Original Research Article

EXPLORING NEEDS OF PARENTS DURING END-OF-LIFE CARE OF THEIR NEWBORNS

ABSTRACT

Background: The progress made in neonatal intensive care delivery worldwide has resulted in optimal health outcomes of neonates, however, newborns and infants still die. The infants and newborns who die, majority of them die in Neonatal Intensive Care Units (NICU). The experiences of many parents following a poor prognosis of their newborns requiring end of life care suggest that parents usually need support from health care professionals who render direct services to their child, however, the extent and nature of this support is perceivably unknown.

Purpose: The purpose of this study was therefore to explore parents' lived experiences of support at NICU in Tamale Teaching Hospital (TTH).

Methods: Using an exploratory descriptive design, a semi-structured interview guide was used to collect data. Ethical approval was sought from TTH ethics review committee which is the final authority to give approval for the data collection. Purposive and convenience sampling was used to select eight (8) parents to inform the study. The participating parents completed an informed consent form prior to their participation in an interview. The results were analyzed using thematic analysis.

Results: Effective communication and the provision of continuous, concise and complete information about child's condition were important to parents during the end-of-life care (EoLC) of their newborns in the NICU; Parents had limited understanding of the nature and benefits of palliative care; Parental support in terms of information and communication, emotional, psychological and spiritual support, as shared decision-making are essential for quality EoLC at the TTH.

Conclusion: Accommodation should be provided for parents of babies on NICU admission. Support groups should be formed to assist parents of babies receiving EoLC.

Key Words: *End of Life Care, Neonatal Palliative Care, Neonatal ICU, Terminally ill, Lived Experiences*

Introduction

Parents confronted with EoLC for their newborns have a strong need for compassionate health professionals' support. Particularly, most parents need emotional support and an explicit share of responsibility before, during and after the eventual loss of their newborns (Caeymaex et al., 2011; Williams, Munson, Zupancic, & Kirpalani, 2008).

Additionally, EoLC is not only seen as the standard of care for terminally ill patients but more so as an ethical obligation for health care professionals and the institution in which the care is provided. According to the World Health Organization (WHO), EoLC is the care rendered to seriously and terminally ill patients including palliative care with the aim of relieving pain, prolonging life, avoiding unwanted life support, and promoting the physical, psychological and spiritual wellbeing of patient, parents and families. Thus, the American Academy of Pediatrics (AAP) and American College of Critical Care Medicine (ACCCM) recommend that pediatric and newborn end of life be offered at the time of diagnosis and continue throughout illness, regardless of outcome.

Overall, studies report that parents and family centered decision on EoLC is one such important domain of quality EoLC in the NICUs of most health institutions (Currie et al., 2016). Therefore, parents value emotional support, attending to the physical needs of the newborn, effective and honest communication regarding newborn condition as well as grief education prior to informing parents of end-of-life care decision (Gold, 2007). Accordingly, health care professionals can make parents feel either supported or helpless following a diagnosis of a terminal illness of a newborn. Yet, there is a dearth of studies focusing on understanding and evaluating caregivers' support for parents during EoLC of their newborns in the neonatal intensive care unit (NICU), particularly in Ghana.

The study seeks to explore parents' lived experiences of support at Neonatal Intensive Care Unit at Tamale Teaching Hospital.

METHODS

Study design: The study adopted exploratory qualitative research design which allows for a description of participants perceptions, and their experiences as well as capturing the subjective feelings of the participants (Neuman, 2011; Ulin, Robinson, Tolley & McNeill, 2002).

Setting: The study was conducted within the Tamale Teaching Hospital in the Tamale Metropolis in the Northern Region of Ghana. Tamale Metropolis occupies approximately 922 square kilometers of land, that is, 13% of the total land area of the Northern Region. Tamale Teaching Hospital is the largest referral facility in the northern part of the country. The facility serves the three regions of the north in varied medical specialty areas including paediatric and neonatal intensive care.

Target Population: The target population is the total group of participants in whom the researcher is interested (Polit & Beck, 2014). The target population was mothers and fathers with babies receiving EoLC at the NICU of TTH.

Inclusion Criteria: Participants were included in the study if they were 18 years and above, delivered a baby with a life-threatening condition and admitted to NICU for not less than 48 hours.

Exclusion Criteria: Mothers with birth complications and parents, who had healthy babies were excluded. This was because they could not have provided the needed information for the study.

Sampling Technique and Size: Purposive and convenience sampling which was to recruit participants of a target population due to the qualities the participants possess, and their ability to meet certain practical conditions (Etikan et al., 2016) were used to recruit the parents. This was utilized to obtain a wide-range of views from eight (8) participants. The main aim of these techniques was to enable the researcher to recruit good informants who had the information needed. A good informant is one who is knowledgeable and experienced about the phenomenon under study. He or she has the ability to reflect, is available, has time to be interviewed and is willing to participate in the study (Creswell & Plano Clark, 2011; Etikan, Musa, & Alkassim,2016; Palinkas et al., 2015). Studies report that there are usually difficulties in conducting research with infants and newborns with life-limiting conditions or life-threatening illnesses and their parents. The recruitment of these participants is usually challenged by barriers including ethical, logistical and clinical considerations (Hudson, et al., 2017).

Data Collection Instrument: The main research instrument was a semi structured interview guide. Open ended questions were developed based on the objectives of the study. The instrument consisted of 5 sections. The Section A comprised of demographic data with the intention to give them an opportunity for them to relax before the interview while sections B through E contained the main questions on parental experiences of support in NICU and neonatal end of life care. The interview guide was pre-tested at Tamale Central Hospital and all ambiguities clarified. The results of the pre-testing were not added to the main study findings.

Data Collection Procedure: Upon receiving data collection approval from the ethics review committee of the Tamale Teaching Hospital, permission was sought from the Head of Child Health Department and the Nurse Manager of NICU of the said hospital to use the facility as a data collection site. The researcher used the admission and discharge register to trace the

location of all mothers who delivered a baby with life threatening condition and discharged home for follow-up care.

Data analysis is the method of making sense from research respondent's understanding and verdicts of circumstances which are converted into findings (Vaismoradi, Turunen & Bondas, 2013). Data was analysed using thematic analysis. At the end of each day of interview, the researcher transcribed the recorded interview verbatim a personal computer taking into account field notes. To ensure accuracy of the transcripts, the researcher compared the transcripts with the audio recordings and missing links filled. The transcripts were then printed out for the supervisor to read and make inputs.

Methodological Rigour: The procedure of ensuring trustworthiness as indicated by Polit and Beck (2014) was adopted. These include credibility, transferability, confirmability, and dependability. Credibility was ensured as the interview guide was pre-tested using two participants in the Sagnarigu Municipality. Transferability was ensured first by thorough, rigorous description of the research design. data of this study is dependable in that, interviews were conducted and analyzed till data was saturated and there were no known new themes that could be documented. To ensure conformability, the researcher made sure that she was watchful of her own stance taking into consideration her professional knowledge about the area being studied in order not to enforce them on the responses of the mothers.

Informed consent was obtained from the participants before beginning with each interview. Anonymity of participants was ensured by not collecting or allowing them to specify their names, identifying data or other details that can be traced on the consent form or the interview guide, hence using pseudonyms.

RESULTS

Two themes emerged from content analysis of the data. They were "Critical condition of newborns and end of life care" and "Poor communication and information flow". The themes are presented and verbatim quotations used to back the claims.

Demographics

The age distribution of the participants ranges from 21 to 40 years; 6 participants between the ages of 21 to 30 years and 2 participants between the ages of 31 to 40 years. All participants but 1 were females and were the biological parents of the infants admitted at the NICU. This is an indication that the care of infants at the NICU is largely the responsibility of the biological mother. The participants exhibited varied educational levels, 1 had formal education, 4 had basic education, 2 had secondary education and 1 had tertiary education culminating in a diploma or bachelor degree. There were no parents with postgraduate degree. Majority, 6 of the participants were married, whilst the remaining 2 were single mothers. The sample comprised of 4 Moslems and 4 Christians, an indication of the general multi-religious nature of the Tamale metropolis. Overall, the infants of the parents in the sample comprised of 5 male and 3 females.

Critical condition of newborns and end of life care

The subthemes that emerged from this theme were: Severe conditions of newborns, End of life care at the NICU and Unawareness of palliative care. The parents indicated that admitting the child to the NICU was premised on the severity of their baby's condition. Participants of the study acknowledged that the condition of their newborns was critical and when NICU and palliative care was suggested, they obliged. The responses of some parents regarding the condition of their newborns are indicated below:

Severe condition of newborns

I went there [the NICU] because when I delivered, he was weak and they were planned to send him to a bigger hospital…I became afraid. It hurt me because when you deliver your hopes are that your baby is going home with you some few hours after birth but there we were for weeks. As the same time, I feared he will die because I had lost a baby to the same condition. **(Amina)**

The bay was so weak and sick that they say he must be in NICU for the necessary care. Because the baby was critically ill, they said it is important to admit him and that state I had to comply. **(Iddrisu)**

Some participants indicated that some of the conditions include respiratory complications, preterm complications, congenital abnormalities and other neonatal conditions. These needed urgent medical attention for survival. In addition, most parents were optimistic and hopeful about the chances of survival of their newborns when admitted to the NICU. Unfortunately, some of these newborns could not survive.

End of life care at the NICU

They were twins. They said they would admit the baby to NICU because he couldn't breathe well and also not strong than the other and was tiny as well. To me he was stronger than the other one. They sent him to the NICU and he died the next 3 days. When they sent the baby to NICU, I had hope that he will be ok but the next 3 days they said he couldn't make it and it is left with the other one. ***(Abiba)***

My baby was so sick I knew he would die….as for me I did not have hope that my baby would survive. I had not seen such a condition before. His condition was critical. Already, I know the baby will go to the NICU because I heard if your baby's condition is critical, he/she will go to the NICU. But when I delivered and saw him, hmmm. I saw it as 50/50 affair. Anything could happen to the baby. **(Asantewaa)**

When I delivered, they said the condition of the baby is crucial so they sent her to NICU…. I thought my baby has died but when I saw him alive, I became satisfied. I wanted my baby to be by my side. The nurse said the baby was not fine that is why we are here [at the NICU]. **(Amelia)**

Unawareness of palliative care

I don't really understand but what they told me was that my baby was seriously ill and requires intensive care in order for him to survive… I felt it shall be well I had the hope but I never saw his face again. When he died, they did not give me the chance to see him. They sent him away. I wish I saw him. **(Abiba)**

I don't know. I am sure the care they are doing anything they can to make sure my baby survives. Every parent who will hear that your child is sick and his condition is

severe and you are not shaken, then you are not a good parent. So, once they said the baby will require that intensive care I did not hesitate. I became afraid. It hurt me because when you deliver your hopes are that your baby is going home with you some few hours after birth but there we were for weeks. At the same, time I feared he will die because I had lost a baby to the same condition. **(Amina)**

I don't know. Already I know the baby will go to NICU because I heard if your baby condition is critical, he/she will go to NICU. But when I delivered and saw him it was hhmm. I saw it was a 50/50 affair. Anything could happen to the baby. **(Asantewaa)**

Generally, it became evident that some parents were experiencing this for the first time, whilst others have an earlier experience. For such parents, this current situation only heightened their fears and distress.

Poor communication and information flow

Another theme identified in the data was poor communication and need for continuous information. Apparently, parents expected adequate information and effective communication from nurses and other healthcare professionals. Participants in the study expected nurses and healthcare professionals to talk to them properly, frequently and to inform them about the pertinent issues regarding the condition and progress of the child under treatment. The following responses by participants underscored the importance parents attach to continuous information about the child's condition and effective communication skills of nurses and healthcare professionals.

Need for continuous information

If they think your baby may go to NICU, they have to inform you and if there is any information on the progress of the child, it should be well communicated. Most interactions are centered on buying diaper, baby's wipes are finished etc. **(Abiba)**

I needed to know what was happening to my baby often. This was done occasionally, but it is not enough. They should give us frequent information about the progress and condition of the child. **(Amelia)**

Some participants were also of the view that some nurses and doctors were not responsive to their information needs regarding the child's condition.

Poor communication

I don't know whether they were nurses of doctors, when you want to ask about your baby's condition, they don't seem to mind you. You want to find out whether your baby is progressing or deteriorating, the current weight etc., but they don't mind you. **(Asantewaa)**

The information is not enough. One would come and say do it this way; another will come and say do it that way. One nurse even said when I wanted to get information about my child, that she is not the person responsible to give me information about my child. **(Agnes)**

Lack of knowledge of care

Trial and error to help the mother and the baby. I had hope and they psyched me I the operating room so I complied. I was very afraid. The baby's condition was critical so they had to admit her and take care of that so how can I prevent that? I was terrified and frustrated because first born died after delivery. **(Akos)**

I have not heard it before. Because the baby was critically ill, they said it important they admit him and, in that state, I had to comply. Hearing something from one of the parents who had lost a baby in the NICU before, I was terrified, because they said when her baby died, they did not tell her. I did not understand because most people are with their babies but for so long, we did not get access to our baby to be by us. **(Iddrisu)**

Effective communication and feedback is the most important measure to improve the satisfaction of parents during EoLC at the NICU.

DISCUSSION

Critical Condition of Newborns and End of Life Care

In analyzing the data in parents' lived experiences of support during end of life care of their newborns at the NICU, it emerged that the conditions of the newborns were critical. The

participants acknowledged that the nature and condition of their newborns was the key factor for being admitted at the NICU and commencing palliative care. Some participants expected that once the newborn's condition was critical, he/she would be admitted to the NICU. This affirms the observation that in Ghana, newborns with critical neonatal conditions are admitted to the NICU. The conditions enumerated by the participants fall in the broad categories delineated by earlier studies including congenital abnormalities, preterm birth complications, severe birth asphyxia, respiratory distress and other neonatal conditions (GSS, 2014; WHO, 2018).

This finding buttresses the fact that palliative care is needed in "chronic and life-threatening conditions" (Connor and Bermedo, 2014). Generally, therefore, the findings suggest that indeed newborns with critical and life-limiting conditions were admitted to the NICU and provided end of life care at the TTH in accordance with the World Health Organization standards regarding neonatal palliative care. These newborns were provided with treatment as long as was deemed necessary. However, end of life care in the case of TTH was limited to the hospital, contrary to the assertions of Connor and Bermedo (2014).

Poor Communication and information flow

According to Clark et al. (2009), effective communication in healthcare requires knowledge, skill and empathy which then influence the individual's ability to speak, what to say and how to say it. The study found that parents expected healthcare professionals to provide adequate and accurate information about the child's condition; discussing the progress, explaining procedures and providing any other information as the parent may require. Parents felt healthcare professionals were not responsive enough to their information needs and request regarding the condition of the child. Additionally, parents were of the view that nurses and healthcare professionals lacked effective communication skills. As a result, nurses and

healthcare professionals were not able to clearly communicate information about the child's condition and progress to parents.

Studies have found that effective communication and information flow is central to parents' perception of quality of care of newborns in the NICU. According to Obeidat, Bond and Callister (2009), parents of neonates in the NICU experience higher levels of distress and anxiety. It is therefore imperative that these parents are provided with timely, honest and complete information about their child's condition to give them peace of mind (Mack & Joffe, 2014). In the case of the present study, it was found that the information provided to parents about the condition of the child was usually not enough, infrequent and dishonest. This only heightens the worries and anxiety of parents and worsens their perception of quality of care (Short & Thienprayoon, 2018).

Measures to improve End of Life Care at TTH

Ghana records 29 deaths per 1,000 live births in terms of neonatal mortality (GSS, 2014) and sixty-eight percent of all deaths among children take place before a child's first birthday, with 48% occurring during the first month of life (GSS, 2014; Annan and Asiedu, 2018). Despite the vast number of children in need of palliative care, several factors limit the provision of palliative care services for the majority of people in Africa (Mwangi-Powell & Olivia, 2011; Downing et al., 2018). One key factor is the relatively newness of the end of life care discipline on the continent and its development is hampered by the fact that it is not integrated into health systems. Moreover, end of life care is not integrated into nursing and healthcare professionals training curriculum thereby creating significant skills deficit (Harding & Higginson, 2005) in palliative care across Africa. In addition, there is a widespread lack of understanding of what palliative care is and its benefits (Clark, Wright,

Hunt & Lynch, 2007; Mwangi-Powell & Olivia, 2011; Downing et al., 2018). All these have also been reported in the present study.

CONCLUSION

The study focused on parental needs during end of life. The study assessed on two dimensions of EoLC service delivery, namely; information and communication. Some parents emphasized the need for counselling to help them cope with the anxiety and stress. The study has revealed that some healthcare professionals in the NICU at TTH exhibited poor communication skills and some other unprofessional conduct. They also lacked the requisite skills to effectively respond to the emotional, psychological and spiritual support needs of parents at the NICU, hence, training is essential. The importance of continuous research, and particularly, the current study which contributes to knowledge on EoLC in the context of Ghana could not be overemphasized.

COMPETING INTERESTS DISCLAIMER:

Authors have declared that no competing interests exist. The products used for this research are commonly and predominantly use products in our area of research and country. There is absolutely no conflict of interest between the authors and producers of the products because we do not intend to use these products as an avenue for any litigation but for the advancement of knowledge. Also, the research was not funded by the producing company rather it was funded by personal efforts of the authors.

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