) Assembling the related data material of each category in one place
- 8) Recording the existing data and conducting a preliminary analysis.

An independent coder verified the findings based on the prescribed protocol. Together with the researcher, consensus

was reached to confirm and change identified themes. Finally, findings were described using the actual words of participants, as well as quotations in order to describe their experiences.

3. Study Limitation

The researcher acknowledges the fact that the interview sessions were very emotional and at some point had to suspend the interviews in order to calm down the mothers. A psychosocial counsellor was of much help and only came in to counsel the most affected mothers. Scarcity of time with the participants was problem because they had to feed their babies on a three hourly basis. There was attrition of the participants.

4. Ethical Considerations

The following ethical issues were put into consideration: An approval from the Institutional Research and Ethics Committee (IREC) of Moi University/ Moi Teaching and Referral Hospital (MTRH) was obtained prior to the commencement of the research to ensure that the risks faced by human participants in this research were minimal (Babbie& Mouton, 2002). Dissemination of results was intended to facilitate improvement rather than just reveal the existing loopholes.

Informed written consent was obtained from hospital and unit managers, as well as the mothers of preterm neonates admitted to the NBU. The respondents' privacy was respected. All the sessions took place in a private room and all the transcripts of the recordings were kept in a safe place.

Respondents were informed in the consent form that they would not be exposed to any physical or emotional harm.

Anonymity and confidentiality was a right ensured to the informants in that the researcher vowed that under no circumstances would the identity of her informants be made public. In the study pseudo-names were used to describe respondents thus avoid chances of respondent identification.

Participation in the study was voluntary. They were reminded of their right to withdraw from the study at any time.

5. Findings

Demographic Features of Respondents

Mothers who participated in the study were women aged 17-40 years. A total of six mothers participated in the individual interview session while 18 mothers were involved under the three focused group discussions. Table 4.1 describes the demographic characteristics of each individual respondent.

Table 4.1: Demographic Characteristics of the Participants

| Features | No | Percentage |
|---------------|----|------------|
| Age | | |
| • <20 years | 7 | 29.20% |
| • 21-30 years | 13 | 54% |
| • 31-35 years | 2 | 8.30% |
| • >36 years | 2 | 8.30% |

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| LOS | | |
|---------------------------------|----|--------|
| • < 5 days | 8 | 33.30% |
| • 5-14 days | 8 | 33.30% |
| • >14 days | 8 | 33.30% |
| Education | | |
| Primary | 9 | 35.50% |
| Secondary | 8 | 33.30% |
| College | 7 | 29.20% |
| Marital Status | | |
| Married | 13 | 54.20% |
| Not Married | 11 | 45.80% |
| Parity | | |
| Nulliparous | 11 | 45.80% |
| Multiparous | 13 | 54.20% |
| Occupation | | |
| Formal | 7 | 29.20% |
| Informal | 17 | 70.80% |

Themes and Categories Derived from Data

The categories and themes are discussed with accompanying quotations from the data. The template derived from the interview guide was used in the analysis of the responses into categories and themes presented in subsequent sections. Table 4.2 below summarizes categories and themes generated from the study.

Table 4.2: Summary of categories and themes generated.

| Objective | Categories | Themes | |
|-----------|---------------|--------------------------------------|--|
| | U | | |
| One | Informational | Need for information | |
| | Needs | 2. Need for explanation of | |
| | | alarm/monitors | |
| | | 3. Updates on neonate's progress | |
| | | 4. Understanding of neonate's charts | |
| | | 5. Discharge needs | |
| One | Support | 1. Lack of support from staff | |
| | Needs | 2. Assistance with ambulation | |
| | | 3. Abandonment | |
| | | 4. Lack of support for mothers with | |
| | | multiple neonates | |
| | | 5. Assistance with the bonding | |
| | | process | |

Category One: Informational Needs

One of the needs that reached thick description was the need of information regarding update on neonate's condition and progress, information regarding medication, interventions, time of treatment, action plan, explanation of alarms/monitors, understanding neonate's charts, consequent advice and use of simple clear language. Below is a description of themes generated that made up informational need category.

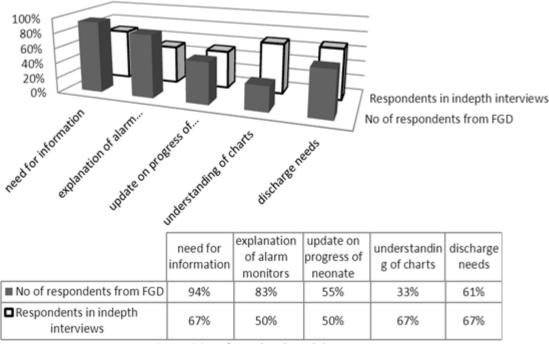


Figure 4.2: Informational needs/Category One

Theme 1: Need for Information

Most mothers felt that most interventions were carried out without their being informed. They needed to be informed on what the health professionals were doing to the baby but unfortunately in several occasions no one took time to inform them regarding the care and progress of the baby. The following comment came from one of the focused group discussion. Ruthie, a 34 year old business lady said:

"...I would like to be told what they are doing to my baby. Nurses keep on attending to my baby in the box(incubator) but no one is interested to inform me whatever is happening to my baby and what they are doing to her!.." Blood samples got drawn from the neonates without the consent of the mother. Mothers only got to know that samples had been taken by the bruises they found on their babies' skin.

They felt so disturbed and some wept because they thought that this was not right and their babies were suffering. During one of the focused group discussion, Anne made the whole group weep when she uncontrollably explained how she found several unexplained bruises on her baby.

"...The blood sample was drawn from my baby without my knowledge. They had pricked my baby

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all over, head, toes, and hands without telling me why...(sobs)..."

Assumpta aged 25 lamented.

"...We mothers should be allowed to listen and ask questions when the doctor is seeing the babies and everything should be explained to us...."

Several respondents (>78%) from other interviews supported this statement and it was clear that several procedures were carried out on the baby without the knowledge of the mother. More still, most mothers expressed that they felt excluded in the care of their baby.

Theme 2: Need for Explanation of Alarms/Monitors

Mothers expressed that the technical surroundings among them; the noisy machines, tubes attached all over the neonate, heat, and lights made the NBU environment very strange and they felt so isolated and lost because there was nobody to give them an explanation. A very emotional Janfred was in despair and she commented.

"...Am so lost! My baby has been admitted for the last five days...(sob). There are these tubes surrounding my baby. Through the nose, tummy...and many other strange things attached to him. I wish someone would explain to me what is happening to my son. What are all these machines for? Imagine I see nurses running up and down, but they never tell me what they are doing to my little baby... (sobs)"

Some mothers learnt about the nursery from their fellow mothers who had been in the nursery for quiet some time though they felt that the explanation was not sufficient and satisfactory. They explained that they would appreciate if a nurse will give them an orientation on all the machines attached to the baby. A worried Stella who works as a sales representative commented.

"...What is important is for me to be informed of all the machines, pipes and medication that have been put on my baby..."

An alarm going off would frighten most mothers and this made them imagine that the condition of the baby had worsened thus the alarm.

Theme 3: Updates on neonate's condition/ progress

Most mothers needed to be updated on the progress and condition of the baby. Just like the need for informed consent, their major interest was to be informed on treatment of neonate regarding interventions, plan of action, time of treatment and medication.

During the focused group discussion, Milly aged 20 years and works as a salonist made the following statement.

"...Basically what we need is to be updated at all times on the progress of our child. I will feel good if I am informed about the treatment of my baby..."

Many mothers were in support of this statement. Some respondents implied that the interventions done on the baby was not explained to them. They needed to know what

medication the baby was on and why, what operations, X-rays and other tests were needed and why?

Most mothers expressed of not being in the picture on the next plan of action regarding treatment of their baby. They did not know when to start breastfeeding a tube fed baby, how to wean off the baby from the incubator, drug regimen, how to monitor temperatures and the breathing patterns of the baby. Liza aged 26 and working a nurse in one of the rural dispensary commented:

"...When off the ventilator what happens next? When can I start breast-feeding or hold my baby? Tungependamadaktariwatuelezeekilamarakuhusu haliyamtoto,

mimihuchanganyikiwanikimpataakiwambayanani ngependawaniambiewanamfanyianini.

(Consistent advice from nursing staff about progress of the baby is important – as a parent you are already confused especially when my baby's condition worsens and have the need for consistent advice)..."

Theme 4: Understanding of neonate's charts

Over 90% of mothers did not understand the neonate's charts. This was made even more difficult by the fact that neither could they access the neonate's file nor be allowed to read it. Most mothers thought that the information in the file only belonged to the medical team and they had no right to access the file. Interestingly, some mothers had to "steal" the file in order to read information regarding progress of the baby. Mercy aged 17 years could not understand why the file was written 'confidential'.

"...Another thing is the file. You see, on the file it has been labelled confidential. I do not know if the information in the file is only meant for the nurse and the doctor? We mothers do not have access to the file. You cannot open and read what is in there. When I at time manage to steal and open the file, I do not understand the progress chart on development and growth of baby..."

They all expressed that they would appreciate if somebody was there to explain to them the charts about their babies even by use of drawings.

Theme 5: Discharge Needs

Mothers became used to the NBU after a while and with less support they managed to learn how to care for their neonates themselves, but still they were afraid to take their neonate home and take full responsibility for him/her.

Most of them expressed their unpreparedness and inability to handle their neonates at home if the condition of the baby deteriorated. They expressed the need to be given discharge instructions to assist them to understand baby's illnesses, growth and development, possible complications and how to manage them at home.

Most mothers expressed disappointment on the routine discharge exercise where a mother was unexpectedly informed that she was going home without prior discharge arrangements and instructions. Milka commented

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concerning her unpreparedness to take her baby home and her comment was supported by several others.

Some wondered what happens on the day of discharge. They expressed the need to be given specific information regarding the care of their baby after discharge. Several mothers came from diverse regions of the country. Some even came from outside the country, specifically Uganda.

They were very uncertain on how to manage their baby especially if the baby's condition deteriorated. They were afraid to travel long distances considering the delicate condition of the baby.

Category Two: Support Needs

Mothers of preterm neonates experienced stress due to social isolation and a lack of appropriate social support. Support from the professional team as well as from family members and friends was essential as evidenced by 20 of 24 mothers reporting this aspect. Furthermore, several mothers got disappointed by their social surrounding either due to lack of support from the medical staff, insufficient understanding and the physical location of the NBU in relation to the mothers' hostels. The category was arrived at from the themes discussed below in figure 3.

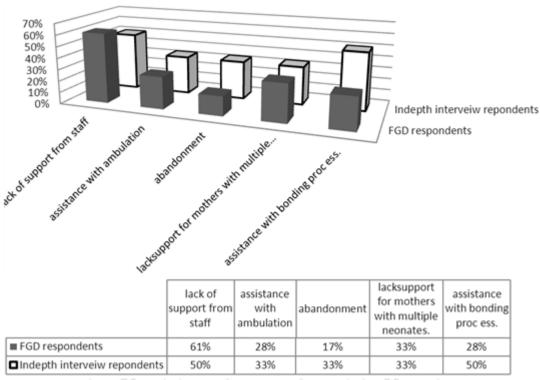


Figure 4.3: Support Needs/ Category Two

Theme 1: Lack of Support from Staff:

Many mothers endorsed that they were disappointed with the little and at times no support from health professionals. Most of them pointed out that the health care providers were too busy, unfriendly and communicated using medical terms that mothers barely understood.

Several admitted that the unsupportive attitude of the staff left them helpless. During feeding times, mothers found it difficult to approach and ask questions concerning the progress of their neonates. Everline aged 26 from the focused group discussion complained.

"...Some nurses are so unsupportive; mothers are left standing for long with their breast milk which has already been expressed into cups. The milk goes cold and when we give to baby, he vomits immediately......Some leave as soon as we are in the nursery and we do not have anyone to help us or ask questions..."

This statement was supported by many respondents from various interviews.

What others said in the group discussion and in the in-depth interviews alluded to the lack of support from the nursing staff, for example.

> "... I wish the nurses could use a more friendly language when they are talking to us. I really fear approaching them whenever I have a question to ask them and I prefer to keep quiet..."

Most mothers agreed that the most important aspect to getting through the NBU experience was support, understanding, information and a helping hand when it was needed from the staff. A more positive form of support came from the peers.

All the mothers expressed that the fact that they all shared the same experience gave them an extra strength to carry on. They felt better when they discussed about their babies. During the focused group discussion Tasha appreciated the fact that they were all undergoing similar situation and had each other for support. She notes.

"...I feel better when we talk with other mothers in the nursery. We talk about our babies, we feed

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them together and you feel like you are not alone..."

Theme 2: Abandonment

While most mothers were preoccupied with hope of taking their baby home, 3 out of the 24 mothers were homeless and felt hopeless because they did not have any form of social support. Hospital had become their home and haven and they dreaded the reckoning day of discharge because they neither had money to pay the hospital bill nor a home to take their baby to. They felt so alone and helpless.

In the moving words of Priscah aged 22 years who was brought in by a good samaritan when she went into premature labour.

"...I do not have a home to go to....Am an orphan, and when I conceived my first baby my uncle chased me away from his home. Unfortunately I conceived again because I had to get money to feed the child....a good Samaritan brought me to the hospital when I was in pain....I had overworked. I left my child with the Samaritan and she has never come back....its only God who knows where he is and if he is ok. I have been discharged but I don't know where I will go to from here (sob)..."

Besides being homeless, Bena aged 19 years old and a class 8 candidate was very sick with multiple diagnoses of endocarditis, severe anaemia and sickle cell. As struggled for her own life, Bena expressed the desire to hold and cuddle her baby whom she had never seen since birth. She longed for someone to shower her with just a little love and care and assure her that all will be fine. However all these were in vain because she was alone with no relative or a friend to turn to. She was evicted from her home when the parents learnt of her pregnancy.

She was a candidate waiting to sit for her form four exams but the school administration had not contacted her after suspension.

> "...I have been all alone since I was brought by my neighbour whom I had gone to seek shelter from when I got very sick. My parents do not want to see me (sob). I really want to see my baby but am feeling so weak to walk down to nursery.. I have never seen my baby. I am feeling so lonely and bad because I missed my KCSE exam..."

Many said staying in the hospital was far much better than being alone and homeless since they got food, shelter, and security for themselves and the baby.

Theme 3: Lack of Support for Mothers with Multiple Neonates

Mothers with multiple babies expressed their need to be given more support and time to feed and bond with their neonates. They concurred that time allocated for mothers to stay with the baby was uniform whether one had one or multiple babies. They reported that they had to feed the babies in a hurry and more than often, they got no assistance from the medical staff. A mother of 35 weeks old twins found it challenging to tube-feed the babies who were both in the incubator. Equally important was the fact that soon after feeding and, the baby had to wind to prevent

regurgitation hence choking. This brought in a lot of worries because mothers feared that the babies would choke since they had no time to wind them up.

Theme 4: Assistance with the Bonding Process.

So much is made of the mother and child bond. Some mothers experienced complications during delivery e.g. preeclampsia, caesarean section where it required them to be on bed rest for a few days until they were stable enough to walk down to the nursery. Some would take up to three or four days and many felt so worried about their baby whom they had never seen.

Days after bed rest, most of these mothers found it difficult to catch up in the bonding process with their baby. They felt that the dyadtie (the bonding between mother and baby) had been delinked.

Time was another factor that came in as a barrier in the bonding process between mother and baby. Mothers felt that time allocated to be with baby was not enough thus they did not get to know and bond well with their baby. A 24 year old Rebeca who works as a salonistopinioned:

"..immediately after feeding my baby, I have to go back to the mothers' hostel. Inaumizasana (it really pains)..."

Most of the mothers with babies in the incubator wanted to know how to bond with the baby. Linah voiced:

"...I fear touching my baby in the incubator because I fear that something bad may happen to him...)

They needed to get an assurance from the staff that nothing bad would happen to the baby when they touched them.

6. Conclusion

Although it is unfortunate that any preterm neonate has to be admitted to the NBU, mothers can be empowered to fulfil their parental role and feel involved in the care of their neonate with a positive experience. The findings of this study conclude that although these neonates may be sick and clinically unstable, they still belong to their mothers. Mothers are just as important in the NBU as their neonate. They have a right to be there, care for and love her baby.

7. Recommendations

The focus is to change the approach in assisting mothers cope while their neonate is admitted at the nursery. Among the recommendations included the need to involve mothers in the basic care of their newborns and continuously inform them of the neonate's treatment plan, procedures and progress. Mothers with postpartum complications should be assisted to walk down to nursery to be with their baby and the social work/ psychological counselling departments need to identify the abandoned mothers and see how best they can help them. A staff should explain monitors and alarms used in the unit. Staff should actively listen to mothers' fears and expectations, and be supportive, assure them that their neonate is receiving the best care possible and demonstrate a genuine concern for the whole family.

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Kangaroo mother care can solve most of the problems identified regarding the bonding process. There is need to assist mothers in understanding neonatal responses to hospitalisation, providing discharge information and preparation to mothers while the baby is still in the NBU and lay terms must be used to explain conditions to mothers.

The case of abandoned mothers should be addressed by the social work department.

8. Suggested Interventions

- NBU seminars and meetings can be held on a regular basis for mothers with neonates in the NBU. This should include information on monitors, alarms, bonding process, and expected developmental milestones according to the neonate's age and condition and to provide support to mothers.
- 2) A discharge programme can be developed and manual discussed with the mothers when they are ready to handle the information. A general manual can be developed and supplemented with additional information to address the mothers' specific needs.
- 3) Healthcare professionals should follow a multidisciplinary team approach to effectively use all the available resources to address the needs of mothers.

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