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# Caregivers' experiences on preterm infants' management in a tertiary care facility in Ghana: a qualitative exploratory study

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**Background** Preterm birth is a process that fundamentally alters parental or caregiver roles, particularly in the early weeks of childbirth. Caregiver experiences can be distressing due to struggles with an unfamiliar and potentially threatening environment of the Neonatal Intensive Care Unit (NICU). These experiences can affect the development of parenting or caregiving roles to a greater extent. Supporting caregivers of preterm infants through education and information sharing can significantly improve neonatal outcomes. This study sought to explore the experiences of caregivers with hospitalized preterm infants regarding the education and information they received from healthcare workers on the care of preterm infants.

**Method** An exploratory descriptive qualitative study that explored caregivers' experiences with the management of preterm infants hospitalized at the Level III Neonatal Intensive Care Unit (NICU) of a tertiary level facility with an annual delivery of almost 7500 and a bed capacity of 26. The study utilized a deductive approach and a purposive sampling technique to recruit 16 caregivers who participated in an in-depth interview using a piloted semi-structured interview guide. The interviews were audio-recorded, transcribed, and analyzed using thematic analysis.

**Findings** The study identified three major themes, which were (1) preterm infant feeding and keeping infants warm, (2) routine procedures and activities at the NICU, and (3) preparation towards homecare after discharge. Seven (7) sub-themes were generated. Caregivers were satisfied with the education and information they received on infant feeding and keeping the infant ward. They also had adequate education that prepared them for home care of the preterm infant. Caregivers did not receive timely information and education on the health status of their infants and the care processes of the NICU. They felt they were left out as they were not involved in decision-making. Regarding the care of the preterm infant. The inadequate flow of information and use of medical terminologies were a great source of worry and frustration for participants. The study showed that although the NICU staff were willing to offer health education to caregivers, information giving and education were not structured and hence did not address all the needs of the caregivers.

**Conclusion** Healthcare providers caring for preterm infants include caregiver education in their routine NICU activities and procedures. These processes start from the period of admission till discharge. Their education sessions primarily focus on breastfeeding, keeping the infant warm and adequate preparation of caregivers for preterm infant home care. This notwithstanding there are gaps in caregiver education and information on routine procedures in

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the NICU as well as information on the health needs of the infant. Participants are not fully involved in the decision-making processes and the use of medical terminologies compound caregivers' frustrations and anxieties. It is important to develop structured educational programs tailored to address the information needs faced by caregivers to ensure optimal health outcomes for their preterm infants.

**Keywords** Caregivers, Education, Healthcare workers, Hospitalization, Infants, needs, preterm

## Introduction

Preterm birth is a major public health problem due to its medical, economic, and social impact. Although there have been great strides to increase preterm survival rates globally, the rate of survival remains minimal in Low- and Middle-Income Countries (LMICs) [1–4]. The challenges associated with preterm births are multifaceted. At the individual level, the condition is associated with long-term physical, and neurodevelopmental challenges in early life and may extend throughout the life course [2, 5, 6]. At the health system level, preterm births result in significant costs to health systems with the total cost for providing initial hospital care in Ghana being GH\$212,776.96 (\$35,462.83) [7]. Similarly, at the family level, preterm births have significant socioeconomic consequences for the affected families as well since caregivers experience considerable psychological and financial hardships. These processes fundamentally alter maternal, parental, or caregiver roles, particularly in the early weeks of childbirth [8, 9].

Ghana like other Sub-Saharan African countries has a high neonatal mortality rate of 23 per 1000 LBs which is unacceptably high [1–4] even though the country has developed, disseminated and implemented the National Newborn Health Strategy and Action Plan [7]. The action plan outlines strategies for preventing neonatal deaths by increasing access to quality neonatal care and a healthy start for neonates. Unfortunately, the Ghanaian health system is challenged with inadequate health infrastructure required for the care of preterm infants [7] since there are limited number of Standard Neonatal Care Units (SNCUs) and Neonatal Intensive Care Units (NICU) in the country. There is also an inadequate number of neonatologists, paediatricians and specialist paediatric nurses who have the needed skills, knowledge and competencies to provide specialist care and services to preterm infants. However, health professionals such as doctors and nurses have been trained in basic skills in managing preterm infants at all levels in the healthcare delivery system with the limited resources available to them [7].

Furthermore, studies performed in Ghana have shown that neonatal care and survival interventions are directed at meeting the physiological and health needs of the neonates with little attention to the caregivers. This situation is of great concern as it has been reported that preterm infant caregiver experiences can be distressing due to

struggles with an unfamiliar and potentially threatening NICU environment, which affects the development of parenting or caregiving roles to a greater extent [10]. According to Govindaswamy et al., (2019), the most important need of caregivers of hospitalized preterm infants is timely and appropriate information and education. Hence optimum support from healthcare personnel in the NICU can address these challenges significantly [8, 11–13].

The negative experiences of caregivers are compounded by the lack of information and education on the processes at the units and the health needs of their infants [14, 15]. There are efforts to help caregivers of preterm infants in Ghana; nonetheless, these support services provided are insufficient in meeting caregivers' needs, furthermore, the forms of education they are given are mostly inadequate [14, 15].

Secondly, studies that involved caregiver education have mostly been performed in heterogeneous populations where there is extensive social security and unique healthcare systems that are different from the Ghanaian context. This paper therefore focuses on the experiences of caregivers with hospitalised preterm infants regarding the education and information they received from the healthcare providers to optimize the survival of their preterm infants.

## Methods

### Research design

The study used an Exploratory Descriptive Qualitative Design (EQD) to explore the experiences of caregivers through face-to-face in-depth interviews. Caregivers' educational needs during their infant's hospitalization at the NICU were studied using EQD above design to enable us to describe what the phenomenon entails in the Greater Accra Regional Hospital.

### The study setting

The study was conducted in the Neonatal Intensive Care Unit (NICU) of the Greater Accra Regional Hospital. This study setting was chosen for the study because the hospital is situated in the heart of the city of Accra, and caters for individuals from various backgrounds and diverse locations. The facility also serves as a referral centre for many maternal and child cases coming from the various districts within the region and beyond. Total deliveries recorded in 2022 and 2023 were 7504 and 7151

respectively. The NICU at the Greater Accra Regional Hospital is classified as a level III intensive care unit and hence manages newborns and preterm infants requiring regular nursery care, intensive care, and comprehensive care for seriously ill infants. The unit has a bed capacity of 26 with an average daily in-patient rate of 26 neonates. About 75–100 neonates are admitted to the unit per month. The unit is managed by one neonatologist (supported by house officers) two paediatric specialists and 23 registered nurses giving a permanent staff strength of 26. The nurses in the unit run a double shift system (Day and night duties) with an average nurse-patient ratio of 1:8 for each shift. Families are occasionally involved in the care of their sick infants through scheduled visitations.

### Study population and recruitment

Caregivers whose infants were born before the 37 weeks of gestation and hospitalized at the NICU of the Greater Accra Regional Hospital for one week and beyond were recruited into this study. We operationalized caregivers in this study as biological parents, grandparents, and any significant other whose infant was hospitalized in the NICU during the study period. Mothers who suffered major complications of pregnancy and were not strong physically and emotionally stable were excluded from the study.

### Participant recruitment, sample size technique, and sampling

The study employed a homogenous purposive sampling technique where the researcher used personal judgment in choosing the cases that answered a set of research questions to achieve the stated objectives [16]. The purposive sampling also involved the selection of study participants with unique characteristics such as knowledge and experiences built over time. In this study, the unique characteristic is having a preterm infant being hospitalized in the NICU. Caregivers with the above-stated unique experience were approached as they came to either breastfeed or see their preterm infants. The study aims, and procedures were discussed with them and those who showed interest in participating in the study were recruited after they consented and signed the written informed consent form. The sample size was determined by data saturation. According to Boddy [18], sample size determination in the interpretivism paradigm does not deal with larger samples compared to positivism but rather an in-depth inquiry into the phenomenon under study. After interviewing the 16th participant, we realised that the information obtained from subsequent interviews was just like what had already been provided by the participants interviewed earlier. Therefore, we were not able to obtain or identify any new themes hence

data saturation was attained, and we ended the interviews on the 16th participant.

### Data collection instrument

We developed a semi-structured interview guide purposely for this study. The data collection tool comprised four separate sections, namely, the background information of the participants, questions on feeding and warmth for the infant (2) routine procedures at the NICU (3) home care of the preterm infant, and (4) danger signs. The questions were open-ended to accommodate probing to get in-depth information from the participants. The tool was subjected to validity procedures with expert review followed by piloting on two caregivers whose preterm infants were hospitalized in another secondary-level health facility in the Greater Accra Region.

### Data collection procedure and techniques

The research was conducted according to the institutional ethical guidelines of Ghana Health Service and the standard ethical practices for conducting research. Approval was sought from the medical director as well as the nurse manager of the institution. The research team had an introduction and a short orientation to the NICU which made it possible for the researchers to become familiar with the unit, staff, and caregivers whose infants were hospitalized. Potential participants were all given information on the overall aim of the study and the procedures involved before and during data collection. Concerns by participants were addressed to their satisfaction, and those who expressed interest in the study were given written consent forms to sign as evidence of willingness to freely. Participants were recruited sequentially, and the interviews followed the same pattern until the 16th participant was interviewed. All the interviews were conducted by the Principal Investigator however trained research assistants took field notes and did the audio recordings during the interview sessions.

The interaction with the participants was done through in-depth interviews using open-ended questions. Non-verbal cues, gestures, and observations were noted and written in the field notes book. All interviews were recorded using an audio tape recorder. Each interview session lasted for 40–45 min.

### Ethics approval and consent to participation

Ethical clearance was obtained from the Institutional Review Board of the Ghanaian Health Service with the number GHS-ERC:028/02/23. An introductory letter from the principal investigator's institution was sent to the study site for authorization to undertake the study. The purpose of the study was explained to the participants, and their **informed consent** was sought through administering consent forms for them to sign. The

Nurse-In-charge permitted the use of the nurses' office for the in-depth interviews and this made it possible for privacy to be ensured during all the interview sessions. The audio recorder used to capture the information was only accessible to the study team. All identifiable information, including audiotapes and field notes kept under lock and key to ensure confidentiality.

### Methodological rigor

This study aligned with Guba and Lincoln's (1986) principles of trustworthiness in research [17]. To ensure credibility, we built trust with all our study participants right from the recruitment phase and this paved the way for successful interactions for in-depth information to be obtained. A comprehensive field note was taken, and member checking was performed on every participant to ensure that the data were not mixed. Dependability, as described by Polit and Beck et al. (2017), is the "stability of data over time and conditions" [18]. In this study, an audit trail of events and procedures was kept. To ensure credibility, we carefully reported all the methodological processes that the research went through to allow for replication by other researchers. Confirmability was ensured such that the meanings of the data collected were not altered by prejudicial means, knowledge, and experiences of the researcher [17]. This was ensured by immediately transcribing interviews to avoid mixing of data.

### Data analysis

Data collection and analysis were performed concurrently. The audio recordings were played and listened to carefully by the research team and played to the interviewee to reaffirm what was said or captured. Audios were transcribed, and the researcher then used thematic analysis to analyze the data. Thematic analysis is the

process whereby patterns (themes) within the data are organized, analyzed, and described in detail [19]. During this process, each aspect of the data, including words, phrases, statements, and sentences made by the participants that depicted education or teaching, was analyzed. Using the Braun, & Clarke, (2006) principle of thematic analysis, the transcripts were read over and over. Transcript familiarization elicited similar and contrasting ideas and thoughts that were combined to develop themes and categories. Field notes were used to support the themes, as for the categories they were coded and sub-categories assigned. The authors confirms that all data generated or analysed during this study are included in this article.

## Results/Findings

### Sociodemographic characteristics of participants

Sixteen (16) caregivers whose infants were hospitalized at the NICU participated in this study. All participants were Ghanaians who lived in Accra; three (3) biological fathers and thirteen (13) biological mothers participated in the study. Out of this number, thirteen (13) were Christians and three (3) Muslims. For the mode of deliveries, ten (10) were by caesarean section and six (6) spontaneous vaginal deliveries. Ten (10) infants were males, and nine (9) were females, including three (3) sets of twins. Details of the demographic data of the participants are presented in Table 1.

**Themes and Sub-Themes** Based on the responses of caregivers, three themes were identified. These areas included feeding and ensuring warmth for their infants, information and education on the routine activities at the NICU and education to prepare them for the care of the infant after discharge. Seven sub-themes were identified from the main themes (Table 2). The themes are

**Table 1** Sociodemographic characteristics of participants

Age of Participant	Relationship with Infant	Employment status	Duration of Hospitalization	Gestation
37	Mother	Employed	14 days	30 weeks
34	Father	Employed	7 days	34 weeks
26	Mother	Employed	7 days	29 weeks
29	Mother	Unemployed	21 days	30 weeks
33	Mother	Employed	8 days	30 weeks
30	Mother	Employed	7 days	32 weeks
33	Father	Employed	9 days	34 weeks
33	Father	Employed	7 days	32 weeks
30	Mother	Employed	5 days	32 weeks
28	Mother	Employed	10 days	34 weeks
32	Mother	Employed	7 days	32 weeks
37	Mother	Employed	28 days	25 weeks
35	Mother	Employed	7 days	32 weeks
39	Mother	Employed	9 days	32 weeks
30	Mother	Employed	20 days	30 weeks
38	Mother	Employed	11 days	31 weeks

**Table 2** Theme and subthemes

THEMES	SUBTHEMES
a. Preterm infant feeding and keeping the infant warm	<b>1. Education on breastfeeding:</b> <ul style="list-style-type: none"> <li>• breastmilk expression and cup feeding,</li> <li>• Positioning of caregiver and infant during feeding</li> <li>• Benefits of breastmilk</li> </ul> <b>2. Education on Keeping the infant warm</b>
b. Routine procedures and activities at the NICU	<b>3 Education on NICU ward rounds</b> <ul style="list-style-type: none"> <li>• Type of routine NICU activities</li> <li>• Purpose of ward rounds</li> <li>• Health providers involved in ward rounds and their roles</li> </ul> <b>4. Education on infants' state of health needs, and medical care</b>
c. Preparation towards care of the infant at home after discharge	<b>5. Education on infants' health needs</b> <ul style="list-style-type: none"> <li>• Hygiene, thermoregulation, feeding and elimination needs</li> </ul> <b>6. Education on danger signs and follow-up visits</b>
	<b>7. Evaluation of caregiver skills and competencies</b> <ul style="list-style-type: none"> <li>• Observation of caregiver in performing preterm infant care</li> </ul>

supported by verbatim quotations from participants, to ensure anonymity numbers were assigned to each participant.

#### Preterm infant feeding and keeping the infant warm

Preterm infant feeding and keeping the infant warm generated two subthemes which include education on breastmilk expression, positioning and benefits, and education on keeping the infant warm.

#### **Education on breastfeeding: breastmilk expression, positioning during feeding and benefits of breastmilk**

Most of the participants narrated how the healthcare workers taught them how to breastfeed their infants and cup-feeding. For some mothers, it was about the position of the baby and good posture during breastfeeding to avoid back pain. Another participant who was a first-time mother of a preterm infant in an incubator narrated how she was taught mechanical breastmilk expression by breast massage.

*"When you start breastfeeding, they educate you on how to sit well and position the baby to suck so that the baby will be well latched on the breast. The nurses told me to rest my back on the chair to avoid back pains. They also taught me to part the baby's back to remove air"* P1.

*"They also told us that the breastmilk will help the baby to be strong and healthy so when I enter, I do my best to get breastmilk for my baby."* P15.

*"The nurses taught me how to express, so the first day, one nurse said the baby has to start eating so she wanted me to express breastmilk. Even if it's little I should try. Therefore, she taught me how to mechanically express breastmilk by massaging the breast. She showed me a room for expression, told me to wash my hands and take the sterilized bottle prepared for that purpose."* P3.

#### **Education on keeping the infants warm**

Participants gave experiences about the education received on keeping their infants warm and the benefits that made it easy for them to comply. According to participants, the education and information received were beneficial as they were empowered and gained confidence in their ability to care for the newborn at home. A 29-year-old hairdresser with a 1.4 kg infant expressed how the education assisted her in bonding with the infant.

*"I have received help from all the health workers here. They told me that the baby is now learning to adapt to the environment and that the baby can become too cold and lose body heat. The nurse said I need to take charge of that temperature control task until the baby is grown to do that. It is all about covering up very well when we are discharged finally. One of the nurses even helped to teach me how to tie the Kangaroo Mother Care (KMC) cloth when I put my baby on my chest"* P10.

*"When we were moved to that ward, a nurse, and a doctor helped me to position my baby and tie him on my chest. They taught me that if I do it, it will help my baby to keep warm and protect him from infection, it will also help me to be able to breastfeed well"* P9.

*"They taught us that when the babies are preterm, sometimes the preterm infants may have breathing difficulties. Therefore, when the baby is tied like that in front of you when you breathe then, the baby also responds. They also said that the KMC prevents infection because there is less touching of the baby by different individuals. It also makes them feel warm like he is in your womb. They told us that the KMC creates that bond between the mother and child. Because the baby now recognizes her mother's body*

*smell and makes them recognize that we are their mothers". P4.*

#### **Routine procedures and activities at the NICU**

Two subthemes were also derived from this section. This includes education on NICU ward rounds and education on the infant's state of health, needs and overall medical care.

#### **Education on NICU ward rounds, the purpose of the rounds and health providers involved in the ward rounds**

One of the routine activities in NICU is doctors' and nurses' rounds. During these rounds, doctors and nurses review and discuss the preterm infants' progress and plan for daily and weekly care. Sometimes multi-professional rounds inclusive of dietitians, therapists, and pharmacists are done.

For the participants, the multi-professional rounds were unusual and new which resulted in anxiety and fear as they thought their infants were in distress. For example, a 33-year-old first-time father said he had never experienced this, and since the infant was not in a stable condition, he got frightened at the sight of many health workers around the baby. The nurses subsequently explained what the rounds meant to the caregivers, to allay anxiety. However, according to the narratives of the participants, the information regarding the multi-professional ward rounds was not timely.

*"The other day when we came, the nurse, and the doctors were all over and around my baby. In addition, when we got there, I got so worried because they were busily working on him. All of them were going to and fro and I didn't get anybody to ask what was going on, initially because they were busy. so, I got very worried.P4.*

*"This scene truly scared me because I thought something had happened to the baby so I looked at my wife and she was very heartbroken, anxious and you could see it in her eyes. Then the nurses called us and sat my wife and me down. They spoke to us at length, then we understood all that they were doing".P2.*

*"The information I got from the interaction with the nurses was that it was nothing to be afraid of and that the specialist and the entire care team were discussing the care of the baby and doing a routine checkup on him. I wouldn't be that scared if I knew that's what happens here".P8.*

One participant lamented and expressed her dissatisfaction openly about her not being adequately educated on ward rounds and then not being part of decisions that were taken regarding her preterm infant.

*"The doctors also take care of him[baby], but I don't know what they do for him. When they come around, we are not allowed in so we don't know what happens. As soon as they come to do their rounds, they will tell you to go out when they finish you can come. After the rounds when I enter and ask them, all they say is they have seen him and made decisions regarding the care of my baby and if there is a prescription they give it to me.*

*They didn't tell me all that they discussed about my baby during the ward rounds. I realized they spent a lot of time there, but they did not go into detail about what was done and said about my baby. They only said that they would continue with the current treatment". P9.*

#### **Education on infants' state of health, needs, and medical care**

The health needs of preterm infants admitted to the NICU vary and include temperature instability, feeding difficulties, low blood sugar, infections, and breathing difficulties. The care of these vulnerable individuals is complex, and each infant requires specific care to meet his or her individual needs. The participants said they were eager to learn and understand their infant's specific health needs and the overall care rendered. However, some of the caregivers expressed their frustrations and lamented about the inadequate flow of communication at the NICU. They reflected that they did not receive timely information regarding changes in their infants' state of health, and that made them very uncomfortable. Few of the participants had this to share.

*"Because this is the NICU and she is in the incubator, I most of the time want to know if she has been taken off the oxygen and how the breathing is and then the level of the jaundice".P2.*

*"I only observed that she was removed from the incubator, I was not told the improvement or gains that were made but I just knew maybe she got better. The nurse did not explain to me what happened and what next would be done for my baby".P5.*

*I observed in the later part of the day that her eyes were yellowish. Then when I went in again, she was put under the machine. I was extremely worried, but I was waiting for answers from them, and they still did not tell me anything. So, this afternoon I asked the nurse what was wrong with my baby, and she said, they knew what that was and they were working on it. She also said they were progressing very well". P2.*

The participants also admitted that they had difficulty getting information from the right people as the medical

terminologies used by the healthcare providers did not give them a better understanding of their infants' condition.

*"My son was suffering from jaundice, and it was an extreme case and for a layman and a teacher, when it comes to the technical and medical issues, I don't get it just like that. The health workers used their medical terminologies and technical words that made it very difficult for me to comprehend."*P3.

Some of the caregivers also gave an account of how the nurses gave them an explanation of some specific processes involved in the care of their infants. The healthcare workers described the procedure for taking the infant off oxygen and explained the use of the gadgets and equipment used on their infants.

*"So, what they told me was that they take her off the oxygen for some time and monitor her and put it back to see if she can breathe without it. However, I was told that her respiration is irregular but apart from that she is doing well."* P11.

*"I didn't understand why monitors were being plugged on my baby. But the nurse explained to me that this is for monitoring the heartbeat, this is for monitoring the temperature, and this cage is keeping the baby warm, and so forth."* P3.

#### **Preparation towards care of the infant at home after discharge**

In this study, participants revealed that they were adequately prepared for discharge, and that helped them to build confidence in caring for their preterm infants at home after discharge. For some of the caregivers, the education started right from the day their infants were admitted and for some others, it started when the healthcare providers noticed improvement in the condition of their infants. Three subthemes emerged from the above theme, and these include (1) education on medication and general care at home, (2) education on danger signs and (3) assessment of caregivers' competencies.

#### **Education on infants health, hygiene, thermoregulation, feeding and elimination needs**

The healthcare workers offered education to the caregivers throughout hospitalization. The education encompasses baby hygiene, administration of medications, and ensuring warmth and feeding. The NICU staff also emphasized the prevention of infection. Before their discharge, a father described how he and his wife were prepared to be able to care for their infant at home. A participant expressed his satisfaction with how the

teaching was done with the main goal of helping him build confidence and have high self-efficacy towards the care of the baby at home. Below are narratives shared by some of the participants.

*"The NICU staff started educating my wife and I since the very day they noticed an improvement in the baby's condition. They taught us how to take care of the baby, and how to handle him in terms of giving drugs and cleaning him up. I believe I can do all that they said."*P10.

*"The education on feeding and keeping the baby warm started right from the second day. The nurse also taught me how to give the medications at home. She said we will be discharged tomorrow. She said I should wash my hands very well before I feed the baby and before I give the medication"*P12.

*The way she talked about it over and over, I think these are all important. I am committed to going by her advice. I can take care of the baby, now I know, even though the baby is very small"* P4.

#### **Education on danger signs and follow-up visits**

Early recognition of the danger signs in preterm infants facilitates early and positive care-seeking by caregivers. The danger signs in preterm infants could indicate a severe disease or a local infection. These signs include refusal of feeds, convulsions, fast breathing, fever, low body temperature, severe chest in-drawing, and movement only when stimulated or no movement at all. In this study, caregivers were given education on the danger signs to expect and when to report to the facility. Many of the caregivers had an idea of how the infant would behave if unwell. A few participants who were discharged emphasized how their confidence had been built through the education they acquired at the NICU. Some participants narrated the following.

*"They taught us how to study them for danger signs and to report early when something like that happens. We were also told that we have to become used to the care of our infant so that when we get home, we will be able to care for them."* P4.

*"The nurses came around and talked to us during breastfeeding. They told us about any danger signs we should expect when we go home and that we should report quickly to the nearest clinic."* P1.

*"Right from the day we came here, the staff have been teaching us how to identify that the baby is unwell and in danger. The nurse said they are danger signs that we should be looking out for at home and report to the hospital the moment we see even one of these signs"*P5.

*"They also told us about the need to bring the baby back when we see those signs. My baby was very well taken care of, aww they did very well". P13.*

#### **Evaluation of caregiver skills and competencies**

At the time of discharge, caregivers should independently and confidently care for their infant; provide medications, nutritional supplements, and any special medical care; recognize signs and symptoms of illness and respond appropriately, especially in emergencies; and understand the importance of infection control measures and a clean environment. In this study, the caregivers narrated the type of assessment they underwent regarding the level of competence on the aforementioned topics before they were discharged. According to them, the healthcare workers ensured that the caregivers were competent to care for the preterm infant before discharge from the NICU. This was done by observing the mother's capabilities during infant feeding and KMC sessions. To determine the effectiveness of the education and the information caregivers received, they were evaluated through a series of questions.

*"Therefore, in that ward, the nurses and doctors monitor the baby and also observe the mother to be sure that she can take care of the baby if they are discharged". P 4.*

*The nurses told us that whatever they have taught us to do are the things we are to do. We should not do it anyhow. After the teaching, they then ask us to repeat what they said to know whether we are capable of handling them when we go home. P9.*

#### **Discussion**

This present study involved caregivers with preterm infants who were hospitalized for various health issues at the NICU of the Greater Accra Regional Hospital. The study explored the experiences of the caregivers regarding the education and information they received from healthcare providers on caring for their preterm infants.

There has been a slight increase in the survival rate of preterm infants globally, especially in developed countries, despite this strive, there is still the possibility of the development of morbidities in preterm infants necessitating intensive care admissions and treatment [20]. Apart from medical interventions that promote the survival of preterm infants in the NICU, education, and provision of information to caregivers and the entire family of the preterm infant have shown positive results. For example, there is evidence that the implementation of education and information-giving strategies for caregivers has advantages including reduced hospitalization

time, reduced costs of care, reduced hospital readmissions, and most importantly a significant reduction in the demand for 24-hour emergency care units [20].

#### **Preterm infant feeding and keeping the infant warm**

In this study, caregivers acknowledged the educational guidance provided by the healthcare workers regarding preterm infant feeding practices. Additionally, the teachings on breastfeeding and its components, adept identification of infant feeding cues, and the fulfilment of their infants' nutritional requirements were regarded as immense support from healthcare workers. This finding is consistent with studies that outlined essential premature infant feeding components and educational packages that meet the needs of the mother [15, 21, 22]. According to researchers, caregiver education on infant feeding enhances parental empowerment, which helps them actively participate in their infants' care resulting in better health outcomes for preterm infants [23].

The caregivers in this study were satisfied with the education they had on how to keep their preterm infants warm. This finding falls in line with what was reported by Apedani et al. and Negarandeh et al. [24, 25]. It was, also found that caregivers with stable infants who were transitioning from the ICU were allowed to perform skin-to-skin care thereby promoting bonding. This finding corroborates the study by Vizzari et al., [28] conducted in an Italian NICU, where the healthcare workers allowed skin-to-skin contact when infants were clinically stable [26]. The best neonatal outcomes are achieved when skin-to-skin contact also known as Kangaroo Mother Care (KMC) is practised well, as the benefits include prevention of infection because of limited handling, increased breastfeeding, and improved maternal role identity [27].

#### **Routine procedures and activities at the NICU**

Our study also found that the caregivers were eager to receive information and understand their infant's specific health needs as well as the overall care processes, and the actions taken to address the needs of the preterm infants. However, they did not receive timely education and information regarding changes in their infants' state of health and the actions taken to ensure the survival of the preterm infants. There was inadequate flow of information and the medical terms and unfamiliar medical language used by healthcare providers made caregivers frustrated. In another related study, half of the study participants were dissatisfied with the information they received regarding the health state and care of their preterm infants [28]. This finding aligns with observations that healthcare workers in the NICU have interactions and communication challenges with caregivers of preterm infants [29].



The purpose of communication between staff and caregivers in the NICU is to share information with caregivers about the infant's health state, treatment, and involvement in decision-making regarding the care of their infants. In this study however, the participants felt that they were not adequately educated on some of the procedures and routines of the NICU. For example, the caregivers were not familiar with ward rounds which are undertaken on daily basis, caregivers also felt left out in decision-making involving their infants. This finding is similar to that of Caldwell et al. [30–34] who found that caregivers recognize the value of ward rounds and therefore should be involved. Including them in this routine fosters a strong relationship between the caregiver and child as well as with the healthcare team. Caregivers feel comfortable speaking directly to the healthcare team about their concerns as this allows them to ask for clarifications.

#### **Preparation towards care of the infant at home, after discharge**

Caregivers who participated in this study attested to being satisfied with the education they had received before the discharge of their infants. According to the participants, the education gave them confidence in their ability to care for the preterm infant and this finding resonates with that of Shillington et al. [33] who emphasized the importance of caregiver preparation before discharge of the infant from the hospital to the home environment. Griffith et al. [34] described support for parents and families post-NICU discharge as important in providing education related to infant care and overall health. Our findings on the need for information and education to caregivers before going home are similar to other studies where mothers who received educational guidance exhibited contentment and satisfaction. This educational guidance encompassed topics such as infant home care, administration of medications, KMC practices, and breastfeeding [21, 24]. A successful transition from the NICU to the home environment is elemental for the long-term health and well-being of the preterm infant. Caregivers educated on their infants' care are knowledgeable about the infants's needs. Caregivers are usually emotionally distressed about taking care of the infant at home due to fear of the infant not surviving [30]. Through information and education fatalities that might have occurred at home are alleviated [25, 33].

#### **Study limitations**

The design of this study did not permit for the assessment of the educational programmes available hence conclusions were based on self-report only. Data from other sources would have allowed for triangulation to enhance

the validity of the findings. This study was performed in a single facility hence findings cannot be generalized.

#### **Conclusion**

The significance of caregiver education on preterm infant care cannot be overstated. Empowering caregivers through education and information on practical skills will enhance infant health outcomes and strengthen the bond between caregivers and their infant and health care providers. Therefore, health professionals should welcome caregivers and the family and provide conditions for active participation in the care of the infant. In the Ghanaian context, it is imperative to develop and implement tailored educational programs that address the challenges faced by caregivers. In doing so, there is the creation of a more supportive environment that leads to improved survival rates and overall preterm health outcomes.

Based on the findings of our study we recommend the adoption of the family-centered care concept which is becoming a model for providing care in the NICU, and this model should be well embraced to provide the needed support for caregivers and families.

#### **Implications for practice**

The study findings indicate that the healthcare workers in the NICU possess a positive attitude towards parent teaching and education. Nevertheless, there is a need for a well-coordinated and tailored approach to meet the specific needs of caregivers. Additionally, healthcare workers must engage in open and timely communication with caregivers, which plays a pivotal role in providing support across the continuum of care.

#### **Abbreviations**

NICU	Neonatal Intensive Care Unit
EQR	Exploratory Qualitative Design
KMC	Kangaroo Mother Care

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#### **Author contributions**

B.M; Conceptualization, Methodology, Data collection, Data Analysis. Writing, Original draft, preparation of manuscript. S-D V. E; Methodology, Supervision, Writing, Original draft preparation of manuscript. O.L. A; Methodology, Supervision, Writing, Original draft preparation of manuscript. A, D; Writing, original draft preparation of manuscript.

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#### **Data availability**

The authors confirm that all data generated or analysed during this study are included in this article.

## Declarations

### Ethics approval and consent to participate

Ethical clearance was obtained from the Institutional Review Board of the Ghana Health Service with the number GHS-ERC:028/02/23. An introductory letter from the principal investigator's institution was sent to the study site for authorization to undertake the study. The purpose of the study was explained to the participants, and their informed consent was sought through administering and signing of consent forms. All the participants in this study were adults above age 18 and therefore consent to participate was not sought from parents or legal guardians as would have been the case for participants who are minors. Privacy was ensured during the interview sessions. The audio recorder was used to capture the information and was only accessible to the study team. All identifiable information, audiotapes and field notes were kept under lock and key to ensure confidentiality.

### Consent for publication

Not Applicable.

### Competing interests

The authors declare no competing interests.

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