

Parental Support Systems During End-of- Life Care of their Newborns

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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. 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).

Methodology: 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.

Key findings: 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; 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.

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

Keywords

End of life care • support systems • neonatal palliative care • neonatal ICU • terminally ill • lived experiences

Introduction

Globally, the importance of involving parents in the end of life (EoL) decision making regarding newborn care particularly in the NICU has received ethical recognition by many countries. This is because parents faced with poor prognosis and or eminent death of

their newborns experience not only intense and painful emotional and psychological trauma but they may also experience prolonged and complicated bereavement [1].

The extant literature suggests that only few studies on EoLC have been conducted in Africa. According to Philips and Lazenby, whereas palliative and hospices care is gradually becoming a health service concern in Botswana, the support needs of caregivers and their relatives regarding this essential service leaves much to be desired. The study reports that the practical, emotional, spiritual and the physical needs of the patient-family dyad in Botswana in palliative and hospices care are not being fully met. However, giving the

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needed support parents and family caregivers can form an integral part of the caring process. To this end, research evidence suggests that parental involvement in EoLC has a buffering effect on parental reaction to newborn death and subsequently their emotional maintenance throughout the entire grieving period. report that parents were central to palliative and EoLC in the pediatric and neonatal intensive care units in South Africa and Uganda. The experiences of parents and caregivers in South Africa and Uganda, revealed that emotional support, awareness of parental and family responsibilities, spiritual, and psychological support needs were relevant to caregivers in palliative and EoLC of their sick relatives [2].

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. 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' support systems during end-of-life care of their newborns at Neonatal Intensive Care Unit at Tamale Teaching Hospital[3].

Study findings

Study design: Exploratory qualitative research was adopted to capture how those being interviewed view their world, to learn their expressions and judgments, and to capture the intricacies of their perceptions and experiences. This design was used to gather data from mothers and fathers of babies with life-threatening conditions admitted to NICU for end-of-life care.

Setting: Tamale Teaching Hospital is the outlet of choice for data collection because, it receives and manages neonatal intensive care cases from the five regions of the north and some parts of the Bono, Bono East and Ahafo regions. Therefore, the outcome of the study is more likely to reflect neonatal intensive care and neonatal EoLC in Ghana in general giving the wider covered and the multi-cultural perspective of EoLC support that parents receive from the NICU of TTH.

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

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 sampling was afforded employed for the study because it afforded the researcher the opportunity to include participants with the required experience that helped to generate rich qualitative data on the issue under exploration. The nurse in-charge of NICU at the TTH was contacted and she provided the lists and addresses of parents of babies

delivered with life threatening conditions. Data was collected from the mothers and fathers who met the inclusion criteria and were available at the time of the data collection. First, details of the study, including information about the purpose of the study, assurance of voluntary participation in the study were explained to these parents. Among the parents who attended the clinic, 9 were recruited but only one declined on account that she is uncomfortable for her voice to be recorded. Out of the 8 parents, 2 could speak English while the remaining 6 could speak 'Twi' (a traditional Ghanaian language) because those were the languages; they were fluent in and could communicate with the researcher.

Purposive sampling technique was used to select the study setting and site as an outlet for the data collection. Purposive sampling which is the careful choice of a participant or study site due to the qualities the participant or site possesses was used to select the study site based on its proximity to the researcher, the services the facility provides (neonatal intensive care) as well as the huge neonatal services the hospital renders as the only tertiary facility serving the regions of the north.

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: Prospective participants were contacted through telephone calls. Relevant information in respect of the study including the purpose, confidentiality, anonymity, benefits, cost were discussed with the prospective participants on phone. Appointment was therefore settled on as soon as the person consented to participate in the study. A day preceding to the agreed appointment date, the participants were prompted through a telephone call from the researcher. Upon arrival, the purpose of the study was re-emphasized, and the participant was given another opportunity to resolve whether to participate or not. Also, approval was sought from the participants to record the interviews after the rationale has been explained to her and the study information sheet given out. Those who agreed to take part in the study were given a consent form (written) to sign or thumb print and were informed that the interview is expected to last for 30 to 40 minutes.

Data analysis: Technique of making sense from research respondent's understanding and verdicts of circumstances which are converted into findings. The actual analysis was done by carefully reading and re-reading through the transcripts to identify to identify the common statements or concepts which were different by assigning codes to them. These codes were sorted into sub-themes based on their similarities. Sub-themes with similar meanings were also grouped into themes. The themes were then revised repeatedly until it was suitable to present the findings according to the objectives of the study.

To ensure trustworthiness which include credibility, transferability, confirmability, and dependability as indicated by Polit and Beck

was adopted. Credibility thus responses of each participant were transcribed verbatim and translated in order maintain the meaning of their narratives. Member checking was carried out by the researcher's supervisor and two participant mothers who delivered received end of life care. Transferability was ensured when researcher asked herself questions such as if the research will necessarily be applicable to other settings and if the same findings will reflect in similar study if conducted in the same settings. To ensure conformability, Literature review was carried out, its purpose however was to help the researcher to make apposite inquiries. An audit trail (which included all forms of data such as interview recordings, raw data and field notes including their date and time and process of obtaining consent form for the interviews) was kept to ensure conformability by others. The supervisor was given the interviews transcripts, field notes and the completed research report to review. Dependability was achieved in this study as the same results will be replicated if the study was to be simulated in similar settings with parents who meet the inclusion criteria.

Ethical consideration: 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.

The themes that emerged from content analysis of the data were "Parents' exclusion from decision making" and "Attitude of Nurses and Healthcare Team". Verbatim quotations were used to back the claims.

Demographics

The study showed that ages of participants ranged 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. 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.

Parents' exclusion from decision making

Exclusion from decision making, anxiety and feeling of guilt emerged as subthemes. Shared decision making about the treatment and care for the child is paramount to parents. Most participants indicated that they were not involved in the decision making concerning the treatment and care of their child at the TTH. This caused great anxiety and sense of guilt of not caring adequately for the child. The following extracts from the interviews corroborates these assertions. Tell me about some decisions you made concerning your baby's care.

Exclusion from decision making

I was not involved. Mostly, when the decision involves money, they informed me. When I want to consult their father, he does not mind me...most decisions were centered on money. I toiled in vain because the baby died. I don't have any hope now because I thought he would live if I was assisted immediately to get money for the necessary things. (Abiba)

They did not involve me in decision making. For instance, I only saw some blue light on the baby but I did not know what it was. Later they said he had jaundice. (Asantewaa)

They used to inform me that they would do this for the baby, go to laboratory, but I don't ask why? Those working on her tell me that we have done this for your baby. So, I don't remember taking decisions. (Akos)

Most parents felt nurses and healthcare professionals only involved them in decision making when it the decision involve money or financial decision.

Anxiety and feeling of guilt

They take their own decisions. It worries me because if I say they inform me of anything before they start it, it is a lie. They finish drawing their plans and after that instead of informing the parent, they do not. When thy finish then they tell you or if it involves money, they say come and give this money. You do not even see their faces.(Iddrisu)

I was not involved in the decisions they took... You don't really see because, parents are not allowed to be present always with their babies. It is not there like that. It was only one day I remember I was called one day to go and buy something and they discussed that it is not quality so I should buy from a different place. They would not inform you of the major decisions. At least there should be mutual respect. Meanwhile, we are also afraid to say 'whe'. For instance, the photo that my baby was under, I was not informed or involved. (Alima)

Most participants were of the view that the healthcare team decides on what to do, then only inform them about it and instruct them on what to do. However, what the participants really wanted was a more engaged conversation to decide together on the treatment and care of the child.

Attitude of nurses and healthcare team

Three sub-themes emerged: 1) professional medical care by nurses and healthcare team, 2) financial and emotional support by nurses and healthcare team, and 3) disrespect and abuse by some nurses. Participants were of the view that nurses and healthcare professionals did their best in caring for the sick child and proving the best medical care and treatment to improve the child's condition. The following excerpts are evidence:

Professional medical treatment

Yes, they [nurses and healthcare team] forced that he may also live but upon all that he could not make it and died. They tried to save his life. (Abiba)

They were doing their best because if they had the gadgets all the other bigger hospitals have, they could do more. When I could not afford to buy a drug, they gave him some. (Amina)

What they have done and I find it satisfying is that they are taking good care of the baby. Yes, since I have been there for some time, they were able to tell from my facial expression whether I am happy or not then they reassure me. They encourage me that I can

overcome. They say they can manage the condition so when you get the good nurses, my sister you will love it. (Alima)

Some nurses and healthcare professionals also provided financial and emotional support to parents.

Emotional support

They used their phones to call me to bring milk and taught me how to position the baby for feeding. They would console me when I cried and tell me. They used to tell me God will do. They encouraged me. Some even gave me food to eat as well. (Amina)

Most of them encourage me. When the breast milk was not coming, there was this woman I will never forget, she would tell me don't worry. She added Madam your baby will live ok, calm down. He will not die. So, whenever I went closer to my baby, I remembered those words and be encouraged. It helped me a lot. (Asantewaa)

Sometimes they help me to feed the baby. They would tap her cheek and all that. I would tell them she does not open the mouth oo. But they were patient with me. As for me, I don't have any problem with them. Even though I don't have money but before evening, I had what I will eat. Some nurses and other parents gave me financial support. (Akos)

Most of the participants appreciated the nurses for trying to console them and inspire hope.

Some are ok. Some will explain things to you that you can overcome the situation. Some also don't sympathize with you. They think you are just breastfeeding. Only two nurses were bold and I am grateful to. It took two people. Before God and man, others don't know the support they gave me. They could explain the baby's condition to me, do other things and even counsel me on the condition of my baby. (Iddrisu)

For me I see it is only one of them who supported me in that sense. She was open, and immediately she comes to work, she picks the baby up and tells me, touch your baby, touch her! That made feel comforted. When she comes and hears that I have cried, she enquires about what caused that. I appreciate that most. (Agnes)

Nevertheless, there were some complaints about the conduct of some nurses. These are depicted below:

Disrespect and abuse

The utterances of some of the caregivers hurt me because it was not my making to be there without money. Some would say because I don't have money to do the necessary things that is why the condition is like this. (Amina)

Collecting of monies; buy this, buy that! There is poor communication. For instance, I was disgraced one day because they did not inform me that visitors are not welcome inside apart from the parents or the caretaker. So, when my pastor came, they sacked him and I was embarrassed. One nurse shouted "Get out! Get out!" They gave me 'crown'. God has ways he speaks to everyone and also protect them and there is some rag that I had prayed on for months before the baby was born which I wanted to tie on the wrist of my child- they said no! and this is not something big so I don't know why. I did not know who is even responsible for my baby. They should let us know the rules there. We are afraid to enter because of the baby's

condition though, they are taking helping us but the way sometimes they talk to us, hmmm. To some extent most of the parents are bitter before they go home. (Iddrisu)

Being here, taking care of the child is something else. Nobody tells you something, be it breathing, whatever, for me I don't know why my child was admitted. Truly, truly other babies are discharged so why not we? When o asked about my baby's condition, it nearly sparked a problem. The communication level is very low. A few will be discussing how your baby looks terrible and it hurts. (Alima)

Some parents expressed the belief that the unprofessional attitude of the healthcare team resulted to a complication in their newborns.

Because of the unsatisfactory nature of the care the care, the baby lost some digits. Whether they were looking for veins and they did not get or whether the child laid in the same position for a long time, I cannot tell. Three of the fingers became black so upon readmission, they decided to take it off. One nurse told me that; you are still alive, your husband is also alive, so if the 'water' pours out of the 'pot', it can be refilled but if the 'pot' breaks, there is no way out. Meaning that if my baby dies it is better and I can give birth again. What she said really brought me down. (Agnes)

Some participants expressed that how they were communicated to was not the best. They needed to know the rules of the unit, who to seek information from and who was particularly responsible for the care of their newborns.

Discussion

Parent's exclusion from decision making

The limited involvement of parents in decision-making decreases their emotional well-being. The results suggest that parents receive very little or no information to participate in decision making about the child during palliative care at the TTH. More so, parents were not involved in decision making about the child, unless it bothered on financial decisions. Parents do not feel part of child's care because they are not involved in decision making about the child's condition and care. This greatly exacerbates parent's anxiety, stress and sense of guilt for caring for the child as much as they would like to [4].

As Howard found, connection with physician may be more important than medical facts. However, parents whose newborns are receiving end of life care at the TTH rather experiences disconnect with the healthcare team and this promotes the feeling of exclusion from the care of the child. To improve the quality of palliative care at the TTH therefore, it is important that healthcare professionals understand and work with parents to design treatment and care that provides "active, and total care of child's body, mind and spirit and also involves giving support to the family" [5-7].

Attitudes of nurses and healthcare team

According to Connor and Bermeo (2014) define palliative care as "active, and total care of child's body, mind and spirit and also involves giving support to the family" (p. 64). The results suggest that palliative care at the TTH only addresses part of the definition—where respondents applaud the effort of the healthcare team to provide excellent treatment of the child. However, the second part

which involves supporting the family through effective and timely communication, emotion and psychological support and shared decision making were lacking at the TTH. This affirms the assertion that parents need emotional and explicit share of responsibility before, during and after palliative care [8-12].

In the particular case of TTH in Ghana, parents are not satisfied with the end of life care services delivered in terms of healthcare professionals' support for the parent and family of the child under treatment, and involvement in decision making and care of the child. This is not different from Streid report that emotional support, awareness of family responsibility, psychological support was relevant to parents. While it was evident that healthcare team provided some support such as buying drugs, giving money and food as well as emotional support to some parents, this is not institutionalized support under end life care at the TTH. Rather, these are random acts of kindness on the part of healthcare professionals in their line of duty. More so, it agrees with the findings of Bergstraesser observation that problems in interacting with staff were commonly reported. These encompassed mainly disrespectful behaviour from the professionals' side and the parents' perception of not being taken seriously and being avoided. Just as in many other African countries, the support needs of parents in palliative care or end of life care of their children are not being met [12-18].

Parent's limited understanding of End-of-Life Care

Palliative care is defined as the "active, total care of the child's body, mind and spirit and also involves giving support to the family of" (Connor & Bermedo, 2014). The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization, n.d.). According to Connor and Bermedo, palliative care is provided at three different levels: i) through a 'palliative care approach' adopted by all healthcare professionals, provided they are educated and skilled through appropriate training ii) 'general palliative care' provided by primary care professionals and those treating patients with life-threatening diseases, with a good basic knowledge of palliative care, and iii) 'specialist palliative care' provided by specialised teams for patients with complex problems [19-22].

Yet, the findings of the study suggest that parents of newborns receiving end of life care at the TTH do not have a good understanding and knowledge of end-of-life care. As a result, parents are not aware of the nature, benefits and what constitutes end of life care for children. This is evident in the several cases where parents were focused on improvement of child's medical condition, and not the total care of the child's body, mind and spirit. Perhaps this limited knowledge and understanding is attributable to the newness of end-of-life care in Africa. According to studies by Mwangi-Powell and Olivia (2011) as well as Downing et al. (2018), a key factor of this lack of parents' understanding of end-of-life care is the relative newness of the palliative care discipline on the continent and the fact that it is not integrated into health systems. Further, Philips and Lazenby (2013) note that end of life care is nascent in Africa, and most

parents are unaware of what end of life care is and the benefits it brings to both parent and child under treatment. To help parents accept palliative care, there is need for extensive education of the general public [23-33].

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 EoLC of their newborns at the NICU of TTH [34-45]. A superior emphasis should be placed on ensuring that all professionals working in the NICU receive some level of EoLC education. In addition, it is imperative that more funding be made available for research and development neonatal PC [46-55]. It is fundamental that well-funded teams are designed to meet the challenges of pediatric EoLC patients and their families' needs, desires, and expectations [56].

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