



Exploring Parents Needs Among Newborn Babies at Tamale Teaching Hospital

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Authors' contributions

This work was carried out in collaboration among all authors. All authors read and approved the final manuscript.

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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. Majority of these infant and neonatal deaths, occur in Neonatal Intensive Care Units. 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' needs among newborn babies in Neonatal Intensive Care Unit at Tamale Teaching Hospital.

Methods: The researchers adopted a phenomenological qualitative design using a semi-structured interview guide to collect data. Ethical approval was sought from Tamale Teaching Hospital ethics review committee which is the final authority to give approval for the data collection. A sample size of 8 participants were drawn for the study. The participating parents completed an informed consent form prior to their participation in an interview. The results were analyzed using content analysis.

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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 of their newborns in Neonatal Intensive Care Units; 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 well as shared decision-making are essential for quality end-of-life care at the Tamale Teaching Hospital.

Conclusion: The study focused on parental support during end of life and a major finding was that provision of adequate and complete information, effective and frequent communication, emotional and psychological support for parents, support from spouses and extended family for parents, involvement in child's care and shared decision making about child's condition are the most important parental needs during the end-of-life care of their newborns at the Neonatal Intensive Care Unit of Tamale Teaching Hospital.

Keywords: End of life care; neonatal palliative care; neonatal ICU; terminally ill; lived experiences.

1. INTRODUCTION

Parents confronted with End-of-Life Care (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 [1].

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 [2,3]. Thus, the American Academy of Pediatrics (AAP) and American College of Critical Care Medicine (ACCCM) recommend that pediatric and newborn EoLC be offered at the time of diagnosis and continue throughout illness, regardless of outcome [4].

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 [5]. 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 EoLC decision [6,7,8,9,10]. 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 NICU of Tamale Teaching Hospital (TTH).

2. MATERIALS AND METHODS

Study design: The study adopted qualitative research design using the phenomenology approach which allows for a description of participants perceptions, and their experiences as well as capturing the subjective feelings of the participants [11,12].

Setting: The study was conducted within TTH in the Tamale Metropolis located in 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. TTH 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 [13]. 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, had 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 [14] 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 [14,15]. 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 [16].

Data Collection Instrument: Data collection was based on a semi-structured interview guide. Before the interview, demographic data was first collected to understand the background of the research participants. The interview guide was developed based on the objectives of the study and by looking at previous studies that explored parents' experiences with NICU. The interview guide consisted of 5 sections. 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 EoLC. 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 TTH, 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 researchers 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. Interview with each participant lasted for 25-30 minutes.

Data analysis is the method of making sense from research respondent's understanding and verdicts of circumstances which are converted into findings [17]. Data was analysed using content analysis. At the end of each day of interview, the researchers transcribed recorded interview verbatim on a personal computer taking into account field notes. To ensure accuracy of the transcripts, they compared the transcripts with the audio recordings and missing links filled. The transcripts were then printed out read repeatedly.

Methodological Rigour: The procedure of ensuring trustworthiness as indicated by Polit and Beck [13] was adopted. These include credibility, transferability, confirmability, and dependability. Credibility was ensured as the interview guide was pre-tested using two participants at a health facility in the Tamale Metropolis. 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 researchers made sure that they were mindful of their own stance taking into consideration their professional knowledge about the area being studied in order not to impose 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.

3. 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.

3.1 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 NICU. This is an indication that the care of infants at NICU is largely the responsibility of the biological mother. The participants exhibited varied educational levels, 1 had no 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 general multi-religious nature of Tamale metropolis. Overall, infants of the parents under study comprised of 5 males and 3 females.

3.2 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 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 admission and palliative care was suggested, they obliged. The responses of some parents regarding the condition of their newborns are indicated below:

3.3 Severe Condition of Newborns

I went there [NICU] because when I delivered, he was weak and they 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. At the same time, I feared he will die because I had lost a baby to the same condition.

The baby 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, in that state, I had to comply.

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 NICU. Unfortunately, some of these newborns could not survive.

3.4 End of Life Care at the NICU

They were twins. They said they would admit one to NICU because he couldn't breathe well and also not strong like the other one and was tiny as well. To me he was stronger than the other one. They sent him to NICU and he died the next 3 days. When they sent him 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.

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 NICU because I heard that if your baby's condition is critical, he/she will go to NICU. But when I delivered and saw him, hmmm. I saw it as 50/50 affair. Anything could happen to the baby.

When I delivered, they said the condition of the baby is crucial so they sent her to NICU.... I thought my baby had 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 were there [at the NICU].

3.5 Unawareness of Palliative Care

Participants were asked what they understand by the term palliative care. The term was new to all of them which can be deduced from their statements:

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.

I don't know what it means but I am sure they were doing anything they could to

make sure my baby survives. Every parent who will hear that your child is sick and her condition is severe and you are not shaken, then you are not a good parent. So, once they said she 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.

I don't know. Already I knew 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 hmmm. very very serious.

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.

3.6 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.

3.7 Need for Continuous Information

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

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.

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

3.8 Poor Communication

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

The information is scanty. One would come and say do it this way; another will come and say do it that way. One nurse said that she is not the person responsible to give me information about my child I should wait for the doctor.

3.9 Lack of Knowledge on Care

They do trial and error to help the mother and the baby. They told me in the operating room that her condition was critical so they had to admit her and take care of that. So how could I refuse? I was terrified and frustrated because my first born died soon after delivery.

Because the baby was critically ill so they said it important they admit him and, in that state, I obliged. I only heard something from one of the parents who had lost her baby in NICU, I was terrified, because she 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.

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

4. DISCUSSION

4.1 Critical Condition of Newborns and End of Life Care

In analyzing the data in parents' lived experiences of support during EoLC of their newborns at 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 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 conditions are admitted to 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 [2,3].

This finding buttresses the fact that palliative care is needed in "chronic and life-threatening conditions" [18]. Generally, therefore, the findings suggest that indeed newborns with critical and life-limiting conditions were admitted to NICU and provided EoLC at TTH in accordance with WHO standards regarding neonatal palliative care. These newborns were provided with treatment as long as was deemed necessary. However, EoLC in the case of TTH was limited to the hospital, contrary to the assertions of Connor and Bermedo [18].

4.2 Poor Communication and Information Flow

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 [19]. 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 their newborn. 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 for newborns in NICU. According to Obeidat, Bond and Callister [20], parents of neonates in 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 [21,7,22,9,10]. 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 [23].

4.3 Measures to Improve End of Life Care at TTH

Ghana records 29 deaths per 1,000 live births in terms of neonatal mortality and sixty-eight (68) percent of all deaths among children take place before a child's first birthday, with 48% occurring during the first month of life [24]. 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 [25,26]. One key factor is the relatively newness of EoLC discipline on the continent and its development is hampered by the fact that it is not integrated into health systems. Moreover, EoLC is not integrated into nursing and healthcare professionals' training curriculum thereby creating significant skills deficit [27,28] in palliative care across Africa. In addition, there is a widespread lack of understanding of what palliative care is and its benefits [19,25,26]. All these have also been reported in the present study.

5. CONCLUSION

The study focused on parental support during EoLC and a major finding was that provision of adequate and complete information, effective and frequent communication, involvement in child's care and shared decision making about child's condition are the most important parental needs during the EoLC of their newborns at NICU of TTH. A superior emphasis should be placed on ensuring that all professionals working in NICU receive some level of EoLC education. In addition, it is imperative that more funding be made available for research and development neonatal in palliative care. It is fundamental that well-funded teams are designed to meet the challenges of pediatric EoLC patients and their families' needs, desires, and expectations.

DISCLAIMER

The products used for this research are commonly and predominantly used 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.

CONSENT

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.

ETHICAL APPROVAL

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.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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