Original Research Article

INFLUENCE OF SOCIAL SUPPORT SYSTEM ON MATERNAL EXPERIENCES, ~~PEDEATRIC~~ PEDIATRIC DEPARTMENT, NORTHERN REGIONAL HOSPITAL, GHANA

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ABSTRACT

Background: Hospitalization of neonates in NICUs may subject mothers to shock and depression as a result of giving birth to babies who have low birth weight or premature babies and hence very fragile. This type of hospitalization disrupts the family process and subjects the parents of these babies to a state of crisis and disarray. These challenges range from social, economic, physiological and psychological in nature. ~~there~~ There are no support groups for mothers with preterm babies to share their pain, experiences or interact with other mothers with similar problems. Overall, the problems of preterm babies may be in the increase yet not satisfactorily documented in the Ghanaian context.

Purpose: This study seeks to explore the social support system and its influence on maternal experiences.

Methodology: The study used a descriptive design. The ~~Study~~ study was conducted in the Tamale Metropolis, specifically targeting women with preterm babies undergoing treatment at the Northern Regional Hospital. The purposive sampling technique was used to recruit participants for the study. A semi-structured interview guide was used to conduct face-to-face interviews with participants and the results were analyzed using thematic analysis.

Results: The findings of the study demonstrated that when the participants were provided with information on how to care and were also shown how to provide the caring activities, they developed confidence in taking care of their preterm baby.

Conclusions: Support from staff, other mothers in the neonatal unit and the participants' families assisted them to cope and promoted bonding. Management should support all neonatal intensive care facilities with adequate equipment and logistics to facilitate newborn care which will help limit the stay of hospitalized preterm babies in the neonatal intensive care units.

Key Words: *Experience, Mothers, Preterm Babies, Pediatric Department*

BACKGROUND

Schenk and Kelley (2010), revealed that mothers with hospitalized preterm babies requested for the need to be socially and psychologically supported individually to enable them build strong relationships and connections with the preterm babies. Iran et al., (2013), reported again that mothers with hospitalized preterm babies in neonatal intensive care units were faced with so many challenges. The level of interaction between the preterm babies and mothers plus that of the mothers and the healthcare providers were severely affected by the admission of the neonates and its associated problems (Iran et al., 2013).

Mothers of the hospitalized preterm neonates were faced with hidden challenges that were not usually detected by the healthcare providers in the neonatal intensive care units. A closer examination of what the mothers explained indicated they were in dire need of psychological and social support in the form of well-established interpersonal relationship, and information sharing in relation to the preterm (Iran et al., 2013). In a similar study by Aliabadi et al., (2011), mothers with hospitalized preterm neonates were faced with both positive and negative issues and events in the NICU. This called for the need to empower and partner with the mothers in taking care of the preterm infants to reduce the negative experiences (Aliabadi, Bastani, & Haghani, 2011). Developing social support groups as methods that provided support to mothers with hospitalized preterm infants could help them emotionally and also served as a form of partnership in caring for the neonates (Iran et al., 2013). Last but not least, Jarrett, (2006), reported that mothers were in support of such a program since they felt that it could improve the quality of services provided. They also felt that the implementation

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of a support program could increase the institution's ability to cater for more patients in a competitive market (Jarret, 2006; Iran et al., 2013).

Based on this premise, a growing number of studies have used qualitative methods to explore what the health team can do to help parents with preterm births improve their stay in the neonatal unit, and to highlight areas of particular importance for their care. Therefore, understanding experiences of mothers during the admission of their babies in the intensive care can help the NICU team plan actions and better confront the situation with esteem and safety for the hospitalised infants (Kyno et al., 2013). When a healthy baby is born in Northern Ghana, these babies are usually celebrated amidst pump and pageantry in a weeklong event. The parents of these neonates usually express joy at their accomplishment and setting future plans with great expectations for their child.

However, parents of preterm infants are often stressed and traumatized (Marley et al., 2017). Additionally, parents of preterm infants often experience separation from their baby from the time of birth, as preterm are quickly whisked away to neonatal intensive care unit for immediate intensive care. This forced separation severely endangers the parents' ability to commence their parenting role in the typical way experienced by parents of healthy term infants at birth, threatening parent-infant bonding processes. Subsequently, these parents often experience long hospital stays of their infant's on NICU where the high-tech environment and events occurring on the unit present parents with atypical parenting roles. (Misund, Nerdrum, & Diseth, 2014).

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METHODS

Study design: The descriptive design was used for the study. The ~~Study~~ study was conducted in the Tamale Metropolis, specifically targeting women with preterm babies undergoing

treatment at the Northern Regional Hospital. The design emphasized the need for rigor in selecting the study setting with the high potential of providing adequate data that will give an in-depth understanding of the phenomenon at hand (Polit & Beck, 2010).

Setting: The Northern Region is one of the 16 regions of Ghana with Tamale as the regional capital. It lies between 9.16^{o} and 9.34^{o} North and 00.36^{o} and 00.57^{o} West. The Metropolis has a land mass of 731km^{2} and approximately 180m above sea level. It is boarded to the North by the Savelugu-Nanton District, South by Central and East Gonja Districts, East by the Yendi Municipal and West by Tolon and Kumbungu Districts. It is divided into three Sub-Metros; Tamale North Sub-Metro, Tamale Central Sub-Metro and Tamale South Sub-Metro. The health administration is sub-divided into Tamale Central, Bilpeila, and Vitting Sub-districts. The 2012 and 2013 projected population of the Metropolis was 383205 and 404609 respectively (Ghana Statistical Service, 2014). Accordingly, the population of women ~~in~~ of reproductive age (WIFA) were estimated to be approximately 11113 and 11734 respectively (3% of total population). Islam is the dominant religion with an affiliated population of 84%. The Metropolis experiences one rainy season from April/May to October, with peak in July/August which is influenced by the moist South-West monsoon winds. It records a mean annual rainfall of 1100 mm with only 95 days of intense rainfall. The dry season is from November to March, which is influenced by the dry North-East winds (Harmattan). Tamale Central Hospital also serves as the regional hospital of the region. It provides secondary level service point with Labor and Maternity Wards including Comprehensive Emergency Obstetric and Neonatal Care (EmONC).

Target Population: This study targeted a population of parents who have neonates admitted to the Pediatric ~~department~~Department, Northern Regional Hospital of the Tamale Metropolis.

Inclusion Criteria: The study included mothers of neonates who have their babies admitted to the Pediatric department of the Northern Regional Hospital for at least 3 days. Mothers who could speak English or Dagbanli language were included in the study.

Exclusion Criteria: Mothers with post-delivery complications who were on admission were exempted from the study.

Sampling Technique and Size: Purposive sampling is a non-probability sampling technique referred to as judgmental sampling. This is also described as a method that enables for the selection of a subset from the entire population based on the investigator's knowledge of the study (Burns, Grove, & Gray, 2012; Polit & Beck, 2010). Purposive sampling also enables the investigator to generate a criterion that represents the characteristics of the target population and select based on the predetermined criteria (Basavanthappa, 2011). Therefore, the researcher employed purposive sampling technique to recruit the participants to participate in the study. The technique allows and guide in the selection of mothers with hospitalized preterm babies.

Data Collection Instrument: Interview guide which was semi-structured was used to give focus and direction to the pattern of the in-depth face-to-face interview in order to retrieve very useful information from the participants (Polit & Beck, 2010). Also, the instrument used for the data collection was adequate enough to retrieve information that will provide answers to the research questions (Burns & Grove, 2010). The interview guide was structured based on the objectives of the research. The semi-structured interview guide had open ended questions divided into sections A (Demographic Characteristic data) and section B (Experiences of admission into NICU).

Data Collection Procedure: An introductory letter from the Ghana College of Nurses and Midwives, and research proposal were used to apply for the ethical clearance and

administrative approval from the Ethics Review Committee of the Ghana Health Service. More importantly, a formal request was made to the in-charge of the Pediatric department of the Northern Regional Hospital to use the nurses' rest room to conduct the interviews with little or no interruptions of any kind, and also to ensure privacy and favourable environment for the interview.

The ethical clearance and administrative approval were obtained from the Ethics Review Committee of the Ghana Health Service. With the help of the nurse in-charge of the NICU, mothers who were on admission for at least three days in the ward were identified using the patient folders. After the introduction and establishment of rapport, the consented participants were interviewed. The interview was done after a thorough explanation to the participants of the purpose and benefits of the study and also after ~~the~~ verbal and written consent were requested from them. Their permission was also sought in order to audio record and take notes of observation that could not be recorded by the device in order to retain relevant information.

The interviews lasted for about 30 minutes to 1 hour and were conducted mostly in Dagbanli language with few participants in the English language. The data Collection was done within five weeks. The investigator personally conducted the interviews using the interview guide. The thoroughness that was applied in the data collection process was to help reduce potential bias to the results of the study. Participants' time loss was highly appreciated with a thank you.

Methodological Rigour: Trustworthiness is very essential in assessing the value of ~~a~~ qualitative research (Johnson & Raslova, 2017). More so, they also warn that qualitative research should be evaluated on the basis of research ethics and respect for participants. The

four criteria namely credibility, transferability, dependability and confirmability pioneers of qualitative research have been used to evaluate the trustworthiness of this study.

The information presented represents the participants' factual data and also demonstrating the value of data and the interpretation. To ensure that the findings and the interpretation are valid, the investigator established rapport with the participants before the interview in order to promote trust. In doing the face-to-face in-depth interview, field notes were taken to include non-verbal gestures that could not be captured by the audio recorder. This was then used for the summary and transcription of the interviews.

As a result, transferring the comprehensive description of the methods with attention drawn to the setting and participants used was done. This will guide the reader to decide on the possibility of replicating the method on another population with different context but similar characteristics. Demonstration through auditing of researcher's record notes of data. Thus, member checking was done; a step-by-step rigor of the methods (data collection, analysis and interpretation) was incorporated to give much understanding of the process.

Confirmability demonstrates that the data and interpretation of the findings are from the participants, not the investigator's perspectives (Lincoln & Guba, 1985; Prion & Adamson, 2014). The data and findings were subjected to the participants review in order to reduce investigator's potential subjectivity.

Apart from permissions that were sought from the Hospital Authorities of Northern Regional Hospital, Ethical Clearance was also sought from the Ghana Health Service Ethics Review Committee and approval granted before data collection. This study did not harm respondents in any form. Apart from the time of respondents that was used, no physical injury was meted unto them. An elaborate explanation of the study was given to all respondents before they were given an opportunity to partake or not take part in the study. Respondents who could

read were given copies of the participants' information sheets to read at their leisure time. All participants were only interviewed at a time they (participants) deemed it necessary for such interviews. Those who agreed to be recruited were made to endorse an informed consent form and duplicate copies made available to them. All interviews were done in the Nurses room of the neonatal intensive care unit of the Northern Regional Hospital to prevent third parties from listening to the interviews. Respondents were only recruited into this study after explaining all that they needed to know about the study. They were reminded that their participation was voluntary hence they could withdraw at any point of the interview without any intimidation or penalty.

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RESULTS

Three themes emerged from the experiences of the participant's interview. They were social support on experiences, Interaction with health care providers and Negative Interaction with health care providers. Although mothers had the chance to see their babies in the delivery unit, the babies were immediately taken to the neonatal unit where they were nursed in incubators. Since mothers were involved in the care of their preterm babies, they went to the neonatal unit every three hours to interact, feed the baby, sponge the baby's body and change the nappy. Initially, the pediatric environment aggravated the participants' fear and anxiety, since they were afraid of the equipment in the unit and other unexpected things that they saw there. This affected mother-infant interaction, but with the support of the staff, other mothers and their families, mothers eventually developed an emotional connection with their babies. The joy of being discharged from hospital was of utmost importance to the mother as she now had hope since the baby, she continued to feed had survived the initial traumatic and critical period in NICU; however, mothers were anxious that something might happen to the baby while at home.

Mothers described their lived experiences of having their preterm babies cared for in the neonatal unit. Fifteen mothers who delivered preterm babies were interviewed.

All the participants gave their informed consent before recruitment into the study. The researcher was introduced to the participants, after which participants were informed about the study with the knowledge that they could provide information regarding the study (purposive sampling). All participants were interviewed in a private quiet room in the neonatal intensive care unit after consenting to participate in the study.

The Table below presents the demographic characteristics of the fifteen participants, the mean age was 29.9 ± 6.0. Majority were Married 19 (95%) and majority of them again 8 (40%) did not have any form of formal education. Exactly half of them had babies of birth weight of 1.41kg-2.0kg (50%).

Table 1 Demographic Characteristics of Participants

Characteristic	**Frequency (n=15)**	**Percentage (%**
Mean Age (SD)	29.3(6.0)	
Age group (Years)		
20-25	7	35
26-30	7	35
31-35	2	10
36-40	4	20
Marital Status		

Married	19	95
Single	1	5
Number of Children		
1	4	20
2	6	30
3	6	30
4	3	15
6	1	5
Level of Education		
None	8	40
Primary	5	25
JHS	2	10
SHS	1	5
Occupation		
Caterer	1	5
Farmer	2	10
House Wife	6	30
Nurse	1	5
Seamstress	4	20
Teacher	1	5
Trader	5	25
Religion		
Christianity	1	5
Islam	19	95
Ethnicity		

Dagomba	16	80
Frafra	1	5
Moshi	1	5
Sisala	1	5
Tampilma	1	5
Birth Weight (Kgs)		
0.68-1.2	3	15
1.23-1.4	7	35
1.41-1.6	5	25
1.9-2.0	5	25
Gestational age (Wks)		
28	2	10
29	2	10
30	4	20
31	4	20
34	2	10
35	5	25
37	1	5
Length of Stay (Wks)		
2	1	5
3	9	45
4	2	10
6	2	10
7	2	10
8	1	5

14	1	5
21	2	10

Social Support on Maternal Experiences

Overcoming fear: Emotional Experiences

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Initially the participants were shocked by the delivery of their babies because they did not expect to deliver so soon. Their parental process of psychological preparation was interrupted. They were emotionally unprepared for the sudden onset of their deliveries, which happened so quickly. When the participants first saw their small babies, they were surprised by the size of their babies.

> *I did not expect to deliver such a small baby ... a baby that small. I don't know why the baby is so small it's difficult to handle the baby. I didn't know it was going to be a small baby. I was crying at first because the baby is small. What can I do….I will take it like that (**P2**).*

Participants who had previously delivered full-term babies were more affected by the trauma of preterm birth as it was their first time to deliver preterm babies. Their expectation of the delivery of a normal-term baby disappeared immediately. Participants wondered why they delivered preterm babies and were shocked, since it was unexpected:

> *My experience is that I did not expect to deliver a preterm baby because it has never happened to me. It was such a shock to me. This is disturbing my mind because the*

*baby is small. The baby was not breathing well and they put the baby in the incubator bed (**P7**).*

After seeing the babies for the first time, participants had difficulty in accepting the baby. They found it hard to understand and it was difficult for them to accept the babies because the babies were too small. They could not cope with the reality of the situation and reacted negatively, such as going away from the babies in order to avoid seeing them. They had questions, were emotional and uncertain and blamed themselves:

*I was wondering why it happened to me to give birth to such a baby...to such a small baby, I became too emotional and left him. I will be in the hospital to take care of the small baby. The baby is small and weaker than other babies (**P2**).*

This participant could not cope with the situation and burst into tears. She could not think of this small infant as the baby that she had expected, and found it difficult to be convinced that this infant was indeed hers:

*I cried while looking at him wondering whether mmm thinking that he is not a baby even if people can say what. Sad hmm. How come and what causes that and why is the baby small like that, I don't know why, my heart is beating …the baby is small (**P7**).*

As time went on, the participants managed to overcome fear as they interacted with their infants. They were now able to touch and hold them. This created a sense of stability and connection:

*I felt happy that I was now able to hold my baby since it was not like the first time. Initially, I used to go to the neonatal unit and when I arrived there, I used to just stand next to him failing to touch him, and wondering what I am going to do. So I was now happy that I was able to hold the baby (**P1**).*

One participant held her baby when she felt that her baby's condition had improved as the baby was awake Holding her baby offered the participant an emotional satisfaction as she felt differently from the time she could not touch or hold the baby:

*Mmm! I first held her when I saw that she was awake. That is the day I felt better. I mean that ... I felt as if I am becoming happy. It was a different feeling from what I felt before. The baby is fine and stops crying if I pick in my hands, I have hope too (**P6**).*

As the participants' feelings became more positive towards their baby, they began to accept them, and the fear of handling the tiny infants lessened. Holding the baby offered them an opportunity to accept them since their feelings towards the babies had changed. The initial feeling of fear and uncertainty had changed; they were able to accept and love their infants and wanted to be closed to them all the time:

*My feelings have changed, since I said I was afraid of him at first but I have now accepted him. I manage to lift him when I get there. Even when I am in the room, I miss him. I have accepted him and I love him (**P2**).*

As the participants continued to interact with the babies, touching and handling them, they began to realize that although tiny and preterm, their babies were just like any other baby:

*You accept the baby as time goes on realizing that the baby is fine. Some of the term babies are also small. This one can also grow too, I have seen that the baby is fine. I have patience and will take care of the small baby in sha Allah (**P5**).*

Being able to feed their infants made the connection with them real and tangible. Participants were able to touch them and made their love for the infants a reality. The constant contact that the participants had with their babies as they interacted with them enabled them to develop a good relationship with their babies:

*So when I started feeding him, I was able to touch him by then ...Hee! I gave him a lot of love. The baby was active, when I tough him he will stop crying, I make attempt to feed him with the breast, the baby is active now (**P3**).*

For the participant who had lost a previous baby, her fear that this infant too would not survive delayed the development of a relationship with her baby. This fear changed into love as she started to interact with her infant:

*I started loving him. At first I gave up because I had a baby who died. I don't want to lose the baby. The babies small and so weak and I don't want to lose him. I am taking care of him but I don't handle her much (**P8**).*

The participants loved their babies even more when able to observe their responses such as opening the eyes. Participants felt that even though they touched their babies before, they had a different feeling when they saw their baby's response. This made them very happy and gave them hope that their babies would survive:

So, it was very nice, yes when I saw that because before, there was no sign of affection since I used to just look at him there. Even when I touched him before, I could feel that yes ….he is alive but there was no ... But the day I saw him open the eyes aa I was not scared at all ***(P7)****.*

Despite the initial fears, the love that developed between the participants and their babies connected them emotionally. The encouragement that the participants received from staff members enabled them to be emotionally connected with their babies:

There is a nurse who told me not to be afraid of him because it is me who is going to take care of him while they show us how to take care of them. I ended up being acquainted with him until he was able ... we got used to each other ***(P1).***

The participants felt that bonding had taken some time because the development of a relationship between them and the babies were delayed by different things such as fear and anxiety:

As time went on and on ... since I already accepted him as a baby...loving him, you see, yes. As time went on and on I ended up getting used to him. (P5).

I started having that love and I am attached to the baby, my brother its not easy for the family too, as we are on admission, we spend a lot of money buying drugs and doing laboratory investigations…. Sometimes the money is not there. The most challenging thing is when you don't know the day you will go home ***(P6).***

The participants expressed the need for them to be allowed an appreciable time to stay in the unit to cuddle the babies or hold them. They however expressed mixed fillings they said the babies were so small to be handled like the term babies.

Interaction with medical and nursing staff

Participants had varied experiences of interaction with staff. While overall participants felt that staff members related well with them, there were participants who described their experience as a poor one with the staff. Participants experiences of interaction with staff have been categorized into positive and negative interactions.

Positive interactions with medical and nursing staff

Good interaction between staff and the participants in the pediatric department allayed their anxiety and enabled them to develop competence in caring for their preterm babies. Participants were reassured when the staff answered their questions and provided adequate explanations to issues affecting participants. When nurses offered explanations about what the participants needed to know, they felt that nurses were being empathetic and thus interacting with them as they expected.

> *I had a good interaction with the Nurses and Doctors. For instance, the Nurses mostly explained the condition of the baby and the progress so far to me, even when I asked a lot of questions, they were patient enough to explain (**P8**).*

Interaction perceived as good by the participants made it easier for participants to provide the needed support care for the babies. Participants felt that the staff explained how they should take care of the babies and were pleased with the way they related to them:

*So, there is a good interaction with nursing staff. They explain to us how we should do things. There is no problem between us at all. Most of them were good to us, when you ask them something they don't shout at us, only few were difficult (**P1**).*

Staff who communicated well with the participants enabled them to realize that they were partners in the care of their babies:

Mostly we call a nurse, maybe the baby unwell, it depends on what the nurse was doing. If they are still doing something, they will tell you that they are still busy and that you should wait for them to finish. But they are busy, they immediate attend to our problems. So there is good interaction with nursing staff (P1).

Even though participants mostly found it difficult to wait when they needed assistance, they still appreciated the fact that staff communicated with them when they could not offer them help immediately:

*A good communication exists between the mothers and the nurses. It is only that sometimes it is very difficult to accept some situations as they occur sometimes, they don't feed the babies with the breastmilk in the small cups and sometimes they do. They are not bad (**P8**).*

When the participants were provided with information and shown how to take care of the babies, they felt encouraged they were reassured and became confident in taking care of the babies. They were informed about the importance of washing hands before touching the babies in order to prevent the spread of infection:

Upon my arrival in the unit...because I did not know that you have to wash hands how to feed him. I did not know that I do not have to bath him while still here. I was taught

*by doctors and nurses since the baby is my first baby. (P19). They taught me that I should wash hands before handling the baby and even after feeding the baby to avoid spread of infection (**P2**).*

The participants were informed about the routine of the unit. They were informed about the feeding times in order for them to come to the unit and assist in feeding their babies. This enabled mothers to fulfil their parental role as they provided care for their preterm babies:

*When you arrive in the neonatal unit for the first time, they will explain everything to you. They will tell you that before you touch the baby you should wash hands and even before feeding the baby. The Nurse will tell you the feeding times, that feeding is done at 6am, 9am, 12 midday and 3pm, etc. **(P8)**.*

Participants experienced less anxiety and were reassured when the nurses and doctors explained the condition of their babies to them and the procedures done on the babies. Explanation of the condition of the babies to the participants helped participants to realize the seriousness of it and prepared them psychologically for complications that could occur. Explanation of procedures equally allayed the mothers' anxiety hence promoted mother-infant interaction.

The participants felt reassured when the team of duty answered their questions in relation to their babies' condition, the procedures and reasons for these. They wanted to know the causes of their babies' conditions and were reassured when doctors explained the possible causes:

*They normally tell me anytime they are to carry out a procedure on my baby. I was even asking them the last time when they were doing a scan on his head. They explained to me why they were doing it **(P4.)***

*They explained to me what caused that and the reason for that… I asked what the dark colour in between was, and then he told me that the dark colour showing on the scan is blood that affected the brain. I was also told the baby will be fine since he is ~~i~~on treatment. The next time they did the scan the colour was fading ~~i~~on the side, the dark colour was not so dark as before. So, I asked why the colour was not so dark, then I was told it shows that the baby is responding to treatment (**P5**).*

Four of the participants had the impression that the Doctors were helpful and five of them felt that the nurses were helpful. Staff were perceived as helpful if they offered the needs of participants, in the form of explanation or provision of information's that the participants needed to use while caring for the babies. Nurses and doctors were perceived as helpful if they provided satisfactory answers and assistance, but as unhelpful if they did not do so:

*Mmm! If it was not for them maybe our babies would not be where they are. Yes, they provide us with whatever we have to utilize in caring for babies. They also explain how we should use them in providing the needed care (**P1**).*

Again, Participants felt that the doctors listened to them and respected their decisions as they were involved in the care. The participants had the courage to advocate for their babies and felt that the doctors were willing to help:

*The Last time they wanted to discharge the baby but I told them that the baby has changed. I did not want the nurse to do that on my behalf and they listened to me. They then gave education on how to care for him. I was happy that I was now able to take care of my own baby (**P4**).*

Six of the participants were happy with the way the team of doctors and nurses taking care of their babies, especially when their babies were gaining weight. They were happy that the team of doctors and nurses had met their expectations and provided satisfactory care to their babies. This reassured them and gave them hope that their babies would one day be well:

> *Aah well! I feel great, I feel fine; I do not have problems with my baby as long as he is growing...and well cared for. I am happy with the care so far. They are doing well; there is nothing that I can say I am not happy about (**P1**).*

Seventeen participants felt that they were supported emotionally by the staff when they reassured them about the babies' conditions. This helped them to perform their maternal roles whiles the nurses encouraged them not to be afraid of their babies:

> *I was afraid of him. It was a bit difficult but I ended up touching him for the first time. A nurse told me not to be afraid of him because it is me who is going to take care of him while they show me how to take care of them (**P17**).*

One participant had a lot difficulty in interacting with her baby because she had lost her previous baby, who was also born prematurely the previous year. This had negative memories of the loss, and raised fears that there current infant too would die. She was counselled by the nurse and after being reassured, she was able to interact with her baby. The support the participant received from the staff enabled her to overcome her difficulties and interaction the baby:

*She then comforted me and told me to focus on the now and forget about the past. She said we should focus on the positive side and hope that the baby will be well. I felt better after talking to that nurse on the twenty-seventh (**P18**).*

Negative interactions with medical and nursing staff

Although Seventeen of the participants felt that there was good interaction between them and the staff members, three of the participants had a bad experience during their interaction with the medical and nursing staff different times, they also acknowledged that some of the staff interacted well with them. Due to the differences in interaction that staff exhibited, these participants found it difficult to trust staff. The participants felt that few of the nurses projected their personal problems on them:

*Hei! Myself I don't think there is any interaction ... Some (Nurses) would go ... and would come with their moods from home. Some of them will not mind you if you yalk to them. Sometimes we don't ask them anything about the babies, hmm (**P7**).*

Participants acknowledged the differences in the personality of Staff on duty as well as their interaction with them. They were of the view that when the nurses' interactions were bad, it went along way to affect their coping with their current situation :

*The nurses are not the same, you see. There are those that treat us well and there are those that do not treat us well at all. If we are not treated well, it affects us especially our ability to contribute to care of our babies (**P14**).*

One participant felt that she was not provided with information on how to take care of her preterm baby on her first day in the pediatric department. Lack of information on how to care

for the sick preterm baby affected the participant's ability to interact with her baby as she was new in an unfamiliar environment:

> *Heishi! No, I was totally lost on my first day here…When I arrived in the neonatal unit there was no form of education to tell me anything…. We were not told anything about care of those babies (**P17**).*

Two of the participants were concerned and upset when their babies had a problem and the team of doctors and nurses delayed when they called them for assistance. This increased their anxiety as they felt that the staff "delayed" in responding to their request:

> *Mmm! The other thing is when you call the nurse…He/she will behave as if she is tired ...not knowing what you are calling him/her for. She comes at his own time so much that maybe if he attended you on time when you called him that would be better. They delay in attending to your needs (**P17**).*

Two of the participants were dissatisfied with the care of their babies, especially when there was poor interaction between the Staff and the mothers. Participants felt they did not get enough help with the routine care, such as nappy changing. They believed this was because of the few numbers of staff on duty, they feel infant might be neglected:

> *Mmm! What made me sad is ... you will find your baby there ... not taken care of... nappy not changed. If you happen not to go to the unit because you were not feeling well, by the time you go there to check on her, you will find the baby in the same sheets and the nappy not changed. there is the need to for government to employ more nurses to help solve this problem of few staff, more work (**P6**)*

Participants became more anxious when the treatment of the babies were not explained to them, since they felt that they did not know whether a particular treatment (such as a blood transfusion) was helping the baby or putting the baby's life in danger. Although they felt that they did not known the reason for the baby's treatment, they had to comply with what was expected of them because they were concerned about the babies' well-being:

> *Even when giving medications, they do not tell us what the medications are for…"You would find the baby on a drip yet you have not been told as a mother, not knowing what the baby lacks (**P6**).*

Enabling Support

Different support systems assisted the participants to cope with their difficulties while they were involved in the care of their preterm babies. The support that the participants received from staff members helped them to cope. The participants were able to perform caring activities for their preterm babies when they were provided with information and shown how to do so by staff members. This helped them to develop competence in providing care to their preterm babies. Staff members also reassured mothers when the babies' conditions deteriorated and counselled them when faced with difficulties in providing care. The support that the participants received from staff enabled them to develop good relationship with their babies and eventually to bond with them:

> *They also encourage us and tell us that if he is like this, you do this and that. They tell us that the baby will survive and it is possible. They are the ones that are always counselling us. S for that they are doing very well, they give us hope (**P2**).*

The participants felt reassured by staff members who counselled them when they had conflicts with other mothers in the unit:

> *The other thing is that if someone hurt you ... those women who supervise how we take care of babies ... the nurses, they call you, sit down with you and talk to you in order to be reassured. They know when we are sad, they talk to us about small babies* ***(P1)***

The participants were advised, reassured and comforted by other mothers while in the neonatal unit. Participants were encouraged to touch and hold their babies by other mothers in the neonatal unit:

> *Some mothers who were there are the ones that comforted me by saying, please touch him, kiss him. I started touching his legs and toes. Some of the other mothers are very good, I will always chat with them and they like me* ***(P7)****.*

Mothers who had been in the unit for some time served as support persons for others as they shared information with them on how to take care of the babies and also reassured them since they had also had the same experience. The participants encouraged others to have hope and to pray and believe that their baby will finally be well. This helped them to overcome their fears and anxieties while caring for their baby and also in developing a relationship with their baby. Participants found the support of others very helpful:

> *Like at first, I was afraid of that baby, a mother whose baby is next to yours ...he/she reassured me quite well by telling me that her baby was not like that before. That she did not expect that the baby will be the way he/she was at that particular time. She said relax and pray, knowing that this baby will be fine* ***(P8)***

The participants supported each other by advocating for one another and assisting each other when they were in the neonatal unit. Although the participants were supported by others, they would also support other mothers in different ways. Through the emotional support of others, mothers were encouraged not to give up hope even if the babies' conditions were not improving:

> *Like now, when one mother is sad, I am able to tell her that I was in the same situation, do not be sad. It will be fine. Even if somebody's baby is in a coma... like there is a certain mother whose baby is in a coma ... this is the fourth day, but I always tell her that it will be fine (**P7**).*

The participants also learnt to put their differences behind them and continued in their journey until they reached their destination. They were able to forgive others when they wronged them and focused on caring for their babies. Participants would go and call the other participants from the postnatal ward at night if they realized that she did not manage to come to feed her baby, especially when the baby was crying:

> *If someone has wronged you, you have to forgive them and interact with them like if someone has not yet come to the unit and the baby is crying, you can go and call them especially at night. Sometimes they stay longtime outside (**P1**)*

Family members supported the participants in this study during the hospitalization of the babies, both socially and emotionally. This they did through visiting them while in hospital. When the participants were visited by members of their families, they felt less isolated, and forgot about being separated from the family. This helped them to focus on the care of their babies:

*Their presence when they came to check on us...when seeing them was of great importance as I would forget about my situation. I was not hurting much. They will tell me not be in a hurry to come home. I should take care of the baby well (**P6**).*

The family members also reassured the participants, comforted them and encouraged them to have hope during difficult times by phoning them. Family members informed the participants about people who they knew been born prematurely in order to reassure them and to give them hope that their baby will also survive:

*My mother phoned me more often and telling me that I should not be scared because that baby survives just like the child of so and so. He/she was born premature and here he/she is working for him/herself. They do not have problems in life (**P7**).*

Participants' religious beliefs served as source of support for them, since they trusted that God was with them. They prayed in order for God to intervene in their situations. The participants felt that God was with them as He answered their prayers:

*God is great because even when I was in labour... I normally do not pray but after hearing that the baby is not alive, I talked to God and prayed seriously. I prayed and God answered my prayers. **(P3)***

Participants completely surrendered everything to God when faced with difficulties. They used to pray and believed that God would not forsake them. This helped them to cope emotionally and psychologically:

*What reassured me is that I trusted in God, I used to pray and believe that it will be alright. Anything that will happen to me...only God knows. I have faith in God, whatever He gives me I have taken it, that's life (**P6**).*

Effect of Admission on Mothers

All participants indicated a negative experience relative to the admission of their babies. To most of them, the admission has affected their activities of daily living. They also reported effects of the admission as social and psychological in nature;

*Hmm. The effects are numerous, I can't even mention all of them…sleeping is a problem because you are not sure of the health of your baby…how can you sleep Most of the time…you keep thinking of what is happening to your baby… you are not sure if he will survive or not (**P6**).*

Effect of Admission on Family

All participants reported a devastating experience for the family. They also indicated that admission had a negative effective on their family process. Family members were faced with challenges of stopping their schedules just to visit the hospital. Again, money that would have been used for other equally important activities were used to pay for medications and medical services as results of the admission of the preterm babies.

My brother it's not easy for the family too, as we are on admission, we append a lot of money buying drugs and doing laboratory tests……. Sometimes the money is not there and you call the house they also complain that there is no money……hmmmmm.

The most challenging thing too is when you still don't know when they will discharge you and the people in the at home don't call you ask for you many times again (**P6**).

Equally, participants expressed how it was challenging getting the family members involved in the stay in pediatric department, especially reaching out to them to settle some hospital bills. They lamented that they still have hope and believe that all is going to get well someday.

DISCUSSION

Enabling Support Network

Taking care of a fragile baby in an unfamiliar environment was distressing for the participants in the current study. The participants needed some form of support in order to assist them to cope. The study findings revealed that the staff supported the participants in different ways, such as explanation of the baby's condition. The staff also encouraged the participants to interact with their preterm baby, and this facilitated the attachment between participants and their preterm baby. Support that parent receive from staff is helpful in developing competence and attachment relationships with the baby.

Schenk and Kelley (2010), found that mothers reported their need to be supported individually in order to help them build a relationship with the baby. Cleveland (2008), conducted a systematic review of both qualitative and quantitative research to identify what is known about the needs of parents having a baby in the pediatric department and which behaviour support them. The review reported that mothers needed correct information which they could easily understand, and that they wanted to be involved in decision-making

concerning their infants' care. Mothers also mentioned that they were stressed if they did not receive the correct information about the condition of their baby.

Nurses Support for Mothers

A study by Mok and Leung (2006), found that mothers reported that they needed information about their infant's care. They expected the information to be given at an appropriate time and to be given in an honest and clear manner. The parents reported that the information they received helped them to know what was planned for their infants. Mothers reported that they needed emotional support since they were disappointed, and had feelings of guilt and anxiety. They felt that nurses were caring when they listened and showed concern towards them. The study also found that mothers reported that they were strengthened and felt like mothers when staff encouraged them to participate in their infants' care. They also reported that they needed to be encouraged in order to strengthen their relationship with their baby (Mok & Leung, 2006).

Comment [K5]: Need to paraphrase the copied one

Participants in this study appreciated the support they received from other mothers, since they felt that it was very helpful. Encouragement of the participants by other mothers to touch and hold their preterm baby emerged from the findings. The encouragement and comfort that the mothers afforded each other assisted the participants to overcome obstacles in providing care and in building a relationship with their preterm baby. The support from other mothers for the mothers with sick preterm infants is helpful since it enables them to overcome their difficulties.

In a study in which a supportive telephonic intervention was compared with standard care, Preyde and Ardal (2003), found that mothers in the intervention group, who received telephonic support from trained mothers who had previously had a preterm baby, reported less stress at four weeks. At 16 weeks mothers in the intervention group reported less state of

anxiety, less depression and greater perceived support than the control group (Preyde & Ardal, 2003; Marley et al., 2017).

Social Support for Mothers

The findings of the current study revealed that although mothers supported each other, most of them supported those mothers who had a baby in the same cubicle as theirs, and did not experience much interaction with others in other cubicles of the neonatal unit. The establishment of a support group in the SCBU by a professional who can empower mothers with information and coordinate the group functioning should therefore be considered. If there is a support group that is recognized by everybody, mothers can support each other effectively by sharing their experiences, thus helping other mothers in similar situations to cope. There can also be a parent support coordinator who is paid and mainly focuses on supporting parents in the neonatal unit.

The importance of support groups for parents of babies admitted to the neonatal unit is recognized in the literature. Jarrett (1996), reported that mothers were in support of such a programme since they felt that it would improve the quality of services provided. They also felt that the implementation of a support programme would increase the institution's ability to attract more patients in a competitive market (Jarrett, 1996; Marley et al., 2017). Hurst (2006), found that parent support programmes are beneficial to mothers and professionals working in neonatal units due to relieving some of the stress experienced by mothers whose preterm babies are admitted to the neonatal unit.

They feel isolated because they are separated from their preterm babies and family members, and the support group can provide a vital connection and an opportunity to engage with mothers with similar experiences (Varonez et al., 2017). The separation from their families and their preterm babies that the participants in this study experienced increased their need

for support, since they were admitted in a separate unit from their preterm baby. The participants needed to be supported both emotionally and socially. They were supported by their families in different ways, such as visiting and comforting them by phone, which helped them to cope with their challenges and bond with their preterm baby.

Support from Family Members

Studies have been conducted where parents of a preterm baby needed emotional and social support from their family members in order to cope with their stress and difficulties. In a study entitled 'The relationship between maternal needs and priorities in a neonatal intensive care environment', Bialoskurski, Cox and Wiggins (2002), found that mothers expressed their need to be supported by their family through reassurance, since this made them realize that the person was concerned about their comfort and health. Mothers need to be assisted and encouraged in order to bond with their infants (Bialoskurski, Cox & Wiggins, 2002). Lee, Miles and Holditch-Davis (2005), recruited 64 mothers to their study ~~i~~on fathers' support to mothers of medically fragile infants during hospitalization of the baby.

Mothers were interviewed at enrolment, at 1 month after discharge of the baby, and after the baby was 12 months old. The study found that mothers felt that the support they received from the fathers during the babies' hospitalization was more than after the discharge of the baby. Mothers felt that support from the father was high during the baby's hospitalization since they provided for the needs of the baby, which was also supportive to the mother.

Comment [K6]: Its better to add the strengths and limitations of the study

CONCLUSION

Social support systems of mothers with preterm babies who were involved in the care of their preterm babies in Pediatric department at the Northern Regional Hospital was the focus of

this qualitative study. A descriptive design was used to explore and describe the participants' experiences. Three themes emerged from the data, which provided a rich description of the experiences: experiences of interaction with medical and nursing staff; overcoming fear: emotional connections; and an enabling support network.

Comment [K7]: Better to include major conclusion from the study

The parents also reported that they wanted to know what was going on when their baby was sick and admitted to the intensive care unit. They wanted to understand and felt that it was important for them to know exactly what was happening concerning their babies' condition. When the doctors and nurses told them what was going on, parents felt as if they were part of the team. Last but not least, Family-Centered care is advocated for in neonatal units. Although the need for the involvement of other family members is not reflected in the findings of the current study, family-centered care is not adequately practiced in the unit in which this study was conducted.

Comment [K8]: Add recommendations if any linked with findigns

Reference

Ahn, Y., & Kim, N. (2007). Parental Perception of Neonates , Parental Stress and Education for NICU Parents. *Asian Nursing Research*, *1*(3), 199–210. https://doi.org/10.1016/S1976-1317(08)60022-5

Arnold, L., Sawyer, A., Rabe, H., Abbott, J., & Gyte, G. (2013). Parents ' fi rst moments with their very preterm babies : a qualitative study. *BMJ Open*, *10*(1136), 1–7. https://doi.org/10.1136/bmjopen-2012-002487

Flacking, R., Lehtonen, L., Thomson, G., Axelin, A., Ahlqvist, S., Moran, V. H., … Dykes, F. (2012). Closeness and separation in neonatal intensive care. *Acts Peadiatrica*, *2012*(101), 1032–1037. https://doi.org/10.1111/j.1651-2227.2012.02787.x

Kildea, S., Stapleton, H., Murphy, R., Kosiak, M., & Gibbons, K. (2013). The maternal and neonatal outcomes for an urban Indigenous population compared with their non-Indigenous counterparts and a trend analysis over four triennia. *BMC Pregnancy and*

Childbirth, *13*(1), 1. https://doi.org/10.1186/1471-2393-13-167

Kynø, N. M., Ravn, I. H., Lindemann, R., Smeby, N. A., & Torgersen, A. M. (2013a). Parents of preterm-born children ; sources of stress and worry and experiences with an early intervention programme – a qualitative study. *BMC Nursing*, *12*(28), 1–11.

Kynø, N. M., Ravn, I. H., Lindemann, R., Smeby, N. A., & Torgersen, A. M. (2013b). Parents of preterm-born children ; sources of stress and worry and experiences with an early intervention programme – a qualitative study. *BMC N*, *12*(28), 1–11.

Misund, A. R. (2016). *Mothers ' trauma reactions following preterm birth Department of Clinical Medicine.*

Misund, A. R., Nerdrum, P., & Diseth, T. H. (2014). Mental health in women experiencing preterm birth. *BMC Pregnancy and Child Birth*, *14*(263), 1–8.

Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., & Ayers, S. (2014). Parents ' views on care of their very premature babies in neonatal intensive care units : a qualitative study. *BMC Pediatrics*, *14*(230), 1–10.

Steyn, E., Poggenpoel, M., Myburgh, C., & Africa, S. (2017). Lived experiences of parents of premature babies in the intensive care unit in a private hospital in Johannesburg, South Africa. Curationis, 40(1), 1–8.