Experiences and Perceptions of Parents toward Health Care Delivery at Neonatal Intensive Care Unit in Tamale Government Hospitals: A Qualitative Inquiry

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Abstract

Neonatal Intensive Care Unit admission is usually unexpected and can be stressful to the parents causing strenuous psychosocial effects. Parents of infants admitted to the Neonatal Intensive Care Units often reported suffering stress, depression, and feelings of powerlessness. This study explored the experiences of parents on health care delivery at Neonatal Intensive Care Units. A qualitative study was conducted using phenomenology design and data were collected from nine mothers taking care of their infants at the Neonatal Intensive Care Units of two government hospitals in Tamale. Face-to-face indept interviews were conducted employing a semi-structured interview guide. The interviews were audio taped, and thematic analysis was performed to analyse the interview transcripts. Three themes were generated from data analysis and organized in line with the theoretical framework adopted in this study. Although participants are willing to cooperate in the health care delivery system, many of them are not comfortable with the behaviour of some staffs in the facilities. The study found that logistics to render health care was woefully inadequate. Inadequate environmental hygiene, a lack of privacy, inadequate health education, and poor communication between patients and parents have all contributed to some patients' negative health care experiences. Hospital management and concerned bodies should consciously and deliberately take efforts to provide the logistics and structural appropriation to improve health care delivery at the Neonatal Intensive Care Units.

Keywords: Experiences and Perceptions, Health Care Delivery, Neonatal Intensive Care, Parents of Neonates,

Introduction

According to [1], the neonatal phase has been defined as the first 28 days of life, and it stands for the moment when a child's chances of surviving are the lowest. Globally 2.4 million children died in the first month of life in 2020 [2]. Sub-Saharan Africa has the highest neonatal mortality rate in the world (27 deaths per 1000 live births) with 43% of global newborn deaths, followed by central and southern Asia (23 deaths per 1000 livebirths), with 36% of global newborn deaths [3]. Msemo et al., (2013) reported that about four (4) million

deaths of children occur within the first 28days of life each year accounting for 40% of underfive (5) mortalities, and the majority (about 3/4) of these deaths happen during the first week of life [4]. Adding that, a vast majority occurs in south Asia and sub-Saharan Africa. The highest death rate in neonates and infants occurs in Africa, yet there is little data on the experiences of parents during admission for care at health centres [5]. In 2020, neonatal mortality rate for Ghana was 22.9 deaths per 1000 live births. Neonatal mortality rate of Ghana declining at a moderating rate from 26.0 deaths per 1000 live

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births in 2015 to 22.9 deaths per 1000 live births in 2020 [6].

The neonatal period is the critical stage of the life of children. It is the time they adjust physically to the external environment outside the mother's body. In utero, the baby functions from the mother. When a baby leaves the womb, its body systems must begin working on their own. Some neonates have trouble making the transition outside the womb including, preterm birth, a difficult birth leading to severe birth asphyxia, and birth defects. But a lot of special care is available to help new-born babies.

A neonatal intensive care unit (NICU) admission is usually unexpected and can be stressful to the parents causing strenuous psychosocial effects. Parents of infants admitted to the NICU often reported suffering stress, depression, and feelings ofpowerlessness [7]. Rihan et al., 2021 conducted a study in Jordan, which reported that all mothers and fathers expressed feelings such as shock, anxiety, and worry when they were informed about their neonate's admission to the NICU. Parents of infants in the NICU must address multiple challenges including handling their premature babies, dealing with people and medical staff in the NICU, and handling their own relationships [8]. Parents' appetite and sleep patterns were also affected [9]. It is common for parents to have disrupted lifestyles at home due to stressful conditions. Studies found changes such as skipping days at work for the sake of finding peace or having time for visits to the NICU [10]. Additionally, parents' relationships as spouses were affected as mothers felt isolated from their husbands [10]. But generally, parents were supportive of each other [10].

Several studies were conducted to examine the impact of the healthcare team in providing support. Heidari et al., (2017) concluded that offering information to parents and engaging them in decision-making regarding their infant, helped in alleviating the anxiety of most parents [11]. This was supported by Kelleher et al., (2022), who did an interventional study and found that most fathers changed their feelings towards the admission of their neonates to the NICU after the education and the information they received [12]. Additionally, parents' trust in the medical staff has increased when they were provided with knowledge about their baby's condition [13].

By sharing knowledge, participating in care, and combining technical know-how with family-centred nursing care interventions promote the best possible father-infant bonds engagement through create meaningful fathering moments [14]. According to Hynan, (2005) and Johnson, (2008), getting a picture of dad cuddling with his baby is one way to support the parents in creating memories of their stay in the NICU [15]. The first time holding or bathing, the first time feeding or changing diapers, the first interacting smile, or any other memorable occasion can all be considered fathering moments [14, 16]. According to Johnson, (2008), the objectives of nursing care include aggressively removing barricades for the newborn in the NICU, promoting parental competence with practical, effective parenting techniques, encouraging a collaboration in the baby's care.

Parental stress related to NICU admissions is a worldwide health care issue. According to the American academy of paediatrics [17], nearly 5% of all newborns require an intensive care unit to stay and another (15-20%) of all newborns require special services. Admission of babies into the neonatal intensive care unit is displeasing to parents of these babies most often. Parents go through symptoms of stress, anxiety and other post-traumatic experience even after discharge from the unit [11]. Even with a short stay in this unit, parents are bound to experience these symptoms which call for more family support.

From experimental survey conducted, it was observed that, most of neonatal intensive care units in Ghana lack facilities that allow parents

to have continuous contact with their babies on admission [18, 19]. Babies are kept under the supervision of nurses and doctors, without much involvement of parents.

A focus group discussion organized by Torab, et al., (2017) in their qualitative research showed that, most participants acknowledged that babies experience discomfort, and several mentioned signs that babies may exhibit, including crying or facial expressions changed during treatments [20]. Instruments such as heart rate monitors and breathing rate drops can be used to quantify pain. Along with temperature, respiration, pulse, pressure, and pulse, pain is regarded as the fifth vital sign. Since babies cannot express their pain, nurses must be cautious and skilled in managing it. Doctors also stress how important pain is for babies because it can agitate and stress them out.

Most parents see admissions of their babies at the health centres as the most difficult treatment-related decisions they face during illness because of moral, cultural and religious basis. Research from the parent's perspective of the quality of care rendered to children during admission is scarce in the Tamale metropolis. Therefore, this study will be conducted to explore the experiences and perceptions of parents on healthcare delivery at the neonatal intensive care units and provide information in this regard. This information will help nurses to develop interventions that promote family-

centred care and supportive care. Understanding parental needs and experiences will also allow for the development of meaningful family-centred care strategies in the NICU. These strategies are key to improving the outcomes of hospitalized neonates by raising awareness of care pathways, and ensuring clear communication, thus reducing harmful practice variation.

Theoretical Foundation and Conceptual Bases

The study was underpinned by Avedis Donabedian structure, process and outcome (SPO) model to measure and evaluate the quality of healthcare which gives an insight into the factors that accounts for satisfaction or dissatisfaction among clients [21]. Donabedian framework was adapted to assess the influence the structure and process have on the outcome (satisfaction with care at NICU). A modification was made by adding demographic characteristics of parents of babies admitted at NICU. The availability of staff either adequate or not can affect the attitude of staff towards work as well as towards parents of neonates which can lead to a satisfaction dissatisfaction of parents of neonates admitted in NICU. The status of the newborn can determine the satisfaction or dissatisfaction of the parents of the newborn admitted in NICU. The neonate, if responding to treatment will lead to a satisfaction of parents. See figure 1

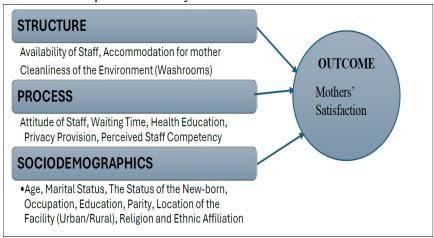


Figure 1. Conceptual Framework Adapted from (Donabedian, 1988) [8]

Method

Study Setting

The setting of this study were the two government hospitals in Tamale Metropolis namely

Northern Regional Hospital and Tamale West Hospital.

Profile of the Northern Regional Hospital

The Northern Regional Hospital occasionally serves as referral points for the communities in Tamale Metropolis. hospital provides quality expertise comprehensive health services as well as technical supervisory support in the clinical services to the sub-district. The Hospital provides Secondary Health care service in the Metropolis. The hospital has a total Bed capacity of 141 and average daily admissions are around 80 while average daily outpatient attendance is between 250 and 300.

Profile of Tamale West Hospital

It was opened in April 1998 as a polyclinic and was upgraded to the status of a district hospital in the same year. It is currently the referral hospital for the Tamale metro subdistrict health centres. It is a 186-bed capacity hospital with eight functional wards and provide 24-hour service that includes OPD, pharmacy, antenatal care, laboratory services, theatre services, ear, nose, and throat care and psychiatry. The Neonatal Intensive Care Unit was built in November 2021.

Study Design

This study is primarily qualitative using phenomenology approach that seeks to explain the experiences and perceptions of parents. It was used to gain an understanding of parents with babies admitted at NICU. This approach was aimed at focusing on commonality (lived experience) of parents with babies admitted at the neonatal intensive care unit to construct the

meaning of events, situation or experience to make a profound conclusion.

Participant Recruitment

The research Participants involved parents or caregivers with babies admitted at NICU in Northern Regional Hospital and Tamale West Hospital. Only parents who consented to take part in the study and only parents with babies admitted for at least 8 hours at the NICU were included in the study. Participants were purposively selected till saturation after the ninth person. Recruitment was carried out alongside data collection, data saturation occurred when the nineth (9th) participant was interviewed, and no newer themes or information emerged.

Purposive sampling allows the researcher to select participants who have experienced the phenomenon and so can provide rich data.

Data Collection Tool and Procedure

The study employed a semi-structured interview guide to collect the data. Semistructured interview guide allowed the researcher to ask flexible questions and probed further to appreciate the experiences shared by the participants on the phenomenon (Creswell & Creswell, 2018). This guide was developed based on literature review and guided by the framework. The interview guide collected data on the biodata, structure of the facilities, process and outcome of health care. Data collection started with collecting information on the demographics of the study participants. This was followed by the main experiences regarding care. An informed consent was given before commencement of interviews which were recorded with a tape recorder and backed with a phone record as well. There were probes where necessary for more clarity.

Data Quality

The data collection was done by only trained research person and that was the researcher. This ensured consistency in the interviewing. The interview guide was pre-tested at a separate

setting different from the study area. This ensured that the questions were eliciting relevant responses. Data was also stored under lock and key.

Ethical Considerations

To guarantee a responsible and ethical study, the researchers gave ethical standards priority

in the qualitative study. Participants gave their informed consent, their privacy and confidentiality were safeguarded, and they were free to decline or withdraw from participation at any moment. Ethical consent was also approved by the University for Development Studies Institute of Research Board with Reference Number UDS/RB/156124.

Data Management and Analysis

The interview recordings were transcribed verbatim. Initial coding was done after reading through each transcript. Repeated readings gave the researcher in-depth understanding, and some codes were modified. These codes were categorized according to similarities and with the framework in mind, into categories and then thematic areas as per the constructs of the Donabedian framework.

Results

Three themes and thirteen subthemes (Table 1) of these parents' experiences and perceptions toward health care delivery at Neonatal Intensive Care Unit were derived from the interviews.

Three core themes were derived and seven sub themes from the study as illustrated below.

Core Themes	Subthemes
Theme: Structure	1. Accommodation
	2. Health Equipment
	3. Ward Hygiene
	4. Qualified Health Staffs
Theme 2: Process	1. Privacy
	2. Healthcare Provider-patient interaction
	3. Waiting time
	4. Health Education
	5. Attitude of staff
	6. Perceived staff competency
	7. Perceived staff knowledge level
	8. Timely health care service delivery
Theme 3: Outcome	1. Satisfaction.

Table 1. Core Themes and Subthemes

Theme 1: Structure

This theme seeks to explain the health care infrastructure of the study settings. It has four subthemes including accommodation, health equipment and logistics, ward hygiene concerns and qualified health staff.

Subtheme 1 Accommodation

Generally, participants' experiences were based on the space of the room, the comfort of the room and proximity to the ward. Participants view it as a central issue in their experiences. Whereas participants' express worries about the closeness of the mothers' resting place and the ward, others were concern about the accommodation space being

inadequate in size. The study settings have accommodation for mothers whose newborns are admitted in NICU.

"There is accommodation for us, but it is not enough, the beds are not closer to our newborns, we sometimes don't hear our newborn cry. Last night, I did not sleep, I became a co-nurse in assisting the night nurses in waking the mothers up to breastfeed their newborn". Participant A, female

"There is accommodation for us, but the room is small, and the number of beds is not enough for the number of admissions. The room is hot. As you can see, I am sweating profusely". participant I, female

Despite the accommodation, participants wished they were much closer to their newborn such as sharing the same bed with their newborn. Being far from them would not only bring insomnia but insecurity as they would be wondering the state of their newborn when they are far apart.

Subtheme 2 Health Equipment and Logistics

Medical equipment or machines as well as medical logistics being it consumables or not should always be available at health facilities. Being an intensive care unit, the health equipment should be in abundance.

However, all participants in the study settings had different experiences about health equipment. All participants complained that there are no consumables in the facilities.

"The hospital consumables are not available at all; common syringes and needles are not available at all". Participant F, female.

All participants have the view that, there are some medical equipment or machines in the ward which aids in health care delivery in the unit. However, most of them do not know their efficacy.

"As for the quality of machines in the ward, hmmmm, apart from the one in which the staff put baby in to warm up baby when they are cold, the rest, I don't think it is of good quality". Participant E, Male.

Some were emotional about the financial burden or extra cost because of lack of medical logistics.

> "The health equipment are not enough for the ward, we buy some consumables, infusions, and medication. We have bought a lot now we don't have money again". Participant I, Female

> "I have been buying injections and other medical consumables. Sometimes it stresses me when am told to buy and I don't have enough money or when it is not available in the nearest pharmacy". Participant E, male.

Inadequate health equipment or machines as well as consumables and non-consumables (logistics) retards health care services to patients. In the long run may lead to death. These health logistics (cotton, syringes and needles of different sizes), emergency medication medications such as Salbutamol; emergency machines such as nebulizers, oxygen cylinder with oxygen in it.

"The most annoying part is one of the newborns was gasping for breath, I called one of the staff to come save the baby's life, when he came into the ward, he just looked at the newborn and said, her mother already wanted the baby dead so leave her. He did not attend to that baby. The following morning, when the morning staff took over, they did their best to save the baby's life, but it was too late". Participant I, female

Subtheme 3 Ward Hygiene Concern

Newborns are susceptible and prone to infections. Exposing them to harmful microorganisms such as Streptococcus aureus, Staphylococcus and *E. coli* among others can lead to diarrhoea in the long run dehydration

and other diseases. The wards and it environ should be cleaned when necessary. A cleaning schedule should be drawn, and cleaners should be up and doing. Committed cleaners should be awarded and dismiss the lazy ones. The hygiene of the ward was viewed by participants as good, better and bad.

"The cleanliness is not good because the cleaners did not come to clean today. See how the place is unkempt. They claim we should remove our sandals before crossing the red line to prevent infection and now the ward and it's environed is not swept thoughtless of mobbing it. So where is the infection prevention?". Participant I, female

Subtheme 4 Qualify Health Staff

Most of the participants said there are qualified health staffs in the facilities. However, participant thought otherwise.

"There are no qualified health staffs in the facilities because they do not exhibit their qualified skills. Being qualified does not necessarily mean administration of medications and other minor invasive procedures but the skills and techniques involve in carrying out nursing procedures". Participant I, female.

Theme 2: Process

This theme seeks to inquire about Perception Level and Quality of Care. Subthemes including privacy, healthcare provider-parent interaction, waiting time, attitude of staff, health education, perceived staff competency, perceived staff knowledge level and timely health care service delivery emerged from the interview.

Subtheme 1 Privacy

It is the ability of an individual or group to seclude themselves or information about themselves. Most participants were of the view that, there is no privacy in the ward. Six out of the nine participants thought so, while the remaining thought otherwise.

"There is no privacy in the ward and the mothers' room at all. Everyone in the ward and room sees what you are doing, sometimes am not comfortable in the mothers' room because of that". Participant F, female.

"... there is no privacy at all. You can easily see the procedures carried out on the next patient and even predict a sign and symptom. For instance, I saw a newborn lying next to mine and some tubes were connected to his nostrils and to a machine. I predicted that, that newborn could not breath and the machine was helping him to do so". Participant D, female.

Interestingly, a participant thought otherwise. "I think there is privacy because no one knows what is wrong with my newborn and I don't know of theirs either." participant H, male

Subtheme 2 Healthcare Provider –patient Interaction

The interaction between health care provider and parents whose newborns were admitted in NICU differ from one another. Most participants said they had good interaction with the healthcare provider while others thought otherwise

"There is effective communication between we and the nurses". Participant A, female.

"There is no effective communication between us". Participant I, female.

"As for the communication, hmmm, some staff don't want to talk to you at all. They only talk to you when they need things like, pampers, or extra white cloth. When I delayed in bringing them, they shout at me and say all sorts of things I don't even understand." Participant D, Female.

"Some of the staff don't care about us. For instance, the night nurses punished us a lot. They did not assist us to attach properly to our newborn to breastfeed. I personally asked for that help, and they refused." Participant C, Female.

Subtheme 3 Attitude of Staff

The attitude of staff especially nurses and midwives, towards the parents whose newborn were admitted in the hospital was relatively warm as narrated by most participants. Interestingly, a participant thought otherwise and was emotional.

Hmmm, madam, the attitude of the health staff is very poor. They don't have time for myself and my newborn at all. ...

My newborn umbilical cord was not cared for and when I reminded one of the morning staff, he told me it was not the duty of the morning staffs, but that of the night staff, meanwhile, the night staff did not do it. When I tried caring for the umbilical cord, I was shouted at and told I was too knowing." participant I, female

"Some staff do not have good attitude towards us. Some of them neglect us and fidget with their phones." Participant D, female.

Subtheme 4 Waiting Time

The waiting time is the duration of time a client spends in the hospital before healthcare is being rendered to them. Most participant thought the waiting thought the waiting period was short while others thought it was long. Interestingly, a participant thought it depends on the individual staff.

"The waiting period depends on the kind of staff you meet. ... the good ones will receive you well whilst the bad ones will neglect you and only start rushing when they realized you are dying." Participant D, female.

"... they attended to us without hesitation." Participant F, female

"The waiting period is very long. It was an emergency case, but we were not treated as such." Participant C, female.

Subtheme 5 Health Education

Generally, participants experience was based on not enough, no education and educated on their newborn ailment. Equal number of participants were of the view that they were educated, and the education was not enough.

"I was educated on my newborn condition." Participant B, female

"There was not enough education given to me about my newborn ailment." Participant A, female.

"I wasn't educated on my newborn's condition, and I actually don't know the reason for the admission." Participant E, male.

Subtheme 6 Perceived Staff Competency

All the participants thought that the health staff are competent enough to deliver health services to their cherished clients, but participant thought otherwise.

"The staff are not competent enough... can you imagine, when they passed the cannula, infusions as well as medications were given, few hours later, the site was swelling but they didn't even notice it. My newborn cried a lot any time that site is being touched. They continued the administration without even bothering at all." Participant I, female

Subtheme 7 Perceived Staff Knowledge Level

Participant were of the view that, the health staff have the requisite knowledge to deliver health services, except participant I.

"They are not knowledgeable and skilful as they are expected to be. ...they do not exhibit their skills." participant I, female

Subtheme 8 Timely Health Care Service Delivery

Few participants were of the view that health care services were rendered on time, while others thought they were delayed.

"...we were attended to immediately we got to the nearest nurse..." Participant E, male

"... health care delivery was not delivered to me on time." Participant I, Female.

Theme 3 Outcome

This theme seeks to inquire about parents' satisfaction or otherwise of health care delivery at neonatal intensive units.

Subtheme 1 Satisfaction/Dissatisfaction

Some expressed how satisfied they are with the health care delivery rendered to them while others lamented with emotions.

> "I am satisfied with how the health staff take care of my child. They are patient and tell me what to do for my newborn and subsequent ones to come not to suffer from rotten umbilical cord again". Participant B, female

> Participant "I" says contrary to that. "I am not satisfied with the health care rendered to my newborn. ...there is no doctor available during weekends. What annoys me is, even emergency cases, there is no doctor available..." Participant I, female

Recommendations of Respondents

According to participant 'A' 'I recommend that, staff should assist in taking of medication for patients and mothers should lye close to their newborn, that is side by side".

According to participant 'D', ''I recommend that the washroom should be washed frequently for instance every 6 hours. As for the attitude of the staff, secret cameras should be placed in every ward and its environment to trap such staff, and they should be punished accordingly

whiles the well-mannered and kind-hearted staff should be awarded accordingly as well. "

According to participant 'I', ''I recommend that, the public should be educated on their rights and responsibilities during the admission of their relatives. By so doing we should know what we are supposed to do and what not to do. This prevents unhealthy quarrels and misunderstanding between health workers and patients or patient relatives.

Discussion

When neonates are admitted in NICU, mothers and care givers do not get in touch with them as often as needed. This has become a new situation for them, and being separated from their neonates reduces their breastfeeding role and relationship. This finding aligns with previous literature where mothers disliked the maternal baby unit policy of only allowing them to visit their newborns at set hours (when neonate needs to be breastfed). This regulation prevented them from having access to their neonates whenever they wished, resulting in a sense of separation and loss of control, which could harm the wellbeing of mothers [22]. However, in contrast to these literatures, in this study, even if mothers were given limited time to visit their babies, none of them complained. The difference might be that mothers trusted the healthcare providers more in this study, or they might have chosen to remain silent for fear of the NICU regulations. Mothers should be allowed to have frequent visits with their babies to increase their relationship with them, and that will contribute to their hope of survival of their

Research shows important benefits of parental involvement in neonatal intensive care. Parents spending time with their newborns and especially their engagement in skin-to-skin contact has positive impacts on cognitive development of neonates and lowers morbidity and mortality rates [21, 23]. To increase the time families, spend with their newborn babies in NICUs, some hospitals such as Norther

Regional Hospital and Tamale West Hospital provide rooms to allow parents to stay with their neonates 24 hours a day. the facilities provided a lounge room for parents but not infant-parent rooms. However, their experiences were based on the space and comfort of the room as well as the proximity to the ward. When the beds are not closer to their newborns, they find it difficult to hear the cry of their newborn.

This study finding indicates that, the environmental hygiene of the study setting is relatively poor, including lack of space for bathing, space for cooking, an inconvenient toilet, and a lack of space for families to rest when they came to visit, especially at night. Following hygiene protocols in hospitals, particularly in the NICU, is recognized as one of the most important means to prevent and control the spread of health care-associated infections. Babies born premature or sick cared for in the NICU are at especially high risk of health

care-associated infections. This study agrees with a study conducted in Ghana, which reveals deficiency of water for toilets and hygiene, insufficient bathroom for mothers to take shower, inadequate space to take rest, and inadequate time to visit their neonates, unsatisfactory hygiene and cleanliness of the ward, improper ventilation, and insufficient comfortable chairs [24]. This is to explain that there is the need to improve upon the hospital and ward hygiene.

Inadequate health equipment and logistics are a major concern to participants as they have reported various experiences during their stay in the facilities for the healthcare of their newborns. This study agrees with previous study in Ethiopia, which discovered inadequate medical supplies for the care of newborns in the NICU, such as medicines being unavailable, reagents not being available, and other medical consumables being inadequate [22].

Attitudes and behaviours of health workers were largely driven by moral judgement of

clients. It follows that some clients who challenged the authority of health workers in this study were labelled as uncooperative or difficult thereby incurring the displeasure of health workers. Participants experienced a variety of emotions including fear, guilt, and anxiety. This study found that parent dissatisfaction of care is because of ill attitude of health workers towards work and parent. This finding agrees with previous studies, which pointed out that improper attitudes of health personnel as people who are in touch with patients impose more pressure on patients [22, 24].

In this study, mothers expressed that healthcare providers are their major source of support and care. This finding is in line with other studies where mothers considered nurses as their major support source and felt more secure when they saw competent and affectionate care for their newborns provided by health workers. Moreover, the nurses support the family by reassuring them that they would be updated with any changes in the infant's condition and strengthening maternal responses to their infants [22]. This suggests that the care and support provided by health care providers to mothers would be beneficial in allowing mothers to discuss their shared experience. So that health care provider support should be encouraged and maintained.

Conclusion

The study concluded that inadequate environmental hygiene, and poor communication between patients and parents have all contributed to some patients' negative ward experiences. Nonetheless, the study found that most parents can cope with medical staff well enough because their newborns are ill.

Recommendation

The construction of a pharmacy and laboratory department, as well as their refurbishment with the required medications and equipment in all NICU departments, should

be of great interest to the Ghana Health Service, NGOs, and Stakeholders.

Health facilities should undergo routine inspections, and meritorious employees should get recognition.

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Conflicts of Interest

The authors declare no competing/conflicts of interests.

Informed Consent

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