Original Research Article

FAMILY CENTERED CARE: THE PERSPECTIVE OF NURSES IN THE NEONATAL INTENSIVE CARE UNIT OF TAMALE TEACHING HOSPITAL

Comment [AH1]: I preferred this topic to be changed like this: FAMILY CENTERED CARE: THE PERSPECTIVE OF NURSES IN THE INTENSIVE CARE UNIT OF TAMALE TEACHING HOSPITAL, GHANA- A qualitative exploration

ABSTRACT

Background: Family-Centred Care is a care approach in which healthcare professionals collaborate with the patient's family to plan and make decisions regarding the patient's treatment. Family-Centred Care (FCC) is widely acknowledged and documented as the optimal care approach for neonatal practice. Despite the growing use of this method, there is a lack of research on the perspectives of healthcare professionals and carers regarding Family-Centred Care. The study aimed to evaluate the viewpoints of nurses regarding Family Centred Care in the newborn critical care unit at the Tamale Teaching Hospital.
Methodology: The study utilised a cross-sectional design employing a qualitative technique, in which focus group talks were held among participants. The material was transcribed and processed via thematic and content analysis techniques.

Comment [AH2]: THE METHOD OF DATA COLLECTION HERE IS INCONSISTENCE WITH WHAT WAS STATED IN THE METHODOLOGY SECTION IN THE MAIN MANUSCRIPT.

Findings: Approximately majority of the participants demonstrated awareness of the idea of Family-Centred Care, which they elaborated upon through two main themes namely provision of care for both the patient and their family, and Involvement of relatives in the care of the patient.
Recommendations: Majority of participants expressed that Family-Centred Care was not practiced in their unit. Nevertheless, all participants unanimously concurred that the approach had the potential to yield positive results in terms of patient care outcomes.

Key Words:*Family Centred Care, Neonatal Intensive Care Unit, Neonates, Nurse Perspectives, Tamale Teaching Hospital*

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Introduction:

Family Centred Care is the model of care where health professionals plan and make decision together with the patients’ familyin care of their patient (Silva, Manzo, Fioreti & Silva, 2015). A focus on improved new-born care practices is critical to reducing under-five mortality across settings (Segers, Ockhuijsen, Baarendse, Eerden, & van den Hoogen, 2018). Such focus is

essential because an estimated 5.9 million children die before their fifth birthday worldwide (United Nations Millennium Development Goals [UN MDG], 2015). In Sub-Sahara Africa alone, an estimated three (3) million deaths among one (1) month olds occurred in 2015 with one (1) death occurring in every twelve (12) under-fives (UN MDG, 2015; World Bank, 2015). The Ghana Maternal and Health Survey reported a childhood mortality of twenty-five (25) deaths per 1000 live births in the country (Ghana Statistical Services, 2018). The neonatal period (the first 28 days of life) is the most period babies are most vulnerable and it is a time that is very critical for the survival of babies. Neonatal mortality accounts for an average of 60% of all infant mortality in Ghana with twenty-nine (29) deaths per 1,000 live births (Ghana Multiple Indicator Cluster Survey [GMICS], 2011). Consequently, neonatal mortality has become a very important component of infant and child mortality and requires very urgent attention (Ghana National New-born Health Strategy, 2014).

The Neonatal Intensive Care Unit is a setting specially equipped with trained staff and resources to care for sick babies especially those born premature for effective care. Such hospitalizations present a challenge to parents as they are usually restricted entry to the NICU during the care of their premature babies due to limited infrastructure or hospital protocols (De Vonderweid & Leonessa,2009). The situation often exclude parents from important discussions and are left in the dark about the management of their Childrens' condition (Barry & Edgman-Levitan, 2012) which result in further aggravation of the already stressed parents leading to anxiety and despair (Franck, McNulty, & Alderdice, 2017; Minton, Batten, & Huntington, 2018). Also, early separation of premature babies from their mothers in the postnatal period have been reported to be stressful to babies (Császár-Nagy & Bókkon, 2018) and impair their emotional,

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cognitive and psychomotor development (Ahlqvist-Björkroth, Boukydis, Axelin, & Lehtonen, 2017).

Similarly, inadequate bonding between mothers and babies results in improper initiation of breastfeeding (Nyqvist et al., 2013). The moment nurses and doctors start to take care of babies in the hospital, parents are reported to lose their sense of control and this birthed the concept of FCC where nurses share the care of children with their families (Tufekci *et al.,* 2015). Several intervention programs have since been designed across many settings including Ghana to care for babies and their parents including Kangaroo Mother Care (KMC), Family Centred Care and Skin-to-skin care (Ghana Statistical Services, 2018). Among these intervention programs, FCC is considered the primary model of care for premature babies and their families in the NICU (De Bernardo, Svelto, Giordano, Sordino, & Riccitelli, 2017).

In the FCC model of health care, family members play a role in all aspects of health care for their babies (Roets, Rowe-Rowe, & Nel, 2012). The Institute for Patient and Family Centred Care (IPFCC) defines the concept of FCC as an approach to organizing, delivery, and evaluation of health care that is grounded in mutual valuable collaboration amid health care providers, patients and families (IPFCC, 2014). Also, the Institute of Medicine (IOM) define FCC as care that is respectful and responsive to individual patient preference, needs and values (IOM, 2010).

In neonatal intensive care (NIC), the concept of FCC refers to the recognition given to families as being integral to the healthcare team (Boykova & Kenner, 2016). In FCC, the healthcare is planned such that both family and the child are cared for but not just the individual child. For FCC to be fully effective, parents should be allowed to enter the NICU without time restriction (Finlayson, Dixon, Smith, Dykes, & Flacking, 2014; Latour et al., 2011; Thiele, Knierim, & Mader, 2016).

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The FCC approach of care in the NICU has been found to be beneficial to both premature babies and parents (Segers *et al.*, 2018). For example, FCC was found to have decreased the length of stay of patients in NICU in the Netherlands (Segers et al., 2018). Similarly, FCC through skin to skin care have been found to improve infants cardiac and respiratory system, stabilize temperature, organised sleep, breastfeeding and neuro-developmental outcome (Skene et al., 2018).

Also, the benefits of FCC to parents of premature babies have been reported in several studies to include reduced stress level among parents in Germany (Enke et al, 2017), increase parents' satisfaction with care in the Netherlands (Segers et al., 2018) and empowerment of parents to have self-confidence and competences in assuming their roles after discharge in the USA (Fleck, 2016). Furthermore, Kuhlthau et al. (2011) found a positive association of FCC with improvements in efficient use of services, health status, satisfaction, access to care, communication, systems of care and family functioning.

METHODS

Study design: An exploratory descriptive design, which fits within a qualitative approach, was employed to explore the perspectives of nurses on Family Cantered Care in Tamale Teaching Hospital. This design enabled the investigator to have in-depth understanding of the phenomenon (Mayan, 2009). This design was chosen in this study because the researcher is interested in understanding the knowledge and attitudes towards Family-Cantered Care among Neonatal Intensive Care Unit nurses. Unlike quantitative studies, qualitative studies major focus is to collect quality data for the purposes of describing and understanding the real meanings (Creswell, 2014).

Comment [AH4]: YES, YOU ARE CORRECT BUT WHICH METHOD DID YOU EXPLICITLY USE TO COLLECT YOUR DATA? IS IT **KII** OR **FGD?**

Setting: Tamale Teaching Hospital was the study centre and was set up in 1974 and was formerly the Northern Regional Hospital. It was upgraded in 2005 to a teaching hospital. The hospital is

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the only teaching hospital in the Northern part of Ghana. The hospital provides health service and receives referrals from the regional and districts hospitals in the region and the surrounding regions. The hospital also provides clinical training serves to the University for Development Studies, Medical School and School of Nursing and Midwifery. Neonatal Intensive Care Unit of the TTH was the site for the study. The unit has a bed capacity of 70 and staff strength of 42.

Target Population: The target population for this study were all nurses working in the neonatal intensive care unit of the Tamale Teaching Hospital for at least three months.

Inclusion Criteria: The study included all nurses working in the NICU for at least three months.

Exclusion Criteria: The study excluded all nurses working in NICU whose children were on admission in the same unit.

Sampling Technique and Size: Purposive sampling technique was used to engage eight (8) participants, data saturation was reached given rise to a sample size of eight (8) nurses. Data saturation was at the point where the researcher no longer gets new insights from the data (Creswell, 2014). This technique is used when the participants have the requisite knowledge on the topic under study (Khan, 2012). As the researcher will recruit participants that will give relevant data until data saturation level is achieved.

Comment [AH5]: YOU STATED PURPOSIVE SAMPLING TECHNIQUE, I DON'T THINK THAT 8 OUT OF 42 PARTICIPANTS ARE ENOUGH TO MAKE GENERALIZATION

Comment [AH6]: was

Data Collection Procedure: The researcher developed the interview guide based on the objectives of the study. A tape recorder was used with the permission of participants to record the interview for adequate interpretation. The researcher also used pens and jotters to take notes of important non-verbal clues to confirm and support verbal responses. The data was enriched with probing

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questions. Before the start of the interview, each participant was guided to complete the participants' background information sheet. This helped the researcher to understand each participant's background and to also facilitate participants easy transit into the sharing of their experiences in the interview. The interview was audiotaped with permission from the participants. The participants were asked questions on their experience on FCC. During each interview session, responses of participants were robed or redirected to focus their responses on the objectives of the study. The non-verbal cues such as change of voice tone, eyes tearing, and facial expression were also noted on the field notes. Each interview lasted approximately 45-50 minutes (Goyal, 2013) notes and audio records were labelled and then stored in the researcher personal drawer under lock and key. The data will be kept for 5 years for the purpose of audit trail.

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Methodological Rigour: Trustworthiness: This research employed the trustworthiness criteria recommended in the works of Lincoln and Guba (1985) to ensure methodological rigour. This included credibility, transferability, dependability, and conformability (Tobin and Begley, 2004; McBrien, 2008).

Credibility involves processes to ensure that the participants can confirm results (Tobin and Begley, 2004; Newman, Lim and Pineda, 2013; Polit and Beck, 2013). Data triangulation and prolonged engagement in the subject matter ensured this (Butler et al., 2019).

Dependability refers to ensuring that acceptable procedures and processes have been followed to establish the study's trustworthiness (Brink, Van der Walt, and Van Rensburg, 2012). To achieve this, there was the provision of a detailed report of the processes involved in the study, which included (1) a description of the research design and implementation, (2) a detailed explanation of the data gathering process and (3) explaining what occurred in the field. An experienced qualitative researcher also did independent co-coding of data compared for analysis. Triangulation data determined consistency and stability across the various data sources and methods employed in the study. Dependability is comparable with reliability (Tobin and Begley, 2004).

Confirmability comprises ensuring that data collected is true and applicable, and supports conclusions drawn and recommendations from the study. This was met through triangulation of the methods (a combination of field notes and interviews) and keeping of audit trails, as well as member checking (McBrien, 2008) by taking the final report back to the participants to determine whether they felt that it was an accurate representation of their input (Creswell and Plano-Clark, 2011). It is comparable with objectivity or neutrality (Tobin and Begley, 2004).

Transferability refers to the applicability of the study. This enables other researchers to use the results on similar participants in a similar context. This was addressed by providing detailed descriptions as presented by the words and phrases used by participants; this comprised sufficient contextual information about the fieldwork to enable the reader to make such a transfer. Also presented was a detailed description of the study setting, the respondents, and the methods involved. Transferability is comparable with external validity (Tobin and Begley, 2004).

Ethical Consideration: An introductory letter from the research committee of the Ghana College of Nurses and Midwives was sent to the Ethics Review Committee of the Navrongo Health Research Centre for ethical clearance before data collection. The researcher also sought permission from management of the Tamale Teaching Hospital before the data collection. The participant's consent was sought by them agreeing and filling a consent form to participate in the study. The participants were given the opportunity to either participate or opt out from the study at any level they desired. The study participants were also educated that consent covers tape recording of the interview, notes taking of observations that cannot be recorded by the tape, description and reporting of findings. The study participants were assured of confidentiality of all the information given during the interview. As such, tape recorder and notebook were constantly under lock and key when not in use and transcript and computed information were pass-worded. Participants were informed not to use their names or any form of identification. The participants were guaranteed of no harm throughout the study.

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STUDY FINDINGS

The study primarily focused on nurses' perspectives on family cantered care. The major themes emerged were **Knowledge of FCC among nurses** and **Practice of FCC at the NICU.** The subjects are introduced and exact quotations are employed to support the assertions.

Participants Demographics

This detail the background characteristics of all 8 participant who took part in the focus group discussion. Among the participants, 4 (50%) of them were aged from 25-30 years, 2 (25%) participants were aged 31-35 years and 2 (25%) were aged 36-40 years. Majority of the participants, 5 (60%) were females and 3 (40%) participants were males. While 5(60%) participants were married 3(40%) were single. Again, while majority, 5(60%) of the participants were Christians, 3(40%) were Muslims. On the highest educational qualification of the participants, 5 (60%) were degree holders whereas 3 (40%) of them were diploma holders.

Comment [AH7]: PARTICIPANTS

Knowledge of Family Cantered Care among Nurses

During the interaction, 6 (70%) out of the 8 respondents said they ever heard of Family Cantered Care and only 2(30%) of them said she had never heard about it. In their responses to the second item (What is Family Cantered Care) two (2) main themes emerged from the data were Family Cantered Careas care for both patient and family; Family Cantered Care as care of patient by involving patient relatives"

4.2.1 Family/Relatives participation in the care process.

Participants in this study held varied explanations as to what constitute Family Cantered Care even though they were familiar with the concept. R3 describes Family Cantered Care in the following passage:

Like the colleague said even though I have not really heard it mentioned, I do understand what the concept is about. But if I understand it is the direct opposite to patient

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*canteredcare. So, whereas patient cantered care is about eh eh… taking care of only the patient, family cantered care deals with taking care of the baby and caregivers as well. (**R3**)*

In a similar way, a respondent described the concept of family centred care and had this to say:

*I know it is about offering holistic care. It is a case where……probably not only the baby is cared for by the health team but all other persons who matter(**R4**)*

The view of another respondent was not different from what the others had said about Family Cantered Care. The participant, also argues:

*it is a form of care given to both patients and their families. It means that we don't only concentrate on the patient but also the… those who brought the patient from home. (**R8**)*

All the participants had similar views regarding the fact they appreciate the Family Cantered Care as being practiced in the unit.

4.2.2Family Cantered Care as care of patient by involving patient relative

From the focus group discussion, some participants argued that Family Cantered Care was care of patient by involving the family. In his attempt to explain the concept of Family-Centred Care, R1, had to say in the following passage:

*Family Cantered Care…family centred care. I have not really heard about it but em em, what I can say about it is that it is the care given to family let me say care centred on the whole family. (pause) like nuclear family of a sort where we involve them in care. (**R1**)*

This explanation was reinforced by the explanation given by:

*A holistic way of nursing where both the patient and relatives of the patient are nursed. In this case there might be need for some assessment to be done on the patient including involving the care givers in planning care. (**R7**)*

It was established in this study that the participants were not too sure of the meaning of the concept of Family Cantered Care. This was noted in the words of participant:

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*care of patients while meeting the needs of families of the Yes, I have heard about it but now and don't really hear about it. I'm not sure what exactly it is about. But if it is like the way they are describing it (silence) then well… about taking patient (**R5**)*

However, there was one (1) participant, who simply said "no idea" admitting he did not know about the concept of Family Cantered Care.R1

4.3 Practice of Family Cantered Care at the Neonatal Intensive Care Unit

On the practice of Family Cantered Care, 7 out of the 8 participants indicated that FCC was not practiced in the ward. Responses to the questions under the practice objective produce two (2) central themes; parents are not involved in the care of the sick" "parents are partially involved in the care ofthe sick.

4.3.1 Parents are not involved in the care of the sick

This study found majority of the participant nurses stating that Family Cantered Care was not practiced in the neonatal intensive care unit. Participant did not hesitate to state his position in the passage below:

*Oh no no, we usually just take care of the baby all alone as health workers. We don't allow that all. That is why we have enough space for their mothers to always stay waiting for their babies. (**R1**)*

One participant, who probably abhorred the practice of Family Cantered Care had this to say:

*Not here. You know (pause), we do not have a policy that says relatives should assist in care of babies. So, we accordingly do not do that. We do the assessment of the baby's situation and we carry out the care all alone. We decide when they should take medication, when to check the vital signs of the child even decide the topics on which we educate them. (**R6**)*

4.3.2Parents are partially involved in the care of the sick

However, the nurses found the need to involve them on a number of occasions. Participant in her expression had this to say:

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*We only call them when the child is hungry and crying for food. What possibly can they do to help apart from feeding the baby? We don't let them take part, Yaa. (**R2**)*

Some participants also blamed the exclusion of caregivers in the care of the sick on physician activity such as conducting ward rounds. Participant was explicit in his statement:

*family members are usually sacked especially when doc comes for review. They are not really allowed to participate in the care at all. (**R3**)*

The participants also argued that caregivers are involved when it came to purchasing drug and other services:

*I don't think we do that here in this ward. We make them sit comfortably while we reassure them of competent care. But when it comes to buying of drugs, we call them to go buy some for us. But as for actual nursing care relatives are not taking part in this unit. (**R5**)*

*involvement views as expressed by participant R4 was not too different that of the others: For instance, if you ask the mother of a child to hold down a baby so that you the care. (……. I will say yes and I say so because any form or level of involvement is the nurse will cannulate the baby, what is that? On that score, I will say they take part in patient's **R4**)*

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DISCUSSION

This presents the detailed discussion of the major findings of this study in association with existing relevant literature pertinent to Family Cantered Care. The discussion is presented according to the major themes and subthemes which were based on the objectives of the study.

Knowledge of Family Cantered Care among Nurses

This study found that about three-quarters of the participants were aware of the concept of Family Cantered Care. This study finding was reflected in the responses of the participants as

they shared their views on what FCC was. However, participant's knowledge of Family Cantered Care varied. This study findings concurs with what has been reported by various authors (Kuo,Houtrow, Arango, Kuhlthau, Simmons, & Neff (2011). This findings could have been influenced by exposure to the various explanations or definitions of the concept of Family Cantered Care as documented by Shields, Pratt, and Hunter, (2006), Gooding et al., (2011) and Coyne *et al*., (2013). This reality of nurses giving varied views of Family CanteredCare could be contributing to the ongoing debate that nurses misunderstand the concept of Family Cantered Care as argued by Coyne *et al* (2013). Comparing the definitions given by the participants to those articulated in literature by various authors, some differences in meaning were noted. Except that participant covered only one of the two key components of the concept. It was also noted that, participants understood the concept as having more to do with the care of the care giver as well as the client. Caregiver involvement which is a key component of Family CanteredCare not captured frequently. Again, this study revealed that participants did not know the typical definition of the concept of Family-Cantered Care. They gave responses that suggested that they were not too sure of what the concept is about. That notwithstanding, participants gave responses that were very close to the concept under study. Their knowledge of this concept could have been influenced by their exposure to similar concepts like patient centred care.

The findings in this study are similar to the findings of Correa et al, (2015) study on Family Cantered Care in Newborn Unit: Nursing perspective. They found that the application of Family Cantered Care is wrongly understood, and portrays the unpreparedness of professionals to deal with the Family process of hospitalised Children.

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Practice of Family Cantered Care at the Neonatal Intensive Care Unit

On the practice of FCC, this study found that more than half of the respondents saying that FCC is not implemented in the unit. The participants were very straight forward with their answers and went ahead to specify what they meant by not practicing Family Cantered Care. For instance, they likened Family CanteredCare with care giver involvement during the care process and said they did not involve caregivers during care. This finding was consistent with that of Harrison, (2010) and Finlayson *et al*.(2014) and Kuo *et al.,* (2012) when they suggested the implementation of Family Cantered Care was problematic in health facilities.

The study also found that nurses occasionally involved care givers in the care of patients. This was noted when the participants argued that caregivers are asked to purchase drugs and also feed their babies. This study revealed a number of factors that accounted for nurses' inability to implement Family Cantered Care. The factors cited include workload, burden of documentation, confused state of relatives and physician ward rounds fear of relatives interfering with clinical duties. This discovery was consistent with what has been reported by Kleine'll et al., (2018) who argued that such factors as unit culture, staff resistance, lack of space and time, clinicians being uncomfortable with family being present, and uncertainty about the benefits of Family Cantered Care were barriers to the practice of Family Cantered Care.This study also revealed that parents or care givers needs may be attended to by Nurses but they often did so when caregivers were sick.

It was also demonstrated that, respondents did not carry out home visiting or follow-up visits. However, the study found commitment to follow-up review where the patient and relatives are expected to come back for further assessment and treatment. This finding was in line with the placement or recruitment policy of the Nurses in this ward. This was probably so because all the

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nurses were registered nurses who are trained to offer services in the wards. It probably was on this basis that one of the participants reported that home visiting was not feasible.

The discovery in this study was consistent to with the findings of Silva et al,(2016) study on Family Cantered Care from the perspective of Nurses in the Neonatal Intensive Care Unit. They found lack of material resources, shortage of staff, creating and updating protocols, training as challenges hindering Family Cantered Care.

CONCLUSION

Family-Cantered Care is a key component of care for neonates at neonatal intensive care units. Its benefits are so keen in the care of neonates in reducing neonatal mortality and morbidity, yet it lacks proper stance in the care of neonates in the Tamale Teaching Hospital NICU. The nurses reported some potential benefits and challenges of adopting FCC approach in the delivery of care. This study highlighted the need for FCC to be used as an approach to planning, delivery, and evaluation of health care that is grounded in mutual beneficial partnership among health care providers, patients and families.

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