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Women's Experience of the Neonatal Intensive Care Unit (NICU) in the Greater Accra Region of Ghana. A Qualitative Study

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Abstract

Background: This article discusses the experiences of women who have had babies at the Neonatal Intensive Care Unit in the greater Accra region of Ghana. **Methods:** A primary data collection samples are women who had babies in the Neonatal Intensive Care Unit (NICU) in some selected hospitals in Ghana. Primary data from a qualitative research methodology samples women. **Aim:** The study creates awareness of the challenges women go through that when they have babies they go through the intensive care phase. It highlights the need for social and the study looks at the women's experience within the context of NICU in one of the hospitals in Ghana. Even though the results cannot be generalized, the result can help and encourage women in similar situations to find strength from the experiences of the interviewed women, draw strength from their shared stories and apply some of their techniques to enable them to go through their experience. **Results:** Social and psychological support helps the women to go through the NICU period. **Conclusion:** Anxiety, uncertainty and powerlessness are some of the negative effects to a mother of an infant in the NICU experiences. This situation can improve with the right kind of socio-psychological support. Access to information, guidance and practical support can help mothers go through the NICU and healing phase with their babies.

Keywords

Women's Experiences, Neonatal Intensive Care Unit (NICU), Social Support, Healing

1. Introduction

What is the essence of a pregnant woman giving birth and having her baby end

up at the intensive care unit of a hospital instead of home? One can appreciate a situation like this if the mother tells her story. Some women feel that "a child is a confirmation of being whole" (Wigert et al., 2006). Studies by Baumgartel & Facco (2018) and Edéll-Gustafsson, Angelhoff, Johnsson, Karlsson, & Morelius, (2015) indicate that mothers of preterm infants experience more stress than mothers of healthy infants. A mother of a preterm infant experiences different stressors to include the stress of having a critically ill child, separation from her infant, postpartum hormonal shifts, frequent breast milk expression, and prolonged exposure to artificial lighting in the NICU (Thomas & Spieker, 2016; Alkozie, McMahon, & Lahav, 2014; Lee & Kimble, 2009). Babies who end up in the Neonatal Intensive Care Unit of Most Hospitals tend to be preterm. As defined by the World Health Organization and Dørheim et al. (2012), a preterm baby is a baby born before the 37th week of gestation. Lee et al. (2013) included low birth weight of 2500g to the weeks of gestation. There is an increasing awareness in the need for education and counselling session for mothers of preterm babies.

Pregnant women in Ghana undergo several sessions and arrangements with the midwives and health professional on what to do to have a safe and healthy child and childbirth. Gomez-Pomar & Finnegan (2018) believe that a "birth plan" is drawn to suit the pregnant woman. With the natural thing being pregnant and having a safe and healthy baby, however, life at times is able to bring about some changes in the natural settings and arrangements. A change in this natural arrangement brings about stress which may be caused by delivery factors, maternal factors and baby factors. Studies by Nystrom & Axelsson (2002); Holditch-Davis & Miles (2000); Heerman et al. (2005) and Brødsgaard, Pedersen, Larsen, & Weis, (2019) talk about women's experiences of having a child cared for at the intensive care unit after the child has been born. This questions her sense of motherhood making her insecure. Hoffenkamp et al. (2015), Singer et al. (2003) and Williams et al. (2018) indicate that the physiological and psychological conditions of babies send parents of preterm babies into some form of trauma. This makes it difficult for the mother to adapt to parenting since their babies requires more medical care in the NICU than parental care. All these studies were conducted outside of Ghana. Looking at the newness of the NICU concept in the health sector in Ghana, the study looks at the women's experience within the context of NICU in one of the hospitals in Ghana.

Three major factors were identified to contribute to children's need for intensive care, namely maternal factors, delivery factors and baby factors.

The maternal factors identified include mothers younger than 16 or older than 40 years; Drug or alcohol exposure; Diseases such as Diabetes, Hypertension (high blood pressure), Bleeding and Sexually transmitted diseases; Multiple pregnancy (twins, triplets, or more); Too little or too much amniotic fluid; Premature rupture of membranes (also called the amniotic sac or bag of waters) all account for babies being sent to the NICU (Nystrom & Axelsson, 2002; Holditch-Davis & Miles, 2000; Heerman et al., 2005; Wigert et al., 2006; Matricardi,

Agostino, Fedeli, & Montirosso, 2013; Caporali et al., 2020; Williams et al., 2018; Brødsgaard et al., 2019).

The delivery factors include Foetal distress/birth asphyxia (changes in organ systems due to lack of oxygen); Breech delivery presentation (buttocks delivered first) or other abnormal presentation; Meconium (the baby's first stool passed during pregnancy into the amniotic fluid); Nuchal cord (cord around the baby's neck); Forceps or caesarean delivery (Nystrom & Axelsson, 2002; Holditch-Davis & Miles, 2000; Heerman et al., 2005; Wigert et al., 2006; Matricardi, Agostino, Fedeli, & Montirosso, 2013; Caporali et al., 2020; Williams et al., 2018; Brødsgaard et al., 2019). The baby factos include birth at gestational age less than 37 weeks or more than 42 weeks; Birth weight less than 2500 grams (5 pounds, 8 ounces) or over 4000 grams (8 pounds, 13 ounces); Small for gestational age; Medication or resuscitation in the delivery room; Birth defects; Respiratory distress including rapid breathing, grunting, or apnea (stopping breathing); Infection such as herpes, group B streptococcus; Chlamydia; Seizures; Hypoglycemia (low blood sugar); Need for extra oxygen or monitoring; intravenous (IV) therapy; or medications; Need for special treatment or procedures such as a blood transfusion. (Nystrom & Axelsson, 2002; Holditch-Davis & Miles, 2000; Heerman et al., 2005; Wigert et al., 2006)

With the goal of the Ministry of Health, Ghana to "reduce the neonatal mortality rate from 32 per 1000 live births in 2011 to 21 per 1000 live births in 2018", measures are being put in place to "reduce the institutional neonatal mortality by at least 35% by 2018". By this, the Ministry is establishing Neonatal Intensive care Units (NICU) in every region of Ghana. So far the main teaching Hospitals in the Country Korle Bu, Komfo Anokye, Tamale, Interberten, the 37 military Hospitals have these intensive care units established. Other regional and district hospitals have small NICU units but if they are unable to manage the cases they receive, they refer these babies to the regional and teaching hospitals. The NICU is specialized clinics with modern technology and specially trained staff to handle the neonates.

In line with population growth, the number of deaths in children under five worldwide declined from 12.7 million in 1990 to 6.3 million in 2013 (WHO, 2014), which translates into about 17,000 fewer children dying each day. Having a neonate is a phenomenon that happens everywhere in the world. Studies by Matricardi, Agostino, Fedeli, & Montirosso (2013); Caporali et al. (2020); Williams et al. (2018) and Brødsgaard et al. (2019) show that parents of preterm babies go through traumatic situations such as anxiety, negative state of mind, bewilderment fear, stress and depression among others. The Neonatal Intensive Care Unit (NICU) is a place that is established with the aim of reducing infant mortality globally and especially in Ghana. Ministry Of Health is seeking to establish more NICUs all over Ghana to support neonates who may require intensive care. There is the need to find out from women what their experiences have been as their babies were admitted into these intensive care units in order to give

holistic care to both mothers and their neonates. The study therefore attempts to answer the question, "what are the experiences of mothers whose babies have been admitted to the Neonatal Intensive Care Unit in a Ghanaian hospital?

Philosophical Assumptions and Theoretical Paradigm

On Ontology, the study acknowledges that reality in the world is a product of individual consciousness or of one's mind (Burrell & Morgan, 2017). It is, therefore, possible to have multiple realities through each individual's lived experiences. Exploring the experiences of these women would give the team an in-depth understanding of what women whose children require intensive care go through different lenses. On the Epistemology, Creswell (2007) acknowledges that knowledge is best acquired if the researcher gets close to the participants being studied. One of the researchers was a participant observer who went through having her baby on admission at the intensive care unit of a hospital in Ghana. She tried to show the "roles of the values (Axiology)" that was placed on herself and the mothers of neonates in intensive care unit by capturing their experiences during the NICU phase. She was able to personalize this study because she was a mother who had a baby in the intensive care unit at the hospital. This made it possible for her to have a first-hand experience of the NICU experience (Creswell, 2007).

On the Theoretical traditions, the study uses Social constructivism to find out how these people construct reality. The study focused on what people's "reported perceptions, explanations, beliefs and worldviews are". In order to understand the world in which these women live in, their subjective experiences were collated and meanings were drawn from these experiences (Creswell, 2013). This approach (social constructivism) gave varied and multiple-meaning to the experiences collated.

The study also uses Phenomenology which seeks to interpret the human experiences described by the mothers as the study tries to depict the "nature of their reality" (Creswell, 2007, 2013). The study explains women's "lived experiences" since "we can only know what we experience", Patton (2002b) and "what all participants have in common" Creswell (2007).

The phenomenological notion is that human experiences are "pre-reflective and taken for granted in everyday life" (Hall & Brinchmann, 2009). They believe that "Knowledge embedded in experiences is silent" that it seeks to bring to the fore the "meaning, structure and essence" of peoples "lived experience", Patton (2002a).

2. Methodology

The study took place during the post discharge out of NICU in a hospital located in the Greater Accra Region in Ghana. The Unit has the capacity to treat babies with gestation age of below 37 weeks, up to new-born and beyond. Treatment at the NICU involved monitoring and observing the newborns, and assessing how they respond to the various treatment that occur with preterm babies. The NICU was made up of a large unit that had the state of the Art machinery and incuba-

tors, a nurses quarters and a resting room for mothers. Proper care was ensured to check that mothers enter the NICU well clothed so as not to transfer any foreign material into the UNIT. Next to the NICU was a parents resting room where parent could catch a breadth whiles caring for their baby. The recall methods were adopted since the study focused on women's experiences as they went through the NICU. The setting for the interview was the large waiting room in the hospital as parents brought their babies for medical review after 2 weeks of discharge from the NICU.

Data was collected until the point of saturation Guest, Namey and Chen (2020); Guest, Bunce and Johnson (2006) and Hennink and Kaiser (2021) was achieved and no new themes emerged. A total of 12 semi-structured interviews were transcribed. These transcripts were read and scrutinized for codes. Emerging themes were put together where meanings were derived. Through reflections on experiences, new knowledge was developed. This helped to blend the researchers' "subjective experience and also interpretative framework" Creswell (2007) with the experiences of these women to ensure reliability and validity. The study was limited to opinions, "personal reflection of events" Creswell (2007) to help capture the experiences of NICU mothers. At this stage, an accurate description of the mothers' experiences in the NICU was rendered. (**Table 1**)

A purposive sample under a non-probability sampling technique was deployed in selecting samples for the study. The selection criteria were that the respondents must be the mother of an infant hospitalized in the NICU and is alive. She must have had previous children before and should not have had any previous experience of children hospitalized in a NICU. And she must be willing to

Table 1. Profile of women interviewed.

Name	Age	Nationality	Marital Status	Educational Level	No Of Children	Duration Of Interview
Adjoa Antwi	31	Ghanaian	Married	Tertiary	2	1:30 Minutes
Ama Asare	24	Ghanaian	Cohabitating	Secondary	1	1 hour
Afia Owusu	30	Ghanaian	Married	Secondary	1	1:10 Minutes
Yaa Mansa	26	Ghanaian	Single	Tertiary	1	1 Hour
Akua Boahen	36	Ghanaian	Married	Tertiary	1	50 Minutes
Yaa Ani	29	Ghanaian	Married	Secondary	2	40 minutes
Yaa Ntiamoa	28	Ghanaian	Married	Tertiary	1	45 Minutes
Ama Serwaa	25	Ghanaian	Married	Secondary	1	49 minutes
Ama Essian	28	Ghanaian	Married	Tertiary	1	45 minutes
Akua Antwi	29	Ghanaian	Single	Secondary	1	53 minutes
Adjoa Ntim	28	Ghanaian	Married	Secondary	2	50 minutes
Akosua Boatema	32	Ghanaian	Married	Tertiary	2	1 hour

(Source: Fieldwork 2015. Pseudo names are used).

participate in the study. Twelve mothers were purposively selected. Our analysis shows that the codebook we created was fairly complete and stable after only twelve interviews and remained so.

The interviews were organized during five review sessions at one of the Hospitals in Ghana. Connelly and Clandinin (1990) look at the dimension of the interaction; "the past, present, future and the place" helped the team capture and situate the story in its context. The interview guide was organized to gain insight into the before the NICU phase, during the NICU phase and after the NICU phase. This helped to gain insight into what the women experienced and how they experienced it.

Hospital administration and staff were not included in the study because permission was not sought from them. The ethical considerations of anonymity, confidentiality and consent were sought before and during the interview process. For instance, Adjoa asked that she gets to read the document after the work has been done. She specifically sought for anonymity.

3. Results and Discussion

As the study unfolded different themes emerged out of the codes used. Initially, the study adopted the use of structural codes where the transcripts were read and coded in structures. The main structures that emerge were the various phases of their experiences. As these women shared their stories the transcripts were coded in terms of the emerging structures/phases identified.

Relationships and social support in the healing process

The study identified that different kind of relationships, both negative and positive (Hoffenkamp et al., 2015; Singer et al., 2003) existed between the mother and her environment. Both relationships influenced how they dealt with their experiences of having their babies on admission at the intensive care unit Caporali et al. (2020); Williams et al. (2018) and Brødsgaard et al. (2019). Most of the mothers indicated that the hospital staff (especially nurses), husband, family, religious leaders and neighbors together played a role in these experiences. This results are similar to results found in studies by Caporali et al. (2020); Williams et al. (2018) and Brødsgaard et al. (2019) indicating the need for social support. Some of these interactions yielded negative consequences which led to emotions such as the mothers feeling no sense of belongingness; insecurity and uncertainty. For instance, Adjoa shared her experience amidst sadness and shedding tears. She recounted that she experienced different emotions when she entered the intensive care unit at a point and did not see her baby in the usual cot because the baby had been moved to another cot without any information to her. She explained that this experience was traumatic since she initially thought that she had lost her baby.

The positive relationships brought about encouragement, faith, spiritual intervention and healing. Adjoa Antwi said that *"The nurses are very nice and well trained. They talk to you and ask that you pray with them and talk to them.*

"They hear you. Talk to them." To her, this was very encouraging and helped her to go through that experience.

Ama Asare said that *"At first it was not coming. They laughed at me. I was sad but I didn't show. They said every woman has the same problem. They asked that I thank God for the life of my baby. That it could have been worse".* Afia Owusu was also of the view that *"for my social life my family supported. Parents, friends and even Neighbors".* She had a lot of support which made her experience much manageable. She did not show a lot of emotions. This could be because she was a staff of that hospital and the environment was familiar to her. She was operating from her comfort zone. For these times social support was very instrumental in helping these women in going through seeing their babies on admission with all these machines and needle pricks on their hands or head.

The emotional state of the women

All the women underwent a series of emotions as they experienced NICU. For the interaction with the NICU environment, mothers indicated the initial sense of humiliation, intimidation and they were overwhelmed. Adjoa said "*whenever a nurse/Doctor stands in front of the door even before the call out the mother's name, we all get frightened. Even though at the time it was to hear good news".* They indicated that a void was created in their lives. Yaa Ntiamoa said she "*was scared*. She did not know where her baby was initially, although her husband had suggested that the baby was ok. This aligns with Gerstein et al. (2019) description of the emotional state of the women and how stressed and depressed they could be. They indicated that having delivered and yet unable to hold your baby or to send your baby home was a difficult experience. As told by Ama Serwa "I w*as confused, where is my baby".* The silence in the intensive care unit and the beeping of these machines as well as they not being able to hold their babies made the experience more traumatizing. The reality of seeing their babies in such a state had a way of changing their perception of life and reality.

Again, with encouragement and support from God, these women were able to forge ahead. To them, combining the task of being a mother of other children and a neonate baby made them draw strength from God who they all acknowledged existed and was the one who healed their babies. In the words of Ama Essien "*This experience has made me stronger and drawn nearer to God. There were times that I cried, I mean really cried (wept). Times I questioned God. Times I blamed myself. But I had to trust God to heal them and He has.*

Akua Antwi reiterated that I remember one of the nurses told me that as for this place "ɜyɜ Nyame" (it's only God)". Similar sentiments were shared by all women who indicated that the support (spiritual) from the health workers was paramount in this experience. Yaa Ani suggested that "*We are just trying, but if you trust in God, and pray, He would use us (health workers) to help heal your babies. So I have become a stronger woman physically and spiritually".*

Finding yourself whilst caring for an intensive care baby.

On caring for a NICU baby, mothers indicated it as being stressful, tiring, and

an emotional experience. Even though all these women are not first-time mothers, every aspect of caring for an intensive care baby is different from what they experienced with their other babies. Akua Boatemaa said she was "*constantly tired and stressed, even my parents say it. These babies are different. Everything about their life is different. You have to be extra careful and neat. It's an entirely new experience. Very different from the firstborn. Cry differently, eat differently, sleep differently".* She also indicated her mother's friend told her that this experience was managed differently when there was no modern technology and specially trained health team were trained to help take care of the neonate babies.

Yaa Ntaimoa said "*when my baby was discharged I was afraid of her. She was small and tiny. I had to change my perception on motherhood. There were times I wondered if I could take care of a neonate baby. My aunt helped a lot, she was always encouraging me".* The women had come to accept that they were not the first people to have their babies at the intensive care unit and they would not be the last, other people go through and survive. *"I got support from family. People told me stories of how it was done traditionally. It's been an existing condition, we just don't talk much about it. But once you have a neonate baby, then people support you and share their experiences with you" Gradually, you became comfortable to deal with her. It gets better by the day" Ama Serwaa.*

For some of the women, the NICU experience gave them a sense of helplessness, powerlessness and vulnerability especially when they had gone through other pregnancies where their experiences were comparatively easier. The difficult physical and medical condition of their new born babies as well as the lack of ability to hold and have bodily contact with your baby made it difficult to adapt to being mothers. This made the mothers overly stressed (Alkozie, McMahon, & Lahav, 2014), scared and depressed (Caporali et al., 2020; Williams et al., 2018; Gerstein et al., 2019; Brødsgaard et al., 2019). This case was extremely difficult for Yaa Mansa as she indicated that *"going through a difficult pregnancy and then the intensive care unit was too much for me. I was angry all the time. I blamed myself for my baby's condition*. However *with counselling and support from family and the health workers at the NICU, I gradually came to accept that this condition was also a part of life".*

The separation, loneliness and questioning phase of the process helped the women to find and draw inner strength to deal with the whole experience (Hagen, Iversen, & Svindseth, 2016). Adjoa Ntim said "*You have to pray when your baby is here. I go for prayers even though my baby's condition was not very serious. I was very afraid initially but when I entered and I saw the conditions of some babies, it gave me hope that mine was better".* Generally, the women had to change their perception on motherhood. They had to go through a process of rediscovering themselves as mothers, especially since by their experiences, they had relatively easier experiences with their previous pregnancies and deliveries.

Healing overtime

It was discovered from the study that at a point through the process, the mothers showed the need to accept that their babies had to be at NICU to help

them to survive (Hagen, Iversen, & Svindseth, 2016), a finding that indicated a step toward healing. This made it easy for them to work together with the hospital staff. They became willing to learn from these nurses and doctors on how to take care of the babies. Yaa Ani said, "It *is a lot of work. They say that makes sure that the baby is really full. They asked that I feed the baby at least every three hours. And if I don't do that the baby will be HYPO* (hypoglycemia) *and die".* The hospital staff made the women aware that healing is a process and that keeping your baby warm, full, healthy, happy and well-loved was a start to the healing process. These mothers shared their experiences that though it was a difficult process, they have the assurance that given time, the social support from the hospitals staff, spouse and their family their infants were responding to the care and treatment. To these women, the healing process was a process and the right attitude helps with the healing process.

Reflexive section

In thinking through the work, the team was biased as a result of a team member's personal experience was shared to help them appreciate the experiences of women in the NICU at that particular hospital. All mothers interviewed had a different account, attitude, perspective and approaches to life in their stories and experiences.

On reflexivity from reading Tracy (2010), we chose a compelling topic both theoretically and conceptually, relevant, timely significant and interesting. The topic was developed from one author's interactions with the NICU at the hospital when her daughter was on admission. We used the right methodological procedure and tried to look and work beyond the basics. We asked the right questions and made sure that the right answers were obtained within the right context and concepts.

We tried to be sincere by being reflexive where we were frank about our work acknowledging our strengths and weaknesses. We tried to show vulnerability and were transparent about our work whiles we took time to audit the data. We assessed our biases and motivation whilst asking whether they are well situated. We tried to learn how not to leave out the negative and unpleasant aspect of the research process that some researchers would want to hide. We relied on the author who went through the NICU experience to help conduct the interview sessions since it was easier for these women to open up to them because she shared in their problems and experience. We linked the study design, data collection, analysis, and theoretical framework to the goal of trying to capture the experiences of women whose babies have been to the NICU. This helped to develop credibility. Tracy (2010) sees this as the ability for the researcher to show trustworthiness, verisimilitude and plausibility of the research findings. Tracy (2010) believes that the ability for research work to show tactfulness and accuracy makes the work credible.

4. Study Limitations

In conducting this study it was observed that literature on preterm and neonatal

birth in Ghana was limited. The limited number of mothers with neonatal babies who were willing to share their experiences was identified as another situation of concern to research in this area of study.

This study has also some limitations. The exploratory study was conducted in a single hospital with a limited sample and it makes it difficult to compare experiences across different hospitals. It would be good to include more hospitals and respondents to be able to identify and describe the experiences of women whose children are in the NICU.

Seeking for the opinions of the medical staff would have enriched the depth of the experiences of these women. It would have been prudent to have expanded the scope of the work to include some quantitative measures to be able to capture the experiences across a much wider population.

5. Conclusion

Mothers told different stories of their experiences. These stories were full of the emotions they experienced. And the candid way they told their stories gives one a sense of their realities. The use of the semi-structured interviews made it easy for the researchers to get the shape of the stories to capture what their experiences were. All the mothers interviewed had previous babies and indicated that those experiences were relatively easier as compared to the NICU session. Twelve women were interviewed and there was a sequence within the stories that were told. Although it was easy to deduce that they all had difficult experiences during the NICU phase. The mothers from the time they were separated from their babies through to the time their babies were on admission and had to rely on the nurses to take care of their babies missed out on the "attachment" and the "bond" they were supposed to have with their babies. These women cried a lot, felt nervous, uncertain, lonely and felt separated from their babies. They felt they had lost so much because for a country like Ghana has diverse cultural beliefs and practices the communal living setting, it was possible for them to feel ridiculed (Adjoa by her neighbor) and get a lot of social support. The women indicated that they felt lucky since they had modern technology and qualified staff to help take care of their babies. The way the hospital staff related to these women also had an effect on them. Some were very supportive and others were not. Because these women were undergoing a lot of emotional stress, they were easily affected by the slightest thing. From the reaction of Yaa, she needed the nurses to be hard on her to get her to be strong for her baby. This is consistent with studies by who used similar small samples in their study and found similar results of social and psychological support.

Anxiety, uncertainty and powerlessness are some of the negative effects a mother of an infant in the NICU experiences. This situation can improve with the right kind of socio-psychological support. Access to information, guidance and practical support can help mothers regain that sense of confidence to be able to handle and manage the situation they may find themselves in. The right me-

dication, breast milk, care, prayer and nurturing are sources of healing mothers with preterm infants indicate helped them through their experiences. The social support as well and mother to mother peer support is also an intervening measures of coping and healing. The women learnt at the NICU and this experience had made them very strong. Though it was a tough place that questioned their sense of motherhood, the women appreciated the role NICU has helped in the health of their babies.

Care and Attention should focus on the psychological, social, cultural and spiritual dimensions of the lives of mothers with infants in the new-born intensive care unit. Policy should focus on providing appropriate family psychosocial cantered interventions to families going through such experiences.

Notes

Abbreviations used in text: Neonatal Intensive Care Unit (NICU).

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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