



Developing conceptual guidelines for Family-Centered Care for standard ICU practice: A constructivist grounded theory

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ABSTRACT

Purpose: To explore the constructs of family-centered care (FCC) from the perspectives of nurses, doctors, and families in the intensive care units (ICU) and to develop FCC guidelines for ICUs.

Design: A constructivist grounded theory (CGT) design was employed.

Methods: We conducted 12 individual interviews and triangulated the data with 12 focus group discussions (FGDs) using an interview guide from February to December 2020. The interviews and the FGDs were conducted face-to-face. Data was analyzed using CGT analysis. The data analysis was assisted by MAXQDA version 2020 plus. The study was guided by the 32-COREQ checklist.

Results: The participants (72) were nurses ($n = 28$), doctors ($n = 8$), and family ($n = 36$). Four themes were generated: respect, family support, participation, and collaboration. Each theme had subthemes to illuminate the participants' perspectives of the FCC constructs.

Conclusion: This study revealed that nurses and doctors had positive perspectives of FCC in the ICU and are willing to accept and implement it into standard ICU practice. Four main constructs of FCC emerged from this CGT study: respect, family support, participation, and collaboration and were used to develop a conceptual guideline.

Practice implication: FCC implementation in the ICU may be facilitated by designing family-inclusive ICUs with spacious subunits, kangaroo rooms, family areas, provision of counselling, as well as adopting regular and effective communication guidelines, and adequate staff training. Conceptual guidelines for FCC have been developed to promote FCC in standard ICU practice.

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Introduction

Family-Centered care (FCC) has become the goal standard of intensive care unit (ICU) practice (Abukari & Schmollgruber, 2023). The FCC framework of care recommends the involvement and participation of family members in the care of their critically ill patients, especially children admitted to the neonatal and paediatric intensive care units (Axelin et al., 2020; Enisha & Arti, 2019; Latour & Coombs, 2019). Although the FCC approach has been well-researched in the context of the developed world, there is still a need for more research in the developing world. Moreover, the constructs identified to facilitate its implementation in the ICU have become contextual and cultural issues (Abukari, 2022; Abukari & Schmollgruber, 2023; Ohene et al., 2019). There is a need to conduct further research to develop specific contextual guidelines of the FCC to facilitate its implementation into standard ICU practice.

Background

Over the years, researchers have identified several constructs of FCC (Abukari & Schmollgruber, 2023). Initially, four main constructs were identified: respect and dignity, participation, communication, and collaboration (Abukari & Schmollgruber, 2023; Mitchell et al., 2018; www.ipfcc.org, 2021). The concept of respect seeks to address the needs of families and sick children in the ICU. Participation as a construct demands the involvement and engagement of families in the care of their critically ill children in the ICU (Abukari & Schmollgruber, 2023; Mitchell et al., 2018; www.ipfcc.org, 2021). Communication has been identified as the central construct to implementing FCC, as it seeks to promote the sharing of relevant information about the care processes and the progress of the child's condition with the family (Mitchell et al., 2018; www.ipfcc.org, 2021). Some settings have used communication guidelines to enhance family participation and promote healthcare outcomes (Benzies, 2016). The collaboration construct promotes building partnerships with families in decision-making about their loved ones in the ICU (Dennis et al., 2016).

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Some new constructs of FCC have been proposed in recent times, including family needs (Alsharari, 2019), family presence (Davidson et al., 2017), family support (Kynoch et al., 2019), and environmental designs (Davidson et al., 2017; Thompson et al., 2012). These new constructs, even though they are largely developed from the four main earlier constructs, seem to add clarity to the integration of FCC into the ICU. This re-emphasises the need to explore the practices of FCC across cultural settings to harness the findings towards holistic implementation.

Earlier research on FCC in Ghana reported sufficient family involvement in childcare and recommended the development of guidelines for its holistic implementation in childcare (Abukari et al., 2022; Ohene et al., 2020a). Additionally, the practice of FCC in Ghana, especially in the ICU, is undocumented. There are no guidelines to support families' engagement in participation and decision-making during the hospitalisation of a critically ill child. The Ghanaian intensive care units (ICUs) operate highly restricted protocols that allow little or no family participation in the care process (Abukari & Schmollgruber, 2024). The design of the ICUs in Ghana leaves no space to accommodate more family members (Abukari & Schmollgruber, 2024). As a result, clinicians find it extremely difficult to practice FCC. A preliminary assessment of these ICUs indicates that the nurses and doctors appreciate the role of families in the care of the critically ill. Most studies in Ghana found that healthcare professionals, including nurses and doctors, especially in ICUs and paediatric settings, had a good understanding of FCC; however, there appears to be a mismatch between their priorities and the needs of families and these healthcare professionals (Abukari et al., 2022; Adugbire et al., 2024; Mohammed & Tak, 2022; Ohene et al., 2019, 2020b; Yombe et al., 2022). These events have thwarted the implementation of FCC, which is largely constrained by the lack of personnel, increased workload and fatigue, and, more importantly, a lack of context-specific guidelines to facilitate its implementation.

Furthermore, the researchers designed this study using a qualitative constructivist grounded theory (CGT) approach (Albert et al., 2019). The Family Systems Theory (FST) was employed as the theoretical foundation for the study (Ray, 2018). The CGT allows the triangulation of multiple perspectives on a phenomenon to construct evidence (Albert et al., 2019). Before adopting the FST, the researchers considered the family care theory, the family nursing theory, and the systems theory. Family Care Theory emphasises the family as the primary source of care and support, especially in healthcare. It recognises the family's role in healthcare decision-making and promotes inclusive, sensitive care (Hill et al., 2018a). According to Systems Theory, families are interconnected systems, and changes or stress in one member affects the entire family unit, requiring a third support to establish the equilibrium in the family (Jakimowicz et al., 2021). Family Nursing Theory, on the other hand, expands on this by emphasising the role of the family as a unit of care (Gilliss, 1991; Looman, 2020). Family Systems Theory (FST) combines these concepts, viewing the family as a complex system in which each member's actions and experiences influence the entire family unit (Erdem & Safi, 2018; Rubino & Serenari, 2023). Therefore, understanding FST necessitates understanding how Family Care Theory, Systems Theory, and Family Nursing Theory contribute to a comprehensive view of families as active participants in care and significant to positive health outcomes. According to the FST, families are interconnected systems that function dependently in equilibrium and provide context for human experiences. The FST posits that the sickness of a child or an individual destabilises the equilibrium and influences the family's health status (Erdem & Safi, 2018; Rubino & Serenari, 2023).

Consequently, this study was developed to identify and describe the constructs of FCC from the perspectives of nurses, doctors, and family members of sick children in the ICU. To enable the integration and deployment of FCC into the ICU, FCC guidelines were conceptually developed using the emerged constructs. Ultimately, this will support standardised ICU practices and provide critically ill children and their families with satisfactory and high-quality healthcare.

Methods

Design

A grounded theory qualitative approach was adopted (Rieger, 2019a; Sebastian, 2019). The grounded theory is grouped into three specific research designs: the Glasserian school (Classic Grounded Theory), the Straussian school (The Reformulated Grounded Theory), and the Charmaz school (Constructivist Grounded Theory) (Rieger, 2019a; Sebastian, 2019) (refer to Table 1 for details). Our study employed the constructivist grounded theory (CGT) design (Rieger, 2019a; Sebastian, 2019). The rationale for the CGT design was to contextually collect data from nurses, doctors, and families and triangulate these multiple forms of data for the FCC constructs to emerge from Ghanaian ICUs to develop the FCC guidelines (Rieger, 2019b). Furthermore, through CGT, researchers directly studied FCC constructs from the participants, facilitating the co-creation of knowledge and understanding of social processes. Before this, the researchers considered other qualitative methods, such as ethnography, which focuses on participants' cultural perspectives, and phenomenology, which emphasises lived experiences, and found that they were unsuitable for a comprehensive FCC guidelines development. Refer to Table 1 for differences between the grounded theory traditions and the justification for using the CGT design.

Setting

Tertiary-level ICUs participated in the current study, one from the south and one from the north of Ghana. The ICUs in this study are tertiary referral centres in the areas that enable them to admit medical and surgical neonatal and paediatric cases. The total number of beds in all four settings is 115, though they frequently admit to using almost twice as many beds as their actual primary capacities.

Participants

In addition to family members of critically ill infants admitted to the ICU for at least a minimum of two days, we included nurses and doctors with at least two years of experience working in the ICU. The participants chosen for the interviews were distinct from those chosen for the focus groups. The goal was for the FCC constructs to emerge constructively by allowing the collection of various types of data from the participants in a triangulation process. For example, we enrolled family members of children admitted to the ICU for at least two days to ensure adequate exposure to FCC practices, a thorough understanding of ICU dynamics, emotional and cognitive adjustment, active participation, and consistency in care experiences. Furthermore, including ICU staff with at least two years of experience in the ICU provides more comprehensive and reliable data on FCC implementation by reflecting how FCC practices were maintained over time in the Ghanaian context. Moreover, the extended observation period enables families to provide more reflective and accurate accounts of their interactions with FCC while ensuring consistency in care experiences. This method ensures a thorough and reliable understanding of FCC in the ICU.

Ethical consideration

We obtained ethical clearance from the University of the Witwatersrand Faculty of Health Sciences scientific review committee (M190980), which was used to gain institutional ethical approval from the Institutional Review Boards at the two main hospitals. The participants were provided information sheets about the study, and those who agreed to participate voluntarily signed informed consent forms as well as an additional consent form for voice recording since the interviews and focus groups were audiotaped. The researchers followed all the institutional and other standard guidelines for conducting research.

Table 1
Differences between the three traditions of the Grounded Theory approach.

Schools	Proponent & Year	Data Analysis criteria	Main Characteristics
Glaserian school (Classic Grounded Theory)	Barney Glaser, 1978	Grounded Theory analysis: Inductive openness, Constant comparison method and conceptualisation	The unstructured procedure of theory development (theory generating method) ignores literature prior to data collection, Zigzag processes of data collection and analysis, the researcher is detached from the processes, Theoretical sensitivity, theoretical sampling and focused questions on the emergent of categories from data, more of objectivity.
Straussian school (The Reformulated Grounded Theory)	Anselm Straus, 1987	Deductive Thematic analysis (hierarchical coding method or coding paradigm): Open coding, Axial coding, and Selective coding	Involves structured, systematic procedures, conditional matrix, full conceptual description, analysis follows a coding paradigm, interpretation, and subjectivism is core to theory development
Charmaz school (Constructivist Grounded Theory)	Kathy Charmaz, 2006	Constructivist Grounded theory analysis: Initial/open coding, Focused/intermediate coding, Advanced coding (theoretical coding, theoretical sampling, and memoing). This design was adopted since the study was designed to develop FCC guidelines using triangulated data from multiple participants.	Literature is used as sensitising concepts, rich data collection, diverse perspectives, socio-cultural multiple perspectives of participants, data triangulation, socially constructed, data is constructed via ongoing interactions between researcher and participants, interpretation of data for guideline or theory to emerge, the researcher is part of the iterative research processes (personal reflexivity)

Data collection

We use institutional ethical clearance to gain access to the ICUs. The heads of the units and departments were engaged to understand the nature of the research. The researchers designed an advertisement flyer to create awareness about the study in the four ICUs. The heads assisted the researchers in identifying participants who met the inclusion criteria. Data was collected by the first author using interviews and a focus group discussion guide developed from the study objectives and constructs of the FST, which were pretested with similar participants. We purposefully recruited participants and conducted six interviews with family members and six interviews with the nurses and doctors in the ICUs. Subsequently, we conducted in-depth interviews to construct the evidence by triangulating the data with 12 focus group discussions (FGDs) (Rieger, 2019b). Each interview took at least 30 min, and the FGDs lasted about 60 min. In all, 24 transcripts were generated.

Data analysis

We transcribed all the interviews and FGDs into English for the data analysis. We adopted the CGT analysis in the present study (Rieger, 2019b). The transcripts were read several times for data-cleaning purposes and to interact with the data for evidence to emerge constructively. We employed an “inductive-abductive logic,” i.e., moving back and forth between the data to confirm or disconfirm emerging evidence to arrive at the most plausible explanation (Rieger, 2019b) of the contextual constructs of FCC. CGT analysis has three main phases: initial coding, focused coding, and theoretical sampling (Rieger, 2019b). The data was carefully read during the initial coding phase, and initial codes were assigned to emerging patterns in the data (Refer to Table 3). The developed initial codes were used to conduct focused coding in the second phase whilst allowing the conceptual infiltration of the FST theoretical constructs. The focused coding was conducted in an iterative manner, employing the initial codes that reappear frequently, starting with the individual transcripts and triangulating with the FGDs as additional data to confirm the emerging patterns (abductive). The first two phases of the CGT analysis resulted in the generation of categories to illuminate the constructs of FCC. As such, the researchers did not proceed to theoretical sampling since the present study was not designed to develop a theory (Rieger, 2019b). The CGT analysis was assisted by the MAXQDA version 2020 plus qualitative software.

Findings

Table 2 provides a detailed development of the codes, subthemes, and themes using the CGT analysis. The study had 72 participants,

mostly family members and clinicians, comprising nurses ($n = 28$), doctors ($n = 8$), and family members ($n = 36$) of critically ill patients in the ICU. The participants were divided into individual interviews and focus group discussions. Both groups were represented equally in the interviews and the discussions, with contributions evenly distributed across data collection methods. Refer to Table 3 for details. Four themes were generated: respect, family support, participation, and collaboration. Each theme had subthemes to illuminate the participants' perspectives of the FCC constructs in the Ghanaian ICUs.

Table 2
Development of the codes, subthemes, and themes using the CGT analysis.

Initial coding (sub-sub themes)	Focused coding (Subthemes)	Main themes
Acceptance, workload, fatigue, frustrations Separate cubicles, respectful information, accommodating to family Handling patient diagnosis, patient records, treatment, and family consent Food, washrooms, family hostels	Subtheme 1: Ensuring patient and family dignity Subtheme 2: Ensuring Privacy Subtheme 3: Ensuring confidentiality	Theme 1: Respect
Information sharing on condition, information for care and unit protocols, regular communication, effective communication Clinical psychologist, counselling team, family anxiety Family visitations, family time, Family visitations, family time Education on KC, Fathers involvement in KC, Importance of continued KC Breastfeeding, Expressed breastmilk, Cup & spoon-feeding, Enteral & Parenteral feeding Family involvement, family consultation FCC workshop, Newborn care training, equipment training, FCC curriculum Cubicle design according to patient needs, triaging area, infrastructure The clinical area is into subunits, Kangaroo care Rooms, Counselling rooms, Family area FCC guidelines, multidisciplinary approach,	Subtheme 1: Meeting family needs in the intensive care units Subtheme 2: Explaining condition and care processes Subtheme 3: Providing family counselling Subtheme 1: Scheduled family visits Subtheme 2: Kangaroo care Subtheme 3: Infant feeding Subtheme 1: Decision making Subtheme 2 Staff training in FCC Subtheme 3: The ICU environment Subtheme 4: Family-inclusive FCC guidelines	Theme 2: Family support Theme 3: Participation Theme 4: Collaboration

Table 3
Demographics of participants.

Category	Transcripts	Participants	Frequency (n)	Percentage (%)
Family individual interviews	6	Fathers (1) and mothers (5)	6	8.33
Clinicians' individual interviews	6	Nurses (4), doctors (2)	6	8.33
Family Focus Group Discussions	6	Fathers (6) and mothers (24)	30	41.67
Clinicians Focus Group Discussions	6	Nurses (24), doctors (6)	30	41.67
Total	24	72	72	100

Theme 1: Respect

In this theme, respect is described as a key FCC concept. From the participant's perspective, respect serves as a natural catalyst for collaboration and can be developed through early socialisation with families.

Subtheme 1: Ensuring the dignity of patient and family.

Families feel dignified when they are adequately addressed and accepted into the facility without disguise. Touching makes the family feel dignified. The workload in the ICU was the cause of the inconsistent show of respect towards families. Other determinants of respect were social status, educational level, and the family's capacity to afford care costs.

"KF3: The staff generally show respect to us. I have not found anyone who has been disrespectful to us, but sometimes their workload frustrates them a bit" (Family interview 3).

"TCD1E: staff should learn to touch and hug our patients, and that shows love, respect, and dignity...touching is even therapeutic to the patient and family." (Paediatric nurse 2).

"KF4: One thing they've been telling me, and I think that's the main reason why I've gotten that respect and dignity from them, is that I have been consistent in whatever they tell me to do, any drug that they write, any lab, anything that they do, within a matter of short time I make sure they get it" (family interview 4).

Subtheme 2: Ensuring family and patient privacy.

Maintaining privacy is very tough in the ICU because of limited space and the lack of counselling rooms. This is compounded by the fact that all the mothers come together in an open space to feed and attend to their infants:

"KF11: Privacy is an issue in intensive care because all the mothers come in an open space to feed and attend to our babies..." (Family interview 1).

"KC11: Very tough as you can see, there is no space here..." (Paediatrician 1).

Subtheme 3: Ensuring family and patient confidentiality.

The design of the ICU should be more spacious to ensure confidentiality. Critically ill children and their families should be nursed in separate side wards or cubicles. Confidential information about the patient is only given to the father or mother of the sick child:

KC15" For babies with congenital abnormalities like cleft lip/palate, we try to avoid any contact of the baby and family with another family to reduce stigma and anxiety. We do not share information about patients with other patients or families (Paediatrician 5).

"KC14: ...birth abnormality, anatomically, you can see that the defect is obvious, we try to hide the baby at a corner in the ICU so that not every family will see such babies" (Paediatrician 4).

Theme 2: Family support

This theme described how family perceived support in the ICU; through meeting their needs, explaining their patient condition to them, and providing counselling sessions. The theme emphasises the importance of providing basic, psychological, and informational support to families in ICUs through regular counselling sessions, information sharing, and efficient communication between nurses, doctors, and families.

Subtheme 1: Meeting family needs in the intensive care units.

The greatest family needs in the ICU include information, psychological, and basic needs. An adequate flow of information and an explanation of the processes may reduce their anxiety. Families are happy when they can touch and feel their babies, even with ICU equipment. Families experiencing anxiety and emotional trauma during ICU stay for sick children reported insomnia. Participants recommended clinical psychologist services for support. The basic needs included food, water, washrooms, and accommodation, with some families not receiving these due to financial constraints.

"TC12: ... they do not know what is happening to their babies... their number one need is information" (Intensive care nurse 3).

"TC14: ... to practice the family-centred care; a psychologist is much needed because they will know how to present the psychosocial problems to the family..." (Paediatric nurse 4).

"KF16: We need food...we will want them to provide accommodation for us" (Family interview 6).

Subtheme 2: Explaining patient condition and care processes to family.

Some nurses and doctors prioritise effective communication with families. Families were educated on the children's clothing, feeding critically ill children, and maintaining the child's body temperature. The provision of an information desk and refresher training in assertive communication for staff in ICUs may facilitate the free sharing of information between families and the staff. Furthermore, effective education may lead to knowledge transfer and empower them:

"TC15: ...effective communication and education are important because if the parent understands what you want to do and you understand the family standpoint ...I am sure collaboration will come in. There will be mutual respect then participation will come" (Paediatric nurse 5).

"KF11: ... we are educated to rub the child in extra clothing to provide warmth so that when you go home, you will know how to continue the care" (Family interview 1).

Subtheme 3: Providing regular family counselling sessions.

A permanent clinical psychologist would help address the emotional stress of the families through counselling sessions. Nurses and doctors counselled families by reassuring them and explaining the child's condition to them. Counselling sessions were also used to update families and answer all their questions to allay anxiety:

"KCD3E: We have a counselling unit, and every patient who comes goes through a first-time counselling session...we explain to them the processes here and the child's condition...is used to updating the patient and answer all questions of the family related to the care of their child..." (Intensive care nurse 3).

"KC11: ...in our small setting, we need a clinical psychologist in the ICU because the ICU is a very stressful place. Hence, the role of a clinical psychologist cannot be overemphasised (Paediatrician 1).

Theme 3: Participation

This theme described how families participated in the Ghanaian ICUs. Family participation in ICUs was enhanced through scheduled visits, kangaroo care, and infant feeding. Hospitals allowed six visits for fathers and mothers, and involved families in infant feeding.

Subtheme 1: Family participation via scheduled visitations to ICUs.

Family involvement and participation were facilitated through scheduled family visitations to the ICU. The hospitals allowed six scheduled visitations for fathers and mothers in the ICU; mothers had four visits, and fathers had two. Other family members, including grandparents, were also allowed to visit when the parents were unavailable to be involved in the care of the ICU.

“KCI2: ... for infection control purposes, we allow just the parents, the mother, and the baby's father. If the father is unavailable, not in town, then we extend that to a grandmother or somebody the mother has designated...the mother has 4 hours to hang out with her baby, and the fathers have two visiting times aside from the mother. So, essentially, baby gets six visits by the family, but it is all daytime till about 7 pm” (Paediatric nurse 3).

Subtheme 2: Family involvement in kangaroo care.

One way of involving parents and building partnerships with families in caring for their children at the ICU was through Kangaroo Care (KC). The KC involves bonding skin-to-skin with preterm babies to provide warmth for improved weight, growth, and development. KC practice helps the babies gain weight gradually enough to be discharged. It also creates the opportunity for families to spend more time with their newborns:

“TCI3: We place them on KC - Kangaroo Care...” (Neonatal nurse 3).

“KCI4: They learn KC for the preterm babies like one hour or two hours. This allows the mothers to practice the KC conservatively to help the babies gain weight gradually to be discharged...” (Intensive care nurse 4).

“KFI2: I can now participate in the care of my baby as I am staying in the KC room, and she is feeding well now. I do the KC to provide warmth so that, together with the feeding, she can recover fast” (Family interview 2).

Subtheme 3: Family participation in infant feeding in the ICUs.

Nurses and doctors involved families in the care of critically ill children during infant feeding. The feeding process in the ICU included parenteral, enteral, cup feeding, and breastfeeding. Mothers were involved in breastfeeding and cup and spoon feeding with expressed breast milk.

“KCI6: ... When the mother comes in, we allow you to breastfeed... after that we allow the mother to express the milk, then we use a small spoon to feed” (Paediatrician 6).

“KFI1: I feed the babies by expressing breast milk with my hand in a hygienic way by using clean cups. The nurses help me to feed my babies in the ICU when I am home...” (Family interview 1).

Theme 4: Collaboration

This theme emphasised fostering partnerships with families in ICU patient care, addressing emotional stress, and promoting specialised child health care skills. It calls for staff training in FCC and the development of clear guidelines for improved child health care.

Subtheme 1: Building partnerships with family in decision-making about patient care in ICUs.

Occasionally, the nurses and doctors involved in families decide to confirm the diagnosis of their critically ill children in the ICU. Families with children who had congenital abnormalities were also engaged to discuss treatment modalities. Some mothers lamented their non-involvement in decision-making, including the purchase of artificial feeds and changes in the management plan. Such practices add to the emotional stress of families:

“KCI7: I had a baby whom I suspect has an intestinal obstruction. Because the baby had bilious vomiting, I managed to get the mother to understand that baby is vomiting greenish substances... so we need to do this X-ray immediately...” (Paediatrician 7).

“TFD3: When I brought the baby feed, another clinician said it was too early to start artificial feeds... I think they should coordinate with the family in making decisions concerning the care of our children...” (Family FGD 2).

Subtheme 2: Staff training in FCC, neonatal and paediatric care.

Nurses and doctors need specialised skills to improve child health care, especially in the intensive care setting. Most nurses and doctors in the ICU are general nurses and general doctors. The authorities including the ICU unit heads need to be involved in sensitising staff so that the FCC can be entirely accepted. According to the participants, the curricula of nursing programs should be guided around the concept of FCC. This will let professionals give families the needed respect and inclusion.

“TCD1C: Sensitization of nurses and doctors working at the ICU is important ... involvement of the authorities in the sensitisation is one of the major ways of implementation of the FCC” (Neonatal nurse 4).

“TCI5: if it is started in the schools as part of the curriculum, I think it will be more effective than in the workshops” (Paediatrician 5).

Subtheme 3: The design of the ICU environment.

The designs of the ICU environment into subunits, family areas, spacious kangaroo care rooms, and counselling rooms may help address both family and nurses' and doctors' needs for easy implementation of FCC. These designs may create more space for ICU equipment, including ventilators and incubators. It may provide a conducive environment and ensure privacy and confidentiality for full family participation.

“KFD1B: they should be in the family area too attached to the ICU... so that they won't interrupt the nursing care (Family FGD 1).

KCI1: We have so many preterm babies in the incubator who could be cared for in the KC room, so a bigger room or ward for KC would be suitable for family participation in the care. (Paediatrician 1).

4: Developing family-inclusive FCC guidelines.

Participants advocated for clear family-inclusive guidelines on FCC at the ICU drafted with a bottom-up approach. The guidelines should be displayed in the unit. A multidisciplinary approach, including experts, policymakers, and management, should be used to align the FCC guidelines with all parties.

“KCI2: ...it will be appropriate if there is a policy guideline coming from the top...some things take roots if we start from the bottom-up” (Paediatrician 2).

“TCD1D - FCC is very important, and it involves a team and not only the nurse. FCC should be approached from a multidisciplinary perspective...” (Intensive care nurse 1).

Discussion

This qualitative CGT study was designed to explore and describe the constructs of FCC from the perspectives of nurses, doctors, and family members in neonatal and paediatric intensive care units, and it met its aim. The constructs have been used to conceptually develop a guideline of the FCC to promote standard ICU practice (Fig. 1). Our current study may be justified as researchers advocated further studies on FCC across settings to harmonise guidelines for improved ICU services (Davidson et al., 2017). The main constructs of FCC from the perspectives of nurses, doctors, and families in the Ghanaian ICUs are respect, support, participation, and collaboration (Abukari & Schmollgruber, 2023; Foster et al., 2018; Hill et al., 2018b; Kokorelias et al., 2019; www.ipfcc.org, 2021). Respect is a catalyst for cooperation that may be achieved through socialising with families. A family's support can be achieved by addressing their immediate needs in the ICU, including prompt, simple information, psychological needs, and basic needs such as food, water, washrooms, and accommodation.

In addition, the participants intimated that communication is critical in gaining families' full participation in their children's care. Nurses and doctors adopted communication guidelines, including information sharing, reassurance, and counselling sessions to keep families well informed and support them in participating in the ICU phase of care. Also, the ICU allows families to participate in their children's care by

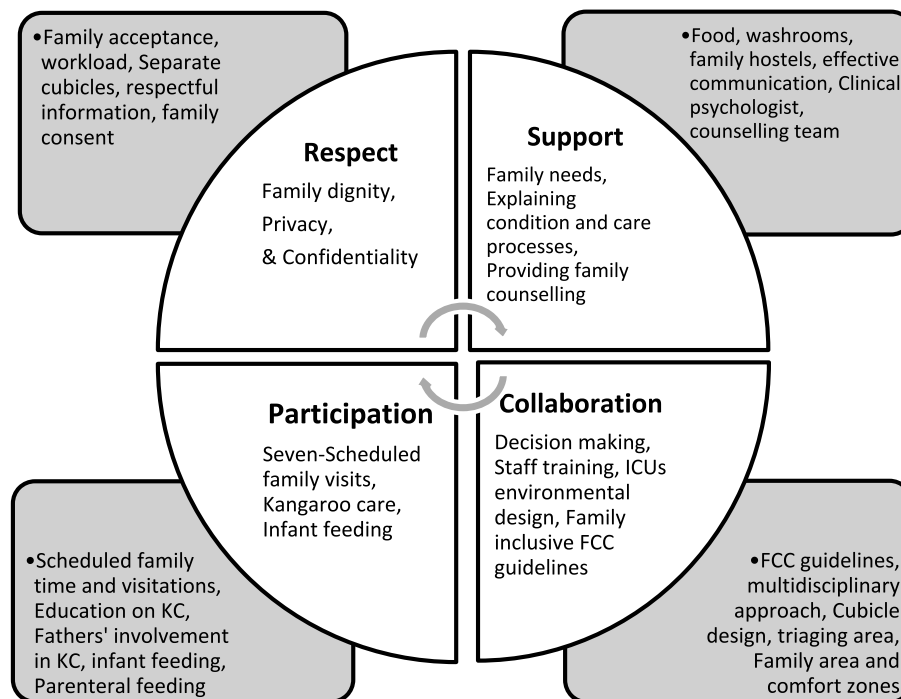


Fig. 1. Conceptual Guideline of Family-Centered Care for standard ICU practice. Key: ICU: Intensive Care Units, FCC: Family-Centered Care, KC: Kangaroo Care.

practicing KC in separate rooms at the ICU, scheduling visitations, and feeding sessions. The participants want the ICU to be spaciouly designed and the staff to be offered additional specialised training, including newborn care, paediatric care, ICU, and FCC to integrate FCC into standard ICU practice. The nurses and doctors acknowledge FCC as a significant approach to neonatal and paediatric care (Boztepe & Kerimoğlu Yildiz, 2017; Mohammed & Tak, 2022; Ohene et al., 2020b) that requires collaborative and multidisciplinary approaches to be implemented in the ICU.

Respect has been described as a component of FCC that ensures the dignity, privacy, and confidentiality of patients and their families. Correspondingly, an integrative review conducted in Hong Kong, China, illuminated respect and dignity as a main construct of FCC (Phiri et al., 2020). The conceptualisation of care for patients with critical illnesses also identified respect and dignity as useful in developing care interventions (de Beer & Brysiewicz, 2017). In this context, respect was initiated through socialising with families from the first day of admission, which may have accounted for this finding. Families feel respected when properly acknowledged and welcomed into the hospital without disguise. However, some families complained about the inadequate respect and dignified care they received from the ICUs. This is possible because the staff are often exhausted due to the workload in the ICUs, and they often vent their frustrations on the families, which accounts for the inconsistent respect and dignity shown to families. The main tenet of respect is ensuring the privacy and confidentiality of patients and their families (Kokorelias et al., 2019). However, maintaining privacy in this context is extremely difficult because of the limited space and absence of counselling rooms in the ICU. This is exacerbated by the fact that all of the mothers gather in an open area to feed and care for their babies. Social background, educational level, and the family's ability to finance care expenditures were also factors in determining the respect and dignity the family received from the staff. Facility managers and heads of ICUs should conduct training in relationship communication and FCC constructs to keep staff updated on these concerns (Abukari & Schmollgruber, 2023; Benzies, 2016).

Additionally, more staff may be assigned to the ICUs to enable them to plan properly for family inclusion in daily ICU services. To maintain confidentiality, the ICU may be designed to be roomier.

In addition, satisfying family needs in intensive care units, explaining the patient's condition and care processes to the family, and giving frequent family counselling sessions shed light on how families in Ghanaian ICUs were supported (Phiri et al., 2020; Scott et al., 2019). An earlier study on how to meet the needs of families in ICU had consistent findings (Cockcroft, 2012). Additionally, family support interventions have been highlighted in a qualitative evaluation study in Swedish ICUs (Naef et al., 2020) and a scoping review findings elsewhere (Davidson et al., 2017). However, a prospective quantitative survey of families and nurses in Europe identified the desire of families to stay overnight in the ICU as their perspective of support (Raiskila et al., 2016). Information, psychological needs, and basic necessities are among the most immediate concerns of a family in the ICU (Alsharari, 2019). Communication guidelines have been employed elsewhere to bridge FCC implementation (Oude Maatman et al., 2020). Providing information on the child's condition, regular updates on the care process, and the child's progress in the ICU are the most important needs of a family that should be given the optimum attention by ICU staff. These family needs may be met through effective communication between ICU staff and families (Adams et al., 2017). Correspondingly, we proposed training nurses and doctors in communication guidelines to enhance their interactions with families in the ICU and promote family satisfaction of care (Kynoch et al., 2019; Pagnamenta et al., 2016).

A family's psychological needs are also important in the ICU. Early initialisation of FCC in French ICUs through the identification of family needs has been reported to improve care outcomes (Pladys et al., 2019). In our context, families were worried and emotionally traumatised over their sick children's care in the ICU. Some researchers reported anxiety and depression as the source of family emotional challenges in the ICU and recommended coping self-efficacy as a support (Kynoch et al., 2019). On the contrary, preterm birth, a lack of updates on the status of care, a lack of encouragement from the nurses and

doctors, and, in some cases, family members were the sources of family anxiety and emotional stress to families. Participants described their ICU experiences as disappointing, and they needed nurses and doctors to help them cope with the psychological stress. Several families observed insomnia as a result of the emotional stress associated with their child's ICU stay. It is recommended that available clinical psychologists be deployed in the ICU to assist families and health professionals in addressing their emotional needs associated with the ICU phase of care. The counselling sessions may also be used to keep families up to speed and address any questions they have in order to reduce anxiety. Alternatively, families may be counselled by nurses and doctors to reassure them and explain the child's condition. Contrary to our findings, an integrative review recommended the use of coping strategies by families to manage their anxieties and depression during hospitalisation (Rückholdt et al., 2019).

Furthermore, adopting an open information-sharing system between the family, nurses, and doctors may help reduce family anxiety (Alsharari, 2019). Also, effective family education may result in mutual respect, collaboration, and partnership between nurses, doctors, and families. Such successful family education may result in knowledge transfer, allowing family members to decide and be more educated about their healthcare needs and continuing care after discharge (Pladys et al., 2019). Again, an information desk in ICUs may make it easier for families and staff to share information freely. Providing a counselling area may further facilitate sharing information with the ICU patients' families while maintaining privacy and confidentiality. Our recommendations may be justifiable as researchers in South Korea also advocated for improved communication skills of critical care nurses to facilitate patient care (Yoo et al., 2020). In divergence with our findings on family support interventions in the ICU, a randomised control trial involving 1420 ICU patients and their families did not find a significant effect of family support on the reduction of psychological symptoms of patients (White et al., 2018).

Contextually, scheduled family visits to the ICUs, family involvement in kangaroo care, and family participation in infant feeding in the ICUs were all used to ensure family participation. A qualitative study in Canada involving 29 family members and 35 ICU staff also identified family participation as a construct of FCC (Roze des Ordonis et al., 2020). To enhance family participation, fathers and mothers in the ICU were allowed six scheduled visits; mothers were given four and fathers were allowed two. Other family members, including grandparents, were only permitted to visit when the parents were unable to assist with the ICU's care. Some researchers have proposed the design of flexible family presence guidelines at the bedside to promote family participation in the ICU (Davidson et al., 2017). The goal of such practice is to prevent infections in the ICUs. Meanwhile, granting full access to families in the ICU is critical for decision-making (Kokorelias et al., 2019), promoting maternal bonding, and improving the health of infants.

The practice of Kangaroo Care (KC) was also one means of incorporating and developing partnerships with families in the care of their children in the ICU (Altimier & Boyle, 2020). This was especially satisfying for families who had progressed from partial participation in the ICU phase to full participation in the KC phase. The KC permitted preterm newborns' mothers and fathers to stay in the ICU with them. KC intervention entails skin-to-skin contact for families with their premature infants to provide warmth and promote weight gain, growth, and development (Birhanu et al., 2022). A premature newborn's mother or father is supposed to keep the baby in front of them, between their breasts and legs, and covered with a cloth while doing KC (Birhanu et al., 2022). The KC practice aids in the progressive weight gain of the babies, allowing them to be discharged early from the ICU (Birhanu et al., 2022; Campbell-Yeo et al., 2015; Mellis, 2016). It also allows families to spend more time with their newborns in ICUs, which increases participation and understanding of care for improved home care (Curtis et al., 2016). The involvement of families in their newborn care, including feeding, bathing, and practicing the KC in separate

rooms at the ICU, promoted a quick recovery. As such, nurses and doctors in ICUs should design care interventions to allow full family participation. The families' skill set in continuing home infant care including feeding was observed to improve as they were able to participate in infant care, including infant feeding with cup/spoon feeding and breastfeeding.

Building partnerships with families in decision-making regarding patient care in ICUs, staff training in FCC, neonatal and paediatric care, the design of the ICU environment, and developing family-inclusive FCC guidelines were all examples of collaboration in this context. Improving partnerships and decision-making with families of ICU patients has been recommended by some researchers (Heyland et al., 2018). On the opposing end, other researchers proposed that the co-creation of knowledge, the design of competencies and the negotiation skills of nurses are relevant to building partnerships with families (Brødsgaard, Pedersen, Larsen, & Weis, 2019). Occasionally, the nurses and doctors involve families in decision-making when it pertains to the confirmation of diagnosis and treatment cost of their critically ill children in the ICUs. Some families expressed dissatisfaction with their inadequate participation in decision-making, such as the procurement of artificial meals and adjustments to the management plan, which exacerbated their emotional stress. Future researchers may design studies to explore family-nurse partnership guidelines to address these challenges.

Participants emphasised the necessity for ICU staff to be trained in some specialised skills in newborn and paediatric care, as well as ICU and FCC constructs. They suggested that professionals may be trained through workshops and that the curricula be updated to include the FCC constructs primarily for nurses and doctors who work with children. Thus, for the FCC to be fully accepted, the health managers may organise workshops and in-service training on the FCC constructs to build staff capacities and improve standards of care. Education and staff training guidelines have been recommended towards a universal approach of FCC in the ICU (Kokorelias et al., 2019). The training may improve staff understanding and appreciation of the importance of family involvement in providing childcare and collaboration with families as partners in planning care interventions.

The participants stressed the need to design an ICU environment that meets international standards, which includes clinical areas divided into subunits (cubicles), family areas and comfort zones, spacious kangaroo care rooms, and counselling rooms (Al-Motlaq, 2018; Thompson et al., 2012). These ICU environmental designs (Davidson et al., 2017) may help meet the needs of families, nurses, and doctors for FCC implementation. Furthermore, such designs could create a welcoming atmosphere while ensuring privacy and confidentiality, permitting full family engagement. For example, having a family room in the ICUs will help families to relax and breastfeed appropriately. Also, these designs may allow for additional space for ICU equipment such as ventilators and incubators. More space for Kangaroo Care (KC) could assist in decongesting the main ICU, allowing more critically ill newborns and their families to be admitted.

Consequently, the participants recommended establishing documented guidelines on FCC practice in the ICU that detail these contextual constructs for smooth implementation. Earlier research has emphasised the nascence of guidelines on FCC in ICU practice (Davidson et al., 2017). For full implementation of FCC in the ICU, participants urged explicit guidelines created with a bottom-up approach and displayed on posters in the ICUs. An open-door policy for family involvement, family counselling, effective communication; involving families in decision-making; follow-up using public health nurses; NICU and PICU design (Davidson et al., 2017) that is friendly and family-inclusive; and available support systems for families with critically ill children should all be included in the proposed FCC clinical guidelines. Perhaps these recommendations by the nurses, doctors, and families demonstrate their acceptance of FCC as a significant aspect of standard ICU practice that should be approached as a

collaborative effort. A multi-disciplinary approach may be prudent to enhance the full implementation benefits of FCC. Thus, all stakeholders, including nurses, midwives, doctors, managers, and family members, may collaborate on a comprehensive approach for FCC integration into intensive care.

Limitation

Although our study included ICUs, the data was rather skewed to participants from NICUs. Again, the inclusion of mothers as families outweighs that of fathers and grandparents due to the sociocultural poor attendance of fathers in ICU and hospital care in our setting. These limitations were managed via the collection of multiple forms of data from the participants in interviews and focus groups to corroborate the findings for the evidence to emerge.

Implications for practice

This present CGT study derived its strength from the multiple collections and triangulation of data from nurses, doctors, and family members in two tertiary ICUs for the evidence to emerge. A conceptual guideline of FCC has been developed from the constructs that may be useful for neonatal care, paediatric care, and ICU practice (Fig. 1). Our study provides insight into the constructs of FCC in the developing world context that may be useful in future research. The findings and recommendations illuminate the need for family-inclusive ICU services to promote quality health services. The findings may serve as a framework for further research to develop FCC models of care that may harness nursing care interventions across settings for standard ICU practice, especially in low-resource settings. For instance, our recommendations on the use of available clinical psychologists, provision of basic needs for families, staff training guidelines, and design of spacious ICUs may be subjected to experts' evaluations to provide further evidence to design guidelines for the development of nursing care interventions for critically ill patients and their families. The evidence presented may make nurses and doctors aware of their significant responsibilities towards critically ill patients and their families, especially regarding the non-pathological aspects of ICU services. A phenomenological study in Ethiopia also underscores the necessity to address the needs of families and plan family-inclusive nursing interventions (Kehali et al., 2020). Ultimately, understanding the constructs of FCC in the ICU may be helpful for intensive care nurses to formulate nursing diagnoses and plan appropriate comprehensive care for critically ill children and their families. Nursing activities, including collecting and analysing clinical data to develop appropriate nursing diagnoses in Italian ICUs, improved care outcomes (Castellan et al., 2016).

Conclusion

The study highlights the significance of FCC in Ghanaian ICUs, emphasising respect, support, participation, and collaboration. Participants stressed the need for ICU staff training in infant care, including FCC concepts, and urged updating nursing curricula. They also emphasised the need for a spacious ICU environment, private breastfeeding room, and regular updates on childcare. As a result, it is recommended that documented FCC clinical guidelines be adopted and displayed in the ICU to assist implementation. Further research may triangulate our findings using mixed methods to build a contextual model of FCC. Future research may design studies to explore family-nurse partnership guidelines for the comprehensive integration of FCC in ICUs.

CRedit authorship contribution statement

Alhassan Sibdow Abukari: Writing – original draft, Visualization, Software, Resources, Project administration, Methodology,

Investigation, Formal analysis, Data curation, Conceptualization. **Shelley Schmollgruber:** Writing – review & editing, Supervision, Methodology, Conceptualization.

Declaration of competing interest

The authors declare that they have no conflict or competing interests.

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