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A MODEL OF FAMILY-CENTERED CARE AT THE PAEDIATRIC AND NEONATAL INTENSIVE CARE SETTING IN GHANA

Alhassan Sibdow Abukari

A thesis submitted to the Faculty of Health Sciences,

University of the Witwatersrand, in fulfilment of the requirements of the degree

of

Doctor of Philosophy

Johannesburg, 2022

DECLARATION

I, Alhassan Sibdow Abukari, declare that this thesis, which is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg, is my own work. It has not previously been submitted for any degree or examination at any other university.

Signature: 

This 11th day of February, 2022

HERC Protocol number: **M190980**

DEDICATION

I dedicate this work to my family, friends, and mentors for their unflinching love, support, prayers, and scholarly guidance throughout my academic and professional journey to this far.

PUBLICATIONS AND PRESENTATIONS

Publications

Abukari, A.S., Schmollgruber, S. 2021. Concepts of family-centered care at the neonatal and paediatric intensive care unit – A scoping review**.** BMJ, *under review***.**

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ABSTRACT

Background: Family-Centered Care (FCC) is an innovative approach of promoting quality healthcare. However, its main concepts remain unclear in different settings, especially in intensive care units. FCC is widely documented and researched globally, yet its implementation in the Ghanaian context has been challenging due to inadequate context specific models.

Purpose: To study FCC in the intensive care setting, develop and evaluate a model of FCC for neonatal and paediatric intensive care units (NICU/PICUs).

Methodology: An exploratory mixed methods triangulation design was conducted in three phases using the Family Systems Theory as a theoretical foundation. Phase one was a scoping review of relevant data followed by a qualitative study (N=84) based on constructivist grounded theory (CGT) and then a descriptive quantitative study (N=446) involving families, clinicians, and health managers at the intensive care units (ICUs). Phase two was a Modified Delphi study (N=24) in order to develop the model of Family-Centered Care which was then evaluated subsequently in phase three by experts (N=25). The scoping data was content analysed, data of the qualitative study was examined using CGT analysis whiles Principal Component Analysis was used to study the quantitative data (with orthogonal Varimax rotations and parallel analysis). Estimation of descriptive statistics, content validity index (CVI), Cronbach's alpha, and Intra-Class Correlation Coefficient (ICC) were performed to evaluate the model.

Results: The main concepts of FCC practiced in Ghanaian NICU/PICUs were respect/dignity, participation, and effective communication in a well-designed NICU/PICU environment through family acceptance (λ=19.793, factor score of -0.814, & 95th λ=1.751), maintaining privacy/confidentiality (λ=2.243, factor score of -0.827, & 95th λ=1.657), psychosocial needs (λ=1.930, factor score of -0.599, & 95th λ=1.597), and respectful communication (λ =1.554, factor score of -0.729, & 95th λ=1.546). The FCC practice in Ghana were challenged with lack of funding (factor score of 0.804), inadequate space (factor score of -0.650), abandoned babies (factor score of 0.780) and inadequate logistics/personnel (factor score of 0.770). These concepts were used to develop the NICU/PICUs FCC model,

which showed sound psychometric properties (Cronbach's alpha=0.953, model content validity index (M-CVI/Ave) =0.924 and average measure of Intra-Class Correlation-ICC=0.951) on evaluation. The model theorizes a Trilogic Multidisciplinary Partnership (TMP) between families, clinicians, and health managers in a well-designed NICU/PICU environment to promote respect/dignity, effective communication, and family participation to facilitate the integration and implementation of FCC in the Ghanaian ICUs for critically ill children and their families.

Conclusion: This study triangulated data from clinicians, families, and health managers in order to develop a model of Family-Centered Care for NICU/PICUs in the Ghanaian context. The model will support clinical practice and training in neonatal, paediatrics, and intensive and critical care as well as instigate further research in the field. Future research should, however, test the model and its recommendations with a large sample in Randomized Control Trial (RCT) and cohort studies for its full-scale implementations as well as conduct 5-year periodic reviews for validation and possible revision.

Keywords: *Family-Centered Care, Model Development, Neonatal, paediatric, Intensive Care Units, Constructivist Grounded Theory, Mixed Methods Triangulation, Factor Analysis, Model Evaluation, Model Design*

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LIST OF ABBREVIATIONS

CCFNI	Critical Care Family Needs Inventory
CFAM	Calgary Family Assessment Model
CFIM	Calgary Family Intervention Model
CGT	Constructivist Grounded Theory
FA	Factor Analysis
FCC	Family-centered Care
FCT	Family Care Theory
FGD	Focus Group Discussion
FNT	Family Nursing Theory
FST	Family Systems Theory
GCNM	Ghana College of Nurses and Midwives
GHS	Ghanaian Health Services
GTEC	Ghana Tertiary Education Commission
HeFRA	Health Facilities Regulatory Authority
ICU	Intensive Care Unit
IFC	Infection Control
IPFCC	Institute of Patient and Family-centered Care
JBI	Joanna Briggs Institute
KBTH	Korle Bu Teaching Hospital
KC	Kangaroo Care
KMC	Kangaroo Mother Care
KMO	Kaiser-Meyer Olkin
PA	Parallel Analysis
PCA	Principal Component Analysis
PICU	Paediatric Intensive Care
PPE	Personal Protective Equipment
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
NAB	National Accreditation Board
NHIS	National Health Insurance Scheme

NICU	Neonatal Intensive Care
NICU/PICU	Neonatal and Paediatric Intensive Care Unit
NMC	Nursing and Midwifery council
MOH	Ministry of Health
SAI	Self-Assessment Inventory
SDG	Sustainable Development Goals
SPO2	Pulse Oximeter Measurement
ST	Systems Theory
RCT	Randomised Controlled Trial
RN	Registered Nurse
TBA	Traditional Birth Attendant
TTH	Tamale Teaching Hospital
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This part of the work presents an overview of the entire research. The chapter contains the background of the study, problem statement, research questions, study objectives, the purpose, significance, and concepts definitions of the study. This chapter also provides a synopsis of the research methodologies applied in the various phases of the thesis.

1.2 BACKGROUND OF THE STUDY

Family-centered Care (FCC) is defined by Shields (2010) as ‘‘a way of caring for children and their families within health services, which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognised as care recipients.’’ It is considered as the pinnacle of current child health nursing services, and it involves shared decision-making about childcare between health professionals and the family, where negotiations are made, as a pivotal element for its achievement in the healthcare setting (Arabiat and Shields, 2018; Corlett & Twycross, 2006; Neill & Fateel, 2016; Shields, 2017). It encourages healthcare professionals in intensive care to involve parents in the non-medical aspects of childcare (Coffin and Zaoutis, 2011). The basis for Family-centered care is on the belief that the successful provision of quality child healthcare requires the medical condition and the value of human interactions in healthcare experiences, beliefs, culture, and preferences. Thus, parents need open and unbiased communication about their children’s health in intensive care. Their involvement will improve the child’s adherence to treatment, speed recovery, and parents’ satisfaction (Coffin and Zaoutis, 2011; Shaul, Kushner and Weisstub, 2014).

The Neonatal and Paediatric Intensive Care Unit (NICU/PICU) is an intricate clinical setting where less attention is given to families, emphasising the clinical needs of the new-born (Neill and Fateel, 2016; Sanders and Hall, 2017). However, it is critical to identify that the family is the constant in a child’s life, while the service systems and professionals within those systems oscillate. Hence, when a child is admitted to the Intensive Care Unit (ICU),

the family must be consulted in the care processes (Neill and Fateel, 2016; Arabiat *et al.*, 2018; Bhalla *et al.*, 2019). Clinicians should accept and respect family members as experts and partners in the care of their infants and welcome them into the neonatal and paediatric ICU (Dall' Oglio et al., 2019; Dennis, Baxter, Ploeg, & Blatz, 2016). Health professionals should continue to engage children and parents in partnerships to clarify their expectations to enhance understanding of environmental influences, including the length of stay at the neonatal and paediatric ICU (Dennis et al., 2016; Shaul, Kushner, & Weisstub, 2014). Infants and their families must be treated with dignity and respect as far as the concepts of applying family-centered care is concerned (Brødsgaard, Zimmermann and Petersen, 2015; Latour and Coombs, 2017; Latour and Coombs, 2019).

Family-centered Care is the central element to providing participatory, satisfactory, and quality child healthcare globally (Yu and Zhang, 2018; Aija *et al.*, 2019). Over the past few decades, Family-centered care has gained international attention and popularity with the underpinning philosophy to put parents and family in a pivotal position for providing healthcare to sick infants (Dall' Oglio et al., 2019; Dennis et al., 2016; Staniszewska et al., 2012). Apart from the underlying disease conditions of children admitted to a health facility, children, parents, and family face emotional, behavioural, cognitive and social problems resulting from the hospitalisation (Tallon, Kendall, and Snider, 2015). Mainly, how parents handle the hospitalisation of their sick infants is hinged on their individualities and connections with the healthcare team (Tallon, Kendall, and Snider, 2015; Friedman *et al.*, 2017).

As the population of neonates and children with special conditions requiring intensive care increases in Africa, this requires particular attention (Butler, Copnell and Wasetts, 2013; Kiwanuka *et al.*, 2019). The focus on family-centered care resonates with many health initiatives that promote patient-led care and encourage the nurse to empathise with parents of sick children on hospitalisation (Staniszewska *et al.*, 2012; Olding *et al.*, 2015). As health service delivery expands gradually across the globe, there are more children and their parents cared for outside their homes, and the idea of family involvement has gained popularity. Meanwhile, few studies have been carried out on family involvement, especially in an intensive care setting (Olding *et al.*, 2015; Lundqvist, Weis and Sivberg, 2019). However, the environmental designs of NICUs and PICUs in Ghana are not environmentally friendly with family comfort zones, as recommended in other settings (Thompson *et al.*, 2012). The

health financing system in Ghana is also a contributory factor as there are funding challenges in meeting the equitable delivery of healthcare, including the provision of intensive care services. Aside from budgetary allocations from the central government of Ghana, donations, and support from private organisations, the only recognised public health financing system is the National Health Insurance (Asundep *et al.*, 2013; Mordi, Eghan and Rankin, 2015; Bonfrer, Breebaart and De Poel, 2016); this makes it difficult to procure the optimum equipment required for intensive care services.

FCC has four main components: "parental participation in children's healthcare; partnership and collaboration between the healthcare team and parents in decision-making; family-friendly environments that normalise as much as possible family functioning within the healthcare setting; and care of family members as well as the children'' (Franck and Callery, 2004). The degree to which these concepts of family-centered care are strengthened by research and applied practices are imprecise, especially in the NICU and PICU (Olding *et al.*, 2015; Aija *et al.*, 2019).

Over the years, there has been a paradigm shift in clinical practice towards FCC to provide holistic and comprehensive care for clients, families, and the community (Shields, 2017; Dall'Oglio *et al.*, 2018; Latour and Coombs, 2019). Quality and safe healthcare can be improved by allowing the collaborative participation of relatives in the care of their clients, especially when they are new-borns (Mackie, Mitchell and Andrea, 2017). Some studies re-affirm the influential role of FCC in shortening the length of hospitalisation of sick infants and yielding positive health outcomes for children and families (Yu and Zhang, 2018).

However, in Canada, for example, the socioeconomic backgrounds of parents influenced their perceptions of family-centered care in intensive care (Shevell *et al.*, 2018). The role of nurses in family-centered care practices is to improve therapeutic communication with clients and families through adaptation to diagnosis and treatment (Tedford, 2011). In India, the practice of family-centered care is hampered by poor education, cultural beliefs and external influences of family members (Vajravelu and Solomon, 2013). The ward environment is stressful to both children and parents, which affects their involvement in the care processes at the hospital (Curtis and Northcott, 2016; Minton, Batten and Huntington, 2019). The main barriers of family-centered care have been captured to include

organisational, individual, interdisciplinary barriers and lack of understanding of the key components to achieve family-centered care (Kiwanuka *et al.*, 2019).

Therefore, parental involvement will stimulate a sense of control of the situation and manage parental anxiety related to the stay in the ICU (Thermaenius, Schandl, and Sluys, 2019). However, nurses are reluctant to involve families in the care of their children in the ICU; perhaps role clarification of family members and open communication in intensive care may be significant in fostering family involvement (Neill and Fateel, 2016). In Canada, the concept of Family-centered care is influenced by parents' perception, beliefs, satisfaction and the complexity of the child's health (Grandjean *et al.*, 2016; Zimansky *et al.*, 2020). In the United States of America (USA), where FCC is adequately implemented in the hospitals, it improved the family's ability to cope with fear, stress, and altered parenting during the hospitalisation of a sick child (Enisha and Arti, 2019; Latour and Coombs, 2019; Phiri, Chan and Wong, 2020).

It is clear that FCC is helpful in the care of hospitalised new-borns, and children and their relatives, and therefore more research needs conducting in the area of family needs, participation, and satisfaction to accelerate its practical application (Tedford, 2011; Ding *et al.*, 2018; Yu and Zhang, 2018). There has been use of FCC in contemporary nursing practice, however, it has not been clearly described as a model but rather an approach of involving family members in client care (Ding *et al.*, 2018). There is a wide theory-practice gap in Family-centered care for sick children, especially infants at the neonatal and paediatric ICU (Enisha and Arti, 2019; Oude Maatman *et al.*, 2020)Franck and Callery, 2004). Therefore, against these backdrops, the researcher conceived this study and explored the family's needs, barriers, and perceived effects of the FCC approach within ICU and developed the family-centered care model for hospitalised children.

The study took place in the northern and southern zones of Ghana, which is a sub-Saharan country located in the west of Africa. It is bordered in the south by the Gulf of Guinea, north by Burkina Faso and at the sides by Togo and Cote d'Ivoire, with an estimated population of 29,472,552 million (World metres, 2018). Ghana has over 100 ethnic groups, with Akan, Moshi-Dagbanli, Ewe, and Ga being the major groups. **Figure 1.1** presents the map of Ghana.



Figure 1.1 Site map of Ghana (Google maps)

1.3 PROBLEM STATEMENT

Ideally, families are an integral part of care in ICU; however, limited visitations into the ICU restricts them. They do not have access to doctors, yet nurses are reluctant to provide information about their sick children at the NICU/PICU. The consequences are that family's face isolation from their children, and they suffer separation anxiety, and post-ICU depression. Traditionally in Ghana, hospitals do not to provide specialised intensive care for neonates and children with critical care needs; intensive care is only available in tertiary healthcare settings, such as teaching hospitals and regional hospitals. There is a call for a model of FCC that is influenced by the advances in clinical practice, research and education, and community contributions towards healthcare design and provision (Butler, Copnell and Wasetts, 2013; Shaul, Kushner and Weisstub, 2014; Hill, Kna and Santacroce, 2017).

Despite this overwhelming agreement across all health delivery systems in the world about the significance of Family-centered care, little has been done about it in NICU/PICUs in

Ghana, and even Africa (Latour, Hazelzet and van der Heijden, 2005; Dennis *et al.*, 2016; De Beer and Brysiewicz, 2017). However, there is a need for a stronger relationship between nurses and families of sick children instead of giving less empowerment to patients and families (Latour, Goudoever and Hazelzet, 2008; De Beer and Brysiewicz, 2017). The Family-centered care has been used in contemporary nursing practice; however, it has not clearly been described as a model but rather an approach of involving family members in client care (Ding *et al.*, 2018). Over the years in Ghana, the practice of family-centered care is via scheduled family and patient relative visitation periods to children admitted at the NICU/PICUs. The lack of parental involvement and participation in care may foster separation anxiety, affecting emotional and cognitive development later in life (Skene *et al.*, 2015).

Even though babies admitted into the neonatal and paediatric ICU receive optimum care from the nurses, parents of such infants are often left depressed as they are poorly involved in the care processes (Staniszewska *et al.*, 2012). Moreover, the neonates cannot express their needs and experiences of the care provided to them in the intensive care, their parents do so on their behalf, which justifies the need for parental involvement (Latour, Goudoever and Hazelzet, 2008; Hill, Kna and Santacroce, 2017). Also, in most cases, if not all, the desire of parents and sick children is incongruent with healthcare professions, with such disparities having a negative toll on quality healthcare (Latour *et al.*, 2010). Therefore, there is a need for neonatal and paediatric ICU professionals to identify the needs of parents and their clients promptly to improve clinical nursing practices (Dall' Oglio et al., 2019; Hill et al., 2017).

There is a wide theory-practice gap in FCC for sick children, especially infants at the neonatal and paediatric ICU (Franck and Callery, 2004; Mccay *et al.*, 2015). However, there has been no nursing clinical research conducted to develop and integrate a model on FCC in Ghana. This research, explored family needs, barriers, facilitators, and perceived benefits of the FCC approach within the intensive care setting, culminating in developing a FCC model for Ghana. This research will stimulate professional nurses' interest in family involvement within the Ghanaian health delivery system and influence countrywide policy on FCC practices in general. This will improve families' satisfaction, address families' unmet needs (relative to Family-centered care and promote quality and holistic child healthcare in Ghana and the world.

1.4 RESEARCH QUESTION

How can there be integration of FCC practices into NICU/PICUs to improve family involvement, satisfaction, quality, and holistic child healthcare outcomes?

1.5 PURPOSE OF THE STUDY

The purpose of this research was to investigate FCC in the intensive care setting, develop and evaluate a model of FCC for NICU/PICUs in Ghana. .

1.6 RESEARCH OBJECTIVES

This research addressed seven objectives in three phases:

1.6.1 Phase 1: Exploration Phase

- To describe the key concepts of FCC through a critical literature scoping review
- To explore family needs at the NICU/PICUs
- To describe how family can be involved in care at the NICU/PICUs
- To explore the barriers of FCC integration at the NICU/PICUs
- To describe the facilitators of FCC integration at the NICU/PICUs

Outcome: The outcome of Phase 1 was to help review existing literature on FCC and identify the key components of the FCC model via mapping the search data and primary data from interviews and surveys among family, clinicians, and managers.

1.6.2 Phase 2: Model Development Phase

- To develop an FCC model for the NICU/PICUs

Outcome: The outcome of Phase 2 was to produce a draft NICU/PICU FCC model.

1.6.3 Phase 3: Evaluation Phase

- To evaluate the validity and reliability of the developed NICU/PICU FCC model.

Outcome: The outcome of Phase 3 helped determine the validity and reliability of the NICU/PICU FCC model.

1.7 SIGNIFICANCE OF THE STUDY

The anticipated benefit of this research was to intersperse the FCC model with neonatal and paediatric intensive care for its complete clinical application. This will improve parent satisfaction and overall quality of child healthcare through pursuance to policy development and implementation of the FCC model at all levels of health delivery. The study was set out to provide evidence-based information on the barriers and effects of FCC on children, family, and health service outcomes in Ghana. This will help to trigger the interest of professional nurses and health facilities in general towards FCC. It may help contribute to knowledge development in family nursing and fill the knowledge gap with specific emphasis on barriers, parent role, nurses' role, and the general effects on quality health. It provided empirical evidence on nursing care strategies to improve FCC for children and their families. This may culminate in the stimulation of national interest and policy, practice, research and education on FCC in Sub-Saharan Africa and resource-limited countries, such as Ghana. Finally, concentrating on this Family-centered care model may improve professional nursing practice for newborns, infants, children, and their families in intensive care.

1.8 RESEARCHER'S ASSUMPTIONS

This part of the study presents the nursing philosophical underpinnings of the thesis. Nursing paradigms are ordered, comprehensible, and methodical articulations of a set of declarations linked to the discipline, whilst a researcher's assumptions describe the connections of concepts representing his values, beliefs, or goals on which a theory or model is formulated for nursing practice (Bartlett, 2011; Giacomello, Canova and Zanotti, 2019). The nursing paradigms provided in this section comprises meta-theoretical assumptions, theoretical assumptions, concepts specific to the study, and the methodological assumptions of the study. These assumptions help to concretise the nursing discipline as a scientific profession

as they re-echo the philosophical underpinnings of nursing practice that serve as the fundamental building blocks of the nursing profession (Weaver and Olson, 2006; Fawcett *et al.*, 2015; Nikfarid *et al.*, 2018). Such development will help integrate theory and practice for quality and holistic healthcare from professional nurses for children and their families in the ICUs (Berndtsson, Dahlborg and Pennbrant, 2020).

1.8.1 Meta-theoretical Assumptions

Fawcett, 1984 and later in 1999, developed the four Nursing's meta-paradigms: person, environment, health and wellness, and nursing. The meta-theoretical assumptions of nursing provide the basis for how professional nurses think and react to human experiences in providing quality healthcare. Therefore, the researcher presented the paradigmatic perspectives of the study by situating the Family-centered care study in the neonatal and paediatric ICU in the four main philosophical meta-paradigms in nursing.

1.8.1.1 Person

The meta-paradigm, 'person' in Philosophy of Nursing, is described as the recipient of care (Carroll *et al.*, 2008). 'Person' in nursing practice is not only the individual it encompasses his family, friends, beliefs, culture, values, and religion. According to nursing philosophy, a person has also considered a bio-psychosocial being who is responsive to the environment, illness, and nursing care. The person has the right and responsibilities to seek optimum healthcare and make independent choices about their health with significant others (family). Hence, the person needs treating as a holistic being, considering the family in the care provision. Therefore, in the FCC study, the researcher considered the child and family as the person's meta-paradigm receiving nursing care. Thus, in providing care to children admitted to intensive care, there needs to be respect and dignity by accepting their family's needs, beliefs, culture, and religion to allow full participation.

1.8.1.2 Environment

Fawcett (2000) identified the environment as a 'place' or 'community' where care is given. Florence Nightingale dichotomised the environment meta-paradigm into internal and external environments in her environmental theory. The external environment consists of

temperature, bedding, ventilation, and the ICU, while the internal environment encompasses food, water, and medication (Carroll *et al.*, 2008; Pijl, 2010). In the context of this study, the researcher posits the external environment as the unfamiliar ICU context with its buzzing technological equipment, and the internal environment is the child and family responses to critical illnesses. Both aspects of the environment constitute stress for the critically ill child and their family, which needs prompt attention from the multidisciplinary health professionals in the neonatal and paediatric ICUs.

1.8.1.3 Nursing

The researcher adopted the famous Virginia Henderson's definition of nursing as his operational definition of nursing in the thesis. According to Henderson (1966), nursing is defined as the unique function of the nurse is to assist the individual, sick or healthy, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will, or knowledge and to do this in such a way as to help him gain independence as rapidly as possible (Henderson, 1966). Henderson expanded her nursing philosophy into 14 basic needs of which nursing care should be anchored (Bartlett, 2011); popularly referred to in nursing practice as Henderson's 14 activities of daily livings. The researcher maintained that holistic nursing care requires the patient, families, and other healthcare professionals to meet these basic needs. Hence, quality healthcare provision can be achieved by adopting a multidisciplinary approach of which the parents and the significant others of the patient (child) are a constituent. Therefore, the researcher explored the family's needs at the ICUs and formulated them as part of the model developed on FCC for hospitalised children.

1.8.1.4 Health and wellness

According to Dorothea Orem (1995), health is "a state characterised by soundness or wholeness of developed human structures and bodily and mental functioning," The primary function of the nurse is to promote health and wellness by ameliorating the suffering of the patient.

1.8.2 Theoretical Assumptions

A theoretical framework is a blueprint on which the entire research is established. It is one of the most significant aspects of the research process and is the basis from which all decisions by the researcher are informed. In the constructivist grounded theory tradition, theoretical knowledge is constructed for a research study (Grant and Osanloo, 2014; Marceglia *et al.*, 2018).

Family Systems Theory (FST), which offers a new hypothesis for the conceptualisation of human behaviour and the treatment of human problems (Hohashi and Honda, 2015; Benzies *et al.*, 2019) underlined this study. The theory stipulates that individual functioning should be understood in the context of his relationships, that each person's emotional functioning is closely interconnected with each other (Bowen, 1974, 1990; Hohashi and Honda, 2015).The Family Systems Theory (FST) framework was therefore presented as a sensitising concept to inform the research problem and questions as recommended by the Constructivist Grounded Theory doctrines (Charmaz, 2006; Albert, Mylopoulos and Laberge, 2019).

The Family System Theory is divided into three theories, namely the Family Nursing Theory, the Systems Theory, and the Family Care Theory. The concept of family nursing in healthcare points to the appreciation that the primary social group that is the family affects the individual's wellbeing, even in his physical, organic part. In Family Nursing, the client is a social being whose formative development occupies the first 20 years of his life. The most significant as well as the earliest social grouping to which clients belong is their family. It is in the entire family environment that nurtures individuals from infancy to adulthood to develop their physical, psychological, and social aspects. From the perspective of Family Nursing Theory (FNT), the family size and composition, culture and ethnic background, as well as the health beliefs of an individual, underscore the predisposing factors of the client's illness and must be addressed holistically to promote prompt recovery (Bowen, 1990; Morgaine, 2001; Friedman and Allen, 2014; Hohashi, 2018, 2019; Ray, 2018).

The Systems Theory sees family as a basic unit of life with sub-units, such as nuclear and extended family. These subunits interact interdependently to function as a whole. Thus, the illness of a member has reciprocal effects on the more prominent family (Bowen, 1990;

Morgaine, 2001; Ray, 2018). This calls for the holistic development of nursing actions and interventions to address the health problems.

The Family Care Theory (FCT) copiously speaks about the needs of healthcare professionals to include the family of a client in the care processes. It holds the stance that the family can support the care provided for their hospitalised loved ones through collaborative partnerships with the health professionals. Thus, it is imperative to identify the needs of both patient and family when planning care for hospitalised children. This will promote family satisfaction, management of stress that comes with the hospitalisation of a loved one and culminates into holistic quality child healthcare outcomes (Schmollgruber, 2019).

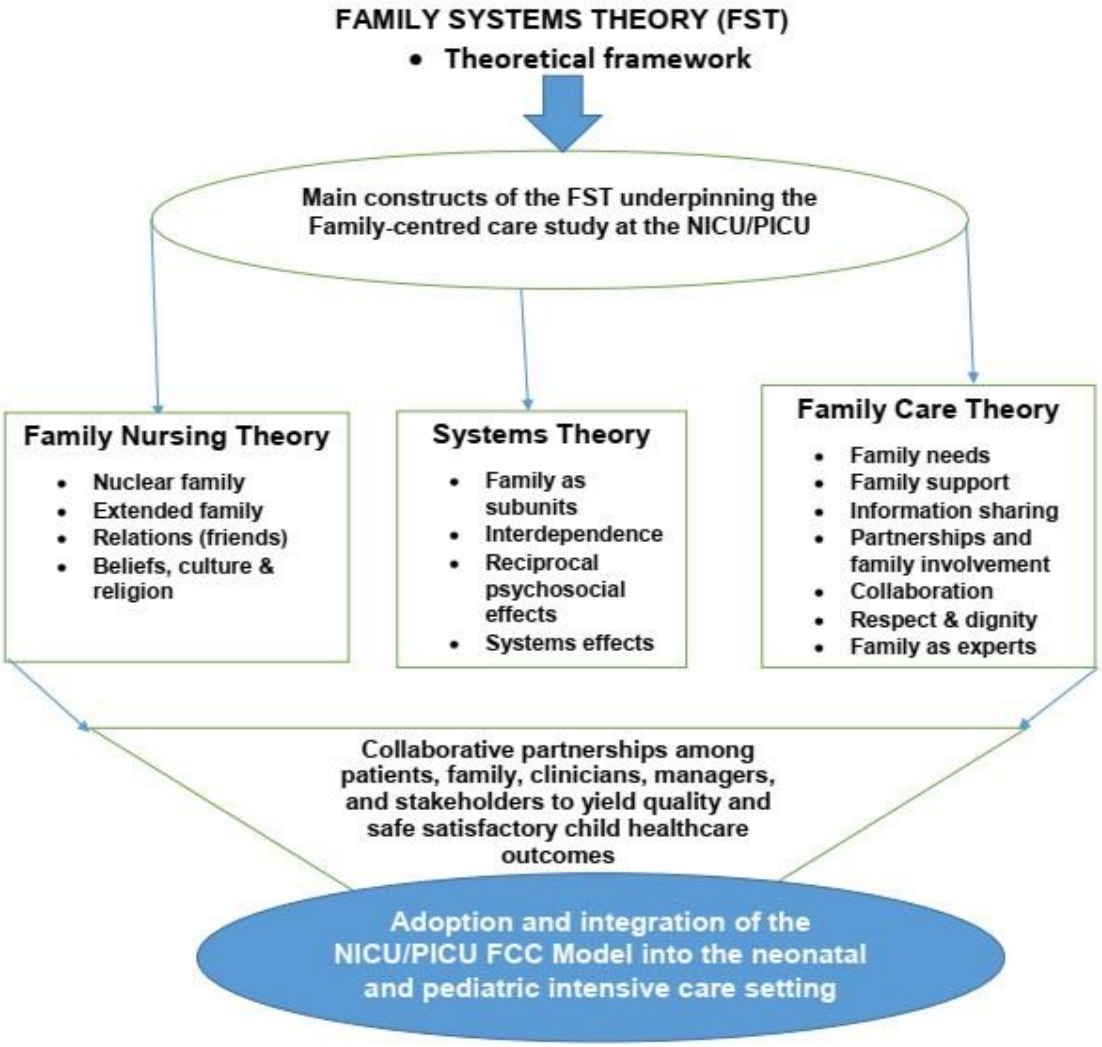


Figure 1.2: Application of the Family Systems Theory (FST) in the FCC model development in the NICU/PICU (author's constructs)

1.8.3 Concepts Specific to the Study

These are terms or words used to explain the study concepts and contextual underpinnings vividly to give meaning to the research setting.

- **Family-centered Care**

Family-centered Care is a practice and method of care for children and their families that emphasises a partnership between families and service providers, focuses on the family's role in decision-making about their child, and recognises families as experts in their child's status and needs (Jeremy Jolley and Shields, 2018). It also involves the adjustments of the facility designs to accommodate family needs (Thompson *et al.*, 2012).

- **Family needs**:

Family needs are expressed desires and wishes of families to healthcare professionals in a hospital setting that facilitates quality care (Altimier and Boyle, 2020).

- **Family satisfaction:**

In this context. it is the extent to which parents/families feel happy and fulfilled about how healthcare providers address their needs (Thermaenius, Schandl and Prignitz, 2019)**.**

- **Family involvement**:

Requires allowing the full participation of patient and family in providing healthcare to clients (Mol, Argent and Morrow, 2018).

- **Family Health Nursing**

The theory of Family Systems explains Family Health Nursing as interventions of the nurse who seeks to address family as experts in the care of a family member, since the illness of one member has a reciprocal effect on the entire family (Ray, 2018).

- **Family-centered Care Model**

This is a basic meaningful conceptual building block designed to promote family participation and satisfaction in the care of hospitalised children and their families (Davies, 2005).

- **Family**

In the context of this study in Ghana, the family comprises father, mother, grandparents, or senior siblings, older than 18years, or any person(s) who play a significant role in the patient's life, and not necessarily the client's legal or biological parent.

- **Neonate**

A neonate refers to a newborn baby from birth to 28 days/4 weeks old (Nevačinović *et al.*, 2019).

- **Premature Baby**

Refers to a newborn born before the completion of 37 weeks of gestation baby: regardless of the birth weight (Abukari *et al.*, 2021).

- **Infant**

An infant refers to a baby from birth to 24 months in the context of this study (Tume and Valla, 2018).

- **Children**

In the context of this study this is an umbrella term that refers to neonates, infants, toddlers, pre-school, and school age from birth to 12 years (Jeremy Jolley and Shields, 2018); often used as a generic term for a neonate, infant, and child.

- **Child Health**

According to the WHO, child health is state of a child's physical, mental, intellectual, social, and emotional well-being and not merely the absence of a disease or infirmity.

- **Paediatric**

Is a discipline that focus on the health and treatment of illnesses of infants, children, and adolescents up to the age of 18 years (Eichner *et al.*, 2012).

- **Intensive Care Unit**

The ICU applied in this study is specific to the intensive or critical care for critically ill children. Intensive care involves the provision of complex and specialised healthcare in acute and life-threatening conditions (Kynoch *et al.*, 2019).

- **Neonatal Intensive Care Unit**

This is a sub-unit in the child health department that provides specialised care for premature, high-risk, and critically ill newborns (Axelin, Raiskila and Lehtonen, 2020). A NICU in the context of this study is a unit that has a minimum of essential life support equipment, registered nurses, and specialised nurses and doctors in intensive or critical care, neonatal, and paediatrics.

- **Paediatric Intensive Care Unit**

This is a sub-unit in the child health department that provides specialised care for infants and children from birth to 12 years including newborns with surgical problems, out-born babies, new borns coming for re-admission, infants, toddlers, and children with: critically ill and life newborns coming for re-admission, infants, toddlers, and children with critically ill and life- threatening health problems (Butler, Copnell and Hall, 2019).

1.8.4 Methodological Assumptions

The pragmatic paradigm within which other methodological assumptions for specific components were nursed, underpinned this study. Pragmatists believe that none of the positivist or the interpretivist paradigms are capable of answering real life questions, therefore recommended an innovative combination of both paradigms in studies that seek to solve real life problems (Morgan, 2017). For example, the qualitative component of Phase 1of this study utilised the constructivist grounded theory design, whereas the quantitative study in Phase 1 utilised non-experimental descriptive research design. Chapter 3 describes the details of these methods and designs of this study.

1.9 OVERVIEW OF THE RESEARCH METHODOLOGY

This research adopted pragmatism as the underpinning philosophy for the entire study. The study embraced a multiphase mixed methods triangulation design to organise the thesis into three main phases of exploration, development, and evaluation. The first phase was an exploration phase, which describes how the scoping literature review, qualitative and quantitative studies arrived at the key concepts of FCC. The second phase was a Delphi study involving families, clinicians, and health managers as experts to develop the model, applying the model development processes. The final phase was a methodological design used to evaluate the validity and reliability of the FCC model.

The Constructivist Grounded Theory (CGT) design was employed in the qualitative study (Charmaz, 2006; De Beer and Brysiewicz, 2017), after a scoping review and critical literature review of Family Systems Theory (FST), to inform the research questions and probes during the qualitative data mining. In the case of the quantitative step, the researcher used a descriptive, quantitative, non-experimental survey to quantitatively examine the family needs, involvement, barriers, and facilitators of Family-centered care in the Ghanaian context. Achieving all objectives in Phases 1, 2 and 3 was through a scoping review and critical literature synthesis, interviews, focus group discussion, survey data collection, a Delphi study, and methodological design processes. These are summarised in Table 1.1

Table 1.1 Summary of the research methods applied in this study

PHASE 1 (Exploration Phase)	**Objectives(steps)**	**Design/ Approach**	**Sample and Sampling**	**Data Collection**	**Analysis**
	Step 1. 1. To describe the key concepts of Family-centered care through scoping review	Scoping literature review using the JBI framework	Peer-reviewed literature (Qualitative & Quantitative articles) at NICUs and PICUs	Desktop Search in-CINAHL, PubMed, Science Direct, Wiley online library & SCOPUS	Literature synthesis
	Fieldwork (Step 2) 2. To explore family needs at the neonatal and paediatric ICUs 3. To describe how family can be involved in care at the neonatal and paediatric ICUs 4. To explore the barriers of Family-centered care integration at the neonatal and paediatric ICU 5. To describe the facilitators of Family-centered care integration at the neonatal and paediatric ICU	Constructivist Grounded Theory (CGT) design	NICU/PICU clinicians & family with neonates, infants, & children admitted at NICU/PICU (18 years and above) **Qualitative:** Purposive sampling Sample size: saturation 24-Individual interviews (n=24) 12-Focus Groups Discussions (n=60) n=84	Individual interview (Head of NICU/PICU, Department consultant, Ward In-charged), ward staff, and families b. Focus Group Discussions (5 membership, 6 families FGD, 6 Clinicians/staff FGD)	Inductive and deductive CGT analysis via initial coding, intermediate coding, and advanced coding using MAXQDA

Table 1.1 Summary of the research methods Applied in this study (continued)

PHASE 1 (Exploration Phase)	**Objectives(steps)**	**Design/ Approach**	**Sample and Sampling**	**Data Collection**	**Analysis**
	Fieldwork (Step 3) Based on the qualitative findings from step 2	A descriptive, quantitative, non-experimental survey	NICU/PICU clinicians and families, health managers **Quantitative:** Convenient non-probability sampling method quota sampling, clinicians: n=100 Families: CL=95% & e=0.05; n=346	Survey Questionnaire	Descriptive statistics & factor analysis (inferential stats. & Cronbach alpha> 0.70) (Slater, Mccance and Mccormack, 2017; Hong and Kang, 2020)

Table 1.1 Summary of the research methods Applied in this study (continued)

PHASE 2 (Model Development)	**Objective (step)**	**Design/ Approach**	**Sample & Sampling**	**Data collection**	**Analysis**
	6. To develop an Family-centered care model for the neonatal and paediatric ICU	Delphi study (McMillan, King, and Tully, 2016; Slater, Mccance and Mccormack, 2017)	**Families, ICU clinicians, health managers** Purposive sampling & snowball sampling Sample size: Delphi method usually employs a sample of 15-60 experts (Allen *et al.*, 2019) This study, therefore, pegged the sample size at 25	An electronic questionnaire with a comment box	a. Descriptive statistics (mean and concordance coefficient), and b. percentages with agreement or disagreement set at least 80% consensus (Norris *et al.*, 2014)
PHASE 3 (Evaluation Phase)	**Objective (step)**	**Design/ Approach**	**Sample & Sampling**	**Data collection**	**Analysis**
	7. To evaluate the validity and reliability of the developed neonatal and paediatric Family-centered care model	Methodological design	Experts Purposive sampling of ICU clinicians, families, health managers, and policy experts Sample size: 25	An electronic questionnaire with a comment box	Content and face validity with an estimation of Cohen's Kappa Index (CKI), Content Validity Index (CVI) with the agreement set at ≥0.78 at 0.05 level of significance

1.10 ORGANISATION OF THE THESIS

This thesis was organised into nine chapters:

- Chapter One: Overview of the study
- Chapter Two: Phase 1: Step 1, literature review
- Chapter Three: Research methodology
- Chapter Four: Phase 1 step 2, qualitative study.
- Chapter Five: Phase 1 step 3, quantitative study.
- Chapter Six: Phase2, Delphi studies and model development
- Chapter Seven: Phase 3, model evaluation.
- Chapter Eight: Integrative discussions of the results
- Chapter Nine: Conclusions, recommendations, and limitations of study

1.11 SUMMARY

This chapter presented an overview of the entire thesis in which it highlighted the concepts of Family-centered care in the background, justification for the study and its significance. There was an outline of the research problem and questions, and synopses of the research methods to answer them presented. The chapter presented the concepts and operational definitions of terms used in the study, and detailed the assumptions of the researcher relative to nursing philosophy and research paradigm.

Chapter 2, the next chapter, outlines a critical literature appraisal to present the context, existing Family-centered care models, barriers, and facilitators of Family-centered care

CHAPTER TWO

STEP ONE: CRITICAL LITERATURE REVIEW

2.1 INTRODUCTION

This chapter critically examined the literature to contextualise the study. The researcher conducted an extensive literature review using the key terms of the study, including Family-centered care (FCC), family support, and barriers and facilitators of Family-centered care, NICU/PICUs, and models of FCC in the ICU. Due to the essence of the concepts of Family-centered care in this study, there was a more focused literature search and synthesis (scoping literature review) conducted and presented. The chapter aims to provide a detailed background of the study to help contextualise the study. The searched data were synthesised, analysed, and the results presented and discussed.

The presentation of the results of the review was in five sections. The first part focused on supporting patients and families with the experiences of critical illnesses, highlighting their needs in ICU, adaptations to critical illnesses, and their satisfaction in the ICU. The second section highlighted the family-centered care, focusing on its definition, brief history, barriers, facilitators, and benefits in the ICU. The third section explored and presented the experiences of Family-centered care in the ICU as published by previous researchers. Subsequently, the key concepts of Family-centered care, as practiced in the neonatal and paediatric ICU, that emerged from 52 articles were extracted, synthesised using Joanna Briggs Institute (JBI) scoping methodology, and presented in section four. The fifth and final section explored existing models in research and Family-centered care models to identify the gaps in those models and give directions to the development of the neonatal and paediatric intensive care Family-centered care model. Before presenting these results and discussions, the beginning sections outlined the literature search, inclusion and exclusion criteria, data charting, and data synthesis.

2.2 SEARCHING THE LITERATURE

A basic computerised literature search took place in electronic databases, including CINAHL, Medline, PubMed, Scopus, and Wiley Online Library using the keywords: family-

centered care, history of Family-centered care, family support, barriers of FCC, and facilitators of FCC, Neonatal and Paediatric Intensive Care, and models of FCC in ICU. The downloading of the articles was through the links provided on the electronic databases or search engines. A request was made of Wits University Health Science Library to help retrieve the studies the student was unable to find. There were forward and backward searches conducted on relevant studies to retrieve cited papers. The initial computerised search occurred in May 2020.

The search string developed and used for the specific scoping search was Family-Cent* Care OR Patient-Cent* Care AND Neonat* OR Paediatric OR Pediatric OR Child* AND Intensive OR Critical Care Units.

2.3 INCLUSION AND EXCLUSION CRITERIA

Initially, there was no restriction in years of publication because of the need to include models developed decades ago. The advanced database search conducted in the concept of FCC restricted the years of publication to between January 2015 and December 2019. Studies were included if they were conducted on FCC in NICU/PICU, in English, from 2015 to 2019. The rationale for the five year review was to obtain literature survey on just the key concepts of FCC to serve as a sensitising concepts for the planned qualitative study based on the CGT design. **Table 2.1** presents the details of the inclusion and exclusion criteria**.**

Table 2.1 Inclusion and exclusion criteria

Inclusion	Exclusion
Primary research articles	Systematic reviews, protocols, trial, pilot, and tools validation articles
Articles published from 2015 to 2019	Articles published before or after the date
Only articles in English	Articles in other languages
The focus was on FCC	Studies outside the concept of FCC
The setting was NICU/PICU	FCC studies and related research in adult ICU

2.3.1 Selection of Studies and Data Extraction

The researcher developed the searched string with guidance from a certified JBI researcher and a university librarian. The researcher tested the string in PubMed, and then forwarded the string to the supervisor (SS) for review. The researcher (ASA) and supervisor (SS) then decided on the five databases for the review, i.e., Scopus, PubMed, CINAHL, Google scholar, and Willey Library online. There was modification of the data extraction, with inputs and recommendations from the supervisor (SS) before data extraction. The researcher did the data extraction with support from SS and EKA to deal with disagreements. The scoping focused on the author (s), year, country, title, aim, methods/paradigm, and key findings, including gaps in the literature. F**igure 2.1.** The PRISMA flow diagram shows the 52 studies extracted from the review. The PRISMA diagram was adopted from the PRISMA Group and used for systematic reviews and meta-analyses (Moher *et al.*, 2009)

2.3.2 Description of Studies included in the Scoping Review

A basic search using the search string yielded 24,609 results from PubMed. The researcher conducted an advanced search, extracting 881 articles from the five databases, and screening these down to 52 full articles per the consensus on the inclusion criteria. See **Appendix A** for the details of the 52 synthesised studies.

The majority of studies (29: 55.8%) included in the scoping review employed qualitative research methodology with exploratory and phenomenology as the most common qualitative designs used to research into FCC in the ICU; the least used qualitative method was the grounded theory method. Additionally, quantitative methods constituted about 14 (27%) of the studies reviewed, whilst the least methodological approach (9: 17%) was found to be the mixed methodology, albeit the multi-method design was also used. The 52 extracted studies were distributed across all continents with a total participant sample size of 7889, of which the majority were parents (6124), clinicians (1755), and the last category of participants were managers (10). The main sampling technique used in the 52 studies was purposive sampling, possibly adopted to recruit the specific participants in such studies.

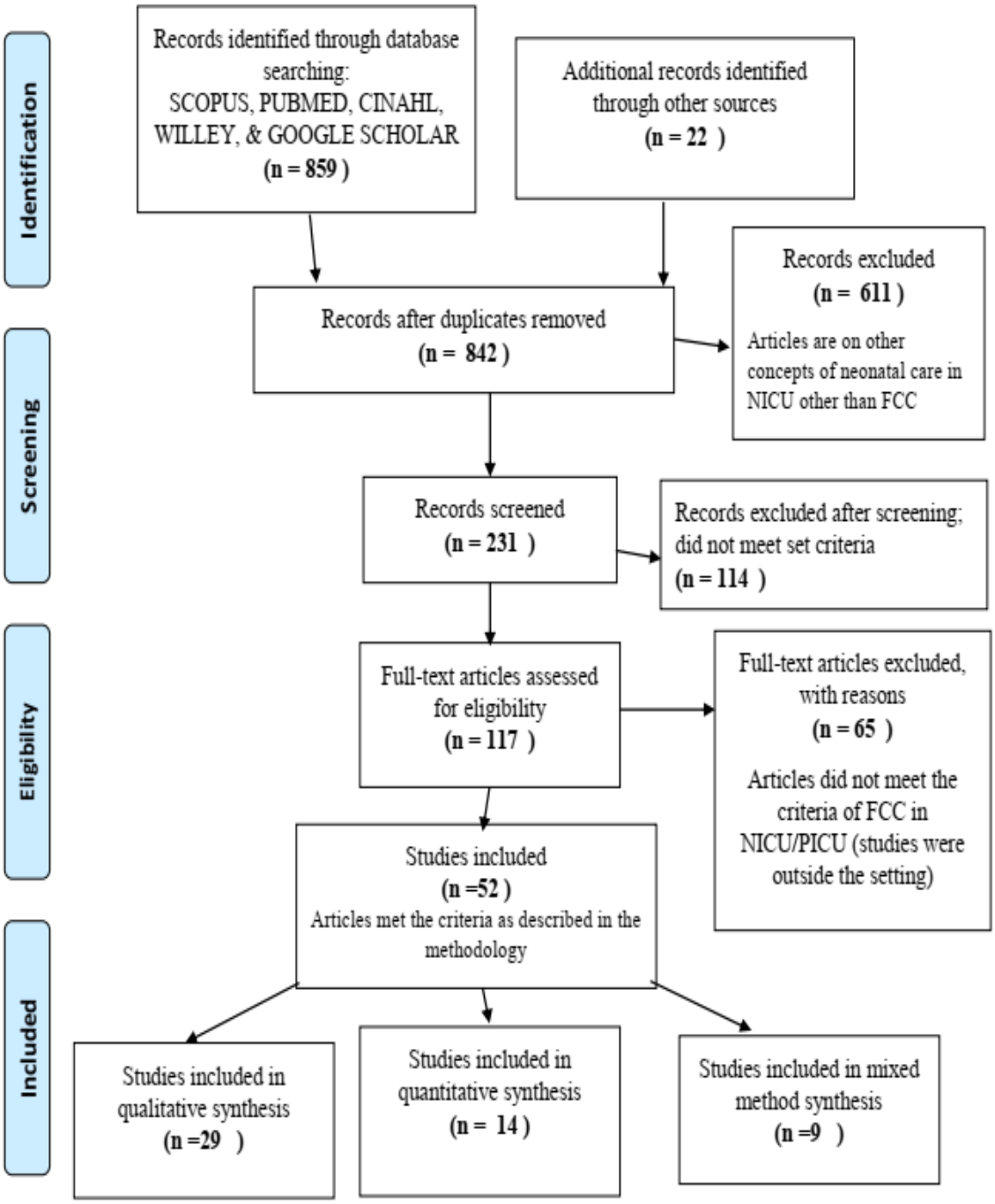


Figure 2.2: PRISMA Flow Diagram Search and inclusion

2.4 CHARTING THE DATA

The data extraction was from only primary research articles and charted on a developed data matrix. The studies were grouped into three, i.e., parents' perspectives, Clinician's perspectives, and parents, clinicians, and managers' perspectives of FCC. The information

charted includes citation (authors, year), study origin, aim, methods/paradigms, and key findings/gaps.

2.5 DATA SYNTHESIS

The researcher focused on the methods, key concepts of FCC, and the gaps in the literature relative to FCC in the NICU and PICU. The reviewers developed the data matrix to compare the data and carefully reach a consensus for the inclusion of 52 articles in the analyses. The articles were imported into MAXQDA, and content analysed for the main themes to emerge. Data analysis was through data reduction, data display, data comparison, drawing conclusions, and verification. The results of the scoping review gave rise to three main categories after thorough content analysis according to the study objectives. The three thematic areas that emerged were the description of the studies reviewed: article description and participants' description; key concepts of FCC: dignity and respect, communication, participation, and collaboration; gaps in the literature.

2.6 RESULTS AND DISCUSSION

The literature search results were synthesised and succinctly presented results and discussion to illuminate the gaps relative to the practices of FCC in the NICU/PICU. Subsequently, there was a summary presented at the end of the chapter to highlight the direction of this study.

2.6.1 Supporting Patients and Families with the Experience of Critical Illness

In this section of the chapter, the researcher explored the reviewed literature for the experiences of critically ill children and their families in the NICU/PICU. These were then synthesised and presented as family needs during critical illness, family adaptations to critical illnesses, and family satisfaction in the ICU.

2.6.1.1 Family needs during critical illness

The expression of the needs of family are as desires and wishes to healthcare professionals in a hospital setting that facilitates quality care. These needs can be at an individual level

and or at the family level since there is an inextricable link between the two. Several studies have reported respect, dignity, information, and support as the needs of families during hospitalisation especially in the ICU (Colon, 2001; Oglio *et al.*, 2014; Umberger, Canvasser and Hall, 2018; Latour and Coombs, 2019; P. Govindaswamy *et al.*, 2019; Priya Govindaswamy *et al.*, 2019a; Altimier and Boyle, 2020; Ocampo, Tinero and Rojas-Ashe, 2020).

For instance, family needs adequate information regarding the care processes in the ICU (Neill and Fateel, 2016; Phiri, Chan and Wong, 2020). Moreover, they need support to adapt to the ICU phase of care and to learn continuity of care after discharge (Hauck *et al.*, 2016; Valizadeh, Hosseinzadeh, *et al.*, 2018). Some families need support to breastfeed and practice kangaroo care, especially new families with preterm babies (Aagaard *et al.*, 2015; Cuttini *et al.*, 2019; Goldstein and Malcolm, 2019). In their scoping literature review, King *et al.* (2019),intimated that unresolved family needs in the ICU can have a negative impact on a patient's transition to home care. In fact, when these needs are not addressed promptly it may add to the parental stress, resulting in anxiety and post ICU depression (Montirosso *et al.*, 2012; Schmollgruber, 2019).

Indeed, the health of family members may be affected by the way the needs of their love one in the ICU are addressed, with such events having possible long term effects (Davidson, 2009; Hirshberg *et al.*, 2020). A comparison of the needs of families and clinicians in the ICUs are incongruent and there is therefore the need for the clinicians to approach the care of the critically ill holistically, and their family with love, respect, and empathy (Curtis *et al.*, 2016; Hirshberg *et al.*, 2020). King *et al.* (2019) reported that adopting the social support needs framework would assist healthcare providers to meet the needs of families. The social support needs framework advocates for the provision of information to families and patients, provision of empathy, trust, love and care, provision of constructive feedback, and provision of tangible aid and services to directly assist family needs (King *et al.*, 2019). In the ICU, nurses and doctors often address these needs, but the continuous complaints from families may constitute some level of dissatisfaction towards ICU phase of care.

The Critical Care Family Needs Inventory (CCFNI) tool is famously noted in intensive care literature as the tool for measuring the needs of family in the Intensive Care Unit (Molter and Leske, 1983; Mitchell *et al.*, 2018). The CCFNI tool measures the needs of the family

in the ICU, including assurance, proximity, support, information, and comfort (Molter and Leske, 1983; Mitchell *et al.*, 2018). Many of these studies in the ICU derived their findings using this tool across different settings. The Self-Assessment Inventory (SAI) tool, developed by the Institute of Patient and Family-centered Care (IPFCC) in the United States, also identified respect, dignity, and information as the key needs of family in the hospital (www.ipfcc.org, 2021), and used equally across different settings to assess family needs and overall practices of FCC.

In Ghana, families demand respect from the clinical team and support staff to go through the stressful ICU phase of care. Most families with sick children in the ICUs are the direct patents of the sick child, including the father and mother, albeit fathers are rarely involved in our context. The fathers often leave mothers in search for finances to support the cost of intensive care, as these services, including regular laboratory screenings, drugs, and ventilator care, are expensive. The needs of the family to cope with the illness of the sick child in ICU usually extends to meeting their socio-cultural and religious beliefs at least halfway to gain their full participation and collaboration.

2.6.1.2 Family adaptations to critical illness in the ICU

Critical illness constitutes a life changing event for the sick child, family, and caregivers (Davidson, 2009; Mendes, 2018). Normally, when a member of a family is sick and admitted into hospital it affects the immediate family processes (Davidson, 2009; Montirosso *et al.*, 2012; Curtis *et al.*, 2016; de Beer and Brysiewicz, 2017; King *et al.*, 2019). Parents are usually disrupted in caring for other children as well as in performing their normal daily activities (Montirosso *et al.*, 2012; Mendes, 2018). Families therefore need to adapt and adjust to the critical illness of a child. Such adaptions come with attending consequences on the family, and may even interrupt the support from the family in the care processes (Curtis *et al.*, 2016; Foster *et al.*, 2017; King *et al.*, 2019). The bases for these adaptations could be the strengths of the family, including emotional, financial, family size, and educational level. Thus, different families may adapt different strategies to cope and adapt with the admission of their sick children into the ICU. Clinicians must strive to understand the strengths and weaknesses of families and their sick children in the ICU to support their adaptations in the ICU phase of care. Such practices may be helpful in improving the quality of life of both the caregivers and the patients (Lim and Zebrack, 2004). There is a need to develop interventions

that will incorporate models of care of adaptation to families and their sick children (Curtis *et al.*, 2016). For example, the conceptualisation of family care in South Africa assisted families to adapt to the critical illnesses of their children (de Beer and Brysiewicz, 2017).

In the Ghanaian context, managing the family and caregiver adaptations to the stress of critical illnesses is usually through the involvement of extended family members and friends to support the adaptation process. These backdrops cement the need for the integration of family-centered care into the ICU practices, thus the significance of a context specific model of FCC for NICU/PICU.

2.6.1.3 Family satisfaction in the Intensive Care Unit (ICU)

Family satisfaction in our healthcare institutions is a hallmark of quality healthcare delivery by the professions (Stricker *et al.*, 2009; Ferrando *et al.*, 2019; McLennan and Aggar, 2020; Haave, Bakke and Schröder, 2021). However, in our ICUs, one often hears the grumbling of families about the care rendered to them during the admission of their critical ill family members into the ICU. Such lamentations call for a review of the care plans rendered in the ICUs to include families at the pinnacle of the care, and these are the key themes of FCC. Stricker *et al.* (2009), in Switzerland, recommended the provision of emotional support, complete information, and coordination in care to improve the satisfaction of families in ICUs. A large cohort study in the United Kingdom revealed a high satisfaction of families with ICU care due to free flow of information and family involvement in decision making in the ICUs (Ferrando *et al.*, 2019). Similarly, what makes the difference for family satisfaction in the ICU in Switzerland is building professional-family relationships and involving family in decision making (Stricker *et al.*, 2009).

It is therefore evident that family satisfaction is the main ingredient for evaluating the care rendered at the ICU and is in tune with the concepts of FCC, with the latter focusing on collaborative partnerships in care to promote family satisfaction. However, the issues of satisfaction may not arise in Ghana, as there are no existing documented practices of FCC in the ICU. The development of this model will be relevant to set the pace for this specific assessment of quality care. The next section is focused on Family-centered Care.

2.6.2 Family-centered Care (FCC)

The section detailed the meaning of FCC, history of FCC, barriers and facilitators of FCC, and benefits of FCC.

2.6.2.1 Definition of Family-centered Care

Several studies have defined FCC as a practice that posits the family and the sick child at the centre of all the care processes to allow their respectful participation in decision making, and collaborative partnerships (Mikkelsen and Frederiksen, 2011; Benzies *et al.*, 2019; Latour and Coombs, 2019; Schmollgruber, 2019; www.ipfcc.org, 2021). This concept of care seeks to advocate family as experts and partners in the care of patients. Family is often described as the basic unit of a child's life and is therefore integral to the care of a sick child (Hohashi, 2018; Ray, 2018). In Ghana, the families play the caregiver role on admission of their loved ones into hospital, although there is poor documentation of the practices of FCC, especially in the ICU. The roles played by families during hospitalisation include supporting activities of daily living, care coordination, and funding in the purchase of needed drugs and supplies for care provisions. In this context, these roles are not only played by the father and mother of the sick child but also by significant others of the family, including grandparents, senior siblings of the child, and in some cases, friends and neighbours of the family. The Ghanaian healthcare system lacks any documented context specific model to integrate families into the ICUs and recognise them as experts in the care of their critically ill children.

2.6.2.2 Brief history of Family-centered Care

The FCC originated in Europe after the Second World War through social change, political and research reforms (Bamm and Rosenbaum, 2008; Jeremy Jolley and Shields, 2018) dating back to the 1950s (Shields, 2010), and gained popularity in the 1980s (Coffin and Zaoutis, 2011). FCC is central to the provision of modern paediatric nursing care (Franck and O'Brien, 2019). It is an approach of care that places the patient and the family at the focus of the healthcare (Jeremy Jolley and Shields, 2018; Smith, 2018). Historically, the approach of accepting and involving parents in the care of children had faced enormous challenges and resistance from nurses and doctors because this was a paradigm shift in healthcare, which is patient and pathologically-centred (Bamm and Rosenbaum, 2008). Carl Rogers

(1940) came up with the idea of FCC in his concept of psychotherapy, in which he argued that patient care should be a mutual process between the individual, family, and the health team (Bamm and Rosenbaum, 2008). The development of the FCC approach continued over eight decades, changing names along the process, such as patient-physician relationship, client-centred therapy, patient-centred care, and relationship-centred care. However, the term 'patient-centred care,' although seldom used now, in child health is FCC. Therefore, FCC acknowledges that a child's health and wellbeing are inextricably linked to their families (Jeremy Jolley and Shields, 2018).

2.6.2.3 Barriers and facilitators of Family-centered Care

Families have often complained of the complex environmental setup of ICUs, especially at first sight with its technological equipment buzzing noises (Hill *et al.*, 2019a). These physical environmental designs and set up, even though necessary in clinical practice, constitute a major form of worry to families with sick infants in the ICU. The connection of respiratory support to sick infants and children in the ICU are reportedly a source of parental anxiety and interrupts family involvement and participation as most of them are unable to withstand such sights (Altimier and Boyle, 2020). Indeed, some researchers have argued that anxiety and depression among families in the ICU can add to the clinical workload (Latour and Coombs, 2017). These families therefore require adequate information and counselling to support them cope with such experiences in the ICU. Kangaroo care rooms in the NICUs have also been documented to improve the weight of preterm neonates for survival throughout the crucial infancy periods (Altimier and Boyle, 2020). Current ICU designs make provision for Clinical Support Zones, including KC rooms that will support the care of preterm babies (Thompson *et al.*, 2012). Staff training on FCC practices, multidisciplinary approach, and instituting mentors in the NICU facilitated the implementation of FCC in Finland (Toivonen *et al.*, 2019). The entire ICU phase of care is challenging to families and their sick children with its complex designs (Lundqvist, Weis and Sivberg, 2019). Some Canadian researchers recommended the facilitators of FCC to include refining staffing models, providing tools to deliver consistent care, and designing family-friendly environments (Benzies *et al.*, 2019).

Furthermore, in the chain of FCC, fathers are usually lost as they often do not go to the hospital in most settings (Raiskila *et al.*, 2016; Valizadeh, Mirlashari, *et al.*, 2018). In Ghana

for instance, mothers support the sick infants and children in the hospital, and the fathers come in for visitations. This phenomenon constitutes a barrier in FCC practices, especially when the clinicians need to make decisions on the care of the sick infants and children in the ICU. Suboptimal communication or lack of it between families and clinicians in most ICUs has been reported as a major barrier of FCC (Adams, Mannix and Harrington, 2017). Over the years in Ghana, FCC practice has faced challenges such as lack of appropriate unit designs to accommodate families for their full participation in the care of the critically ill infant and children. This suggests that the NICUs and PICUs have to be redesigned to allow for easy application of FCC (Al-Motlaq, 2018). Families are only able to visit babies admitted at the NICU during scheduled visitation periods; such visitation periods are often for infant feeding (breast feeding and expressing breast milk) and settling payments (which is not part of FCC). Therefore, conscious involvement of families of a sick child in the ICU will facilitate the care processes and promote early discharge (Segers *et al.*, 2019).

2.6.2.4 Benefits of Family-centered Care

Research in the intensive care literature underscores several benefits of FCC implementation in the ICU, including shorter length of stay, improved quality care, family satisfaction, promoting information sharing, reducing family anxiety, among others (Hadian *et al.*, 2016; Brødsgaard *et al.*, 2017; Shahul *et al.*, 2017; Yu Xiaoyan and Zhang, 2018; Dall'Oglio *et al.*, 2019; Segers *et al.*, 2019; Yu and Zhang, 2019). For instance, a systematic review by researchers in the Netherlands found strong evidence of FCC implementation shortening the length of stay in the ICU. Out of the 17 studies, seven were intervention studies that reported reduced length of stay and the remaining 12 studies reported high family satisfaction in participating in NICU (Segers *et al.*, 2019). Non-medical care processes, including diaper change, cleaning of sick children, breastfeeding, consolability, changing clothing, and assisting in bathing can be improved with implementation of FCC in the ICUs (Staniszewska *et al.*, 2012; Brødsgaard, Zimmermann and Petersen, 2015; Mehta *et al.*, 2017; Dall'Oglio *et al.*, 2019; Frechette *et al.*, 2019; Segers *et al.*, 2019; Altimier and Boyle, 2020).

Families remain an integral part and a constant in a child's life, whilst the healthcare professionals oscillate, hence, the implementation of FCC would inure to the benefits of the children and their families since the confidence of the latter would be improved to continue

home care for a full recovery (Grandjean *et al.*, 2016; Shields, 2017; Arabiat *et al.*, 2018; Dall'Oglio *et al.*, 2019).

A study involving families and nurses in the ICU in 11 NICUs across Europe concluded that FCC implementation would help improve overall quality of healthcare and therefore should be accepted into the intensive care (Raiskila *et al.*, 2016). Healthcare professionals in the ICUs should embrace the idea of FCC for its full implementation. Contextually, the environmental designs of the ICUs are conducive to allow full family participation, albeit clinicians accepting the fact that FCC is relevant. In the interim, fathers and mothers have full access into the NICU/PICU to tap into some of these benefits. There is the need to explore the contextual barriers and facilitators to the implementation of FCC for families, children, and the health system to achieve its full benefits. The next section focuses on the experiences of critically ill children and their families in the ICU.

2.6.3 Research Exploring the Experience of FCC

Family-centered Care (FCC) is an approach of care for children and their families that has been widely researched and practiced in the developed world (Eichner *et al.*, 2012; Latour and Coombs, 2017; Skene *et al.*, 2019a; www.ipfcc.org, 2021). Globally, paediatricians and intensive care experts have embraced it to improve child health outcomes (Eichner *et al.*, 2012; Kuo *et al.*, 2012; Ambardekar, Litman and Schwartz, 2013; Enisha and Arti, 2019). The Institute of Patient and Family-centered Care (IPFCC) has identified four main concepts of it including respect/dignity, communication, participation, and collaboration (www.ipfcc.org, 2021). Indeed, FCC should be viewed as polices that place the parent and family at the fulcrum of ICU services and informed decision making about medical care (Uniacke, Browne and Shields, 2018; Franck and O'Brien, 2019). FCC initiatives are more than just flexible visiting hours, they encompass but not limited to family presence during rounds and resuscitations, family involvement and participation in care and decision making, information and education, and placing families at the centre of care (Latour and Coombs, 2019).

The FCC practices reportedly require environmental design, including family comfort zones, washrooms, and more space; this would help build respective collaborative partnerships between healthcare professionals and families of sick children in the ICU to meet their

physical, emotional, social, and developmental needs (Dennis *et al.*, 2017; Ding *et al.*, 2019; O'Connor, Brenner and Coyne, 2019). In most jurisdictions across the world, clinicians have accepted and implemented FCC in neonatal and paediatric care, which resulted in parental satisfaction and shortened the length of stay in the ICU (Hagen *et al.*, 2019; Segers *et al.*, 2019; Toivonen *et al.*, 2019). Family involvement in ICU has culminated in improved weight gain, breastfeeding practices, and reduced infection rates (Zhang *et al.*, 2018), yet its application in the ICU in some parts of the world, including Africa and Ghana for that matter, face several challenges due to contextual preferences. In reality, few compendia exist in Ghana relative to the practices of FCC in the ICU compared to the rest of the world.

As an illustration, in Asia, the main concepts adopted were support, visual information, collaboration, partnerships and mutual trust (Shimizu and Mori, 2018a; Hassankhani *et al.*, 2019; Uhm and Kim, 2019). On the American continent, the core concepts of FCC are information sharing (education and communication), participation (parental involvement), respect and dignity, and shared decision making (Discenza, 2018; Clarkson, Gilmer, *et al.*, 2019). Similarly, in Sweden, training of nurses and physicians improved their support for parents to participate in the care of their children. Mentorship to junior clinicians in the ICU was used to appreciate families as experts in the care of children (Kjellsdotter, Lantz and Ottosson, 2018). Norway employed respect and empathy to yield family satisfaction (Hagen *et al.*, 2019), whilst Denmark used family support to address the barriers of FCC (Brødsgaard *et al.*, 2017). South Africa employed family involvement and provision of adequate information for infants and families to gain the satisfaction of parents in the ICU (Mol, Argent and Morrow, 2018), and flexible visiting times were allowed for parents to connect with their hospitalised children in Tanzania (Saria, Mselle and Siceloff, 2019). Apart from Europe and the United States, which utilised and implemented these four concepts, other parts of the world have implemented portions of it based on what works in their context. In the case of Africa, little or no studies exist on FCC in the NICU, especially in Western Africa and Ghana. These findings in intensive care literature cement the argument of contextualising the practices of FCC, as different settings adopted what worked best per context.

What is also evident in these studies is that the findings are largely emanating from families' perspectives, albeit a few from clinicians' perspectives. Meanwhile, the involvement of fathers, mothers, nurses, midwives, doctors, and health managers in one study will broaden

the contextual practices and appreciations of FCC in any setting. There is therefore the need to explore the practices and experiences of both families and clinicians extensively to gain broader understandings of the contextual practices of FCC. In Ghana, there is poor documentation of the practices of FCC in the NICUs and PICUS, and hence its contextual practices, family needs, barriers, and facilitators as well as the experiences of families and clinicians are vague.

2.6.4 Key FCC Concepts

Primarily, the scoping review was to map and examine literature for the key concepts of FCC in the NICU/PICUs. The review question was *What are the key concepts of Family-centered Care in the neonatal and paediatric intensive care units?* The researcher followed the Joanna Briggs Institute (JBI) methodology for scoping reviews. The final report conforms to the PRISMA-ScR guidelines (Peterson *et al.*, 2017). This checklist was used to synthesise primary published literature and analyse available models of FCC to identify knowledge gaps, set the research agenda, and map the concepts of FCC (Tricco *et al.*, 2016).

There was identification and presentation of some key concepts of FCC used in different contexts across the world. In Asia, for example, the main concepts adopted were support, visual information, collaboration, partnerships, and mutual trust (Shimizu and Mori, 2018a; Hassankhani *et al.*, 2019; Uhm and Kim, 2019). On the American continent, the core concepts of FCC are information sharing (education and communication), participation (parental involvement), respect and dignity, and shared decision making (Discenza, 2018; Clarkson, Gilmer, *et al.*, 2019). Norway employed respect and empathy to yield family satisfaction (Hagen *et al.*, 2019), whilst Denmark used family support to address the barriers of FCC (Brødsgaard *et al.*, 2017), and South Africa employed family involvement and provision of adequate information for infants and families to gain the satisfaction of parents in the PICU (Mol, Argent and Morrow, 2018). The following sub-sections present the results and discussions based on the four key concepts of FCC, i.e., dignity and respect, participation, communication, and collaboration.

2.6.4.1 Dignity and respect

From the data synthesis**,** three sub-themes emerged for this concept of FCC, i.e., family needs, building rapport, and sociocultural background. The review found that the needs of families with sick children in the ICU include privacy, sociocultural, and emotional needs (Amorim *et al.*, 2019). The fundamental concepts that emerged under building rapport sub-theme were mutual respect, reassurance, and accepting the individuality of families (Brødsgaard *et al.*, 2017; Hagen *et al.*, 2019). The review found that families required clinicians to respect their social norms, beliefs, fatherhood, and cultural-religious backgrounds when dealing with their sick children in the ICU (Vasli *et al.*, 2015).

A focused ethnographic study in Iran, involving nurses and mothers in intensive care, built trust between parents and nurses. This impacted family involvement and participation in the care of neonates at the NICU (Hassankhani *et al.*, 2019). Thus, building trust with patients and family is a manifestation of good respect, which has an automatic reflection on their participation and promoting quality outcomes for child health. A similar study by Vasli *et al.* (2015) emphasised the need for nurses to deal with the socio-cultural background of parents (fathers) to narrow the theory-practice gap in the implementation of FCC in the NICU. This implies that family involvement, and respect for their socio-cultural background, in the hospital by clinicians through effective communication may help build partnerships and collaborate with families. A narrative inquiry in the United States also revealed the negative impact of social inequalities, race, and ethnicity on family involvement (Sigurdson *et al.*, 2018). This shows that respecting individual and family social, race, and ethnic disparities may invoke family involvement in NICU care.

A Danish qualitative grounded theory study alluded to the influence of fathers' involvement in the care of their sick neonates at the NICU. The study cautioned nurses to consider fathers as co-parents by ensuring that their child's progress directly informs them (Noergaard *et al.*, 2017); this may address the role fatherhood plays in childcare. A mixed-method study in Europe, ensuring the privacy of neonates and their families, irrespective of their sociodemographic background, was able to deal with parental emotional stress and facilitate FCC implementation (Amorim *et al.* 2019). Families' cultural characteristics were obstacles to FCC implementation in Turkey; this called for contextualising the concepts of FCC for its full integration into different health systems (Boztepe and Kerimoğlu Yıldız, 2017a). Hill

et al. (2019) identified the culture of the families as a key component for the provision of care in the Intensive Care Unit. In South Africa, a good professional attitude towards parents with sick infants in the PICU culminated in family satisfaction and positive child health outcomes (Mol, Argent and Morrow, 2018). Healthcare professionals in the NICU must accept the individuality of families, even including the extended families, and recognise them as an essential part of the care in the NICU (Brødsgaard *et al.*, 2017). Therefore, maintaining the respect and dignity of parents and their sick children was a major pillar in the acceptance and implementation of FCC in the NICU/PICU. Further exploration into FCC in different socio-cultural contexts is necessary to foster its full implementation.

2.6.4.2 Participation

Two sub-themes emerged from the content analyses, involvement and support. The involvement of families in the care of their children in the ICU was enhanced through building partnerships, kangaroo care, enteral feeding, communication, building trust, follow-ups, overnight stay, and the Partnership in Pain Care Model (Benzies, 2016; Clarkson, Bc, *et al.*, 2019). The review found that families can be supported in care to improve child health outcomes in several ways, including encouraging mothers to participate in the care, building close relationships with families, parent-friendly visual information, addressing barriers of care, individualised supportive care of families, and addressing psychosocial needs of a family (Serlachius *et al.*, 2018).

Contrary to what most health providers think about family involvement causing infection at the NICU, a study conducted in China could not derive an association (Li *et al.*, 2016). Enke *et al.* (2017) reported from their study in Germany that parental involvement in care by clinicians from the beginning of a child's stay in the NICU was responsible for reducing parental stress and yielding good prognoses for young parents with severely ill neonates. Similarly, in the United States, the family involvement in the care of their preterm babies using kangaroo care resulted in positive outcomes, including early recovery. Therefore, there should be a conscious policy supporting father involvement in NICU care (Clarkson, Gilmer, *et al.*, 2019). A randomised control trial in Taiwan corroborated the significances of family involvement as it was found to have promoted earlier full enteral feeding and hospital discharge, greater weight gain, and better neurobehavioral performance (Hsieh *et al.*, 2017). Thus, healthcare professionals in the NICU should play a significant role by assisting parents

and ensuring they are directly informed about their children's progress to be fully involved in the care processes (Noergaard *et al.,* 2017).

Additionally, managers must be involved in the whole idea of FCC to eliminate the barriers and provide the requirements for service providers and families to build a close relationship among them in the NICU (Hadian *et al.,* 2016). Canadians build partnerships by using effective communication and education, and mutual expectations via an open and transparent dialogue with parents (Denis-Larocque *et al.,* 2017). By implication, supporting parents with high-risk neonates from admission to discharge will address barriers of FCC and family needs in the NICU and improve FCC practices (Serlachius *et al.,* 2018). In Sweden, family involvement in intensive care helps them manage their stress and anxiety associated with a child's illness and admission in the NICU (Dahav and Sjöström-Strand, 2018). Thus, FCC's philosophy has envisioned easing parental involvement and improved outcomes for infants and families. This confirms the reasons for more empirical research into FCC in the NICU to understand its contextual implementation. An Asian study by Heo and Oh (2019) reported how partnerships with parents led to the change in facility protocols to foster parent participation (Heo and Oh, 2019). In the United States, nurses aspired to involve parents in intensive care, especially for those with acute pain, to help manage the pain experience, reduce anxiety, and increase family satisfaction (Vasey *et al.*, 2019). Finally, partnerships, support, and family involvement have a direct impact in addressing family needs, which may ultimately pave the way for collaborative care in intensive care. These findings need examining in a different setting to contextualise FCC integration.

2.6.4.3 Communication

Two sub-themes emerged from the content analysis of the data matrix, i.e., education and information. Information sharing through effective communication between clinicians and families with critically ill children in the ICU is yet another key concept of FCC (Uhm and Kim, 2019). The review found empathetic communication, modification of clinicians' attitudes to deal with varied socio-cultural backgrounds, application of Relational Communication Theory, identifying and removing communication obstacles, and education were useful strategies for the implementation of this concept of FCC in the ICU (Benzies, 2016; Butler *et al.,* 2019). In Japan, for example, parent-family visual communication was used to deal with family needs for effective coordination in the ICU (Shimizu and Mori,

2018a). Oxley (2015) used Heidegger's interpretative phenomenology to explore the experiences of parents in a United States PICU and found that support and communication resulted in reduced parental stress and post-traumatic stress syndrome relative. Also, a relational communication theory was used to improve FCC implementation in a Canadian NICU (Benzies, 2016). A Korean quasi-experimental study found that collaboration and information sharing between nurses and mothers led to a positive influence on mothers' emotional and cognitive outcomes, parental satisfaction, parental self-efficacy, perceived partnership, and anxiety in the ICU (Uhm and Kim, 2019).

In Brazil, parents' education improved their easy integration into the NICU (Felipin *et al.*, 2018). The education provided adequate and reassuring information to the families regarding childcare (Priya Govindaswamy *et al.*, 2019b). Again, in the works of Amorim *et al.* (2019) in Portugal and France, information and education gave enough emotional support to parents with sick neonates and resulted in the implementation of FCC. The provision of adequate information for families was also the core concept of FCC in the United States (Hill *et al.*, 2019b), as it helped to reduce post-traumatic stress syndrome associated with transfer and admission into the NICU (Oxley, 2015). In Denmark, knowledge sharing by clinicians provided the basis for the families' understanding of the child's illness, and the ability to perform competent supporting roles in the care of neonates in the NICU.

Similarly, a relational communication approach was adopted in Canada to yield improved infants and families' health outcomes and implementation of FCC in the NICUs (Benzies, 2016). Communication with Asian families was an essential foundation for family participation in newborn care (Heo and Oh, 2019). These findings underscored the relevance of information sharing and effective communication in providing the needed support whilst addressing the needs of families and their children in the ICU under varied contexts. Therefore, more research is required to identify the barriers to nurse-family communication and build appropriate strategies for the practical application of FCC in NICU/PICU.

2.6.4.4 Collaboration

The researcher identified three sub-themes under this concept of FCC, facility design, professional training, and policy implementation. Although nurses are ready to implement FCC in the NICU, sufficient resources are required for its full implementation (Van Den

Berg *et al.*, 2017). The provision of tools to deliver care and enhanced clinicians through professional development led to the optimisation of parental capacity to be involved in care (Kjellsdotter, Lantz and Ottosson, 2018). The design of NICU in Sweden, according to national and international recommendations, ensured a more physical and psychosocial environment for clinicians and families with sick children in the NICU (Van Den Berg *et al.*, 2017). Finally, flexible visiting times are allowed for parents to connect with their hospitalised children in Tanzania (Saria, Mselle and Siceloff, 2019). The review found that policy and in-service training of nurses in the PICU contributed to their active involvement of families, which promoted the implementation of FCC. A Brazilian study also recommended conceptual assistance through models of education for both clinicians and families to close the theory-practice gap and ensure the holistic implementation of FCC (Felipin *et al.*, 2018). Similarly, in Sweden, training of nurses and physicians improved their support for parents to participate in the care of their children. Mentorship should be given to junior clinicians in the ICU to appreciate families as experts in the care of children (Kjellsdotter, Lantz and Ottosson, 2018). Clinicians' models and professional development needs optimising to meet the dynamics of unpredictable workloads. Clinicians view FCC in the ICU as capable of promoting the best outcome for children and their families but requires conscious policies on building partnerships and communication for its full integration in the PICU. FCC needs integrating into ward policy and protocols. The review found that protocols on partnerships, attachment, and communication facilitated parent participation in South Korea (Uhm and Kim, 2019). The development or revision of policies and practices, which are crucial when implementing developmentally supportive care, particularly in resource-poor settings, were identified as useful in FCC implementation (Austin, Downing and Hastings-Tolsma, 2019).

Nurses and physicians require education and family involvement to support their participation in intensive care. Families should be considered experts in the care of their babies (Kjellsdotter, Lantz and Ottosson, 2018). Researchers in the United Kingdom reported positive outcomes from the implementation of information sharing, participation, collaboration, and dignity and respect in the ICU (Skene *et al.*, 2019b). A Hermeneutic Phenomenological study in Iran noted the significant impact of managers in addressing the barriers of FCC and providing support to parents (Hadian *et al.*, 2016). Similarly, a Turkish study corroborated that managers must provide nurses with the necessary logistics for implementing FCC in the health system (Boztepe and Kerimoğlu Yıldız, 2017a). Other

studies suggested improvements in refining clinicians' models, enhancing professional development, providing tools to deliver consistent care, optimising parental capacity to be involved in care, strengthening continuity of care, supporting families with their infant, and designing family-friendly environments (Benzies *et al.*, 2019). There appears to be an omission of the collaboration aspect in many countries that implemented FCC. Hence, more studies on FCC relative to collaboration are required, especially in different research settings.

2.6.5 Research Exploring the Models FCC

A model simplifies a phenomenon to reduce its essential components to facilitate decision making and promote efficiency (Caro *et al.*, 2012). Models are derived from theoretical constructs and observed data that can be used to explain concepts (Batty, 2012; Caro *et al.*, 2012); thus, model development is simply a reductionist methodology. In the development of models, it is relevant to collect data from different sources to enrich the model and give it more applicability and generalisability (Cowan, Mendes and Blinov, 2019; Orr *et al.*, 2021). In this study, the researcher harmonised data from nurses, doctors, midwives, and families in two separate clinical settings. This was to ensure model validity and achieve representation and acceptability of the model. The consultation of stakeholders in model development is necessary to capture all concerns (Davies, 2005; Husbands *et al.*, 2018). Generally, models are developed by researchers and scientists to deal with some key objectives that can be modified by others (Davies, 2005; Fawcett *et al.*, 2015; Andersen, Ross and Fenske, 2018; Cowan, Mendes and Blinov, 2019).

In contemporary nursing practices, the development of nursing models, especially conceptual models, is significant to serve as building blocks to the advancement of the scientific nursing practice via the development of theories to support professional practice (Jacqueine Fawcet, 2006). These conceptual models can provide vivid answers to questions arising from nursing practice especially to nurse educators, nurse administrators, nurse researchers, and clinical nurses (Fawcet, 2006). Recent meta-theoreticians, such as Alfa Meleis and Jacqueine Fawcett, encourage nurses to conduct research and develop models and theories based on their clinical practices to address nursing problems and advanced the profession as a scientific discipline (Fawcet, 2006; Meleis, 2009; Fawcett *et al.*, 2015).

2.6.5.1 Types of models

There are three main types of scientific models in research, i.e. physical model, conceptual model, and mathematical model (Egger and Carpi, 2020). Physical models employ experiments to study the physical world and develop a simplified version of a physical state. Physical models are often employed by scientists in engineering, such as the model of the small delta river (Egger and Carpi, 2020). Conceptual models involve building known components of a system into a comprehensible whole to serve as the pre-requisite guidance for efficiency in practice (Robinson *et al.*, 2013; Egger and Carpi, 2020). Conceptual models are non-software driven and concise representations of a system's structural and behavioural elements (Robinson *et al.*, 2013). Social science researchers often develop conceptual models. Examples of conceptual models include the Ernest Rutherford atom model, the Emergency Medicine model, and the Public Health Intervention model (Winch *et al.*, 2005; Robinson *et al.*, 2013; Counselman *et al.*, 2017). Mathematical models are developed through computer programming using numerical variables, and this can be illustrated by the climate model (Márquez-Flórez *et al.*, 2018; Egger and Carpi, 2020; Voit and Voit, 2020).

2.6.5.2 Existing models of Family-centered Care and gaps in literature

The review of literature showed the existence of some FCC models, especially in the developed world. For instance, IPFCC have developed a hospital self-assessment inventory tool for FCC with its famous four thematic areas of respect/dignity, information sharing, participation, and collaboration (www.ipfcc.org, 2021). This particular assessment tool has been the dogma for most researchers to develop other contextualized FCC models. In an integrative review, Hills (2018) and others conceptualised a model of FCC that proposes the provision of physical and cultural environment in the PICU to promote family respect/dignity, participation, and information sharing (Hill, Knafl and Santacroce, 2018). Thus, the design of the ICU environment is a key precursor to the implementation of FCC. The Neonatal Integrative Developmental Care Model presented seven core measures to evaluate new-borns neurodevelopment: healing environment, collaborating with families, positioning and handling, safeguarding sleep, minimising stress and pain, protecting skin, and optimising nutrition. These interventions are expected to improve neuroprotection of the premature infant in the ICU (Altimier and Phillips, 2016). Dennis *et al.* (2016), in their model of partnerships in FCC, advocated for the clinicians to build healthy partnerships with

families in acute paediatric settings. A multi-phased participatory action research was used to developed FCC interventions in the United Kingdom (UK) NICUs, which resulted in information sharing between families and nurses, parental support and participation producing family competence in caregiving. An FCC intervention model reported satisfactory changes in practice in the NICUs (Skene *et al.*, 2018).

Famous among these FCC models is the POPPY model of collaborative care in UK NICUs. The rigorous development of this model, in seven research steps, sought to champion the plight of parents of preterm admitted into the NICUs. The model, among other things, advocated for respect/dignity, parents recognition, parental involvement, communication, psychosocial support, whilst putting the parent and sick baby at the centre of care (Staniszewska *et al.*, 2012); however, it is illness-specific, targeting only NICUs, and does not address the needs of children in the PICUs. Kelly (2018) contended that FCC, as an approach of care, can be more practical to deal with parental stress, anxiety, and interrupted family processes if families are put at the heart of their baby's care (Kelly, 2018). The Calgary Models, including the Calgary Family Assessment Model (CFAM) and the Calgary Family Intervention Model (CFIM), all advocated for designing healthcare around children and their families; in that way, the entire family can be included in the care to gain massive assistance from healthcare providers and build healthy practitioner-family relationships for improved health outcomes (Levac, Wright and Leahey, 1997). The family integrated care model is reported to have yielded improved outcomes in Spanish NICUs for the care of neonates and infants of all conditions, including medical-surgical conditions (Moreno-Sanz *et al.*, 2021). Furthermore, a review towards a universal model of FCC concluded that 40 of the 55 articles reviewed were illness specific to paediatric populations and the rest were focused on the context of families (Kokorelias *et al.*, 2019). The gaps pinpointed in that review included relationship between care plan decision making and privacy, as well as lack of evaluations of those models on the patient, family, and the healthcare system (Kokorelias *et al.*, 2019). This perhaps reaffirms the important role family play to support the provision of quality healthcare and the need to develop and evaluate a model of FCC.

It is evident from the models that they take place in the NICU or PICU alone, and in most cases with a focus on specific needs of sick children or family. The populations drawn to develop these existing models are skewed to present family or provider perspectives. In fact, these models have left out the facility management perspectives in their development of the

family assessment and intervention models for care plans. Moreover, these models are contextualised in their settings and the cultural and contextual differences makes it prudent to develop a Ghanaian context specific model of FCC for NICUs and PICUs. This study therefore sought to explore all dimensions of stakeholders in the ICU, including mothers, fathers, nurses, midwives, neonatal nurses, paediatricians, critical and intensive care specialists, and the health managers of the NICU and PICU units and Department of Child Health to develop the model comprehensively.

2.6.5.3 Choice of modelling for the Family-centered Care model development

The researcher leans the development of the FCC model towards Conceptual Modelling (Robinson *et al.*, 2013). Conceptual models are hooked on the principles of good practice, validity, credibility, and feasibility (Squires *et al.*, 2016). The rationale for adopting Conceptual Modelling was to offer an opportunity to capture the lived experiences of multiple stakeholders to study the FCC phenomenon in a natural setting. The adoption of Conceptual Modelling was, in part, to ensure that the critical components of the FCC model emanated from the participants' concepts and context rather than a programming perspective. Thus, making the FCC model a contextual, conceptual model rather than a behavioural conceptual model. Conceptual Modelling aims to retain an adequately large and comprehensive part of a real-world problem in the new model. In the FCC model development, the researcher collected data from clinicians and families at two different settings; this was to obtain the FCC phenomenon's multifaceted view and incorporate the same in the model. The choice of Contextual Conceptual Modelling in this study sinks well into the researcher's philosophical views of ontology and epistemology, as stated in the methods section.

2.6.5.4 Overview of model development processes

In the works of Meleis (2009), nursing models are the fundamental building blocks of theory that should be developed from the knowledge of clinical practice and research by the nurse. As such, model development processes are relevant to explicitly guide novices in the development of their models to contribute to nursing as a professional discipline (Jacqueine Fawcet, 2006; Meleis, 2009). Several model development processes exist in literature (Davidson *et al.*, 2006; Minkman, Ahaus and Huijsman, 2009; Overland *et al.*, 2009;

Kidholm *et al.*, 2012; Squires *et al.*, 2016; Beeson *et al.*, 2020; McGuire, Schultz and Kelly, 2021), but the framework of every model, especially a conceptual model, should be iterative enough to account for validity and reliability of the model for its use in healthcare interventions (Squires *et al.*, 2016). The conducting of the literature survey was to present an overview of the model development processes considered prior to the development of this model. Many of those models lacked rigour in their methodological pathways from which the models evolved (Department of Health Western Australia, 2009; Fernandez *et al.*, 2012; Kidholm *et al.*, 2012; White *et al.*, 2017; McGuire, Schultz and Kelly, 2021). Some of the model development processes were collaborative but lack testing for validity and reliability as such it was difficult to adopt them into the NICU/PICU model development (Nastasi *et al.*, 1998; Fernandez *et al.*, 2012; Staniszewska *et al.*, 2012; Huybrechts *et al.*, 2021). The development of intervention models should be multi-layered and multi-disciplinary to integrate the best available evidence to ensure validity of the model (Davidson *et al.*, 2006). The Squires *et al.* (2016) six-step model development process was therefore considered suitable for this study because of its iterative steps to accommodate all the phases of the thesis to clothe it with sound methodological rigour. Refer to **Appendix B** for details of models reviewed.

2.6.5.5 Common stages of model development

The common themes that run through the models in their development are grouped thematically in six stages. These stages are literature review, defining the problem, empirical data collection, model development, testing the model, and model evaluation.

1. Literature review: Most models examine literature to review the concepts of the study on which the model is developed. This is usually the first step of the model development process achieved via scoping review, systematic review, or meta-review. (Minkman, Ahaus and Huijsman, 2009; Kidholm *et al.*, 2012; Staniszewska, Brett, Redshaw, Psychol, *et al.*, 2012; Salisbury *et al.*, 2015; Squires *et al.*, 2016).
2. Defining of the problem: Beyond the literature synthesis, some of the models conduct qualitative exploration of the study phenomenon to contextualised and define the problem (Overland *et al.*, 2009; Staniszewska, Brett, Redshaw, Hamilton, *et al.*, 2012). In some models, this stage is combined with the literature synthesis or is done alone without the synthesis (White *et al.*, 2017; Beeson *et al.*, 2020).

3. Conceptualisation or understanding the concept: At this stage, further empirical data collection is mostly quantitative. Few models incorporate this step in their development processes (Minkman, Ahaus and Huijsman, 2009; Salisbury *et al.*, 2015; Squires *et al.*, 2016). This stage is however important to quantify, conform and triangulate the data before developing the model (Hesse-Biber and Johnson, 2015; Sangster-Gormley *et al.*, 2015; Davidov *et al.*, 2020).
4. Model development: The model is conceptually developed based on the empirical data from previous stages and/or additional data collection using experts panel either via nominal group technique or Delphi study (Overland *et al.*, 2009; Salisbury *et al.*, 2015; Squires *et al.*, 2016). Most models are developed after stage three without clarification of the findings from experts in the field of study (Minkman, Ahaus and Huijsman, 2009; White *et al.*, 2017; Beeson *et al.*, 2020).
5. Testing: At this stage the researcher put the model through initial testing to elicit the validity and reliability (Staniszewska, Brett, Redshaw, Psychol, *et al.*, 2012; Squires *et al.*, 2016). This stage is critical to evaluate the internal and external validity of the model developed.
6. Evaluation: This stage is the final stage of the model development process where the researcher(s) tests the model on a large scale for implementation purposes and also to evaluate its use in different settings other than where it was developed (Squires *et al.*, 2016).

Based on these backdrops, the researcher used the six-step model development processes and the Dewey's five-step pragmatic model since they were robust enough to accommodate all the phases of the thesis. The detailed explanations and how the Squires *et al.* (2016) six-steps and the Dewey's model of inquiry (Morgan, 2017) were adapted and applied in this thesis to develop the NICU/PICU FCC model are presented in the method chapter. Refer to **Appendix B** for details of models reviewed.

2.7 SUMMARY

The foregoing analysis, discussions, and presentation of literature review contextualise the FCC study in Ghana. Presented are the main concepts of the study including family, family-centered care, barriers and facilitators, and existing models of FCC; this laid the context for the appreciation of the study. Also outlined was the scoping review on the concepts of FCC.

This chapter is therefore a sensitising concepts to inform the research problem and questions to collect the qualitative data as Charmaz suggests. There was a content analysis of research model development processes from literature conducted, and the common model development processes presented to justify the selection of the six-step intervention model development; further details of this are in the methodology chapter.

The researcher found that the results largely emanated from nurses, doctors, and family perspectives of FCC. Meanwhile, to get the FCC concept well-rooted in the NICU/PICU, the health facility managers and the Department of Child Health must be involved in the design and implementation processes (Van Den Berg *et al.*, 2017; Enisha and Arti, 2019). Thus, the recommendation is for more research on FCC in the NICU/PICU involving the three dimensions of stakeholders (clinicians, parents, and managers). Africa had the least primary research on FCC in the ICUs, with just four articles clustered in Southern and Eastern Africa (de Beer and Brysiewicz, 2017; Saria, Mselle and Siceloff, 2019); this calls for more research, especially in West, North, and Central Africa. This will facilitate its integration into the ICUs for quality child health and family satisfaction. The review also found that the methodological deployment in exploring clinicians and family experiences had been skewed towards qualitative paradigms (Malusky *et al.*, 2011; Brødsgaard *et al.*, 2017; Butler *et al.*, 2019; Mirlashari *et al.*, 2020). However, the FCC phenomenon is a complex social problem that perhaps mixed methods could explain better, albeit using a quantitative approach as the basis to extrapolate. This would allow all the stakeholders in child health to give their valid inputs.

Furthermore, the review found there has been extensive research on FCC in the developed context, but little for the developing world. The scoping literature review has identified the four concepts of FCC and with clear evidence of its positive outcomes in the NICU/PICU. There are varied applications of the four concepts of FCC, which are apparently underpinned by contextual preferences and what works best per setting. Apart from Europe and the United States, which utilises and implemented these four concepts, other parts of the world have implemented portions of it based on what works in their context. In the case of Africa, little or no studies exist on FCC in the NICU/PICU. There is, therefore, the need for more research in that regard to provide the contextual evidence for its implementation in the NICU/PICU. This may culminate in improved child health outcomes and tentatively contribute to reducing neonatal and infant mortality.

Finally, this particular review was limited to a five-year period as it was to serve as a sensitising concept for the constructivist's qualitative aspect of the research, as per the CGT design. The review focused on only English language research papers, possibly neglecting valid research findings in non-English papers across different settings of the world. The majority of the studies (29; 55.8%) were qualitative, with the emphasis on clinicians and families mainly without the facility managers' perspectives of FCC. Further research may consider all stakeholders in child healthcare, including the managers, clinicians, and families as participants, and adopt other methodologies including constructivist grounded theory and mixed methods design, to study FCC to yield a comprehensive understanding within a particular context. The next chapter of the thesis presents the research methodology.

CHAPTER THREE
RESEARCH METHODOLOGY

3.1 INTRODUCTION

The methodology is the study of the philosophy of the methods in a scientific inquiry. The primary purpose of this chapter is to provide concrete justifications to the paradigms, design, and methodology used in this research. The research employed the multiphase mixed methods triangulation design. The chapter highlights the research methods and procedures used in the thesis to answer the various research questions. Philosophical assumptions underpin every academic research. Philosophy, as often related, is to research what grammar is to language. Therefore, this chapter explored and presented the research paradigms and justified selection of the pragmatist paradigm for this thesis. There are detailed descriptions of all the phases provided and the execution of each stage. The content of this chapter includes the research paradigm, designs, setting, study population, sampling and sampling techniques, sample size, data collection procedures, data management and analysis, methodological rigour, validity and reliability, and ethics. There is an outline of the six steps of developing a model in intervention research, with clear-cut links to its application in the NICU/PICU FCC model in the Ghanaian setting. These processes were to enhance the validity and reliability of the study and the final product.

3.2 RESEARCH PARADIGM

3.2.1 Description of a Paradigm

In the works of the American Philosopher Thomas Kuhn, research paradigm means 'philosophical way of thinking,' which in today's parlance means 'school of thought,' and this inherently reflects the researchers' principles and abstract beliefs within the world (Johnson and Onwuegbuzie, 2004; Mackenzie and Knipe, 2006; Morgan, 2017). A research paradigm, also known as research philosophy, is the set of shared beliefs and agreements that provide a theoretical framework and shared between scientists about how problems should be understood and addressed (Johnson and Onwuegbuzie, 2004; Hall, 2014; Kivunja, Ahmed and Kuyini, 2017; Perera, 2018). It remains the conceptual lens through which the

researcher sees the world (Kivunja, Ahmed and Kuyini, 2017) and plays a vital role that informs the scientific foundations in the entire research processes, including the choice of methodology and design of the study. A research paradigm has four primary characteristics: epistemology, ontology, methodology, and axiology (Kivunja, Ahmed and Kuyini, 2017); these attributes of paradigms were later put into three (excluding axiology) by Guba, 1990. Axiological assumptions are the study of values in qualitative or quantitative approaches (Kivunja, Ahmed and Kuyini, 2017; Corry, Porter and Mckenna, 2018; Perera, 2018; Rapport and Braithwaite, 2018). The next section details the characteristics of a research paradigm.

3.2.2 Ontology, Epistemology, and Methodology

A research paradigm is characterised by three main features, namely ontology, epistemology, and methodology. Ontology is the branch of metaphysics that deals with the study of existence, nature, or reality. Ontology is the theory of being and existence that questions the existence of the real world; thus, it is concerned with the nature of reality about the world and its existence. Epistemology has its roots in the Greek word episteme, which means knowledge; therefore, epistemology is the study of knowledge (Breuker and Hoekstra, 2004; Furlong and Marsh, 2010; Brown, 2017; Kivunja, Ahmed and Kuyini, 2017). Epistemology is one of the significant characteristics of the research paradigm, which holds the view that knowledge is unique and based on an individual's perspective. The epistemological position of a researcher expresses his view of what we can know about the world, whereas ontological positions speak about the researcher's view of the world (Furlong and Marsh, 2010; Bunge, 2015; Kivunja, Ahmed and Kuyini, 2017).

Philosophically, epistemology emanates from Socratic and Plato's dialogue, indicating that knowledge is a justified true belief with two dimensions (a priori knowledge and a posteriori knowledge). Prior knowledge arose from the works of Rene Descartes (a great mathematical philosopher), who held the view that knowledge should be justified through intellectual, analytical reasoning (this is the worldview of positivism). On one side, "*posteriori"* knowledge is that of physical objects justified by our sensory or perceptual experiences (Breuker and Hoekstra, 2004). There are two ontological positions of the existence of being in the world. One ontological stance is about the "*being and existence*" of foundationalism, objectivism, and realism, which speaks of a "real" existence of the world; the other aspect

embraces anti-foundationalism, constructivism, and relativism, which sees the world as socially created (Breuker and Hoekstra, 2004; Furlong and Marsh, 2010; Muramoto, 2014; Brown, 2017; Sagen, Keitsch and Magerholm, 2017). Foundationalist ontology believes that nature is composed of discrete objects independent of the researcher, and as such, every researcher should view and understand the world in the same way; thus, there is a real world that exists, irrespective of our knowledge. This stance gave birth to the study of objectivist and unconditional truth (positivism epistemology) (Cordella and Shaikh, 2006; Furlong and Marsh, 2010; Muramoto, 2014). Therefore, the ontological and epistemological philosophical underpinning of the Foundationalist is positivism and realism.

Methodologically, positivism epistemology adheres to quantitative methodology, and realism epistemology practices quantitative and qualitative methodologies altogether. Conversely, anti-foundationalism holds the constructivism, interpretivism ontological and epistemological philosophical viewpoints. They adhere to the qualitative methodology of inquiry. Pragmatism employs mixed methods as its research methodology. It is critical to highlight that the decision to apply a research paradigm will infiltrate the methodology through to data collection and data analysis in the quest to find credible answers to a particular research question(s) (Kivunja, Ahmed and Kuyini, 2017). In essence, the research paradigms from philosophical ontological and epistemological angles are positivism, constructivism, realism, and pragmatism (Mackenzie and Knipe, 2006; Shah and Al-bargi, 2013; Kivunja, Ahmed and Kuyini, 2017; Corry, Porter and Mckenna, 2018; Perera, 2018; Rapport and Braithwaite, 2018). The next section explains pragmatism as the research paradigm applied in this study.

3.2.3 Pragmatism and its Application in the Family-centered Care Study

This research lends itself to the pragmatic research paradigm. Pragmatism originated from the Greek word *"pragma,*" which means action, which has remained the central tenet of pragmatist philosophy. They believe that human actions and their lived experiences have an intrinsic link and are inseparable. Pragmatism is a research philosophy where the meaning of actions and beliefs are found in their consequences. Pragmatism as a philosophical movement in research dates back to the 19th century and can be traced historically to the works of American philosophers, including Charles Sander Peirce, William James, Chauncey Wright, Oliver Wendell Holmes, John Dewey, and *"Kant's Kritik der Reinen*

Vernunft (critique of pure reasoning).” Pragmatism had contributions from several disciplines of knowledge aside from philosophy, including law, sociology, psychology, and education. Pragmatist scholars emphatically refute the notion that research can access reality solely by one scientific method, and as such, embraces a plurality of methods in conducting research. Dewey summarises pragmatism as going with “what works best to solve the research problem” (Johnson *et al.*, 2006; Morgan, 2014, 2017; Kaushik and Walsh, 2019).

Furthermore, Johnson and Onuwuegbuzie (2004) recommended the “contingency theory” as the methodological stance for the pragmatic research paradigm. Creswell (2003) also earlier pointed to mixed-method research as the methodology for pragmatism. They argued that this methodology offers the opportunity for choosing methodological mixes that can better answer the research question(s) (Johnson *et al.*, 2006; Creswell and Plano Clark, 2011; Cameron, 2015; Kivunja, Ahmed and Kuyini, 2017; Morgan, 2017; Davies and Fisher, 2018; Rapport and Braithwaite, 2018). Combining both qualitative and quantitative methodological rigours ensures quality criteria.

Again, pragmatism has three main characteristics as a research paradigm. Firstly, pragmatists posit that one cannot separate actions from the situations and the context in which they occur. Thus, there can be no objective concept of truth directed to any particular action, the reason that the consequences of any action depend mainly on the situation of occurrence. As such, pragmatists underscore warranted beliefs, which mean repeated actions will intimately produce repeated experiences of predictable outcomes. Secondly, pragmatists believe actions and consequences have a connection that is open to change. The idea that consequences of actions can change relatively to situations is the situational nature of change. For example, the action of a Registered Nurse (RN) in an emergency can vary from that of a general ward setting. Thus, as far as pragmatism is concerned, it is never possible to experience precisely the same situation twice. Nevertheless, the significance of this type of paradigm is that actions are proportionate to consequences; hence, beliefs are repeatedly developing due to continuing experiences (Morgan, 2017; Kaushik and Walsh, 2019).

Finally, other pragmatists say that actions depend on worldviews that are socially shared sets of beliefs. As a result, they treat beliefs as interrelated rather than secluded and that the definitive outcome of the experience is a worldview that outlines actions. Pragmatists who

follow this trajectory of thoughts are of the school of thought that in as much as there are shared experiences of people, they will undoubtedly exhibit shared beliefs. Pragmatism is thus independently unique at the most in-depth level and socially shared at the broader level (Morgan, 2014, 2017; Kaushik and Walsh, 2019). Pragmatism, therefore, uses relational epistemology, multi-reality ontology, and value-laden axiology to conduct mixed method research (Johnson *et al.*, 2006; Kivunja, Ahmed and Kuyini, 2017). Therefore, the rationale for adopting the mixed or pragmatic paradigm is because of the use of different research methodologies to answer the various research questions in this three-phased thesis. This is critical in the development of the model, especially where little has been done in the situation under study, FCC in NICU/PICUs (Johnson *et al.*, 2006; Anguera *et al.*, 2018; Kaushik and Walsh, 2019).

Consequently, the researcher used the Dewey's model of pragmatism in this scientific inquiry. John Dewey, an American Philosopher, presented the pragmatist approach to research his book "How We Think." David Morgan developed his works (2014) and presented them as the "Dewey's Five-Step Model of Inquiry." This model provides the best explanation of pragmatism as a research inquiry and as such, was adopted into the model development (Morgan, 2014, 2017; Kaushik and Walsh, 2019).

The first of Dewey's five-step pragmatic model to research involves recognising a problem, which involves a situation where the current range of experience of the researcher does not provide a solution (line of action) to the problem identified. At this stage, the researcher conducted a JBI scoping review and critical literature review to inform proper contextualisation of the research problems. The second stage is problem reflection, which involves thinking through the problem and reflecting on the nature of the diverse solutions. The researcher used qualitative CGT design to study the problem in the Ghanaian context leading to possible diverse solutions form the participants' perspectives. The third stage is suggested solution, which is developing a possible line of action as a response to the problem by recognising possible outcomes that will address the problem. The application of this was through a quantitative descriptive design to identify the key concepts of FCC from the respondents of families, clinicians, and managers in the NICU/PICU. The fourth step uses exciting beliefs to think about the likely outcome of actions, thus evaluating potential actions regarding their likely consequences. The researcher used a Delphi study with an expert's panel to develop the model. The fifth and final step of Dewey's model of pragmatic research

is taking actions that will likely address the problem identified. This he called the action step, and is the stage of the model development and evaluation where the researcher conducts an evaluation of the NICU/PICU FCC model by sending the model to the end users, including the families, clinicians, and managers for their experts evaluation, of which subsequently there was the validity and reliability of the model estimated (Morgan, 2014, 2017; Kaushik and Walsh, 2019).

In conclusion, the embracing of Dewey's philosophy by the researcher, as his pragmatic philosophical stand, seems to unify the paradigm wars that existed between positivists and constructivists. Pragmatism gives attention to the research question and mutes the epistemology and ontology arguments while paving the way for a scientific inquiry that embraces qualitative and quantitative research designs. Thus, data collection and analysis are determined based on those that appropriately provide credible answers to the research question(s) without loyalty to a specific paradigm (Johnson and Onwuegbuzie, 2004; Morgan, 2014, 2017; Kaushik and Walsh, 2019). The next section explains the specific type of mixed method design employed in this study.

3.3 MULTI-PHASE MIXED METHODS TRIANGULATION DESIGN

Research design is a framework for collecting and analysing data in a scientific inquiry. This research was a system analysis, evaluation research that explored and described the complex social, cultural, and contextual factors about FCC in the NICU/PICU to enhance quality care for families and their children. The outcome of this intervention research was to prescribe changes to improve quality nursing practices in the intensive care setting (Power *et al.*, 2016). According to Creswell, there are six mixed method designs in social science research: convergent parallel mixed methods, explanatory sequential mixed methods, exploratory sequential mixed methods, transformative mixed methods, embedded mixed methods, and multiphase mixed methods designs (Creswell, 2014). The specific research design of this thesis was a multiphase mixed methods triangulation design (Creswell and Plano Clark, 2011; Morgan, 2014, 2017; Sangster-Gormley *et al.*, 2015; Davidov *et al.*, 2020) with five iterative stages in three phases of exploration, development, and evaluation. The rationale for this design was to triangulate the data for confirmation, complementarity, expansion of the concepts from multiple perspectives for stronger evidence to inform the NICU/PICU FCC model development (Cathain, Murphy and Nicholl, 2007; Creswell and Plano Clark,

2011; Sangster-Gormley *et al.*, 2015; Morgan, 2017; Davidov *et al.*, 2020; Gaglio *et al.*, 2020). This was because the researcher's ontology was that the world consists of multiple individual realities influenced by the context of the phenomenon's occurrence. Epistemologically, the researcher was of the philosophical assumption that the knowledge of FCC could be constructed subjectively and from multiple dimensions of the participants to develop the conceptual model of FCC (Kivunja, Ahmed and Kuyini, 2017; Seidl, 2017; Beer and Brysiewicz, 2019).

A multiphase mixed method triangulation design involves qualitative and quantitative methods used to answer specific research questions at different phases of a research project and the data triangulated to form a comprehensive whole (Davidov *et al.*, 2020). Thus, each method is relatively complete on its own and sticks to its worldview (Hesse-Biber and Johnson, 2015; Hunter and Brewer, 2015; Shibin *et al.*, 2018). In multiphase mixed method triangulation design, each method used at each phase of the project is analysed independently based on its assumptions to obtain more detailed information from different sides of the problem explored and the results integrated into the final project (Sangster-Gormley *et al.*, 2015; Anguera *et al.*, 2018; Davidov *et al.*, 2020). Tashakkori and Teddlie (1998), cited in Waddington (2005), argued that multiphase mixed method is a product of pragmatism, refuting the strict philosophy of positivist and interpretivism and applying a combination of methods at different stages of study to find answers to specific research questions.

This research was categorised into three phases, i.e., exploratory, model development, and evaluation with each preceding phase informing the next and as such, the adoption of the multiphase mixed method research design in answering the different research questions posed in the different phases of the study. This was done to complement one another to produce a holistic outcome worthy of generalisation and application of the FCC model in child healthcare at the ICU (Shibin *et al.*, 2018). Earlier studies conducted on FCC were largely qualitative while some were quantitative; hence, conducting a multiphase mixed method triangulation design will provide the opportunity to explore innovatively the questions hindering the implementation of FCC in the NICU and PICU from different concepts and context to obtain a holistic picture of the complex FCC phenomenon in the ICUs. The researcher collected multiple forms of qualitative and quantitative data in the three phased study and combined them for the themes of the model to emerge, hence the used of the term multiphase mixed methods triangulation design (Johnson *et al.*, 2006;

Creswell and Plano Clark, 2011; Hesse-Biber and Johnson, 2015; Davidov *et al.*, 2020). Creswell (2014) reported that the use of mixed methods among researchers was when there were multiple forms of quantitative and qualitative data collected.

Moreover, Tashakkori and Teddlie (2010) define mixed methods as "research designs using qualitative and quantitative data collection and analysis techniques in either parallel or sequential phases" (Anguera *et al.*, 2018). Some methodologies maintain that as much as the mixed method is helpful, it is not without unresolved challenges, including the confusion of combining or not combining the various data collected (Hesse-Biber and Johnson, 2015; Hunter and Brewer, 2015; Anguera *et al.*, 2018).

Therefore, a multiphase mixed method design was appropriate to answer the different research questions at each stage in the Neonatal and Paediatric Intensive Care Units. The basis for adopting this multiphase mixed methods triangulation design was the pretext that all research designs have their inherent strengths and underlying flaws; thus, by combining or mixing various methods, each method compensated for the flaw of the other, and this produced more credible and valid results (Hunter and Brewer, 2015; Morgan, 2017; Davidov *et al.*, 2020).

To conclude, FCC is a social phenomenon with complex characteristics, hence, different kinds of methods are needed to best understand these complexities (Byrne and Humble, 2007). Therefore, the decision to use a multiphase mixed methods triangulation design was to offset the flaws of qualitative or quantitative methods and provide a complete appreciation of the needs of families and involvement in ICU to direct the processes of developing and evaluating the NICU/PICU FCC model for Ghana. The researcher outlined the detailed research methods used in the study in the following sections.

3.4 RESEARCH METHODS

Research methods are the tools and techniques for conducting a scientific enquiry into a specific phenomenon, and a theoretical assumption underpins it. The whole concept of doctoral research contributes to the body of knowledge. Hence, combining methods from different research paradigms will provide a deeper comprehension of the area and perhaps reveal divergent findings to add to knowledge. However, to combine the different

methodologies, the researcher needs a better understanding of the various methods. Combining different research methods can be done at some or all phases of the research process, including instrumentation, analysis, and presentation of findings (Nastasi *et al.*, 2007; Lal, Suto and Ungar, 2012; Cameron, 2015; Schoonenboom and Johnson, 2017). There were specific research methods applied to the three phases of the study.

The first phase is an exploration phase, which describes how the scoping review, qualitative and quantitative studies arrived at the key concepts of the FCC. The second phase of the study was a Delphi study involving families, clinicians, managers, and clinical nursing researchers as experts to draft the model applying the model development processes. The final phase was a methodological design, which employed validity and reliability to evaluate the FCC model. F**igure 3.1** summarises the three phases.

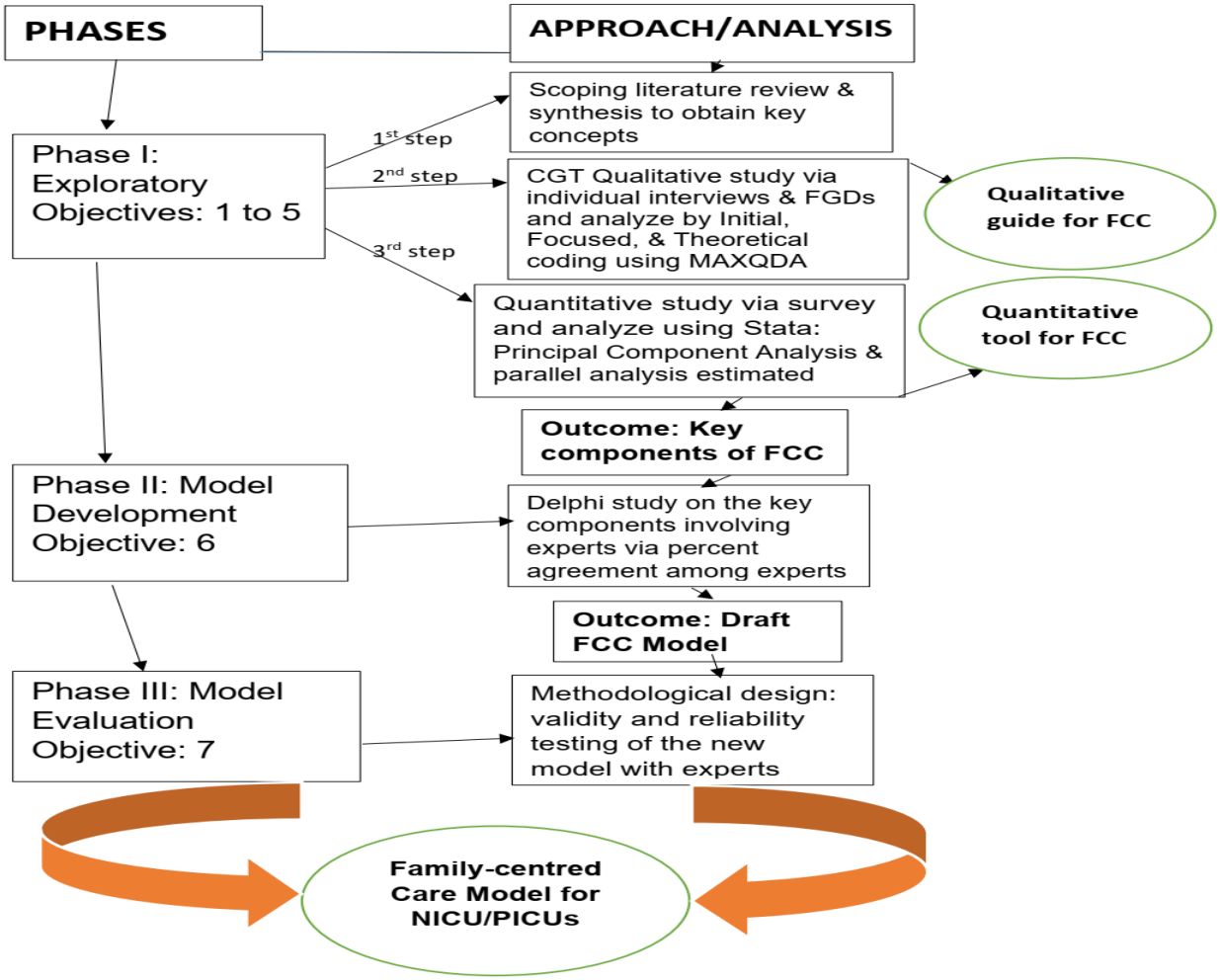


Figure 3.1: Summary of the Multiphase Mixed Methods Triangulation design in the FCC model development (author's constructs)

3.5 RESEARCH SETTING

Research setting is the physical sociocultural site where the researcher conducts the study (Creswell, 2014). A vivid description of the setting is important to put the research findings into perspective. The researcher presented the setting in two sections: the two tertiary teaching hospitals followed by the units and department in which the research took place. This was necessary to contextualise the study.

3.5.1 The Two Tertiary Teaching Hospitals

The study took place in the NICU/PICUs of the Korle-Bu Teaching hospital in Accra and Tamale Teaching Hospitals in Tamale, Ghana. The Tamale teaching hospital provides tertiary and specialised health services for the northern part of Ghana, and the Korle-Bu teaching hospital for the southern part of Ghana.

The Tamale Teaching hospital is the single Ministry of Health tertiary facility located in the south eastern part of Tamale, the capital city of the Northern region of Ghana. It has a bed capacity of 800 and is currently under expansion work to increase its capacity. It is the largest and significant health facility serving the northern part of Ghana, including Northern, North East, Savannah, Upper East, Upper West, Bono East, and Oti regions. It also provides health services to Ghana's neighbouring countries, such as Togo, Burkina Faso, and Mali.

The hospital is a centre for teaching and research in medicine, nursing, midwifery, pharmacy, nutrition, and laboratory science. It has a clinician population of about 2500, including registered nurses, medical officers, and specialists in intensive care, paediatrics, and child health, orthopaedic, urology, neurology, internal medicine, obstetrics and gynaecology, plastic surgery, and general surgery. Health services provided by the hospital include Child health, Intensive Care, Obstetrics and Gynaecology, Neurosurgery, Ear Nose and Throat (ENT), Ophthalmic, Dental, Clinical pharmacy, Orthopaedic and Trauma, Laboratory, Pathology, Physiotherapy, Radiology, among others.

Korle Bu, which means the valley of the Korle lagoon, started as a regional hospital in 1923 under Sir Gordon Guggisberg's administration, the then Governor of the Gold Coast, as a pioneer health facility for the southern zone of Ghana.. Korle Bu gained teaching hospital

status in 1962 following the establishment of the University of Ghana Medical School (UGMS) to train medical doctors. The Korle Bu Teaching Hospital is currently the third-largest hospital in Africa and the leading national referral centre in Ghana. The rapid population growth of Ghana has propelled the expansion of the hospital from its initial 200-bed capacity to 2000 beds.

Korle Bu is a medical hub for the research and training of medical professionals and the provision of specialist healthcare services. Its clientele includes neighbouring countries such as Burkina Faso, Nigeria, and Togo. It is the national referral centre for critical care and other medical services, and has 17 clinical and diagnostic departments with an average daily attendance of 1,500 patients and about 250 patient admissions. The hospital's clinical and diagnostic departments include Medicine, Child Health, Obstetrics and Gynaecology, Pathology, Laboratories, Radiology, Anaesthesia, Surgery, Polyclinic, Accident Centre, and the Surgical/Medical Emergency as well as Pharmacy.

Korle Bu Hospital provides sophisticated and scientific investigative procedures and specialisation in various fields such as Neurosurgery, Cardiothoracic surgery, Paediatric surgery, Dentistry, Ophthalmology, Ear Nose and Throat, Renal, Orthopaedics, Oncology, Dermatology, Radiotherapy, and Reconstructive Plastic Surgery and Burns. It houses the National Reconstructive Plastic Surgery and Burn Centre, the National Cardiothoracic Centre and the National Centre for Radiotherapy and Nuclear treatments. Examples of the unique services provided by the hospital include kidney transplant, brachytherapy intervention for the treatment of prostate cancer, and keyhole surgeries.

The choice of these two main facilities will help enrich the study and make the findings representative of the needs, barriers, and facilitators of FCC practices in Ghana. Ghana is a multi-cultural community that coexists with tolerance and cohesion for national growth and development. Christians and Moslems religiously dominate it, as well as the traditional Ghanaian religion. The numerous cultural dimensions are also worth noting since culture influences our way of life and, by extension, our health. Whether northern or southern, Ghanaian culture centres on unity, cohesion, and support for one another, especially in terms of difficulties, including illness and financial problems.

Even though there have been tremendous improvements in the health sector countrywide in terms of health service delivery, the growth of intensive care services is at a snail's pace, especially for the neonatal and paediatric settings. Very few regional facilities offer high-quality intensive care in Ghana, which creates a considerable threat to patients and families whose loved ones require intensive or critical care services. The teaching hospitals provide a good structure and execution of intensive care because they have the infrastructure and the specialised personnel to manage these cases. The researcher used the two teaching hospitals because they largely act as the leading referral centres in the country for intensive care services (Ministry of Health, 2017). The researcher also aimed to capture the opinions and constructs of all specialist categories in the intensive care setting to help build the model holistically to reflect current practices, and to integrate FCC into the NICU/PICUs.

The population of newborns and children with critical illnesses, such as birth asphyxia, prematurity, jaundice, diabetes, renal problems, trauma, and injuries, requiring intensive care are increasing in our setting. There is, therefore, the need to pay special attention to manage such delicate children holistically and effectively with optimum professionalism and collaborative partnerships with families. For instance, in 2017 about 4,000 babies were delivered with asphyxia, of which 16.6% died, representing the highest under-five mortality that year countrywide (GHS, 2017). These deaths are preventable if appropriately managed with the proper infrastructure, personnel, and collaborative partnerships and education of parents. The Ghanaian population is becoming increasingly aware of the availability of these special services in our hospitals. This comes with increased patronage with demands for quality, satisfactory and inclusive healthcare for their loved ones admitted into Intensive Care. Families are unhappy about the restrictions of access to their children and information about the care processes and lack of involvement when admitted in the Intensive Care Unit. Healthcare providers may need to rethink their definition of healthcare provision from a patient focus and widen the scope to include significant others, such as parents; after all, the WHO has defined health to include psychosocial aspects of the individual, not just the absence of disease.

3.5.2 The Neonatal and Paediatric Intensive Care Setting in Ghana

In Ghana, the NICU and PICU are all under the Department of Child Health in the hospitals. These facilities are largely located in the regional and teaching hospital levels of care. The

NICUs specifically admit neonates with critical illness. Some of the medical surgical conditions admitted in the NICUs include preterm, birth asphyxia, respiratory distress syndrome, neonatal jaundice, seizures, hypoglycaemia, hypothermia/hyperthermia, sepsis, intestinal obstruction, birth injuries such as torticollis, fractures, intracranial, congenital abnormalities such as gastroschiasis, cleft lip and or cleft palate, spinal bifida, and hydrocephalus. These Ghanaian NICUs are a blend of level I, II, and III, because in terms of the pathology there are all kinds of conditions admitted although not all equipment is available to support the care. For example, some NICUs lack ventilators and so babies requiring such respiratory support are often admitted to the PICU instead, but apart from this, NICUs are well equipped with phototherapy machines, incubators, radiant warmers, ambu bags, pulse oximeters, walled oxygen delivery systems, bilirubinometers, etc. The subdivision of the wards into cubicles is to segregate and manage the babies based on their needs.

Each NICU has separate kangaroo care (KC) rooms for accommodating and managing preterm babies with the families. The bed capacity of NICU in Tamale hospital in the northern part of the country is 60 and that of Korle Bu hospital in the southern part is 45. The wards usually admit beyond their maximum capacities, sometimes to almost double their numbers, since they are referral centres and because the districts within their catchment areas lack these specialised services; with the congestion in the NICUs, the spill-overs are admitted into the PICUs. Sometimes, neonates who stay in the NICU for up to three weeks move to PICU to create more space for new admissions. The NICUs have some specialised staff such as neonatal nurses, paediatric nurses, neonatologists (only southern) and paediatricians, but largely general nurses, doctors, and midwives are the majority of the staff in the ICUs. Some of the interventions and treatments provided for the sick babies at the NICUs include feeding, resuscitation, bathing, phototherapy care, oxygenation, monitoring, and incubator care.

Each setting has a paediatrician as the head doctor, and a neonatal nurse specialist (hospital T) and paediatric nurse (hospital K) who head and manage each NICU. These are the managers recruited in the study together with the head of department managed by a consultant paediatrician in Tamale Hospital and a professor in paediatrics at Korle Bu hospital; they provide oversight management and supervision of the units. These managers in both NICU and PICU still practice as clinicians in our context. The average monthly

admission for each setting is 250 babies, with a total admission of 3000 babies at each setting annually.

The PICUs in Ghana admit infants and children from birth to 12 years. Aside from the issue of spill-overs, which result in some neonates being admitted in the PICUs, the Ghanaian PICUs are designed to have a sub-NICU. This sub-NICU houses surgically operated babies, new born babies after 24 hours or readmitted babies, without mixing them with the main NICU admissions. The reason is to control nosocomial infections, which are a threat to the rapid recovery of the new-borns. The PICUs have all modern equipment and supplies, including ventilators adapted for infant use, monitors (cardiac, apnoea), intravenous pumps and endotracheal tubes, catheters including central venous, laryngoscopes, radiant warmers, oxygen delivery devices, and pulse oximeters. Generally, the PICUs are relatively small compared to the NICUs, with bed capacities of about 20 in each setting. The turnover of patients is relatively slow in comparison to the NICUs, and some weeks there would just be one child admitted into the PICU in addition to the neonates and infants. Some common morbidities admitted in the Ghanaian PICUs include chemical poisoning, respiratory distress, renal failure, nephrotic syndrome, sickle cell crisis, diabetes in children, burns and trauma for surgeries, etc. The staff in the PICU include intensive and critical care nurses and doctors, paediatric nurses, paediatricians, registered nurses, midwives, general doctors, dietician (not stationed), and clinical psychologist (not stationed). The PICUs provide interventions such as parenteral nutrition, renal replacement therapies, monitoring, endotracheal intubations, oxygen therapy, tube feeding, phototherapy, resuscitations, among others, performed by the staff.

Both NICUs and PICUs have no designated family areas nor family amenities. Families leave their sick neonates and children and go home to return each day to the ICUs. They are normally allowed in during scheduled visitations, where mothers can either breastfeed or express breast milk for cup, spoon, and nasogastric tube feeding by the nurses later. Sometimes the families have to buy supplies, including drugs and feeds, as well as move outside the facility for diagnostic investigations. The units have no in-house pharmacy or laboratories, and depend on those in the main hospital for their services. The majority of the staff in both NICU and PICU in Ghana are registered nurses. Contextually, all family come to the facility to support the care of the critically ill, however, mothers are in the majority

with minimal involvement and participation of fathers due to socio-cultural and religious reasons. The next section detailed the phases of the thesis.

3.6 PHASES OF THE RESEARCH

This section presents detailed descriptions of the three phases of the research: exploration, development, and evaluation.

3.6.1 Phase 1: Exploration Phase

The first phase of the study was an exploratory research and employed a scoping review, qualitative study, and quantitative study to answer the specific research questions. In this study, the researcher applied the Joanna Briggs Institute (JBI) approach to conduct a scoping review on FCC, which then provided the basis to set the research agenda. Existing literature in peer-reviewed journals were then content analysed to identify and describe the key concepts of FCC. Content analysis is a traditional research method used to draw out themes from literature. The qualitative study adapted a CGT design to construct multiple ontological or realities (Cand, Bonner and Francis, 2006) from participants and uncover the meaning of FCC. The CGT design, as explained in the works of Charmaz and Michelle, was adapted by the researcher to inductively construct FCC practices since the phenomenon of FCC was fairly new in the Ghanaian nursing practice, especially in the ICU (Charmaz, 1997, 2008; Cand, Bonner and Francis, 2006; Charmaz and Liska, 2015). In addition, the conducting of a quantitative study was to clothe the results with internal and external validity, triangulate, confirm, quantify, and make the findings 'generalisable.' Epistemologically, the researcher was a registered nurse who trained and practiced in Ghana, hence, his understanding of the beliefs and cultural dynamics enriched the study.

The next sections provide detailed descriptions of the exploratory phase categorised into three steps:

- Step 1: Scoping literature review to address objective one
- Step 2: Qualitative study on objective two to five
- Step 3: A quantitative study on objective two to five

3.6.1.1 Phase 1, Step 1: critical literature review

The first step of this entire research was to conduct a critical literature and scoping review with a primary objective to review existing FCC models and identify the key concepts of FCC. This part forms the basis for the conducting of the other steps and phases of the thesis. It identified the gaps and the major themes and concepts of FCC applicable in the NICU and PICU.

Method: A scoping literature review is the first step in research development that involves assessing existing research to yield emerging evidence (Peterson *et al.*, 2017). This design was used to synthesise literature (both qualitative and quantitative) and analyse available models of FCC to identify knowledge gaps, set the research agenda, and map the concepts of FCC to guide the development of the Ghanaian specific model (Tricco *et al.*, 2016). The search was conducted on databases for studies carried out within the last five years in Sub-Saharan Africa and the world as a whole and analysed using the Joanna Briggs Institute (JBI) methods of evidence synthesis (Khalil *et al.*, 2016). Research articles and documents from recognised databases online, such as CINAHL, PubMed, Wiley online library, Google scholar, and SCOPUS, were accessed and used for the scoping literature review (Khalil *et al.*, 2016; Tricco *et al.*, 2016). The keywords used to conduct the scoping and literature synthesis were Family-centered Care, Family needs, Neonatal Intensive Care Unit, Family Involvement.

Analysis: the JBI method was the methodology for the scoping review. In the JBI approach, the researcher identified the research question and relevant studies, selected the appropriate studies, and then presented the data and collated the results (Khalil *et al.*, 2016). Literature gathered was analysed using a content analysis approach. Categories of information gathered concerning the keywords used for the literature search were grouped into themes, and synthesised towards developing a logical flow of key themes in literature for meaningful integration into the new model. Secondly, there was consideration given only to applicable models in the NICU and PICU setting for synthesis. After selecting relevant and appropriate models for the study, there was careful and critical analysis of their domains and themes to identify the key components for the model.

3.6.1.2 Phase 1, Step 2: Qualitative study

The objectives set out in this phase were:

- To explore family needs at the NICU/PICUs
- To describe how family can be involve in care at the NICU/PICUs
- To explore the barriers of FCC integration at the NICU/PICUs
- To describe the facilitators of FCC integration at the NICU/PICUs

Qualitative Research design: Constructivist Grounded Theory (CGT) design and its application in the study

The researcher set out the qualitative study to construct family needs, family involvement, as well as the barriers and facilitators of FCC in the Ghanaian context. There are five approaches to qualitative research, namely grounded theory, case study, phenomenology, ethnography, and narrative inquiry (Creswell, 2014). All qualitative methods share a similar goal of trying to understand a particular phenomenon from the perspectives of the participants experiencing it (Aldiabat, 2011). The grounded theory tradition was suitable for achieving the primary objectives of the study; grounded theory is generally applicable to research situations that are somewhat new phenomena in a particular context to generate theories and models about human behaviour and interactions/experiences (Cand, Bonner and Francis, 2006; Levers, 2013; Creswell, 2014; Lauridsen and Higginbottom, 2015; Moser and Korstjens, 2018; Rieger, 2019). In the grounded theory concept, data is triangulated and analysed concurrently for the model to emerge (Hallberg, 2006; Charmaz, 2008). There are three main variations of the grounded theory tradition, i.e. Glaser and Straus, 1967 (no formal procedure is required for developing the theory), Straus and Corbin, 1990 (guideline analysis), and Charmaz and Mitchell, 2001 (procedure with different names are used, and participants are part of data analysis) (Hallberg, 2006; Creswell, 2007; Rieger, 2019; Sebastian, 2019). This current project was hooked on the Charmaz and Mitchell school of grounded theory, i.e., the Constructivist Grounded Theory (CGT).

Table 3.1 presents the differences between the three main traditions of grounded theory methods.

Table 3.1 Differences between the three traditions of Grounded Theory Methods

Schools	Proponent	Data Analysis criteria	Main Characteristics
Glasserian school (Classic Grounded Theory)	Barney Glaser, 1978	Grounded Theory analysis: Inductive openness, Constant comparison method and conceptualisation	Unstructured procedure of theory development (theory generating method) ignores literature prior to data collection; Zigzag processes of data collection and analysis; researcher is detached from the processes; theoretical sensitivity; theoretical sampling and focused questions on the emergent of categories from data; more 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 a 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)	Literature is use 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 model or theory to emerge; researcher is part of the iterative research processes (personal reflexivity).

Kathy Charmaz, a student of Glaser and Strauss who were the founders of the traditional grounded theory, dichotomised grounded theory into two designs: the Positivist Grounded Theory and the Constructivist Grounded Theory (CGT) (Charmaz, 1997; Mills and Francis, 2006; Lal, Suto and Ungar, 2012). She argued relativist ontological and transactional epistemological perspectives informed constructivism; thus, in developing a model or theory to stand a holistic academic rigour, multiple perspectives of the research problem from the participants and the researcher's views are significant (Charmaz, 2006). The researcher's epistemological underpinnings are the cornerstone in the research process (Mills and Francis, 2006; Lal, Suto and Ungar, 2012; Lauridsen and Higginbottom, 2015; Ashleigh E. Butler, Copnell and Hall, 2019). This study used a rigorous approach to transform the socially constructed qualitative ideas of the participants into contextual concepts of FCC via interviews and focus group discussions (FGDs).

The CGT design was conducted via engaging families, clinicians, and managers in individual interviews and FGDs in the ICU to explore the needs, involvement, barriers, and facilitators of FCC (Charmaz, 2006; Rieger, 2019). This design was chosen because it provided the scientific exploration of the FCC phenomenon, with priority given to participants to provide their perspective and experiences on FCC under a natural setting to unearth the contextual practices of FCC in the Ghanaian NICU and PICU from the perspective of families, clinicians, and managers (Goudoever *et al.*, 2011; Albert, Mylopoulos and Laberge, 2019; Rieger, 2019). This choice also offered a deeper understanding of the FCC issues in the Ghanaian context (Creswell, 2006; Häggström *et al.*, 2018; Butler *et al.*, 2019). The CGT design paves the way for interactions between the researcher and the participants, with the researcher's viewpoint being part of the process. It also promotes contemporary collection and analysis of data by exploring essential social relationships and the behaviour of groups where there has been a little exploration of the contextual factors that affect individuals' lives (Mackean, Thurston and Scott, 2005; Iwata *et al.*, 2018; Butler, Copnell and Hall, 2019).

Furthermore, by employing the CGT design, the researcher can move grounded theory methods further into the realm of interpretive social science consistent with the emphasis on meaning, without assuming the existence of a one-dimensional external reality (Mills and Francis, 2006; Ring, Gross and Mccoll, 2010; Lal, Suto and Ungar, 2012). This allows the researcher to use multiple research methodologies to obtain relevant data to answer the different research questions of the study (Charmaz, 2006; Grant and Osanloo, 2014; Tie, Birks and Francis, 2019). This scientific foundation answers some of the reproaches of the modernist grounded theory.

Finally, through the CGT design, the researcher can outline the differences between rich data collected from several sources (data triangulation) to situate the research questions concerning time, culture, and setting contextually to present solutions to real social issues of clinical significance. For example, this FCC study utilises individual interviews and focus group discussions (FGD) from families, clinicians, and mangers to construct the concepts of FCC in Ghanaian context carefully. **Figure 3.2** shows the application of the Constructivist Grounded Theory design in the qualitative stage of the FCC study in the NICU/PICU.

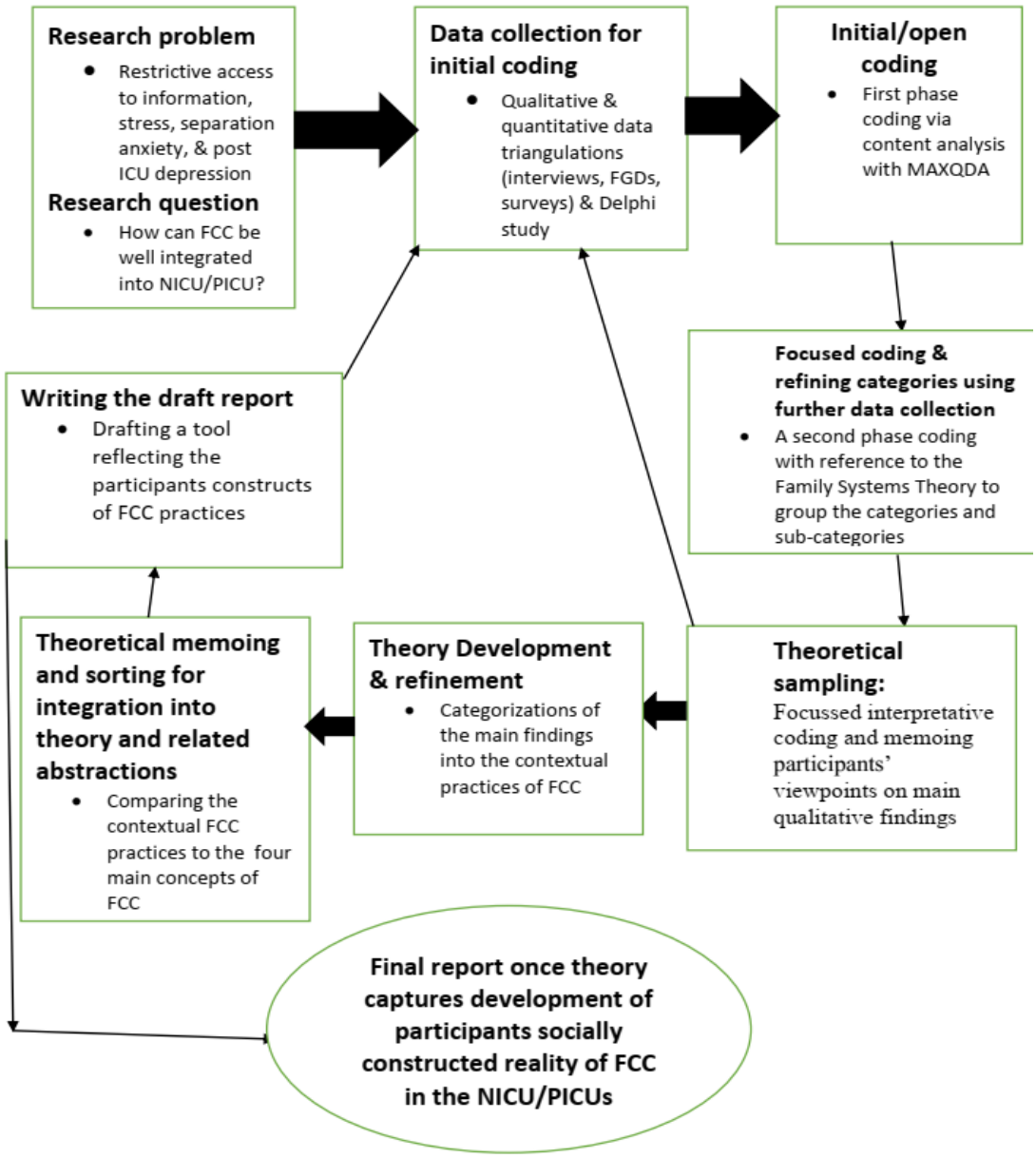


Figure 3.2: Diagrammatic explanation of the Constructivist Grounded Theory design and its application in the qualitative stage of the study (author's constructs)

Study Population and Sample

Population: Family with a neonate or child admitted to the NICU/PICU and ICU clinicians. Family in this study included a father, mother, senior sibling, and grandparent. Families age 18 years and above with their sick neonates and children admitted to the NICU /PICU for at least 48 hours were included. Family who could speak English, "Twi," or "Dagbanli"– a common vernacular in Ghana - were eligible for the study. Also included were senior-level registered health professionals (doctors and nurses) and managers (head of departments and unit heads of Child Health, Paediatrics, NICU, and PICU) with at least 2 years working

experience at NICU/PICUs. Excluded from the study were families with neonate or children less than 48 hours and those who died on admission. The participants recruited into the qualitative study were different from those of the quantitative study as the researcher designed the study to allow for at least 6 months between each of the two phases.

Sampling and Sample size

Non-probability purposive sampling (Berndt, 2020) obtained qualitative data from the families and clinicians until data was saturated. The choice of this sampling method was because it offered the opportunity to recruit specific participants involved in intensive care of neonates and children or currently having a child admitted in the ICU. There was segregation of the family FGDs from that of the clinicians. There were three FGDs for families and three for clinicians conducted in each setting. In all, there were 12 FGDs conducted, six FGDs of five family members and five ICU clinicians in each setting, to collect data on FCC. There were also 24 individual interviews conducted, 12 from each setting with six each for the clinicians (two of which were managers) and families, and four individual interviews (two at each setting) for managers. The managers were the head nurses and doctors of the NICUs and PICUs at the two settings. In this study, data saturation was determined by the triangulation of the data processes using different participants in the interviews and FGDs (Charmaz, 2008; Rieger, 2019). The participants in the interviews were different from those in the FGDs to allow the presentation of divergent views on FCC from several perspectives.

Data collection tools and processes (instruments)

The gathering of qualitative data was through individual interviews and FGDs of both families and NICU/PICU clinicians. The individual interviews targeted the families, clinicians, and stakeholders in the NICU/PICU (heads of department, ward in-charge, and departmental physician); the reason was they were directly involved in intensive care of neonates and children. The interview guide comprised of sections A and B developed from constructs of the scoping review, Self-Assessment Inventory (SAI), Critical Care Family Needs Inventory (CCFNI) tool, and the study objectives. Section A was about the biographical data of participants, including age, gender, occupation, marital status, education, and professional group. Section B targeted exploration of family needs, family participation/involvement, barriers, and facilitators of FCC at the NICU/PICUs.

The SAI is a standardised tool developed by the Emergency Medical Services for the Children's National Resource Centre in the United States for Family-centered Care to assess family and patient involvement in FCC (Almaze and Beer, 2017; www.ipfcc.org, 2021). The tool is based on four main principles for patient and FCC, "dignity and respect, information sharing, participation, and collaboration" (www.ipfcc.org, 2021). This offered the chance to have one-on-one discussions with the families and clinicians to solicit their perspectives and experiences on the FCC. This involved open-ended questions with probes where participants had the opportunity to talk about their views and express themselves (Dall'Oglio *et al.*, 2019). The interview guide was pilot tested at the Ridge Hospital and given to supervisors to review to validate it before the main research. This gave the opportunity to re-phrase the questions for clarity.

Respondents received information sheets (**Appendix C**). The participants signed a consent form (**Appendix D**) as proof of consent to participate in the study before interviews commenced. Each interview was audio-recorded after obtaining additional consent for voice recording (**Appendix E**). The interviews were at least 30 minutes and the FGDs lasted about 60 minutes. The designed interview guide (**Appendix F**) underwent pilot testing as well as a face and content validity by the supervisor and two other qualitative researchers. The researcher used populations with similar characteristics and conducted two pilot interviews (one family, and one clinician), and two FGDs (one on family and one on clinicians). This helped the researcher to refine and make the questions and probe clear prior to the main data collection. Data of the pilot study was not included in the main study data as the primary purpose was to modify the questions for the main study. Finally, the transcribing of the tool from English to Twi and Dagbanli occurred before the main study. All these processes helped check the validity and reliability of the qualitative tool.

Qualitative Data analysis

Analysis of the qualitative data occurred concurrently with ongoing interviews. This was to help the researcher know when data became redundant, with no new information emerging. The ideologies of CGT inductively and deductively analysed the data. All interviews underwent verbatim transcription into English. A language expert transcribed the audio recordings of the interviews in "Twi" and "Dagbanli" into English whilst maintaining confidentiality. The transcripts underwent scanning several times to obtain a complete

understanding of respondents' accounts. Reviewing and adding the data from field notes to the transcripts was to enhance the meaning of the information gathered.

Data analysis in CGT design is in six steps, i.e., initial/open coding, focused coding, theoretical sampling, refinement, memoing, and writing the draft report (see **Figure 3.2**) (Charmaz, 2006, 2008). This was later grouped into three stages of CGT data analysis, initial coding, intermediated coding, and advanced coding (Tie, Birks and Francis, 2019). During the initial coding stage, the researcher conducted open inductive content analysis by comparing data transcripts in document groups to look for similarities, differences, and patterns to obtain fractured data. The initial codes were kept close to the participants words, in an effort to ensure methodological rigour (Tie, Birks and Francis, 2019). At the second stage of intermediate coding, the researcher conducted focused coding by identifying key words that refined and theoretically sampled the fractured data into categories by words that could subsume the initial codes generated from the data. At the final stage of advanced coding, the researchers reflected on the categories emerging from the data through memoing and theoretical coding to integrate and weave all fractured data together to arrive at the contextual constructs of FCC practices in the Ghanaian ICUs. Memoing in CGT is the process of developing interpretative notes of ideas generated from the data to keep an audit trail (Tie, Birks and Francis, 2019). Facilitation of these iteration CGT qualitative analysis processes was by importing all the 36 transcripts into MAXQDA version 2020 qualitative software. The employing of lexical search, word clouds, comparison of retrieval patterns, code/sub-code models function of the qualitative software were to conduct the analysis.

The researcher and supervisor discussed the interpretations from the data to ensure that the themes were entirely developed. Sections of data that best suited the themes identified were organised appropriately and used to support the findings.

Methodological rigour of the qualitative study

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).

3.6.1.3 Phase 1, Step 3: Quantitative study

The researcher used quantitative methods to describe family needs, family involvement, barriers of FCC, and facilitators of FCC in the ICUs from the perspectives of family, clinicians, and managers that emerged from the participants perspectives. This was necessary to triangulate, compare, confirm, and quantify these contextual practices of FCC for the key components of FCC to emerge from the data for the model development.

Quantitative Research Design

There are four main designs of quantitative research, namely descriptive, correlational, causal comparative or quasi-experimental, and experimental research. This quantitative step adopted the descriptive quantitative non-experimental survey design (Carson, 2005; Creswell, 2014; Drummond and Murphey-Reyes, 2017). A descriptive quantitative design usually forms part of a complex research design to give an account of what exists in a population, discover new meaning, determine the frequency of occurrence of a phenomenon, and categorise the information (Carson, 2005; Creswell, 2014; Drummond and Murphey-Reyes, 2017). This provided families, clinicians, and managers' input on FCC from the quantitative angle. This research design was chosen because it provides the opportunity to examine several variables and compare them with inferences to reveal the most significant variables of interest (Belli, 2009; Egerod *et al.*, 2018). This culminated in identifying the key component of the model and provided the foundation for the model development in Phase 2 (Creswell, 2006; Johnson *et al.*, 2006).

Study Population and Sample

Population: Families with neonates and children admitted in the NICU/PICU, as well as the NICU/PICU clinicians and managers at the two teaching hospitals. The families included were fathers, mothers and senior siblings of the sick child, aunties and grandparents. The clinicians recruited were general nurses, general doctors, paediatricians, paediatric nurses, neonatal nurses, intensive and critical nurses, and doctors. The managers in this study included the nursing and medical heads of NICUs and PICUs, as well as the heads of department of paediatric and child health at the two settings.

Inclusion/exclusion criteria

Family members aged 18 years and above with their sick neonates/children admitted to the NICU/PICU for at least 48hours were included. Families who could speak English, "Twi," or "Dagbanli"– common vernaculars in Ghana - were eligible for the study. Senior-level registered health professionals (doctors, midwives, and nurses) with at least 2 years working experiences and the NICU/PICU department managers who appreciated the study phenomenon and ready to 'buy-in' were included in the study. Some of the clinicians who consented and participated included registered nurses, registered midwives, neonatal nurses, paediatric nurses, general practitioners (doctors), doctor paediatricians, and paediatricians (specialist and consultant levels). The managers recruited were the head nurses and physicians of NICUs and PICUs as well as the head of department of child health and paediatrics in the two settings. Excluded from the study were those families with neonates or children who were less than 48 hours old, or who had died on admission, as well as clinicians with less than 2 years experiences in the ICU. Most of the clinicians in the Ghanaian NICU and PICU were general nurses and doctors, with nurses being the majority, hence, nurses were the majority of the participants in this study. Also recruited were the managers working as clinicians in addition to their management responsibilities, and tne management of their data was with the clinicians; therefore, the term clinicians used in the study is management inclusive.

Sampling and Sample size for clinicians

Quantitatively, convenient non-probability and quota sampling methods were used to include 50 NICU/PICU clinicians in each facility, including the heads of departments of the NICU/PICU in the selected hospitals (n= 100, CL=95% & e= 0.05). This sampling method allowed the researcher to recruit key participants who mattered, were knowledgeable and could provide enough information on the subject matter. Lead persons, in this case the units' heads, were first identified in each department and assisted in determining the participants who stayed beyond 48 hours in the ICU (family), as well as clinicians who had worked in the ICU for more than 2 years consistently. Based on their numbers, they were then conveniently and quota sampled.

Sample size determination for family

The calculation of the sample size used the Yamane (1967) formula for sample size determination. The average total monthly admissions at the NICU and PICU at the two settings was 200. Using the formula, **N= (200),** the population and an alpha level (**e**) of 0.05, the sample size was estimated using Yamane's (1967) formula.

$$n = \frac{N}{1 + N(e)2}$$

Where: **n** = required sample size, **N =** Accessible population and **e** = alpha level. Thus,

$\mathbf{n} = \frac{N}{1+N(0.05)2}$ = n = 200 / 1+200(0.05)$^{2 =}$ 200 / 1+0.5 = 200/1.5 = 133.33

Estimating a 30% non-response and incomplete data and/or errors (Fincham, 2008) was 40. The estimate of the total respondents was 133 + 40 = 173.33 = 173 respondents. Therefore, there were 173 families selected from hospital T and 173 from hospital K (n=346).

Data collection tools and processes (instruments)

A research questionnaire is the most widely used tool to gather data because it can obtain the most reliable and valid data (Taherdoost, 2018). Constructs of FCC models reviewed in Step 1 and the outcome of the qualitative study in Step 2 of this research modified the existing tools of FCC to fit in the Ghanaian context for the quantitative questionnaire **(Appendix L & M**). Specifically, the SAI tool (www.ipfcc.org, 2021) and the CCFNI tool (Leske, 1992; Mitchell *et al.*, 2019) guided the development of the quantitative questionnaire. The Self-Assessment Inventory Tool is a standardised tool developed by the Emergency Medical Services for Children National Resource Centre in the United States of America for Family-centered Care to assess the perspective of clinicians, and managers on family needs and their involvement in FCC (Almaze and Beer, 2017). The tool is based on four main principles of FCC: "dignity and respect, information sharing, participation, and collaboration" (www.ipfcc.org, 2021). The Critical Care Family Needs Inventory (CCFNI) was developed by Leske, and consisted of 45 multiple questions (Molter and Leske, 1983; Mitchell *et al.*, 2018). "It includes five sub-scale dimensions: support (15 items); comfort (six items); information (eight items); proximity (nine items) and assurance (seven items)" (Egerod *et al.*, 2018; Mitchell *et al.*, 2019).

This offered the opportunity to conduct surveys with the clinicians and families to solicit their perspectives of family needs, participation, barriers of FCC, and facilitators FCC in the Ghanaian ICUs. Respondents received an information sheet (**Appendix J**), and those who agreed to participate signed a consent form (**Appendix K**) as evidence of consent to participate in the study before interviews commenced. The final survey tool was in two sections, Section A was to collate the biodata of participants, and Section B was on the concepts of Family-centered Care in intensive care; Section B was in six sub-sections of dignity/respect, participation, communication, collaboration, barriers of FCC, and benefits of FCC. The participants' biodata included age, duration of stay, and relationship with the child, professional group, and years of practice at the ICUs. The Likert-scale is widely used by researchers to rate the degree of agreements with specific concepts of a particular research project (Molter and Leske, 1983; Mitchell *et al.*, 2019). Participants were required to indicate their degree of agreement with statements drafted based on the concept of FCC using a Likert-scale (strongly disagree=1, disagree =2, agree=3, strongly agree=4), where 1 and 2 negatively implied agreement and 3 and 4 represented positive (favourable) agreements to the FCC concepts emerged from the context. The questionnaires were in two forms, one for families and the other for clinicians (clinicians and managers). An electronic version of the questionnaire was developed for the data collection using RedCap (Project Redcap, 2018).

Validity and reliability of quantitative instruments

There were several steps were undertaken to ensure the validity and reliability of the questionnaires. This was achieved by using existing tools (SAI and CCFNI) in addition to the empirical evidence from the qualitative study in Step 2 of Phase 1 and submitting it for expert review (Devon *et al.*, 2007; Goldberg, 2016). The CCFNI scales have a face and content validity for five sub-scales, and its psychometric properties have been studied in the general intensive care population and confirmed with a high internal consistency of 0.92 (Devon *et al.*, 2007; Mitchell *et al.*, 2018). The drafted survey tools were submitted to five different researchers: two senior nursing researchers at the doctoral level (one in Ghana and one in South Africa), one qualitative researcher in Ghana, one quantitative researcher in the United Kingdom, and a professor (model expert) in Ghana; there was further evaluation by another nursing professor and supervisor for the project. The supervisors and two other external researchers (experts in neonatal/paediatrics and intensive care) also examined the

face and content validity to improve the tools for the Ghanaian context before the main study commenced.

A pilot study was then conducted at the NICUs and PICU of the Ridge Hospital and the 37 military hospitals in Accra, Ghana, with 30 families and 30 clinicians (n=60) to further check the tools' validity and reliability (Devon *et al.*, 2007). In addition, there was an estimation of the validity and reliability coefficients from the pilot studies (for the clinicians' survey tool and the family survey tool). The final family quantitative tool was transcribed from English to Twi and Dagbanli before its use for the data collection.

Data management and analysis

Data analysis commenced after Step 3 of the exploration phase (Phase 1). Firstly, the data were scrutinised for completeness, accuracy, and consistency before coding; this was to discard incomplete and poorly answered questionnaires. For data analysis, the completed questionnaires underwent coding and capturing into the SPSS software. There was additional advice sought from a statistician and a researcher to use the SPSS for the statistical analysis to ensure that the results were credible and of standard.

Descriptive statistics were estimated for participant demographics and other relevant study variables (Goldberg, 2016; Mitchell *et al.*, 2019). For continuous variables, checks were conducted on the state of distribution; means and standard deviations and median and inter-quartile ranges were calculated appropriately (Moxon *et al.*, 2015; Butler *et al.*, 2019). However, categorical data were reported as frequencies and percentages, and Cronbach alphas of the six sub-scales were calculated (Cramer *et al.*, 1999; Mondal and Baidya, 2018). To examine the key concepts of FCC from the two data sets in the six sub-scale, factor analysis was used (Niranjan, 2004; Balasundaram, 2009; Jöresko, 2015; Harerimana and Mtshali, 2020; Lamash and Josman, 2020) and the level of significance was generally set at $p < 0.05$ (Mackie, Mitchell and Andrea, 2017; Mondal and Baidya, 2018; Taherdoost, 2018; Mitchell *et al.*, 2019). The results were finally reduced using principal component factor analysis and parallel analysis (Franklin *et al.*, 1995; Wood, Gnonhosou and Bowling, 2016) to arrive at the key components (Balasundaram, 2009; Jöresko, 2015; Harerimana and Mtshali, 2020; Mahmoudi *et al.*, 2020) of FCC for the model development. Data such as families and clinicians' demographics, respects/dignity, family needs, communication,

barriers and facilitators/collaboration, family participation, and benefits of FCC were analysed and presented in charts and tables.

Factor model: Factor Analysis

The researcher adopted Factor Analysis (FA) as the data reduction method to identify the key components of FCC in the Ghanaian setting. Factor analyses belong to a family of analysis techniques known as the General Linear Model (GLM), which operates on the principles of linear relationships and normally distributes data (Balasundaram, 2009). The performing of factor analysis was for purposes of dimension reduction to a minimum of explainable component and underlying constructs of FCC that can be useful in the development of a model. FA has two main types, i.e. Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA) (Decoster and Hall, 1998). The EFA usually conducted via PCA is used to explore the data to determine variations of an underlying constructs and to identify the load of the factors for exclusion to achieve parsimony (Matsunaga, 2011). The FA methodology was used to achieve a parsimonious model of FCC (De Los Campos and Gianola, 2007; Li *et al.*, 2020). Thus, the rationale for this approach of data analysis was to yield the least variables from the study with the greatest explanatory power to the phenomenon of FCC in the intensive care. The choice of FA was also as a novel technique for data analysis technique, as its use is rare in the field of nursing. Perhaps, it will illuminate the path of nursing research for its subsequent adoption by future researchers. This current study employed Principal Component analysis (PCA) followed by parallel analysis to decide the number of factors to retain.

The use of PCA is usually to obtain a smaller number of variables from a large data that can provide a valid account for all variables in the data. Thus, it trims extraneous and repetitive variables in the dataset to produce the components that provide vivid explanation of the underlying constructs of a phenomenon (Decoster and Hall, 1998; Sharma *et al.*, 2019; Tripathi and Singal, 2019; Mahmoudi *et al.*, 2020). Conversely, CFA is conducted to validate the factors arising from the initial analysis and to identify the degree of the model fit (Harerimana and Mtshali, 2020; Heiss, Timko and Hormes, 2020).

The researcher first conducted separate PCA for both data sets, i.e., family data and clinician's data. All six subscales of the constructs, as derived from the first two steps

(scoping and qualitative studies), underwent PCA. Components with good factor loadings (>0.50) (Balasundaram, 2009) were selected to form part of the model development. After combining the family and clinicians' datasets, there was a repeat of the analysis of PCA with Varimax rotations to obtain the key components of FCC in the Ghanaian context; this was because the two datasets measured the same concepts of FCC. The key components developed an electronic Delphi questionnaire for the experts' review in the next phase of the project.

3.6.2 Phase 2: Model Development Phase

The key concepts of FCC obtained in the first phase of the study were the basis to conduct a Delphi study with experts. The Delphi study included families, ICU clinicians, managers, model experts, and nursing researchers to examine the components identified from Phase 1 to help develop the model. The section also describes the methodological processes of the Delphi study. Again, the use of a quantitative approach was to expose the model to external rigour whilst applying the model development processes of interventions research. The six steps of developing a model in intervention research are outlined with clear-cut links to its application in the NUCU/PICU FCC model in the Ghanaian setting. The researcher also adopted the Dewey's Five-Step Model of Pragmatic Research, as explained earlier, since the thesis was underpinned by pragmatism as described earlier (Morgan, 2017; Kaushik and Walsh, 2019).

3.6.2.1 Model development processes as applied in the study

This research used the six steps of model development processes in intervention research to support the model development processes of the FCC model because of its robust iterative research processes that accommodate multiple methods (Wight *et al.*, 2015; Squires *et al.*, 2016). The model was an intervention to improve the practices of FCC in the Ghanaian NICU/PICU, hence the adoption of the this particular model development processes. Moreover, the study was in multiple phases which best fit with the six steps in the intervention model development processes. This decision was taken to help improve the applicability, implementation of the model and lend a good scientific foundation of the FCC model. In achieving this, the researcher used the collaborative engagements of all parties, clinicians, managers, and families of sick children, to get the model well integrated into the

health delivery system. This maximised the fit of the FCC model with target groups and promoted acceptability and applicability (Creswell, 2006; Creswell and Plano Clark, 2011; Wight *et al.*, 2015; Squires *et al.*, 2016). According to Squires *et al.* (2016), there are six steps in model development processes, namely:

1. Defining and understanding the problem
2. Identifying the causal factors and the contextual factors that can be modified or changed
3. Identifying the mechanism of change
4. Clarifying how the change was delivered or achieved
5. Testing and adapting the intervention or model on a small scale
6. Evaluation and implementation of the model

In this study, the last step was not executed due to the time limitation of the PhD study. Therefore, **Figure 2.2** shows Steps 1 to 5 and how the researcher vividly applied them in the FCC model development in the Ghanaian intensive care setting.

Step 1: Defining and understanding the problem

The researcher did a thorough background of FCC via a scoping literature review of existing models on FCC to obtain the key concepts that defined FCC. The FCC is an approach of childcare that recognises both the sick child and family as care recipients through promoting collaborative family involvement and effective communication while respecting the family's dignity in the care processes. The research problem was well stated, and its implications for quality child healthcare presented. This offered the research community and policymakers a clear understanding of the problem at hand relative to FCC integration in the intensive care setting (Creswell, 2006; Polit and Beck, 2013; Squires *et al.*, 2016). Furthermore, the statement of the problem will provide the purpose of the model as suggested by scholars of model developemnt (Levac, Wright and Leahey, 1997; Davies, 2005; Jacqueine Fawcet, 2006; Meleis, 2009; Fawcett *et al.*, 2015).

Step 2: Identifying the causal factors and contextual factors that are modifiable

Firstly, the downstream and upstream factors were identified in a qualitative exploratory study through individual interviews and FGDs involving managers, families, nurses,

midwives and doctors at the NICU/PICU. Then, a quantitative study took place using a blend of existing tools: The self Assessment Inventory tool and the Critical Care Family Needs Inventory tool. These tools have a high psychometric of 0.92 and assisted the researcher to identify the causal and contextual factors of FCC in a Ghanaian cultural and health care setting. Both families and clinicians were enlisted to present the factors that could be modified going forward as far as the integration of FCC into intensive care was concerned. This culminated in realising the key components of the FCC at the end of the exploration phase of this research (Wight *et al.*, 2015; Butler *et al.*, 2019).

Step 3: Identifying the mechanism of change

Identifying the appropriate mechanism in the research methodology is the heart of a good scientific study, especially an intervention study. The researcher chose a mixed method design to explore all the contextual barriers and facilitators of FCC in a Ghanaian context. The mixed method design allowed the researcher to cure the weaknesses of both qualitative and quantitative research designs. In addition, FCC is a complex social phenomenon that requires different kinds of methods to unravel its complexities. This research was grouped into three main phases to apply the chosen methodology. The first phase was an exploratory study into the contextual factors. A scoping review was first conducted using CINAHL, PubMed, and ScienceDirect to identify the key concepts of FCC. A qualitative study was then conducted, and finally, a quantitative study to identify the key components of the FCC in the NICU/PICU. Phase 2 involved developing the model using the key components as a Redcap questionnaire in a two-round Delphi study involving 15 experts in clinical research, emphasising modelling, nursing, critical and intensive care backgrounds. The third phase was an evaluation phase, which entailed estimating the face validity, content validity, and Cronbach's alpha of the drafted model via a methodological design. This design allowed experts at different locations to evaluate a model whilst permitting quantitative analysis of the outcome variables (Creswell, 2006; Polit and Beck, 2006; Creswell and Plano Clark, 2011; Wight *et al.*, 2015).

Step 4: Clarifying how the change was delivered or achieved

At this stage, the research adequately described the instruments for data collection and explained how the methodological rigour and reliability were followed in the entire study.

Data triangulation was done as several data sources were collected from families, NICU clinicians, managers, and experts in clinical research. The researcher used individual interviews and focus group discussions (with families, clinicians, and managers) and surveys through Redcap questionnaires at two tertiary clinical settings to gather enough data to support the model development. This clarified how the change processes were achieved in the Ghanaian ICU setting. Additionally, theoretical triangulations were done using two scientific theories to back the study, the FST and the CGT. A vivid explanation of the setting and context of the study has also been provided. All these processes clarified how the study was conducted to enable other researchers to replicate the study, thus giving the model optimum validity and reliability (Creswell, 2006; Creswell and Plano Clark, 2011; Wight *et al.*, 2015; Squires *et al.*, 2016).

Step 5:Testing and adapting the intervention or model on a small scale

The researcher tested the validity and reliability of the FCC model using a small sample of experts (25) at the final phase of the study. The model was given to experts (families, managers, clinicians, and clinical researchers) to evaluate its validity and reliability. Initially, the face validity of the model was sought from the experts where the grammar, clarity, and elimination and modifications of ambiguous wordings occurred. The researcher also estimated the content validity index (Yusoff, 2019), which was set at 0.78 agreement at 0.05 significance. Also, the researcher ensured the reliability of the model by calculating the Cronbach alpha and the Intra-Class correlation coefficient (Bobak, Barr and O'Malley, 2018) of the model.

Step 6: Evaluation and implementation of the model

This final step was not executed in this current stiudy due to time constraints of this PhD thesis. The final evaluation and implementation of the model will be considered in post doctoral research upon completion of the programme (See **Figure 3.3** for details).

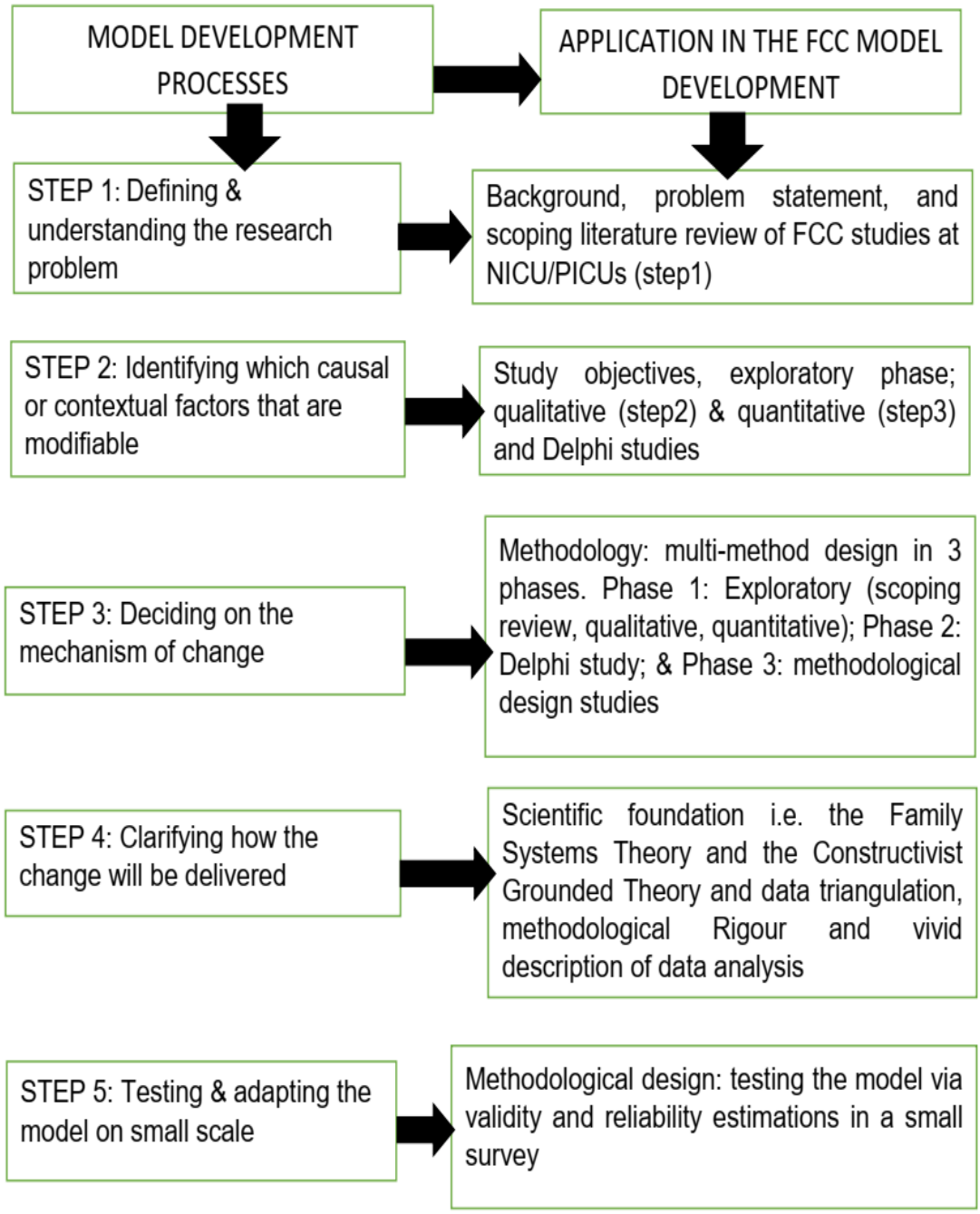


Figure 3.3: Research model development processes applied in the NICU/PICU FCC model development (adapted from Squires *et al.*, 2016).

3.6.2.2 Delphi study

The Delphi study was used to achieve the objective of the second phase of the study, i.e., to develop the FCC model. A two-round Delphi occurred using experts to develop the model.

Methodology

Delphi's study means “eliciting and refining group judgments” (Rowe and Wright, 1999; Grime and Wright, 2016). The Delphi study involves a sequence of rounds of data collection in which participants offer and then refine their views on defined issues in an iterative process (Ma *et al.*, 1999; Rowe and Wright, 1999; Laukvik, Mølstad, and Fossum, 2015). This model development phase employed a two-round Delphi to address the objectives, starting with selecting a panel of experts (Norris *et al.*, 2014). Then the experts were invited to put forward their views, indicate the extent of their agreement or disagreement with the opinions that have been expressed, and then re-score their agreement/disagreement in the light of group responses to arrive at the main components of the new FCC model (Norris *et al.*, 2014; Grime and Wright, 2016; McMillan, King and Tully, 2016).

The rationale for selecting the Delphi technique was because it preserves the interpretative aspects of qualitative research, and because Delphi allowed the analysis of collective data via a sequence of statistical operations in a mixed method study (Rowe and Wright, 1999; Grime and Wright, 2016).

Additionally, in evidence-based practice, the Delphi study provides a means of collating expert views where little evidence exists, as in the case of the FCC in Ghana (Skulmoski and Hartman, 2007). The Delphi can also build consensus on opinions in a multi-phase study such as this one (Ma *et al.*, 1999; Teijlingen *et al.*, 2006; Skulmoski and Hartman, 2007). The Delphi method also helps obtain collective, subjective judgments or decisions when group dynamics do not allow for effective communication, such as time differences, distance, and personality conflicts (McMillan, King, and Tully, 2016), and saves resources as physical group meetings may be too costly (Grime and Wright, 2016). This Delphi was achieved by selecting experts and sending questionnaires for their expert opinions in a repeated manner called rounds until a reliable judgment was reached on the subject matter (McMillan, King, and Tully, 2016; Berman *et al.*, 2018).

Study populations: experts in clinical nursing and research as well as families. The nurses, doctors, and managers recruited were all categories or ranks that worked at the ICUs for at least 2 years. Also recruited were researchers into nursing and medical practice as well as

policy. The families were educated family members with at least high school qualification who could speak and understand English language.

Sampling technique: purposive and snowball sampling was employed. These sampling methods are both non-probability sampling where the researcher's selection of the sample from the population is based on subjective judgement and applied in research in which the focus is for exploratory, descriptive, and analytical purposes (Berndt, 2020). Experts' recruitment of the participants was purposefully determined based on researcher's judgement of some key and knowledgeable participants in the study area. These existing participants then assisted the researcher to identify other relevant participants they knew (snowballing). This was carefully and systematically done for all categories of the participants, i.e., family, clinicians, managers, until reaching the sample size.

Sample size: Delphi method usually employs a sample of 15-60 experts (Allen *et al.*, 2019); this study, therefore, pegged the sample size at 25.

Inclusion criteria: In this study, the basis for the recruitment of the experts was the following criteria:

- Family (literate) above 18 years whose child has been detained in the NICU/PICUs
- Knowledge and experience in FCC, clinical nursing (paediatric, critical, and intensive care) and clinical nursing research
- Ability and readiness to contribute to the study
- Adequate time to contribute to the Delphi
- Effective communication and computer skills

Exclusion criteria: experts not falling under the above criteria

Methodological rigour for the Delphi study: the basis for the designed questionnaire for the Delphi (**Appendix Q**) was on the outcome of the first phase of this research. Firstly, the supervisor and an external consultant in model development of clinical research background reviewed the questionnaire before the main study. Additionally, a pilot study of the questionnaire took place to improve comprehension; this was to help check the validity and reliability of the questionnaire before going for the experts' judgment and agreements.

Data collection tools and processes (instruments)

An electronic questionnaire with a comment box (**Appendix Q**) was developed with inputs from the supervisor based on the outcome of the first phase of the research (Laukvik, Mølstad, and Fossum, 2015). Experts were required to indicate their judgment on the key components identified in the first phase. The experts ranked the components using a Likert scale (strongly disagree=1, disagree =2, agree=3, strongly agree=4). The background and purpose of the study and consent for participation in the study were included in the questionnaire. Also collected were the background data of the experts, including age, speciality, and years of practice. An initial email sent to the experts requesting them to participate in the study (**Appendix S**) included an information sheet (**Appendix T**) before the questionnaires were forwarded electronically with the consent to participate (**Appendix U**). The administering of the questionnaire was via electronic email in two rounds.

- **Delphi Round One: Draft NICU/PICU FCC Model for Ghana**

The outcome of Phase 1 was the key component, and used to develop a Delphi questionnaire for the experts' sessions. The outcome of Phase 2 (the factor loadings) was attached to the Delphi questionnaire as a summary background information sheet to guide experts in making their judgements. At this stage, experts were involved in giving their valid opinions on the key components, which were then used to develop the second Delphi questionnaire (Norris *et al.*, 2014; Laukvik, Mølstad, and Fossum, 2015; Grime and Wright, 2016).

- **Delphi Round Two: Review of the draft NICU/PICU FCC model for Ghana**

Experts who took part in the first round Delphi session were contacted again (**Appendix R**), and the drafted model sent back to them for their experts' comments (clarity and coherence). This was to ensure the model, specifically the domains and items, were consistent with the target goal. After reviewing the experts' comments on the draft copy, their inputs were then incorporated into the second and final draft of the FCC model for Ghana (Mccormack and Mccance, 2006; Laukvik, Mølstad, and Fossum, 2015; Skene *et al.*, 2015; Keeley *et al.*, 2016).

Data Management and Analysis of Delphi Study

Descriptive statistics such as the mean, standard deviation, inter-quartile range and percentages for each component were estimated (Norris *et al.*, 2014; Butler *et al.*, 2019). The consensus was agreed via analysis, such as Kendall's Coefficient of Concordance (Norris *et al.*, 2014; Birko, Dove and Özdemir, 2015; Mackie, Mitchell and Andrea, 2017), and interquartile range >/=1 and agreement > 80%. "The Kendall coefficient determines whether consensus has been reached, whether the consensus is increasing with subsequent rounds and its relative strength" (Roscani *et al.*, 2015). "The coefficient can be interpreted as a very weak agreement (0.1), weak agreement (0.3), moderate agreement (0.5), strong agreement (0.7), and unusually strong agreement (0.9)" (Rowe and Wright, 1999; Norris *et al.*, 2014; Slater, Mccance and Mccormack, 2017). PASW statistic 20 was used to conduct the analysis (Hashimoto and Yanagisawa, 2017).

3.6.3 Phase 3: Evaluation of Model

This was the concluding phase of the model development, where content and face validity of the NICU/PICU FCC model for Ghana took place with the experts and managers/authorities of the health systems. The model underwent face and content validity, item statistics, and intra-class correlation coefficient of reliability. The purpose of the evaluation was to seek experts' consensus and test the validity and reliability on a small scale. This was significant to evaluate the psychometric properties of the model to achieve the generalisation, applicability, and integration into the day-to-day care of family and sick children at the NICU/PICU. This was to set the basis for a full-scale evaluation and implementation approach into ICU practices later.

3.6.3.1 Research Design

A methodological design guided this phase. Methodological designs involve the "assessment of content validity, evaluation of the conceptual structure of the model, face validity and reliability of the model (Mitchell *et al.*, 2016; Moallemi, Elsawah, and Ryan, 2018; Grove, Burns, & Gray, 2013, pp. 255). This transpired by carrying out a survey in Ghana with the developed NICU/PICU FCC model involving all stakeholders who participated in the model development, including the beneficiaries and policy experts.

3.6.3.2 Population and Sample

The populations were families and nurses, midwives, doctors, health managers, and policy experts. In total, there were 25 experts recruited to participate in the model evaluation. Inclusion criteria for the families was educated families 18 years or older; identification of these was by asking about their educational backgrounds, and families with at least senior high school education were included. Health professionals with at least five years of working experience with neonates and children and those in health management, nursing research, and policy were included.

3.6.3.3 Data Collection Procedure

The invitation for experts to participate in the evaluation was via emails. They received an information sheet upon acceptance to participate in order to provide them with enough background of the study. An electronic questionnaire (**Appendix V**), compiled based on the outcome of the Delphi study, was delivered to the experts via Redcap. The quantitative approach of content validity and reliability was selected because it allowed the researcher to send the questionnaires to experts at different locations (Polit and Beck, 2006; Masuwai Azwani, Nor'ain Mohd Tajudin and Noor Shah Saad, 2016), thus, distance was not a barrier to its use (Taherdoost, 2018). The content validity of the model was established based on the extent of the content validity index (CVI) values related to the degree of agreement among the expert evaluators (Devon *et al.*, 2007). Each expert gave a rating to indicate the relevance and clarity of each item and provided comments on each item and the model diagram. The response of the panel of experts was indicated on a five-point Likert scale using "strongly disagree-1, disagree-2, neither disagree nor agree-3, agree-4 and strongly agree-5" using Redcap. Experts had five working days to study and submit their objective ratings of the model.

3.6.3.4 Data Analysis

After retrieving the data from Redcap in Excel format, it underwent cleaning for incomplete and repeated entries, and validity and reliability tests of the model. Data was analysed using the Excel spreadsheet and SPSS version 20 (Eckes, 2014; Arat *et al.*, 2016; Han, 2019; Randrianarivony, Ravelomanantsoa and Razanamihaja, 2020). The researcher estimated

Cronbach's alpha and inter-rater reliability of the model (Wind *et al.*, 2016; Han, 2019; Randrianarivony, Ravelomanantsoa and Razanamihaja, 2020; Kit, 2021), as well as content validity for the new model. Content Validity Index (CVI) values represent the degree of agreement among the expert's evaluators. Individual item content validity of the 10 underlying blueprints were calculated. The universal average of the level of agreement among the experts and the scale or model content validity index were calculated and assigned a numerical value. This was to provide the extent of the internal consistency of agreement on the concepts of the model among the expert evaluators (Masuwai Azwani, Nor'ain Mohd Tajudin, and Noor Shah Saad, 2016; Taherdoost, 2018). In this study, the agreement among the experts was set at ≥0.78 and a significance level of 0.05 (Masuwai Azwani, Nor'ain Mohd Tajudin, and Noor Shah Saad, 2016).

- **Validity of the model**

The researcher conducted the face and content validity of the model.

- **Face validity:** The experts used face validity to evaluate the model qualitatively by reviewing grammar, clarity, and construction of the FCC model (Masuwai Azwani, Nor'ain Mohd Tajudin, and Noor Shah Saad, 2016). Face validity is a subjective judgment on the operationalisation of a construct that explains the degree to which a measure appears to be related to specific constructs in judgment by participants of a study (Newman, Lim, and Pineda, 2013; Taherdoost, 2018). It assesses the appearance of the model in terms of feasibility, readability, consistency of style and formatting, and the clarity of the language used (Devon *et al.*, 2007; Taherdoost, 2018)

- **Content validity:** Validity means "to measure what is intended to be measured," and explains how well the collected data covers the actual area of the research (Taherdoost, 2018). Content validity, also called logic validity (Newman, Lim and Pineda, 2013), refers to the degree to which items in a tool reflect the content universe to which the tool was generalised (Taherdoost, 2018) and is the most frequently used to validate the trustworthiness of a research instrument or model (Newman, Lim, and Pineda, 2013). Content validity comprises the appropriateness with which the content of a text can assess the construct of what it is supposed to assess (Polit and Beck, 2006; Newman, Lim and Pineda, 2013; Thermaenius, Schandl, and Sluys, 2019).

This was also done qualitatively by asking the experts reviewers to comment on the clarity and appropriateness of the items in the instrument based on their location (Devon *et al.*, 2007). The expert review focused on the structure and clarity of each domain, removing superfluous concepts, and adjusting unclear wording.

- **Reliability of the model**

To estimate the model's reliability, internal consistency and test-retest reliability methods were used (Devon *et al.*, 2007; Goldberg, 2016; Taherdoost, 2018). The extent to which individual responses remain steady over time, regardless of the sample completing it, was determined by internal consistency measures (Masuwai Azwani, Nor' ain Mohd Tajudin, and Noor Shah Saad, 2016).

The internal consistency reliability of the model was estimated by calculating the Cronbach alpha coefficient of reliability to an acceptable ratio for the developed model (Polit and Beck, 2013; Goldberg, 2016; Minary *et al.*, 2019). The test-retest and inter-rater reliability of the model was estimated by calculating the model's Intra-Class correlation (ICC) coefficient (Eckes, 2014; Zhang *et al.*, 2015). Secondly, ICC was also calculated for all the key components of the model to test the model stability (Arat *et al.*, 2016; Bohman *et al.*, 2018; Liljequist, Elfving and Roaldsen, 2019).

3.7 ACADEMIC RIGOUR

Academic rigour refers to the extent to which the researcher ensured the quality and accuracy of the entire research processes. The researcher estimated the psychometric properties of the designed research instruments before its use in the Ghanaian setting to ensure academic rigour. The psychometric components used in this research were reliability and validity. Validity is the degree to which a particular concept undergoes accurate measurement in a research study, whereas reliability relates to the consistency of the instrument's measurement used in the research. A pilot study was conducted at the Ridge Hospital, Accra, after ethics approval involving families and NICU/PICU clinicians to satisfy the study's rigour (Kain, 2007; Heale and Twycross, 2015; Bujang, Omar and Baharum, 2018). For a research instrument to stand the test of academic rigour and evidence of quality, a Cronbach alpha and intra-class coefficient are the commonly used statistic to estimate its psychometric

property. Cronbach's alpha is a psychometric test that estimates the internal consistency of an instrument (Kain, 2007; Bujang, Omar and Baharum, 2018; Taber, 2018). The psychometric properties of both quantitative instruments were excellent on pre-test.

The qualitative interview guide was equally tested on a convenient sample of two FGDs of five membership; one for families and another for the clinicians (Kain, 2007). The supervisor checked the final versions of the instruments and a language expert then transcribed them back-to-back into Twi, Dagbanli and English. These processes helped refine the study instruments prior to the main study in Ghana's northern and southern zones.

Several forms of research triangulations were involved in the thesis. The researcher used both qualitative and quantitative research methods (methodological triangulation), collected different types of data at various phases of the study at the northern and southern zones of Ghana (data triangulation), and more importantly, the research was underpinned by the CGT and the FST (theoretical triangulation) (Tobin and Begley, 2004; Perera, 2018). The employment of trustworthiness criteria was to ensure methodological rigour of the qualitative aspects of the study; this included credibility, transferability, dependability, and conformability (Tobin and Begley, 2004; McBrien, 2008).

Finally, there was an evaluation of the developed model of FCC, and another Cronbach alpha, intra-class correlation coefficient and content validity index of the model calculated to ensure the reliability of the NICU/PICU model. Content and face validity of the model were equally done, all to meet the academic rigour of the entire research.

3.8 ETHICAL CONSIDERATIONS

The aim of ethics in research is to protect the rights of participants, protect them from any harm that might befall them due to research activities and ensure the following of appropriate channels to obtain institutional permission for the study.

- Institutional permission: The researcher sought clearance from the Postgraduate and Human Research Ethics Committee of the University of the Witwatersrand. The approved proposal of the project, after faculty defence, was submitted for ethical clearance. The researcher did three research ethics assessment exams in introductory

to research ethics (CID: SBTfcKCslL), informed consent (CID: YpTryJAY4J), and research ethics evaluation (CID: K82Nb9H43c) and received certifications to meet the university's ethics committee requirements. The Chief Executive Officers of the two teaching hospitals granted permission and ethical clearance (**Appendices X, Y & AA**). The Wits University Ethics Committee received these institutional ethics **(**TTH/R&D/053 and STC/IRB/000145/2019**)** for the final ethics approval of the project (**Appendix W; No. M190980).** Invitational letters went out to respective experts needed for the study (**Appendices S & T**). **Consent by participants:** Haigh's (2008) principles of autonomy, informed consent, beneficence, non-maleficence, and dissemination of research findings were applied in the study.

- Qualitative research: Individual interviews and focus group discussions. Participants in the FGDs and face-to-face in-depth interviews were provided information sheets (**Appendices C & G**) explaining the purpose, conduct, risks, and benefits of the study, and then asked to voluntarily sign a consent form (**Appendices D & H**) as proof of their consent to participate in the interviews and for the interviews to be recorded (**Appendices E & I**). The scheduling of the interviews was at a time and place convenient for all participants. The use of pseudonyms instead of the actual names of the participants was to ensure anonymity. All transcribed data remained under lock and key, with soft copies saved on a password-controlled computer and memory stick. The engagement of a clinical psychologist during the data collection was to provide psychological support for families who exhibited psychological challenges in the study.

- Quantitative research: Each participant received an information sheet explaining the purpose, conduct, risks, and benefits of the study (**Appendix J**), after which they signed a consent form (**Appendix K**) to participate in the survey. Administering the questionnaires to them individually ensured understanding and privacy. The use of codes on the questionnaires instead of the names of participants was to guarantee anonymity and confidentiality. All completed questionnaires remained under lock and key. Data was only accessible to the researcher and the supervisors to ensure confidentiality. Information that identifies participants in the study received a code before any publication from this work.

3.9 SUMMARY

The methodology section presented the research processes and procedures used to answer the research questions. It highlighted the research paradigm applied in the study, the design, and methods, as well as the details of the three phases of the research, instruments used, data collection and analysis, and the psychometric properties. It presented the processes that led to the model development as well as ethics. This has provided the foundation for the filed aspect of the research project, starting with the qualitative study presented in Chapter Four.

CHAPTER FOUR

STEP TWO: RESULTS OF THE QUALITATIVE STUDY

4.1 INTRODUCTION

This chapter presents a detailed description of the qualitative findings and the discussions. The purpose of this chapter was to explore qualitatively the constructs the family needs, family involvement, barriers, and facilitators of FCC from the perspectives of families, clinicians, and health managers in the NICU/PICU. The researcher used the CGT design and FST to study FCC in the NICU/PICUs to present these findings. Therefore, the findings represent the participants' perceived perspectives of the concepts of FCC in the Ghanaian context. There is a presentation of the characteristics of the participants recruited in the study. Theoretical sampling occurred from the findings, as per the CGT design, and presented in six thematic areas: respect and dignity, participation, communication, collaboration, barriers of FCC, and benefits of FCC. These findings then formed the basis for the quantitative stage of the study using the Ghanaian context to construct the key concepts/components of FCC practices in the NICU/PICUs.

4.2 BACKGROUND OF THE PARTICIPANTS

4.2.1 Background and Presentation of the Participants Codes

The researcher identified and included three sets of participants in the study, families, clinicians, and managers.

- The families, coded as "F" and "no colour," were parents interviewed for their perspectives and experiences of their involvement in the care of their critically ill children admitted in the NICU/PICU.
- The clinicians, coded as "C" in this context, were the nurses, midwives, and doctors who directly provided intensive care to critically ill children.
- Managers, coded as "M" represented the department and unit managers of child health in NICUs, and PICUs. The study took place in two public tertiary teaching hospitals. Hospital Korle Bu, coded "K," is located in the southern sector, and Hospital Tamale, coded as "T" is in the northern sector of the country. The individual

interviews received the code "I," and the FGDs code "D;" serial number codes were attached to these codes to differentiate them.

An example of a code at hospital T is TCI6, meaning sixth clinician individual interview conducted at hospital T, and KCD3, meaning third clinicians FGD conducted at hospital K. The FGDs had five members each, coded as A, B, C, D, and E; for instance, the code TFD3A means the first member of a parent in the third family FGD at hospital T.

After attaching these codes to participants' transcripts, their consistent use throughout the presentation of the results ensured anonymity, privacy, and confidentiality to keep to the demands of research ethics and methodological rigour.

Table 4.1 Summary of interviews conducted at the two settings.

Category	**Frequency (n)**	**Percentage (%)**
Family individual interviews	12	33.3
Clinicians' & managers individual interviews	12	33.3
Family Focus Group Discussions	6	16.7
Clinicians Focus Group Discussions	6	16.7
Total	**36**	**100**

From **Table 4.1**, there were 36 interviews conducted, i.e., 24 individual interviews and 12 FGDs from the two settings.

Table 4.2 Summary of participants recruited in the qualitative study

Category	**Frequency (n)**	**Percentage (%)**
Mothers	35	41.67
Fathers	7	8.33
Nurses and Midwives	29	34.5
Doctors	9	10.7
Managers	4	4.8
Total	**84**	**100**

Table 4.2 reveals there were 84 participants recruited for the qualitative aspect of the FCC study. The majority of participants (41.67%) were mothers, while the least participants were managers (4.8%; n =4)). More mothers than fathers participated in the study (8.33%; n=7) due to limited fathers' involvement in care due to sociocultural and religious reasons. Most of the clinicians were nurses because they constitute the majority of staff in Ghanaian ICUs.

Table 4.3 Characteristics of family individual interviews

Code	Gender	Age (Years)	Education	No. of children	Baby's Condition	Length of stay	Interview language
TFI1	F	31	SHS	1st child	Birth asphyxia	3 days	English
TFI2	F	26	Tertiary	1st child (twins)	Preterm	2 weeks	Dagbani
TFI3	F	33	None	5	Preterm	4 weeks	Dagbani
TFI4	F	20	SHS	1ST child	Birth asphyxia	3 weeks	Dagbani
TFI5	F	18	None	1st child	Preterm	2 weeks	Dagbani
TFI6	F	27	None	3	Birth asphyxia	1 week	Dagbani
KFI1	F	34	Tertiary	2	Preterm (twins)	2 weeks	English
KFI2	F	21	SHS	1st child	Preterm Infection Jaundice	3 weeks	English
KFI3	F	29	Tertiary	1st child	Preterm, jaundice, pyloric stenosis	3weeks	English
KFI4	M	34	Tertiary	2	Preterm (twins)	5 weeks	English
KFI5	F	41	Tertiary	4	Sickle cell crisis	9 days	English
KFI6	F	54	SHS	2	Kidney Failure	2 weeks	English

Table 4.4 Characteristics of clinicians' individual interviews

Code	Sex	Age (Years)	Marital Status	Profession/Speciality	Working Experience (Years)	Interview language
TCI1	F	32	Married	General practitioner	5	English
TCI2	F	33	Single	Neonatal Nurse	9	English
TCI3	F	36	Married	Neonatal Nurse	21	English
TMI4	F	41	Married	Nurse Practitioner (DDNS)	19	English
TCI5	M	36	Single	Registered Nurse (PNO)	13	English
TMI6	M	42	Married	Consultant paediatrician	15	English
KMI1	F	43	Married	Specialist paediatrician	16	English
KCI2	M	40	Single	Resident paediatrician	15	English
KCI3	F	30	Married	Post-Basic Midwife	8	English
KCI4	F	26	Married	Registered Nurse	6	English
KMI5	F	51	Widow	Nurse Paediatrician (DDNS)	26	English
KCI6	F	52	Married	Midwife (DDNS)	24	English

4.2.2 Individual Interviews

The second stage of this research project was a qualitative study built on relevant scoping literature spanning five years in credible databases. Overall, 24 individual interviews were conducted, of which 12 were from families, eight from clinicians, and four from managers in the two settings. **Tables 4.3 and 4.4** present the detailed breakdown of the characteristics of participants of the family who took part in the study, and that of clinicians**.**

Only one male parent participated in the family interviews, and the ages of the family participants ranged from 18-54 years; the minimum age was 18 years, and maximum age was 54 years, and the average age of the family participants was about 31 years.

The majority of the family participants (67%) had employment, with only 25% officially employed. Again, most of the family participants (75%) had at least senior high school education, with approximately 42% having tertiary education. Fifty percent of the family were first-time parents and were entirely new to childbirth and infant care. Families had babies admitted to the NICU/PICU with different conditions, which spanned their length of stay at the NICU/PCU from a minimum of 3 days to a maximum of 5 weeks. The admission of the majority of the babies (58%) was due to prematurity, about 25% of the babies had birth asphyxia, and 16% jaundice; others were admitted due to congenital pyloric stenosis, infection, sickle cell crisis, and kidney failure. The interviews were mainly in English, with some in Twi and "Dagbani," which are common local Ghanaian languages in the south and north.

The researcher conducted 12 individual clinician interviews. The clinicians included nurses, midwives, doctors, and managers, i.e., heads of Child Health departments and respective unit heads of NICU and PICU at the two settings. The participants were between the ages of 26-52 years, with an average age of 38 years, with a mixture of gender (nine female and three males), eight nurses/midwives and four doctors. The researcher was able to obtain the participation of five clinicians who specialised in paediatrics in the qualitative study; this included a paediatric consultant, a paediatric specialist, two neonatal nurse specialists, and a paediatric nurse. The clinicians had various ethnic backgrounds and were a mixture of Christians and Moslems, which helped posit the study in the multi-cultural dynamics of the study setting. The clinicians had a minimum of 5 years and a maximum of 26 years working

experience, with this person coincidentally being a nurse manager. This shows the significant roles of nurses in the care of critically ill children in ICUs. All the clinicians' interviews were in English language.

4.2.3 Focus Group Discussions (FGDs)

Table 4.5: Characteristics of family and clinicians focus group discussions

Code	Number (characteristics)	Age range (Years)	SETTING (ZONE)	Interview Language
TFD1	5 (All mothers)	20-45	TTH (Northern)	Dagbani
TFD2	5 (All mothers)	23-26	TTH (Northern)	English
TFD3	5 (All mothers)	20-36	TTH (Northern)	Dagbani
KFD1	5 (All mothers)	32-45	KBTH (Southern)	English
KFD2	5 (All fathers)	26-32	KBTH (Southern)	Twi
KFD3	5 (4 mothers, 1 father)	26-36	KBTH (Southern)	English
TSD1	5 (1-RN, 4-Neonatal Nurses)	30-43	TTH (Northern)	English
TSD2	5 (All medical doctors)	25-28	TTH (Northern)	English
TSD3	5 (2-PN, 3-RN)	28-36	TTH (Northern)	English
KSD1	5 (2-RN, 1-CCN, 1-PN, RNA)	26-32	KBTH (Southern)	English
KSD2	5 (2-RNA, 1-RN, 2-CCN)	29-35	KBTH (Southern)	English
KSD3	5 (1-RNA, 3-RN, 1- DP)	28-32	KBTH (Southern)	English

Key = *RN= Registered Nurse, CCN= Critical Care Nurse, PN= Paediatric Nurse, NA= Registered Nurse Assistant, DP=Doctor Paediatrician*

At the two setting, there were 12 FGDs, six family FGDs and six clinicians FGDs conducted. The family FGDs were in English, Twi, and Dagbani. Table 4.5 presents the details of participants recruited for the FGDs.

4.3 Themes and sub-themes that emerged from the data

Seven major themes emerged, contextual practices of FCC, respect and dignity, communication, participation, collaboration, barriers, and benefits of FCC. **Figures 4.1** and **4.2** illustrate the word clouds of the final code system and the retrieved segments from the 36 transcripts.



Figure 4.1 Word cloud of retrieved segments of qualitative transcripts



Figure 4.2 Word cloud of code system including codes and sub-codes

Table 4.6 shows the steps of the CGT analysis, i.e., open initial coding, focused coding, and theoretical coding, as adopted from Charmaz (Tie, Birks and Francis, 2019).

Table 4.6 Development of the themes and sub-themes in relation to CGT design

Initial coding (sub-sub themes)	Focused coding (sub-themes)	Theoretical coding (themes)	Example of coded segment
Information; Financial; Psychological	Family needs	Respect/dignity	*"TCD1: The clinicians should be accommodating and talk to parents more calmly to help them understand treatment given to their babies"*
Kangaroo care; Decision making; infant feeding	Family Involvement	Participation	*"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 teaching; education, counselling	Information sharing	Communication	*"TCI5: …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"*
NICU/PICU design; FCC guidelines; multidisciplinary approach; training	Implementation of FCC Staff training	Collaboration	*"KMI5: the setup must be well-designed into partitions or cubicles to make the environment conducive to ensure privacy and confidentiality for full family participation"*
Abandoned babies; Socio-cultural; lack of space; Inadequate logistics; Inadequate specialised personnel	Family barriers Institutional barriers	Barriers of FCC	*"TMI6: There are some parents who do not also want the baby, especially for preterm babies and those with congenital anomalies"* *"KMI1: ...due to lack of space, babies are all lying in the incubators. Mothers will come to sit to express breast milk and further congest the ICU"*
School family; continuity of care; early discharge; reduce mortality; reduce workload; quality care	Family benefits Institutional benefits	Benefits of FCC	*"KMI5: the family involvement and participation will help continuity of care at home by the family, reduce resources in managing the care, and prompt recovery of the child"* *"TCD1C: …it makes the family feel part of the care rendered to their baby and this boost their confidence to care for the baby at home after discharge"*

Table 4.7 Themes and sub-themes that emerged in relation to the CTG design from the interviews and focus group discussions with family members and clinicians

Themes	Sub-themes
4.4 Theme 1: Contextual practices of family-centered care	4.4.1 Sub-theme 1: Definition of FCC
	4.4.2 Sub-theme 2: Clinicians experiences of FCC in Ghana
	4.4.3 Sub-theme 3: Family experiences of FCC in Ghana
4.5 Theme 2: Respect and Dignity	4.5.1 Sub-theme 1: Family needs
	4.5.2 Sub-theme 2: Acceptance, respect and Dignity
	4.5.3 Sub-theme 3: Culture, beliefs and religion
	4.5.4 Sub-theme 4: Privacy and confidentiality
4.6 Theme 3: Family involvement and participation	4.6.1 Sub-theme 1: Schedule visitations
	4.6.2 Sub-theme 2: Infant feeding
	4.6.3 Sub-theme 3: Running ICU errands
	4.6.4 Sub-theme 3: Kangaroo care
	4.6.5 Sub-theme 4: Decision making
4.7 Theme 4: Communication	4.7.1 Sub-theme 1: Counselling sessions
	4.7.2 Sub-theme 2: Education and communication
4.8 Theme 5: Collaboration	4.8.1 Sub-theme 1: Funding child healthcare
	4.8.2 Sub-theme 2: Staff training
	4.8.3 Sub-theme 3: Implementation of FCC
4.9 Theme 6: Barriers of FCC in Ghanaian ICUs	4.9.1 Sub-theme 1: Family barriers of FCC
	4.9.2 Sub-theme 2: Facility barriers of FCC
4.10 Theme 7: Benefits of FCC practices	4.10.1 Sub-theme 1: Family benefits of FCC
	4.10.2 Sub-theme 2: Institutional benefits

4.4 THEME 1: CONTEXTUAL PRACTICES OF FAMILY-CENTERED CARE

Three sub-themes emerged from the data under this theme: definition of FCC, clinicians' FCC experiences, and family FCC experiences in the Ghanaian NICU/PICUs

4.4.1 Sub-theme 1: Definition of Family-centered Care

Participants described FCC as shared decision making and respect between families and clinicians to bring their ideas on board in prioritising care for children. They acknowledged that clinicians often do not see families as experts, which leaves a gap in the care of children; this is because the NICU environment presents a challenge for full family participation. Thus, there is no practice of the best form of FCC in Ghana. However, participants considered FCC an essential concept in child health that must employ a multi-disciplinary approach, including clinical psychologist and social welfare, to provide childcare in the NICU/PICU and not just the nurse. The community health nurses (CHNs), for example, would promote continuity of care through the identification of community support groups. This will provide family support and integration of the sick child into the family and community, especially for congenital abnormalities. The extracts below amplified these findings:

> *"KCD3A: …it should be one of the priorities when taking care of children"*
>
> *"TCD1E: … FCC involves shared decision making between the caregivers and the parents as well as relatives… I think there is a gap in the care that we are providing"*
>
> *"TCD1C: … In family centred care (FCC), the first thing is to respect their opinions, involve them, and then make sure you understand their perspective based on their culture and beliefs"*
>
> *"TCD1B: ICU is a different environment in a hospital setting, and dealing with these little ones without their families is going to be very challenging... The paramount thing is you bringing their ideas on board is very important as it helps in decision-making about the care; even though we do not get to practice it in its best form, we try to practice some family-centered care components"*
>
> *"TCD1D: FCC is a very important concept, and it involves a team, not just the nurse. FCC should be approached from a multidisciplinary perspective… "*
>
> *"TCD1A: Public and community health nurses (CHN) should also be involved to get the support systems of families… CHN promote continuity of care. FCC is team care; social welfare plays a role in meeting the needs of the patient, preterm baby or one with a congenital anomaly. We must identify community support groups to help families with sick children, especially those with congenital abnormalities"*

4.4.2 Sub-theme 2: Clinicians' Experiences of FCC in Ghana

The clinicians narrated that families need the support of clinicians and the system to deal with the stress of participating in the care of their critically ill children. Many mothers go

through caesarean section, and often left alone to do laboratory and pharmacy errands. The clinicians usually assist the families to meet these needs. In our context, some families are supportive in the care of their critical children, and others are not. Some families may not involve themselves in the care due to their sociocultural background. Normally, families from rural setting leave the child with the mother without any form of family support. However, they anticipate early discharge regardless of the child's condition, challenging the care. Such families sometimes request for discharge against medical advice (DAMA) because they are alone to support the care, with limited resources to sustain their stay in the ICU:

> *"KMI1: You can just imagine a mother who has just had a baby, probably through caesarean section. Her husband has to be away to work and bring money. So, she is left alone with no sister and support"*

> *"TCI2: … my experiences with mothers in the care of their newborns have been okay; some are ready and supportive, and some are not supportive in the care of their newborns"*

> *"TMI6: Depending on the background, the experience in handling them differ quite a lot. For instance, families from the rural areas come with just the mother and the baby and rarely with an accompanying relative, then after some days, they vanish when they realise the baby will not be discharged soon. The mother will then be left alone to take care of the baby. In those instances, the issue that you will encounter is that the mother expects to be discharged irrespective of the baby's state of health; because of the lack of resources to take care of the baby"*

FCC is essential for child healthcare. One major concept of FCC in this context was respect for families. Respect for families reduces anxiety and makes them feel free to share their sociocultural perspectives of the child's illness. However, the challenge of this is the lack of funding and institutional arrangements. For instance, the hospital system does not make enough arrangements for children's relatives to procure medical supplies, such as medication. Some medications, such as intravenous fluids, are usually in adult formulations, which is a challenge for the care.

> *"TCD1C: FCC is very important, especially when you are taking care of children because they come to a state where they are anxious and not sure about what exactly is happening and this stage you have to involve them in order to gain their cooperation. In family centred care (FCC), the first thing is to respect their opinions, involve them, and then make sure you understand their perspective based on their culture and beliefs"*

4.4.3 Sub-theme 3: Family experiences of FCC in Ghana

Families with children admitted to ICUs experienced anxiety and emotional stress. They described their experiences *as "feels empty," "very anxious," "very awful," and "harrowing experience."* This anxiety was due to the phenomenon of going home to sleep without the child - "y*ou cannot sleep,"* "*you feel like your baby is crying,"* and "*boxes carried with dead babies.*" The participants observed that the lack of free flow of information on their child's condition and progress was a major challenge to their full participation and involvement in the care. The coping strategies adopted by families to deal with the anxiety associated with the NICU/PICU phase of care, included prayers, leave from work and occasional support from the clinicians. Even though some mothers cried due to these experiences, the crying was also a way of ventilating and dealing with these stressors. Some of the participants recounted their experiences as follows:

> *"KFI1: It is a very anxious experience, especially if you have given birth before; it feels empty when you do not have your child beside you when sleeping. Sometimes I wake up in the middle of the night, and I cannot find my baby, and sometimes it keeps me awake. Sometimes too, we pray as we do not know what is going on at the hospital when we are home, and we are always afraid for our children…Some doctors and nurses are very supportive"*
>
> *"KFD1B: …I was also very anxious because every morning, like before you enter ICU, you will see boxes carried with dead babies"*
>
> *"KFI3: It is awful, and it is something I do not wish for anyone. Because your baby is somewhere and you are home, you feel like your baby is crying, you feel like being with your baby though you know that your baby is in safe hands, that motherly instinct will not just give you that peace of mind down and sleep… I was crying almost every day and at night. It is a harrowing experience"*
>
> *"KFI4: You cannot sleep… I took twenty working days off to be with my family here…"*
>
> *"TFD3B: when they examined my baby, they did not share any information on the progress of my child's condition…and it worsened our anxiety"*

4.5 THEME 2: RESPECT AND DIGNITY

Respect and dignity imply that healthcare providers listen to, honour and accept the patients and family's perspectives and choices, values, beliefs, privacy and confidentiality. The researcher examined the content of the transcripts for this concept of FCC and identified four sub-themes, family needs, acceptance, cultural beliefs, and privacy and confidentiality.

4.5.1 Sub-theme 1: Family Needs

Five sub-sub-themes emerged from the content analysis relative to the family needs: information, involvement, psychological needs, financial needs, and basic needs. The greatest need of a family is information on the child's condition, regular updates on the care processes, and progress of the child in the ICU. Most families are anxious, and they want the clinicians to reassure them, involve them, and explain the care processes. Families want the clinicians to build relationships with them, like husband and wife, and use patience to handle them. For example, families want clinicians to be accommodative and to speak to them calmly to understand the treatment process. Families are happy when they can touch and feel their babies, even with gadgets. However, there was a lack of free flow of information from clinicians to families, culminating in their anxiety. Adequate flow of information and explanation of the processes may reduce their anxiety. Three participants in the study intimated this:

> *"TCI2: **……**they do not know what is happening to their babies… their number one need is information"*
>
> *"TFI2: They should have time to reassure the mothers to get us involved in the care by explaining to us to understand some of their actions so that next time we will not repeat that. They need to see our relationship with them like a husband and wife as they have control over us and use patience to handle all mothers"*
>
> *"TCD1: The clinicians should be accommodating and talk to parents more calmly to help them understand treatment given to their babies"*

The family needs to be involved in the care processes and decision-making during the child's care. They want to support the care of their babies, including bathing, changing diapers, clothing, and feeding. Some families want the facilities to allow grandmothers and traditional birth attendants (TBAs) to support clinicians in bathing babies at least twice a week. Hence, the facilities should consider the engagement of the TBAs to support the bathing of babies to reduce the workload on the clinicians. The involvement of families in the care of critically ill children will help monitor the sick child and notify the clinicians for prompt actions to promote quality and adequate care.

> *"TFD3D: I think they should allow us to bathe the babies. If they feel we cannot handle them safely, they should employ trained traditional birth attendants to be doing the bathing…"*

“TFD3C: even the grandparents of the children, if they allow, will help bath the babies. They should make a schedule for the bathing at least every 2 days so that the grandmothers can come and do the bathing”

"TFI4: Our presence in the ICU will assist the nurses in the care of the babies by feeding them, cleaning them, change diaper and clothing, and notifying the clinicians of any sudden changes in the babies’ conditions"

Another major need of a family in ICU is psychological needs. Families were anxious and emotionally traumatised about the NICU/PICU phase of care for their sick children. The sources of family anxiety and emotional stress were due to babies’ condition, such as preterm, lack of updates on the progress of care, lack of encouragement from clinicians and, in some cases, from family members. Participants described their experiences in ICU as disheartening, and requiring the support of the clinicians to cope with the psychological stress. Some families reported insomnia related to the emotional stress associated with their child’s admission to ICU. The participants recommended the services of a clinical psychologist in the NICU/PICU to support both families and clinicians to address their emotional needs.

"TCI2: Their needs are that they are anxious and mostly the anxiety is because they do not know what is happening to their baby. You sometimes see mothers cry and be in those states and still support the care, though it is disheartening"

"KCD1C: emotional needs… some of the mothers need someone to encourage them”

“KFI2: It was stressful because I cannot sleep at night; I used to miss my baby…"

"TMI4: … to practice the family-centered care; a psychologist is much needed because they will know how to present the social problems to the family…"

Furthermore, families faced financial challenges to support expensive ICU care processes. The income source(s) of most families at the NICU/PICU was either non-existent or small; this was because most families were unemployed and had no source of livelihood. Women relied heavily on their husbands to provide for their basic needs, such as food and medication. The lack of funding to support the care in terms of purchasing drugs and conducting laboratory screening promptly, had a negative impact on the quality of care rendered. The expensive nature of intensive care services at the NICU/PICU as laboratory investigations, and repeating of expensive drugs until full recovery, aggravated the problem.

The expensive nature of services and the lack of finance for families often made it impossible for some families to even afford food during their stay in the NICU/PICU. Therefore, participants called for financial support for families, especially those with congenital abnormalities, requiring surgical interventions.

> *"KFI2: My needs are a lot; I need to buy some stuff for the baby and me, and because I am here, I am unable to work, so it is challenging to get money to meet our needs"*
>
> *"KFI1: Mothers need support because is not everyone who works and the cost of treatment here is expensive"*
>
> *"TCD1C: Per expert assessment and interaction with families especially those who come with congenital issues, it is identified that they have challenges like financial and employment-related issues…"*
>
> *"KFD3D: Again, some of the labs and treatments are requested in repeated forms without explanation"*

Finally, basic needs required by families who participated in the study included food, water, washrooms, cleansing agents for babies (wipes), and accommodation. Two of the participants corroborated this by stating that families received no food due to lack of money, and there was no accommodation and washrooms:

> *"KFI6: We need food...we will want them to provide accommodation for us"*
>
> *"KFI3: I think with the wipes, they get donations, so they should supply the wipes…"*
>
> *"TFI2: We have no toilet facility, no accommodation, no feeding for us…"*
>
> *"TCD1D: … we do not give mothers food… They do not have money to buy food every day, so they cannot even produce breast milk for the baby"*
>
> *"TMI6: The family also need accommodation and washrooms, and this is another pressing need of the families that must be captured in the new NICU design for family-centered care to thrive in our setting"*

4.5.2 Sub-theme 2: Acceptance, Respect, and Dignity

The participants interviewed indicated that clinicians must accept families coming into the ICU from day one and make them feel welcomed; the absence of such rapport will affect mutual respect. Respect is a natural stimulus for cooperation, and achievable through initial

building of socialisation with families from the first day of admission. Families feel dignified when adequately accepted into the facility without disguise. The workload was the cause of the inconsistent acceptance and respect towards families. Other determinants of acceptance and respect were social status, educational level, and family's capacity to afford care costs. Some families were worried about the lack of acceptance and respect from clinicians, especially the female clinicians. Some of the families wanted to take their babies home because of the disrespect from some clinicians. When families are not accepted and respected, it affects their participation in the care:

> *"TCD1D: **…** it is the responsibility of the clinicians to let the family feel welcomed to allay their fears. However, that is missing because of the workload. We should respect their opinions and find a way to accept them, and it will promote their participation in the care"*
>
> *"TCD1B: Let us accept families of patients as who they are and what they can offer to change their negative perceptions towards clinicians…*
>
> *"TCD1E… our approach to families should be respectful and their dignity preserved as sicknesses can cause disorientation. Respect and dignity should be ensured regardless of race, colour, ethnicity, status, or language"*
>
> *"KMI5: Yes, if you do not build the initial rapport or socialisation with the family and involve them in the care, they will make your work difficult for you…"*
>
> *"TFI1: … some of them will shout on you as if you are a goat…is the male clinicians who know how to handle the mothers… A male clinician will never shout on a mother, even if they have to talk to you, they take their time with patience to talk to you… the female clinicians will disrespect you a mother then you feel like taking your baby out of the NICU and going home"*
>
> *"KFD1D: sometimes they look at your class, your level of education, and then the way you have dress, the kind of visitor you have before they accord you the rightful respect…"*

4.5.3 Sub-theme 3: Culture, Beliefs, and Religion

Contextual understanding of the culture and religion of participants is a fundamental block of the Family Systems Theory and the practice of FCC. Participants maintained that families should receive respect irrespective of their race, ethnic or cultural backgrounds to get their full participation. Some families will refuse treatment, such as blood transfusions, based on their religion. For instance, in this context, the gender of a child significantly determines the participation of most families in the care processes. Some families can abandon the baby in

the hospital due to their cultural preference of a male child over a female child. In some cultural practices, a baby born premature or with congenital abnormality is a "spirit child," which ultimately affects family participation in care. Therefore, before there can be implementation of FCC, clinicians must strive to understand the culture and religion of their patients and their families:

> *"TCD1A: Before you can practice FCC wherever you find yourself, you need to identify and understand the culture and religion of the individual families…"*
>
> *"KMI1: you know we have religious groups that will not allow blood transfusion…"*
>
> *"KMI5: …we treat everybody equally, whether poor, rich or educated. Sometimes we have clinicians coming here with their children, but we still treat all equally..."*
>
> *"TCD1D: When family come, they want to know if the baby is a male or a female (the gender). The main thing is what the gender of the baby is, is a culture here"*

4.5.4 Sub-theme 4: Privacy and Confidentiality

Maintaining privacy and confidentiality in this context is hard in the ICU because of limited space and the lack of counselling rooms. *Privacy is an issue in ICU because all the mothers come into the open space to feed and attend to their babies.* In some cases, clinicians hide babies with obvious *birth anatomical abnormalities* in a corner in the NICU. Some mothers are concerned about their privacy in the ICU, especially during breastfeeding sessions; this is because they breastfeed in the open ward without any privacy, making most of them uncomfortable. The following excerpts illuminate the participants' perspectives at the two settings.

> *"KMI1: Very tough as you can see, there is no space here…"*
>
> *"KCI4: …birth abnormality, anatomically, you can see that the defect is obvious, we try to put the baby at a corner in the ICU so that not every family will see such babies"*
>
> *"KFI1: Privacy is an issue in intensive care because all the mothers come in an open space to feed and attend to our babies…"*

4.6 THEME 3: FAMILY INVOLVEMENT AND PARTICIPATION

This refers to clinicians' involvement of families in the care of their critically ill children in the Ghanaian context. According to this concept of FCC, clinicians and families must work in partnership to provide satisfactory and participatory care for the critically ill child in the ICU. However, family participation practiced in this context was through scheduled visitation, infant feeding, running errands, decision-making, and Kangaroo Mother Care, even though visitations and errands are not technically part of FCC practices.

4.6.1 Sub-theme 1: Schedule Visitations

Family involvement and participation was through scheduled family visitations into the NICU/PICU. The hospitals allow six scheduled visitations for fathers and mothers into the ICU; mothers had four visits, and fathers two visits. Other family members, including grandparents, could only visit when the parents were unavailable to be involved in the care at the ICU. The rationale for such practice was to prevent infections to the unimmunised babies in the ICU. Granting full access to families in the ICU is important to help in decision-making, promote motherly love, and improve babies' health.

> *"KCI2: … for infection control purposes, we allow just the parents, the mother, and the father of the baby. 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 mothers. So, essentially baby gets six visits by the family, but it is all daytime till about 7 pm"*

> *"KFD1D: They should involve the mothers and explain the procedures they are doing to the babies to them so that the mothers will also understand. When mothers are involved in the treatments, it promotes motherly love that will also encourage or improve the baby's health…"*

4.6.2 Sub-theme 2: Infant Feeding

The clinicians involved families in the care of critically ill children during infant feeding. Two major themes emerged after the inductive and deductive content analysis of the data: determinants of feeding and feeding processes of the critically ill child in ICU. The determinants of feeding had three sub-themes that evolved from the findings: experts'

knowledge/skills, medical conditions, and gestational age. The feeding process in ICU had four sub-themes: parenteral, enteral, cup feeding, and breastfeeding; the mothers were involved in breastfeeding, and feeding expressed milk with a cup and spoon. The extracts below to illuminate this sub-theme.

> *"KCI4: They learn how to do the cup and spoon-feeding, which is much easier and safer"*

> *"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"*

> *"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…"*

4.6.3 Subtheme 3: Running ICU errands

Parents with children admitted to the ICUs run errands, including registration and folder collection, buying medication, and sending samples for laboratory diagnosis. Clinicians relied heavily on parents to collect drugs and processed laboratory samples. Some mothers had challenges running the errands due to their health post-delivery and non-availability of family support systems. This affected prompt delivery of care for the sick children in the ICUs:

> *"KMI1: Once you are the father, and you brought your baby here, you are going to do a lot of the errands like preparing a folder, buying medications, and taking samples to the laboratory and bringing back the results. Parents need to go out looking for medications, and sometimes even getting the emergency drugs to work with becomes a problem because you have to wait for a father to come and buy the medication, which negatively affects the care, we provide in the ICU"*

> *"KFI2: Some mothers are operated on and are not strong enough to support the care at the intensive care"*

> *"KFI5: … they will call you and tell you that go and do this lab, go, and do this scan, go, and do this X-ray"*

4.6.4 Sub-theme 4: Kangaroo Care (KC)

One way of involving parents and building partnerships with families in the care of their children at the NICU was through the practice of Kangaroo Care (KC). This was most gratifying to families since they migrate from partial involvement at the ICU phase to full involvement at the KC phase. The KC allowed families (mother and father) of preterm babies to stay with them in the ICU. It involves bonding skin-to-skin with their preterm babies to provide warmth for improved weight, growth, and development. During KC, a premature baby is kept in front of the mother, in-between her breasts and thigh, and covered with a cloth. KC practice *helps the babies gain weight gradually to for discharge.* It creates the opportunity for families to spend more time with their newborns in ICUs and enhances participation. Involving families in KC will promote continuity of care at home since they will understand it and appreciate its benefits. Besides practicing the KC in separate rooms at the ICU, families were able to get full participation in the care of their babies, including feeding and bathing, for a speedy recovery.

> *"TCI3: We place them on KC - Kangaroo Care…"*
>
> *"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…"*
>
> *"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"*

4.6.5 Sub-theme 5: Decision-Making

Occasionally, the clinicians would involve families when confirming the diagnosis of their critically ill children in the NICU/PICU. Laboratory and diagnostic investigations were sometimes discussed, with families also sent to the request and bring back the test outcome. Families with children with congenital abnormalities were also engaged to discuss treatment modalities and refer them to the right specialist. However, some families said they were only involved in the care when a decision about their babies required money. Some mothers lamented their non-involvement in decision-making, including the purchase of artificial feeds and changes in the management plan. Such practices added to the emotional stress of families. The participants in the family interviews revealed the following:

"KMI1: Just two days ago, I had a baby whom I suspect have 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…"

"KFD3B: we are only involved when it is about money. We are normally not called for any decision regarding the care of our babies"

"TFD3: When I brought the baby feed, another clinician said it was too early to start artificial feeds. Meanwhile, we even struggled to raise money to buy the feed. I think they should coordinate with the family in making decisions concerning the care of our children. They should involve us in the decisions and care processes…"

4.7 THEME 4: COMMUNICATION

This involved ensuring a free flow of information between the clinicians and families with critically ill children at the ICUs. Families were not satisfied with the information sharing between them and the clinicians at the NICU/PICU. Two major sub-themes emerged, counselling sessions and education.

4.7.1 Sub-theme 1: Counselling Sessions

There was a counselling room used for sharing information for the families at the ICUs. Clinicians counselled families by reassuring them and explaining the child's condition to them, updating families and answering all their questions to allay anxiety. This did not occur for all families admitted to the ICU due to personnel challenges. However, the clinicians indicated that a permanent clinical psychologist in the ICU would help address the emotional stress of the families through counselling sessions.

"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 update the patient and answer all questions of the family related to the care of their child… "

"KFI4: They called both of us (myself and my wife) that one is critically ill because she went off"

"KMI1: ....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..."

4.7.2 Sub-theme 2: Education and Communication

The clinicians provided information for families by educating them on the specific process of childcare in ICUs. Some clinicians prioritised effective communication with the families as one of the key concepts of FCC that will keep families involved in the care of their children. Families were educated on the children's clothing, feeding critically ill children, and maintaining the child's body temperature via KC and extra clothing. Families' effective education will automatically promote mutual respect, collaboration, and partnership between the clinicians and families.

> *"TCI2: Letting them know the rationale. To even tell a mother to bring a dress, I go ahead even to specify"*
>
> *"TCI5: …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"*
>
> *"KFI1: … we are educated to rub the babies in extra clothing to provide warmth so that when you go home, you will know how to continue the care"*

4.8 THEME 5: COLLABORATION

Collaboration means patients, families, and clinicians team up in care, training, policy, and programme development to implement FCC for quality child healthcare. Three major sub-themes emerged from the content analysis of the data: funding child health, implementation of FCC, and staff training. Funding child health had four sub-sub-themes, i.e., donations, health insurance, institutional funding, and national fund. Implementation of FCC had two sub-sub-themes, i.e., FCC protocol and ICU design. The staff-training sub-theme also had two sub-sub-themes, i.e., education and FCC curriculum.

4.8.1 Sub-theme 1: Funding Child Healthcare

From this qualitative study, it emerged that funding child health was a key intervention to facilitate the implementation of FCC in Ghana. The content analysis evolved four themes relative to the provision of funding: health insurance, donations, institutional funding, and National Child Health Fund.

The *National Health Insurance Service (NHIS) should be widened to cover all the expenses regarding mother and baby care,* especially critically ill children in the ICUs. For example, participants want the NHIS to cover all the laboratory investigations and drugs for childcare in the NICU/PICU. This will empower and encourage families to better participate in their childcare. Thus, even though not sufficient, participants identified the NHIS as a funding source for improved child health services and therefore called on the government to strengthen it. The NHIS has challenges with irregular payments to facilities, causing financial constraints towards providing quality health services:

> *"TFD3D: … the support I want from the hospital and government is that the national health insurance should be widened to cover all the expenses regarding the care of mother and baby"*
>
> *"TMI6: …all these things are done with one bundle from the health insurance…the health insurance does not pay promptly is also a challenge"*
>
> *"TFD3: If the insurance can cover all the care including the labs and drugs, families can better participate and get involved in the care of their sick children…"*

Aside from the health insurance, participants want the government funding complemented with donations from individuals. The facilities should consider soliciting donations from *individuals, institutions, and organisations*. Participants, however, maintain that such individuals are hesitant to donate because they are not sure of its proper management. The donations can be in the form of medical supplies, equipment such as incubators and ventilators. They maintained there could be integration of FCC into ICU if there was enough and regular funding provided to support families and the hospitals to deliver quality child health. While others called for donations to support funding of child health, some participants believed that such contributions would not be enough unless the government sets up a fund to augment such donations. Such a fund would provide *financial support for families with critically ill children:*

> *"KMI5: There should be financial support for families with critically ill children. Some people donate, but the government must come in to support the family…"*
>
> *"KFI3: Everything is funding, so the government, individuals, institutions can donate to provide more funding support to implement FCC…"*
>
> *"KCD3A: …we have a ward fund contributed by patients who come to the ICU as well as donations from benevolent individuals and institutions, but that is unable to meet these challenges…"*

Other participants believed strengthening the *social welfare* department of the hospitals would improve institutional-based funding. This would provide support for poor and needy families with critically ill children, such as *teenagers*. In some cases, families could not *buy the drugs and food,* which eventually affected their full participation in the care. Meanwhile, when a mother *eats well and gets nutrients, the baby too can do well.* Their families abandon some parents to go through the NICU/PICU phase of care alone. This underscores the need for institutional support through a well-strengthened social welfare. Another institutional funding source that emerged from the participants was a *ward fund,* which was a local arrangement by ward managers for clients to contribute a small amount. This then supported needy families in ICUs.

> *"KCI4: … the social welfare should work because some of the parents are teenagers who cannot fend for themselves, let alone their critically ill children. So, social welfare should improve their processes to support families"*
>
> *"KFI2: The main support that we need here is finances to be able to buy the drugs and also food…"*
>
> *"KCD3A: we have a ward fund contributed by patients who come to the ICU…"*

Finally, the participants recommended that the government set up a national *Child Health Fund*. A nurse manager with 26 years of working experiences in the department of Child Health observed that the institutional funding alone was *inadequate to meet the financial needs of families* for the provision of quality child healthcare. Therefore, the government should set up a fund to support child health in Ghana effectively. This call had huge support from other participants in separate interviews and FGDs because the NICU/PICU care is *costly and, besides, children deserve special benefit*. The lack of funding support for families affects the prompt delivery of ***emergency*** care for clients. The extracts below codify these observations:

> *"KMI5: …We need a national fund to support the family in the care of their critically ill children. Without such, fund support is difficult to provide the care"*
>
> *"TCI4: we could have funds where there will be donations for us to use to support the needy ones, especially children with cancer, malnutrition sickle cell, those with sickle cell… If the financial burden is taken off, they will be willing to listen. Some of them run away from the hospital because they do not have money… so, we need to set up funds"*

"KCD3E: The fund is very necessary. One of our patients we have been going back and forth is with the cost after getting discharged. Because they owe so much, and they are unable to pay..."

4.8.2 Sub-theme 2: Staff Training

This sub-theme had two sub-sub-themes under it, i.e., specialised skills and FCC curriculum. Participants recommended training of clinicians via *workshops* and an updating of the curriculum with concepts of FCC for nurses and doctors providing care for children. *Newborn care itself is a very specialised area and* a *new concept,* let alone FCC, therefore, the clinicians need specialised skills to improve child healthcare, especially in the intensive care setting. This skills acquisition could be regularly available for new and old clinicians through *training* and workshops. Most clinicians in the NICU/PICU are *general nurses and general doctors who require additional training on newborn care.* There is also the *need to involve the authorities in the sensitisation* of staff for FCC to be entirely accepted.

"KCD3B: ... FCC can be implemented through workshops so that clinicians can have much information on the involvement of family in the care of children. They may be specialised in their various fields, but they can get information on FCC through workshops"

"TMI6: ... newborn care itself is a very specialised area of care, and most of the professionals in the NICU are just general. So, they have little training in newborn care not to talk of Family Centred Care. FCC is a very new concept, has been done in other jurisdictions, but in this part of the world, even newborn care is a very new concept"

"TCD1C: Sensitisation of clinicians working at the ICU is important as well because if all structures are in place and clinicians are not aware of FCC, nothing can be achieved, therefore, involve the authorities in the sensitisation. It is one of the major factors hindering the implementation of the FCC"

Furthermore, the participants called for integrating FCC concepts into the curriculum of training health professionals, including nurses and doctors. This would better strengthen their understanding and appreciation of family involvement in providing quality childcare and reduce trainer fatigue from in-service training. The modelling of nursing programmes, in particular, should be around the concept of Family-centered Care so that professionals can recognise families as experts in the care of their clients. The training of the professionals in school will let them *give families the needed respect and inclusion.* The curriculum will be more effective than the in-service training as the clinicians will undergo assessment; they will take the training seriously and learn to be inculcated from the onset. This was illustrated by three of the participants:

"KMI5: … once the clinicians have that training, as soon as they are posted here, they will be able to involve the family in the care processes. Training from the school to see family as part of their patients and give families the needed respect and inclusion in the care will be very helpful"

"TCI3: When you start from the training, people will know it…"

"TCI5: if it is started in the schools as part of the curriculum, I think it will be more effective than in the clinic"

4.8.3 Sub-theme 3: Implementation of FCC

This sub-theme emerged from the data analysis with two sub-sub-themes: FCC protocols and NICU/PICU design, which further had sub-sub-themes. The researcher considers the implementation of FCC as the cornerstone of this entire project because it is a key tenet of the collaboration concept of FCC as shown in the scoping literature review. Hence, the data was analysed for themes to support the implementation of FCC in the Ghanaian context. The details of these results follow.

4.8.3.1 Sub-sub theme 1: FCC protocol and guidelines

Participants recommended having a written protocol and guidelines on FCC in the ICU, detailing the specific concepts in our context, would facilitate its implementation. The sub-themes that emerged under this are institutional policy, and multidisciplinary approach.

Participants advocated for *clear protocols and guidelines* on *FCC* at the ICU drafted with a *bottom-up approach* for its full implementation. The *guidelines* and *policy* should be on display at the unit. The protocol should include, among other things, an open-door policy for family involvement, family counselling, effective communication, involving families in decision making, *follow-up for babies* using community and public health nurses, friendly and inclusive design of NICU/PICU, and available support systems for families with critically ill children.

"KMI1: …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"

"TCD1A and TCD1C: there should be clear protocols and guidelines in the ICU for family-centered care to be fully practiced"

"TMI6: Yes, we follow up on babies, especially the preterm ones, normally via scheduling a review for them every Tuesday for child health review as a form of follow up care. We establish contacts with the family and health centre in the community to continue the care if they are coming from outlying communities or districts"

As FCC is *important,* it should involve a *team* approach. There should be a *multidisciplinary perspective* adopted to align the model to all parties for the implementation of FCC. *Experts and policymakers, and management* should be involved *to align the model to all parties.* Thus, all stakeholders, including nurses, midwives, doctors, managers, family, and the community, should facilitate its full integration into intensive care. For example, managers of health facilities, especially those at the Department of Child Health, need engaging at all stages of developing the protocols and guidelines on FCC for its full acceptance and integration. This will make the FCC a *holistic approach since all parties, including families, clinicians, and management, are involved.*

"TCD1D - FCC is very important, and it involves a team and not only the nurse. FCC should be approached from a multidisciplinary perspective…"

"TCD1A - Experts and policymakers, as well as management, should be key in implementing FCC"

"TCD1E: If we want to get FCC implemented, we also need to look at the management of our health institutions and bring them on board. It should be a holistic approach to bring all parties involved, such as the clinicians, family, and management. The model should be aligned to all parties to get the FCC implemented"

4.8.3.2 Sub-sub theme 2: NICU/PICU design

The participants also indicated there should be better designing of the ICU to create more space for family involvement, and have adequate logistics and specialised personnel to manage the children and their families in intensive care. Two major sub-themes emerged from the data relative to this policy concept: logistics/personnel and infrastructure.

Logistics and personnel in this context of the study refer to the materials, equipment, and specialised personnel to provide quality ICU care for children. Participants recommended that the NICU/PICU be *partitioned into cubicles* to meet the needs of the children and their families with different conditions, including congenital abnormality and prematurity. T*here*

should be a provision of enough logistics for the ward; for instance, adequate incubators, oxygen saturation monitors, phototherapy machines, and *a mini-lab and pharmacy*. There must be adequate deployment of personnel specialised in intensive care, newborn care, paediatrics, and *public/community health nurses* to the ICU for quality holistic childcare. Therefore, ICUs need *enough clinicians* of varied backgrounds to practice FCC.

> *"KMI5: ... there should be a provision of enough logistics for the ward. The unit also needs a mini lab and pharmacy to ensure prompt care…"*
>
> *"TCD1: … we need enough clinicians who are dedicated to practice FCC. Engaging every family and in the care until discharge involves a lot"*

Again, the ICU infrastructure should be one of the focal points towards achieving FCC integration and implementation. The design of the ICU environment should be done to meet both family and clinicians needs for the implementation of FCC. The NICU needs *well designing into partitions* or *cubicles* to meet the needs of families and their children, especially those with a preterm and physical congenital abnormality. This will provide a *conducive environment* and *ensure privacy and confidentiality for full family participation.* The setup should also have a room for families (*family area*) to meet and relax for breastfeeding, a counselling room, and more space for Kangaroo Care (KC). If the design of the NICU is to meet the family and clinicians needs, it will reduce the congestion of families in the ICU and provide more space at the inner perimeter for the clinicians to work.

> *"KMI5: the setup must be well-designed into partitions or cubicles to make the environment conducive to ensure privacy and confidentiality for full family participation"*
>
> *"TMI6: The design of the ICU needs to have separate space for the mothers to spend more time with their babies beyond the feeding sessions to allow more family interactions and involvement. So, the KC is one way we can expand to have the FCC implemented. This will allow more involvement of parents in the care processes before they go home"*
>
> *"KFI1: … we need a place to relax. There should be a place to rest and breastfeed adequately…"*

4.9 THEME 6: BARRIERS OF FCC IN GHANAIAN ICUs

Several barriers hindered the implementation of FCC in the Ghanaian context. The researcher had two major sub-themes under this theme, i.e., family barriers, which had five additional sub-themes, and facility barriers, which also had three sub-themes.

4.9.1 Sub-theme 1: Family Barriers of FCC

This refers to the challenges of family involvement and implementation of the concepts of FCC relative to the family of the critically ill child admitted to the NICU/PICU. Five major sub-sub-themes emerged from the data analyses: abandoned babies, lack of information, socio-cultural, lack of funding, and parental anxiety. Presented below are the results from the extracts of some of the participants in the interviews and FGDs.

4.9.1.1 Sub-sub theme 1: Abandoned babies

Some families do not want the baby after birth and therefore abandon the babies. This was primarily due to the baby's *conditions;* the detection of most birth abnormalities in Ghana occur after birth. Most of the time, the family abandons the babies with obvious *congenital anatomical* abnormalities and those born *preterm.* Other reasons for abandoning the babies in the ICU by families include *maternal psychosis*, *teenage motherhood*, and *stigmatisation* (KCI1, TCI6, KCD1, and TCD1). Four of the participants explained this in the interviews and the FGDs.

> *"KCD1A: It depends on the babies' condition. Maybe the mother has not seen the condition before, and the mother is thinking about the stigmatisation out there. Maybe when she is discharged, the family members will say, you have brought something home. So, looking at all these, they will abandon the baby here"*
>
> *"TMI6: There are some parents who do not also want the baby, especially for preterm babies and those with congenital anomalies"*
>
> *"KCD1E: … maternal psychosis, it also prevents the mothers the bonding with their babies…"*
>
> *"KCD1C: We had one teenage mother. She runs away from the ward, did not come to see the baby again…"*

The participants explained that the facilities manage the abandoned babies at the cost of the *social welfare* department of the hospital. Sometimes, the clinicians contribute monies

personally to support the care of the abandoned babies, and even those with families without sustainable funding support. When the abandoned babies recover from the illness, social welfare takes them out of the ward for adoption and/or send them to children's homes and orphanages within the hospital's catchment area. Some *families come back* for the babies, and others give them out for adoption facilitated by the social welfare department. The extracts below illuminate the findings from the study.

> *"KCD1A: We take care of them, we do our best, and we provide all the necessary nursing care. We also talk to the social welfare who come for the babies. Because they cannot live here forever"*
>
> *"KCD1B: ...and they give them for adoption or the homes"*
>
> *"KCD1C: ...there was a case here that, the baby was here, we went to the labour ward to trace the contact, and we called, the family members did not even know the mother had abandoned the baby, so they came to pick the baby"*

4.9.1.2 Sub-sub theme 2: Lack of information

Inadequate flow of information between the clinicians and families was a major challenge of family involvement in the care of their critically ill babies in the ICU. Participants observed that parents do not often ask clinicians to seek information, and because of the *overwhelming workload,* the clinicians scarcely share information with the families. Sometimes, the families do not *know why their babies are* in the Intensive Care Units even after several days of their stay in ICU, and that adds to parental *anxiety*.

> *"TMI6: there are instances where a family would stay in the hospital for up to a week, but they will end up telling you that they do not know why they are on admission…"*
>
> *"KMI1: ... the workload is overwhelming, so making a conscious effort to sit and share information becomes a challenge"*
>
> *"KCI4: ...sometimes they do not know why their babies are admitted into the ICU…we should have time to explain things to them to ease their anxiety"*

Two mothers who participated in one of the interviews at the two settings corroborated this statement. They complained that the clinicians do not provide information on the condition and management of their children, families are only required to *buy medicine and to express breast milk.*

“TFI1: They did not tell me up to now. I do not know what is wrong with my child. They just asked me to buy medicine to inject her and to express breast milk to feed her”

"KFI4: … my biggest challenge is the lack of communication with me to whatever is going on in there … I mean not giving us information. All we got was a prescription…but at least they should tell me that this is the condition that your kid has, and whether he is getting well, is not getting well, or is worsening"

4.9.1.3 Sub-sub theme 3: Socio-cultural challenges

This refers to the family's religious, cultural, and norms that challenge their stay, involvement, and participation in the ICU. For instance, some families may refuse blood transfusion due to their religious beliefs. This is because the children do not have *autonomy.* Again, for babies with injuries such as fractures, their families usually request discharge. against medical advice (DAMA). to send the baby for local traditional care. This often results in conflict between clinicians and families, as families usually refuse to accept the protocol that there is nothing like DAMA in paediatric. The Ghanaian cultural settings collectively believe in solidarity, hence, when one family member or a friend is admitted into the hospital, most relatives, if not all, will flood the unit on visitation to show solidarity, love, and care.

“KMI1: Occasionally, you will have a parent who will tell you that we belong to this religion, and so they do not want the blood transfusion. So, when it comes to decisions like that, it becomes very difficult. Because here is a baby who does not have the autonomy to say that I do not want the blood transfusion”

“TMI6: …babies with congenital anomalies and birth injuries like fractures, the family want to take the baby home for local traditional care. Especially with the fractures, they will be requesting discharged against medical advice (DAMA)”

“TCD1D: The family itself … pose a barrier to FCC due to their varied cultural and religious background”;

“TCD1E: In our culture, we believe that friends and extended family are all part of the immediate family, so is challenge…”

4.9.1.4 Sub-sub theme 4: Lack of funding

The major barrier of family involvement in the care of their critically ill in the ICU was lack of *finances.* Some families wished for discharge due to the lack of finances to support the

care, even though their babies had not recovered fully. Parents were *unable to buy medicines* to sustain the care of their babies in the ICU.

> *"KMI1: …I can confidently say without any research, but based on the observations I have made over years of practice here that finances are a major challenge of their involvement and participation in the care of their babies"*

> *"TFI2: I am pleading with them to discharge us to go home and continue the treatments. Because we are financially challenged to continue staying here"*

> *"KFI4: This morning if they write any medicine I cannot buy. Because much money is spent within one week from here and the debt keeps increasing…"*

4.9.1.5 Sub-sub theme 5: Family anxiety

Families go through many *anxieties* and *psychological toll* caused by complex ICU care processes and the critical nature of their babies' condition. Clinicians confirm that the families are often in a dilemma about the outcomes of their baby's condition. Most babies are born *preterm* with *multiple diagnoses*, which contributes to the *emotional trauma the families go through at the ICU.* Some clinicians maintained that the number one need of families in the ICU is a psychological need. The extracts below from three of the participants illustrate the psychological toll of ICU stays on families.

> *"KMI1: I think that they go through much anxiety. The psychological toll on parents at the ICU, I think, is a very big one…"*

> *"KFI3: My baby, too, was vomiting due to the multiple diagnoses. He weighed 1.3Kg at birth but later lost weight, became very tiny with the ribs showing… when I go home, I will cry at night and ask God, "God, why me"*

> *"KCD1D: …most mothers who give birth to preterm babies or a term baby who is ill are psychologically down because of the emotional trauma alone"*

4.9.2 Sub-theme 2: Facility Barriers of FCC

Several facility-based factors hindered the implementation and integration of FCC into the ICU. Three sub-sub-themes emerged from the data analyses: service challenges, personnel challenges, and logistics/resource challenges.

4.9.2.1 Sub-sub theme 1: Service challenges

Two sub-sub-themes emerged, restricted access, and expensive ICU services.

Restricted families' access into the ICU by clinicians was one major facility barrier of FCC in the Ghanaian ICUs. Families felt frustrated by strict entry protocols operated at the ICUs, enforced by the security officers at the ICUs. Access was restricted to only the *father and mother*, with no other family members allowed to visit the critically ill child at the NICUs in particular. This affected family involvement, as in most cases the mothers were unwell, often due to caesarean section and post-delivery concerns. The rationale for these restrictions were due to the risk of infections from families to critically ill children.

> *"TFI5: they only allow me and the father to come into the ICU to see the baby…"*
>
> *"KCD3D**:** the visiting hours is restricted to only mother and father, and that can also affect the family involvement in the ICU here"*
>
> *"TCD1D: …this is intensive care, so you may not want many people to come into the unit because of infection… because the setup is designed in that way"*

Another major barrier to FCC integration into the NICU/PICU was the expensive ICU services. Families were required to buy emergency drugs and pay for emergency services, which hugely challenged the provision of quality care. The expensive services were due to repeated diagnostic and routine laboratories at the ICU to evaluate the care of critically ill children. Participants complained that the health delivery system itself does not appreciate that newborn care or child healthcare is expensive and poorly resourced. *Much more resources are required to take care of babies*, especially the critically ill ones*;* families, therefore, had to complement the cost of child health services in the ICUs, which contributed to the expensive nature of ICU services.

> *"KFI6: for here it is costly, and we were not told from the beginning…"*
>
> *"TFI4: we have spent much money. Daily, they will request laboratories and drugs that we have to buy to treat the baby…"*
>
> *"TMI6**:** Neonatal intensive care is expensive and is quite a new concept in this part of this country, where they cannot afford the care and people do not appreciate that many resources are required to take care of babies…"*

4.9.2.2 Sub-sub theme 2: Logistics and infrastructural challenges

Three sub-sub themes emerged from analyses of the transcripts: inadequate logistics, inadequate space, and lack of accommodation.

The Ghanaian NICU/PICUs have inadequate logistics and resources to operate thoroughly. The ICUs lack adequate resources, including oxygen saturation monitors, incubators, ventilators, and basic supplies to render quality, satisfactory childcare services. For example, the inadequate pulse oximeters compelled clinicians to monitor the SPO_2 of asphyxiated babies undergoing resuscitation manually, which delays the care. Sometimes, clinicians run out of basic supplies, including *supplies like gloves, cannulas, and gauze.* The *increasing patient numbers* in the ICU heightened these challenges.

> *"KCI4: **…** the ward has only one oxygen saturation monitor. All the saturation monitors in the incubators are not working. So, we have to do everything manually. We check pulse and respiration manually; the oxygen saturation is just one mobile device…"*

Inadequate space in the ICUs was another barrier and the clinicians could not grant full access to families because they were already operating beyond their primary capacities. For example, the design of Hospital T was to admit 60 babies, but it was admitting up to 100 babies in most cases. Similarly, Hospital K could admit 40 babies, but admits up to 80 babies. Participants lamented that allowing families into the ICU would further *congest the ICUs* even though they recognised that *the immediate need of families was their desire to spend more time with the baby*. The clinicians demanded *more space* in the ICU for easy integration and implementation of FCC.

> *"KMI1: ...due to lack of space, babies are all lying in the incubators. Mothers will come to sit to express breast milk and further congest the ICU"*

> *"TMI6: In normal times, the families have more contact with the baby than this enhanced restrictions in intensive care. Space is created for only the mother and father to take care of the baby. Their immediate need is the desire to spend more time with the baby. The way we could do that better is to have more space. Because all the cubicles are already full of babies"*

There was a lack of *accommodation* for families with children admitted to the NICU/PICU. Families had to *sleep outside* the facility *on the floor with their clothes* in the open *corridors*,

exposing them to infections that may risk their babies' recovery in the ICUs; such unhygienic circumstances could expose the sick infant to infections, especially during breastfeeding. Some families come from distant communities for the specialised ICU services, so the lack of *accommodation* for them greatly affects their stay and full participation in the ICU care of their sick children. The families lamented the ICU's lack of basic amenities, including washrooms and water for bathing and cleaning. Hence, some families called for a re-design of the NICUs to allow their inclusive participation in the ICU care of their sick children.

> *"TFI1: Accommodation is the pressing need for mothers; we do not have a place to urinate and bathe…"*
>
> *"KMI1: … you will have the family laying outside on the floor with their clothes, then they come in and pick their babies and breast feed even though we make them wash their hands…"*
>
> *"TFI5: We sleep outside and sometimes in the corridors, and there are mosquitoes"*

4.9.2.3 Sub-sub theme 3: Personnel challenges

Two sub-sub-themes evolved from the data relative to this theme: inadequate clinicians and clinicians' attitude.

One major barrier was inadequate clinicians, which compounded the workload in the NICUs/PICUs. Specialised clinicians' inadequacies in the ICUs were the main personnel challenges for the practice of FCC. Families observed that clinicians were overwhelmed with increased admissions, making the clinicians tired and frustrated to involve families fully in the care processes. The workload, especially at night, affected clinicians' quality of care for the critically ill children, which contributed to prolonged clinicians and parental anxiety. The participants noted the workload on clinicians' made them *stressed out, tired, and frustrated, which displaced the frustrations on families in the long run.*

> *"TCD1D: One major barrier is inadequate clinicians. So, we need enough clinicians who are dedicated to practicing FCC…"*
>
> *"KFD3D: Sometimes, I do not blame the clinicians because the children are many, and you go and meet the same person in the morning, afternoon, and evening. The clinicians are also stressed up with the work, tired, and frustrated. I see they end up displacing their frustrations on families"*

"TFI3: The main challenge in the KC is that there is no nurse with us in the night. Most of us here are twins' mothers. In the night, they can all be crying, and then you, the mother, will be consoling one baby then leave the other one"

The negative attitude of some clinicians was a barrier to practices of FCC in the NICU/PICU. Some families observed that some clinicians would involve them or respect them based on their social status and financial capabilities to provide for the care of their children. Clinicians exhibited attitudes such as shouting at families, snubbing family's needs, and poor communication. These attitudes affected the family emotions as some were seen crying. Families observed female clinicians largely exhibited such negative attitudes, as most of the male clinicians showed respect and compassion towards families. Some of the clinicians do not show any form of sympathy to the already stressed families.

"TFI2: ...I noticed that the cot sheets were soiled, so I decided to take them out to wash. However, the way one clinician spoke to me made me cry…."

"TFI3: Truly, is the male clinicians who know how to handle the mothers, is the female clinicians who are hash towards mothers… they will shout at you as if they are not women …they will disrespect you then you feel like taking your baby out of the ICU…".

"KFD3B: ...I have realised that some clinicians do not seem to sympathise with families. We are already stressed about staying here under such conditions…"

4.10 THEME 7: BENEFITS OF FCC PRACTICES

This refers to the importance of practicing FCC in the ICU. Two major themes emerged under this concept: family benefits and institutional benefits.

4.10.1 Sub-theme 1: Family benefits of FCC

The practices of FCC offered the opportunity for families to learn specific childcare during their stay and involvement in the NICU/PICUs. This will facilitate continuity of care after discharge. For example, clinicians taught families to give insulin injection to their diabetic children to empower them to continue the care at home. Clinicians taught mothers how to express breast milk and cup feed their preterm babies in the NICU. The education of families helped them *prepare their minds for continuity of care at home.*

"KMI1: ... we teach the mothers to put to breast but then also express so that the mother herself does the cup and spoon-feeding of the baby in preparation for going home…"

"KMI5: There was one time we had a diabetic child, and the parents were able to give a subcutaneous insulin injection. Initially, the parents were hesitant that they cannot do it …we educated them well on how to give the insulin…"

"TMI6: …it helps the family to prepare their mind about the outcome of the care process"

A consultant paediatrician underscores the advantage of involving families to participate and learn some nursing duties, including feeding, which they can practice after discharge. This continuity of care will *reduce resources in managing* the children. When families *participate in the nursing duties,* it builds their confidence to *practice better home care, including feeding. Thus,* FCC *promotes rehabilitation, especially for congenital anomaly,* as it will boost family *morale* and confidence during the ICU phase of care.

"KMI5: The family involvement and participation will help continuity of care at home by the family, reduce resources in managing the care, and prompt recovery of the child"

"TMI6: …they participate in the nursing duties; they start practicing care including feeding when they are finally discharged"

"TCD1B: It promotes rehabilitation, especially those with congenital anomaly as a family will accept those babies and accept them as part of their family. So, it gives the family good moral on parenting of babies for continuity of care…"

Again, FCC make families *cooperative* and become *motivated* to participate in the care of their critically ill children. This boosted their confidence to continue care after discharge.

"KMI1: ... I have realised that parents who are updated and involved in the care of their babies are very cooperative"

"TCD1C: …it makes the family feel part of the care rendered to their baby and this boost their confidence to care for the baby at home after discharge"

FCC practices *build bonding* between the family and the baby and create a positive *triangle between the healthcare provider (doctors and nurses), the family, and the baby*. Some parents could *touch, hold, and talk* to their newborn babies in the NICU, promoting *bonding between* them:

"KMI1: …allowing the family into the ICU, especially the father and the mother, to be part of the management builds that bond between us; so, it is a triangle between us the health care workers, doctors, nurses, the family, and the baby"

"KFD1B: …one clinician asked me to go to the cot where my baby. He said, talk to your baby, and your baby knows your voice. Immediately I talked, the baby stopped crying, so I realised there was some bond"

FCC reduces family *psychological trauma* and diseases such as *hypertension*.

"TCD1A –FCC makes them feel part of the treatment process and reduces the psychological trauma to the family";

"KFD1D: I think it will reduce diseases like hypertension among nursing mothers and bring down the anxiety…"

Finally, FCC practices *limit interferences* and promote *speedy recovery* of the sick child, thereby *shortening the length of stay* in the ICU. *Early discharge* means the efficiency of the health system, and the involvement of the family can facilitate that achievement. The practice of FCC may promote *quality care* since the *health team, and the families are all targeting one goal.* There is, therefore, the need for *collaboration between families and clinicians* to make *family-centered care very effective.*

"TCI2: ...it would limit many interferences and help in the speedy recovery and, in effect, limit the length of stay of the babies"

"TCD1C: it reduces the length of stay as the recovery rate will be faster. Hence, clinicians should be motivated to practice FCC"

"TCI5: some quality care can be rendered to the patient because the health team and the family are all targeting one thing or goal for the child to be discharged immediately. In our certain, early discharge means you have done a good job. If there is a kind of collaboration, I think we will do a lot, or the family-centered care will be very effective"

4.10.2 Sub-theme 2: Institutional Benefits

Firstly, working hand-in-hand with families will bring the *best outcome* for the babies as families play significant roles in handling the baby. Mothers, for instance, can *handle and bond* with their babies when allowed to participate in the care, which are all *beneficial to the*

babies. For instance, when families are fully involved, they hardly return to the facility with *complications* after discharge.

> *"KMI1: I think that working hand-in-hand will bring out the best outcome for the baby…FCC is a good thing to implement in the IC"*

> *"KMI5: We do not have an experience where we discharged patients, and they go home and return with complications because we involved them in the care before their discharged"*

Secondly, FCC practices in the ICU further *reduce neonatal and infant mortality*. Families can be educated to help clinicians provide quality care and reduce infant mortality. The presence of families in the NICU will assist clinicians in *feeding, cleaning, and observing* any changes in condition, eventually reducing *the workload.* For example, mothers were educated to assist in feeding their babies to prevent possible aspiration and *reduce infant mortality*.

> *"TCD1AD: It further reduces neonatal mortality rates as families are involved in the care, and they can continue the care at home"*

> *"KFD1A: it will reduce infant mortality if the education goes down well..."*

> *"KFD1C: they can also assist the nurse in caring for the kids especially the feeding…it can reduce infant mortality"*

> *"TFI4: Our presence in the ICU will assist the nurses in the care of the babies by feeding them, cleaning them, change diaper and clothing, and notifying the clinicians of any sudden changes in the babies' conditions"*

> ***"**KFD1E: the work overload will reduce if mothers are involved"*

Finally, FCC practices in the ICU will provide additional *information* regarding the child's illness, which helps in *decision-making*. FCC *clarifies the whole process of childcare,* which solidifies the need for family participation:

> *"TCI2: ...family-centered care can help us because the mother would give all the information you need about the baby to make decisions regarding the care you give to them. The parents sometimes draw your attention to some things you might miss out on as a professional in the care you give to them"*

> *"TMI6: FCC setup clarifies the whole process of care for the appreciation of the families and that is one very important issue about having the family participation in the ICU"*

4.11 THEORETICAL SAMPLING

These are the blueprints of FCC derived from the qualitative study through focused interpretative coding and memoing participants' viewpoints (Hallberg, 2006) on the practices of FCC in the Ghanaian context. This was subsequently the basis for the quantitative tool development through tool development processes for the next stage of the research project in Chapter Five.

4.11.1 Barriers of FCC

This refers to the challenges of FCC implementation in the Intensive Care Units. The perceived barriers from participants' perspectives included:

- Inadequate space in intensive care to accommodate families and implement FCC
- Inadequate logistics, including ventilators, incubators, bilirubin meter, phototherapy machines, and SPO_2 monitors
- Inadequate specialised personnel in intensive care, neonatal care, paediatrics, and psychologist at the NICU/PICU
- Insufficient family involvement and provision of information on care processes
- Lack of financial support for families to fund the expensive ICU services
- Religious and cultural beliefs of families may hinder intensive care services
- Parental anxiety as some families fears the baby's conditions and the ICU environment
- Some families abandoned the babies in the ICU
- Lack of guidelines and policy on FCC at the ICU
- Families may be a source of infection to critically ill children at the ICU
- Inadequate knowledge of clinicians on concepts of FCC

4.11.2 Dignity and Respect

Refers to family needs, privacy, and confidentiality in providing care to the child and family. The perceived needs of families in ICU from the participants' perspectives included:

- To have clinicians show acceptance to families in the ICU regardless of sociocultural backgrounds

- To ensure privacy and confidentiality of families and their children in the NICU/PICU
- To have clinicians respond positively to the psychological needs of families in the NICU/PICU
- To have clinicians communicate positively with family in a respectful manner
- To have clinicians provide care that respects the religion of the child and family in the NICU/PICU

4.11.3 Communication

Refers to the clinicians' information sharing and education to the family in intensive care. The perceived communication practices in the NICU/PICU from the participants' perspectives included:

- To have clinicians communicate effectively with families all the time
- To provide regular information on the progress of the child's condition
- To explain child's condition and ICU care processes to families in simple terms
- To have clinicians educate families on newborn and infant care, including feeding and clothing during hospitalisation at the NICU/PICU
- To have clinicians build rapport and reassure family in all phases of care in the NICU/PICU

4.11.4 Participation

Refers to family support and involvement in the care of critically ill children in intensive care. The perceived participation practices of FCC from the participants' perspectives included:

- To have family fully involved in the feeding of their own critically ill children
- To provide a family with regular updates on the care processes in the NICU/PICU
- To have available financial support systems in the hospital for needy families and their children
- To provide accommodation and food for families and children at the NICU/PICU
- To have family involved in all stages of decision making about childcare in the NICU/PICU

- To have in-house pharmacy and laboratory services in the ICU for prompt care
- To have more space for families to be involved in Kangaroo Care (KC) in the NICU
- To provide regular educational and counselling sessions for families in the NICU/PICU
- To have families involved and participate in bathing, changing clothing and diapers, and medications
- To provide adequate Personal Protective Equipment (PPE) and ensure strict Infection Control Practices (IPC) for parents involved in the care of critically ill children to facilitate their participation

4.11.5 Collaboration

Refers to partnerships, training, policy, protocols, and designs for appropriate and effective implementation of FCC in intensive care. The perceived collaboration practices of FCC from the participants' perspectives included:

- To have a guideline and policy on FCC implemented at the NICU/PICU
- To have a National Child Health Fund to support quality child healthcare services
- To have a revised curriculum on FCC incorporated into the training of doctors, nurses, and midwives
- To have a family-friendly and inclusively spacious designed NICU/PICU
- To have the NICU/PICU designed into sub-units based on the needs of children and their families, including preterm and congenital anomaly
- To have regular training of clinicians on newborn and infant care and the concepts of FCC
- To have adequate logistics in ICU, including ventilators, SPO2 monitors, flow meters, and phototherapy machines
- To have adequate specialised professionals in the ICU, including neonatal nurses, paediatric nurses, paediatricians, and intensive care nurses and doctors

4.11.6 Benefits of FCC

Refers to essential outcomes of family involvement in the care of critically ill children in intensive care. The perceived benefits of FCC from the participants' perspectives included:

- FCC practices serve as a school for families, especially new families with preterm, chronic conditions, and congenital anomaly babies in intensive care
- FCC practices empower the family to continue appropriate care of a child at home after discharge
- FCC practices reduce anxiety and motivate psychologically stressed families to support/participate in the care of critically ill children
- FCC practices promote bonding and initiate good parenting for critically ill children
- FCC practices promote early recovery and shorten the length of hospitalisation of child and family in the intensive care
- Families play significant roles in providing timely information and resources to support the clinical care of critically ill children
- Family participation and involvement support the basic care, including financing care, errands, bathing, feeding, consolability, and clothing which reduce workload
- FCC practices reduce legal infractions as patients are informed of the care processes

4.12 SUMMARY OF KEY FINDINGS

The major findings of this qualitative study are:

- FCC, in this context, is partly practiced, and it refers to a shared decision- making and respect between the families, clinicians and managers using a multi-disciplinary approach to prioritise the provision of quality and adequate childcare.
- Clinicians consider FCC practices as an essential strategy to improving the best outcomes of child health.
- Families described their experiences in the ICU as stressful and emotional.
- Families feel respected and dignified when clinicians accept them into the ICU, and there is the prompt addressing of their child's needs whilst maintaining their privacy and confidentiality.
- The perceived family needs in the ICU are financial, psychological, accommodation, involvement, and socio-cultural needs.
- Family participation in ICU care of their critically ill children was mainly through kangaroo care (KC), running errands, schedule visits, and feeding.
- Communication between clinicians and families was through counselling and education sessions.

- The implementation and integration of FCC into the ICU could be by adopting family-friendly-inclusive ICU design, written institutional FCC policy, mother support groups, provision of funding and logistics, training of specialised clinical personnel, and integrating FCC into the curriculum of training nurses and doctors.
- Funding for quality child healthcare could improve by strengthening the National Health Insurance, institutional funding, donations, and setting up a national child health fund via legislation.
- Improved child health practices is achievable by training the specialised nurses and doctors through improved curriculum in newborn care and family-centered care.
- The perceived family barriers to FCC practice in the ICU include abandoned babies in ICU, lack of information, socio-cultural challenges, lack of funding, and family anxiety.
- Families who abandoned their babies in the ICU did so because of lack of finances, medical conditions of the baby (preterm and congenital abnormalities), teenage motherhood, and maternal psychosis.
- The perceived institutional barriers to FCC practices in the ICU included restricted family entry, expensive services, inadequate logistics, lack of space and personnel, workload, and inadequate FCC knowledge.
- The perceived benefits of FCC practices in the ICU may include family teaching on newborn care for continuity of care, family motivation and satisfaction, bonding, stress and workload reduction, early recovery and discharged, reduced neonatal and infant mortality, provide information to support decision making for quality childcare.

4.13 DISCUSSIONS OF THE QUALITATIVE STUDY FINDINGS

The CGT approach with the application of FST to study FCC at the NICU/PICUs underpinned the qualitative study in this project. The constructivist approach to research promotes a subjective view of social problems to provide real solutions to those problems (Rieger, 2019). The CGT is important in constructing a model in a new setting (Lauridsen and Higginbottom, 2015; Albert, Mylopoulos and Laberge, 2019). The FST is focused on relationships that propose that individuals are separate basic entities, but emotionally and closely interconnected, with mutual impact (Tomlinson, Peden-mcalpine and Sherman,

2011; Ray, 2018). This stage of the project was set out to explore family needs, family involvement, barriers, and facilitators of FCC in the ICU from the family, clinicians (nurses, midwives, and doctors), and the managers of child health units and departments.

The study was comprehensive and collaborative to widely, and inclusively construct the contextual meaning participants gave to the phenomenon of FCC in the two tertiary hospitals. The inclusive nature of this study paved the way for the comparison of data collected for a straightforward concept of FCC to emerge per the context. For instance, there was a comparison of family's data to that of the nurses and doctors. These multiple approaches to data triangulation were performed to satisfy the assumptions of the CGT (Lauridsen and Higginbottom, 2015; Butler, Copnell and Hall, 2019). The discussion had seven thematic areas as per the most significant findings and study objectives. Some of the findings corroborated with prior research conducted in different settings, whilst others were contextual to the Ghanaian NICU/PICUs.

4.13.1 Meaning of FCC in the Ghanaian context

FCC in the Ghanaian context is only partly practiced in the NICU/PICUs. Participants defined FCC as shared decision-making and respect between the clinicians, managers, and families using a multi-disciplinary approach to prioritise quality and satisfactory childcare. The shared decision-making aspect of the finding is consistent with the philosophy of FCC in the Canadian context (Benzies *et al.*, 2019). In Norway, ensuring family satisfaction is a key concept of delivering FCC (Hagen *et al.*, 2019). In the works of the WHO, decision-making and patient satisfaction are essential components of ensuring quality healthcare (Moser and Korstjens, 2018). The clinicians restricted the definition of family in ICU to only the father and the mother of a sick child and therefore granted access to them alone. Perhaps this finding in the Ghanaian setting was attributable to a lack of space and personnel at the ICUs to engage families as experts proposed by the FCC concepts fully. Maybe they would have attached more meaning to it if there were the removal of the bottlenecks in spaces and inadequate personnel. This suggests that health professionals, managers, institutions must create the needed spaces and professionals to involve families of sick children in the ICU in making decisions on the care processes. In that way, there could be a guarantee of quality care as families would feel involved, and satisfied with the care.

The study findings also suggest a multi-disciplinary approach towards FCC practice. This means the implementation of FCC in the health system should be approached by all stakeholders, including clinicians (e.g., nurses and doctors), managers (e.g., directors and administrators), specialists (e.g., clinical psychologist and community/public health nurse), and institutions such as MOH, GHS, and Health Facilities Regulatory Authority (HeFRA). Thus, the implementation of FCC practices should not just be in the hands of nurses and doctors; there has to full integration of all these parties for it to be successful. For instance, families can be linked to community health nurses prior to discharge from ICU to track and monitor critically ill child after discharge; this can be through home visits and follow-up care. The handing over of clients to the community health nurse in ICUs will help with the immunisation of babies to prevent vaccine-related diseases and improve the referral system in Ghana.

Similarly, a clinical psychologist in the ICUs will help both clinicians and families manage the emotional and psychological stressors, including anxieties associated with the ICU phase of care. By so doing, the health system will be better positioned to address the non-pathological aspects of maternal and child health that may affect their physical health. This may also promote the general health and wellbeing of families and clinicians working in the NICUs and PICUs.

Furthermore, the study revealed that the clinicians are willing to support families to participate in ICU carefully. Clinicians recognised the significant roles families play in the NICU, such as providing information and purchasing medicines and supplies to support the care of their critically ill. This finding resonates with the concepts of FCC practiced in Japan (Shimizu and Mori, 2018b). Informed families helped complement the efforts of clinicians in the ICUs in most cases to provide quality care at their best. Thus, clinicians are not against the policies on the concepts of FCC practices in the NICU/PICU. The clinicians showed empathy to families with critically ill children in the ICU; however, they maintained that the provision of the needed logistics for ICUs including incubators, and consumables would facilitate successful integration and implementation into the ICU. Families with critically ill children in the ICUs described their own experiences as being anxious (Wong *et al.*, 2015). This finding buttressed the initial call for a multi-disciplinary approach to FCC practice, where services of a clinical psychologist, including professional counselling, could be

available for families to manage their anxiety. Further studies may focus on examining the quality of ICU care and measuring client satisfaction to identify the drivers of quality care.

4.13.2 Concepts of Dignity and Respect

Families feel respected and dignified when clinicians accept them into the ICU, and see the prompt addressing of their child's needs whilst maintaining privacy and confidentiality. Thus, the exhibiting of this FCC concept was by addressing family needs, privacy, confidentiality, and respecting their socio-cultural domains. These findings resonate with some concepts of FCC practiced in Europe, Tanzania, and Australia (Govindaswamy *et al.*, 2019; Saria, Mselle and Siceloff, 2019).

Perhaps the socio-cultural beliefs of families played a role in exhibiting respect as their most valued need for their full support in the care of their critically ill children. The greatest need of a family in intensive care was respectful information about their child's condition, the care processes, and updates on the progress of treatments. The lack of information flow between clinicians and families may worsen their anxiety, as they remain uncertain. Other pressing needs were financial needs, psychological needs, and involvement in meeting the basic needs of their babies. Families wanted to be involved in the ICU phase of care of their critically ill babies, especially in feeding and meeting the personal hygiene needs. The psychological toll on families, especially mothers in the ICU, was overwhelming as most mothers were seen crying in coping with the ICU stress. This reaffirms the need for a clinical psychologist in the NICU/PICU to provide counselling and support to the families. Therefore, clinicians should plan regular updates and counselling sessions for families with critically ill children in the ICU. Families wanted their socio-cultural aspects to be acknowledged by clinicians (Vasli *et al.*, 2015). Thus, there is an interconnection of religion, beliefs, culture, values, and social norms of families to their socio-spiritual beings, which need addressing.

Again, most families in the study setting were unable to pay for intensive care services because of the lack of funds. This affected the prompt delivery of ICU care for critically ill children. This implies there was a sharing of family needs between the sick child and the parents, with its reciprocal effects on the sick child and as such, nursing care must engulf all. The socio-cultural needs, basic needs of one's relations, are the major tenets of the FST (Ray,

2018; Hohashi, 2019). Additionally, in nursing philosophy, a person is described as a bio-psychosocial being with components such as family, culture, and religion that respond to nursing care (Branch *et al.*, 2016). Future nursing studies should examine the application of the four metaparadigms of nursing, i.e., person, environment, nursing, and health in nursing practice. Such studies will help redirect nursing science to its theoretical roots.

4.13.3 Concepts of Communication

This current study revealed that communication could be achieved through family education and counselling. Cumulatively, communication was the least practiced concept of FCC in the Ghanaian context. Meanwhile, communication and education were key concepts of FCC employed in Colombia, Iran, Denmark, and Canada (Benzies, 2016; Hadian *et al.*, 2016; Hernández, Grillo and Lovera, 2016; Noergaard *et al.*, 2017). This was attributable to workload and clinicians' fatigue, language barrier, and inadequate personnel. Families received erratic counselling sessions in the southern sector; however, there was little evidence of this practice in the northern part. There was a room assigned for the counselling team, which usually consisted of the attending doctor and nurse and occasionally the unit head, and a clinical psychologist, to engage the families in the southern part. The counselling sessions were to build rapport with families, share information on the nature and progress of treatment, and manage the psychological needs of families. Despite counselling, education was a means of communication with the family in the ICU at the two settings.

Further research needs conducting to identify the barriers to family-clinician communication in the ICUs. This will map out interventions to address them and facilitate family involvement and the implementation of FCC in our context. In the meantime, managers of facilities should conduct in-service training in relationship communication for clinicians to augment their assertive communication strengths. Facilities in the northern part can adopt a designated counselling room in the ICU for regular family counselling sessions.

4.13.4 Concepts of Family Participation and Involvement

The practice of the concept of family involvement and participation in Ghana was mainly through kangaroo care (KC), running errands, schedule visits, and feeding. This implies that families could participate in the care of their critically ill children during these tasks. In

Taiwan, the involvement of parents of preterm babies encouraged timely enteral feeding and discharge (Hsieh *et al.*, 2017). A cross-sectional study on KC in a United States NICU resulted in improved outcomes of preterm babies (Clarkson, Gilmer, *et al.*, 2019). Contrary to this finding, building partnerships with parents through communication was a major barrier for implementing FCC in Canadian PICUs (Denis-Larocque *et al.*, 2017).

Families in Ghanaian NICU/PICUs families could have six visits in a day: four visits for mothers and two visits for fathers. This was the optimum time families spent and were involved in the ICU care of their sick children. However, another study in Europe recommended that parents be allowed in the ICU overnight (Raiskila *et al.*, 2017). Also, nurses in the United Kingdom used the Partnership in Pain Care Model to involve parents in managing pain, which proved effective (Vasey *et al.*, 2019). Families were involved in the NICU/PICU care when the clinicians required some medicines and laboratory investigations. The family, especially fathers, usually did the errands to get whatever the clinicians needed to take care of their precious child; this was because the system had inadequate personnel, and the few there were dedicated to providing professional ICU care for sick children. These practices affected the prompt delivery of ICU services. The facility managers should perhaps place an in-house pharmacy and laboratory for the NICU/PICU for prompt provision of such services. The facilities should stock the emergency medicines and supplies to facilitate the quick delivery of critical care services. It is recommended that the delivery of ICU services, including documentation, pharmacy, and laboratory, be digitalised to remove these bottlenecks and promote quality child healthcare. This may culminate in the reduction of infant and child mortality.

Infant feeding was yet another strategy used by clinicians in the ICU to involve families. The clinicians primarily fed critically ill children. This was because their conditions required professional hands and continuous care even after feeding to prevent possible aspirations and deaths. In the NICU, for example, cup feeding was a common practice, especially for critically ill preterm babies. During cup feeding, the baby is positioned on the clinicians or mothers' laps, and a tiny cup half-filled with expressed breast milk is placed on the lower lip and gradually tilted for the baby to feed at her own pace. The cup feeding technique feeds fragile infants who could not grasp and suckle their mothers to feed. This technique helps to top-up the feeding of infants who could latch onto the breast, but not reach satiety.

Additionally, breastfeeding was another feeding process widely used in the Ghanaian ICU. Mothers came into the NICU every three hours for breastfeeding. Breastfeeding remains the single most effective and reliable source of infant nutrition (Casey, Fucile and Dow, 2018; Gertz and DeFranco, 2019). However, the breastfeeding practices in the ICUs were not without challenges; for instance, some mothers were producing more quantities of breast milk than the babies needed, which resulted in storage challenges for expressed milk. Managers of the facilities should provide special refrigerator storage facilities for breast milk to sustain the infant feeding in ICUs; there is merit in this, especially as families did not have full access to the Ghanaian ICUs.

Conversely, some mothers were unable to produce breast milk, which also presented a considerable challenge to infant feeding in the ICUs, especially infants exposed to HIV infections. Researchers should employ mixed-method research to develop feeding protocols for critically ill children at NICUs and PICUs in our context. Future studies should also investigate the feasibility of establishing milk banks in Ghana to support families with critically ill infants at the NICUs. Families were poorly involved in decision making relative to their sick children detained at the NICU/PICU. Meanwhile, involving families in the decision-making processes in the ICU resulted in improved health outcomes for infants and their families in Canada (Benzies, 2016) and Norway (Hagen *et al.*, 2019). Clinicians and managers of NICU/PICUs in Ghana should adopt an open-door policy to grant full access to family involvement and participation to promote satisfactory quality child healthcare delivery.

4.13.5 Concepts of Collaboration

Patients, families, and providers collaborate in care when they team up in training, policy, and programme development to implement FCC for quality child healthcare. Three major sub-themes emerged from this current study: funding child health, implementation of FCC, and staff training. The study revealed that bridging the funding gaps in healthcare could improve quality child health. This could occur through strengthening the National Health Insurance, institutional funding, donations, and setting up a national child health fund via legislation. In Tanzania, providing maternal and child health insurance alone did not guarantee improved maternal and child health (Kuwawenaruwa *et al.*, 2016), although conscious child health policies drafted and implemented through legislation have seen

improved child health outcomes in the United Kingdom (Turner and Ahmed, 2019). These results possibly imply that the National Health Insurance Scheme (NHIS) alone was insufficient to handle the funding challenges of the Ghanaian health system. The NHIS does not cover certain health services, especially intensive care services such as ventilator care, cancer treatment, kidney problems and dialysis. These are the major services of sick children and their families in intensive care in Ghana, and the cost element of seeking intensive care in Ghana is high for families. Therefore, the recommendation is that the government review the NHIS by extensively improving its funding base to cover child health costs. This will cater for the financial burden on families with critically ill children and promote their full participation in ICU services. Again, the government should consider setting up a national child health (NCH) fund through legislation similar to the Ghana Educational Trust (GET) fund. Such a fund could be decentralised and administered through the hospitals under the child health department to provide funding support for families and general child health services. The NCH fund can receive donations from benevolent individuals, institutions, and non-governmental organisations (NGOs) to strengthen and fund child health through clinical services and research.

Additionally, improved child health practices are achievable by training specialised nurses and doctors in paediatrics and child health, through integrated curriculum development and in-service training in newborn care and FCC. Evidence from research elsewhere alluded to the effectiveness of improved child health via the training of health professionals (Nestel, Taylor and Spender, 2004; Shahul *et al.*, 2018; Kurtulus, Yıldız and Ozyazicioglu, 2018; Benzies *et al.*, 2019). Finland has implemented FCC in the neonatal units through multi-disciplinary training and commitments from all stakeholders (Toivonen *et al.*, 2019). Perhaps the fact that general doctors and nurses largely managed the Ghanaian ICUs with few having specialisations in intensive care and paediatrics may have necessitated this finding. For example, there could be an update of the curriculum of basic nursing programmes, including registered nursing, registered midwifery, registered community nursing, and registered mental health and medicine, with FCC concepts. The curriculum framework for child health practices developed in South Africa has recommended family health nursing as the main course (Christmals, 2019).

According to international standards, there could be integration of FCC into the Ghanaian ICUs if they were specifically and family-inclusively designed. For example, NICUs in

Sweden were built to meet national and international recommendations, which provided the requisite psychosocial environment for families and clinicians (Van Den Berg *et al.*, 2017). The participants argued that the space in the NICU, for example, could facilitate the implementation of FCC if addressed. The current design of Ghanaian NICUs/PICUs had no space for families. This makes integrating families into the ICUs difficult, even if the clinicians were willing to do so. A well-designed NICU/PICU should have the provision of specialised personnel and adequate resources. The provision of personnel should consider a multi-disciplinary approach to address all the needs of families and their children in the ICUs. Turkey, for instance, provided sufficient resources, which led to the implementation of FCC in the NICU (Boztepe and Kerimoğlu Yıldız, 2017).

Further studies should explore the strategies for improving child health services in Ghana quantitatively. This would cement these findings for generalised policy development on improving quality child health. Among all these strategies, there is the need for an institutional policy designed to suit the Ghanaian context. Facilities may adopt such a policy on FCC for its holistic implementation.

4.13.6 Barriers of FCC

The main family barriers to FCC practice in the Ghanaian ICUs were socio-cultural challenges, abandoned babies in ICU, lack of information, lack of funding, and family anxiety. Research findings in Iran, Denmark, Turkey, and the United Kingdom had reported religion, culture, social norms, and psychological stress respectively as the obstacles of FCC (Boztepe and Kerimoğlu Yıldız, 2017; Noergaard *et al.*, 2017; Valizadeh *et al.*, 2018; Fowler *et al.*, 2019). The emotional and psychological stress associated with NICU care prevented the participation of families (Lewis *et al.*, 2019), thus, clinicians must support families to handle the emotional stressors of the NICU/PICU phase of care. Health financing has always been a challenge to providing quality healthcare (Vidya Putcha, Arjun Upadhyay, Michelle Neuman, Minju Choi, 2016). It emerged from this context that some families abandoned their babies for hospitals to carry the burden of care alone. The reasons for abandoning babies at the NICU/PICU were teenage motherhood, lack of funding, babies' conditions, such as physical congenital anomaly, and preterm. In most cases, the facilities and doctors contributed monies to fund the care of the abandoned babies in the NICU/PICU. Such situations were unsustainable, and might have thwarted the provision of quality healthcare

for those children and impeded the reduction of child mortality to achieve the SDGs. This, calls for more education and support for families with critically ill children. This finding buttresses the need for the earlier call for instituting NCH-fund.

Additionally, the institutional barriers of FCC practices in the ICUs included restricted family entry, expensive services, workload, inadequate FCC knowledge, and inadequate logistics, space, socio-cultural beliefs, and inadequate personnel. Fathers in particular poorly participate in the care of children in the ICUs. These findings were congruent with studies in Iran, Denmark, and Turkey conducted on fathers' NICU involvement. It found out that fathers' participation in NICU care was limited due to their traditional attitudes and cultural-religious backgrounds (Boztepe and Kerimoğlu Yıldız, 2017; Noergaard *et al.*, 2017; Valizadeh *et al.*, 2018). Usman *et al.* (2019) in Ethiopia reported similar outcomes in their study on health system readiness to support preterm care. Perhaps these settings may share some sociocultural and religious characteristics with Ghana. Thus, for the proper integration of FCC into the health system, adequate personnel, space, recognition of the socio-cultural perspectives of families, and logistics need providing by the Ministry of Health to achieve quality healthcare. Further research is required to obtain a broader insight into the barriers and facilitators of FCC in the NICU/PICU using quantitative methods.

4.13.7 Benefits of FCC

The major benefits of FCC practices in the ICU included family teaching on newborn care for continuity of care, family motivation and satisfaction, bonding, stress and workload reduction, early recovery, and discharge, reduced neonatal and infant mortality, provide information to support decision making for quality childcare. Some aspects of the findings were consistent with previous findings of FCC studies elsewhere. For instance, Brødsgaard, Zimmermann and Petersen (2015), in Denmark, reported that FCC implementation resulted in the early discharge of infants from intensive care. Similarly, the implementation of FCC in intensive care resulted in positive health outcomes and reduced parental anxiety (Oxley, 2015; Skene *et al.*, 2019a). In South Africa, Maree *et al.* (2017) recommended FCC integration in the NICU because it enhanced bonding and attachment and long term positive outcomes. This plethora of evidence on the significance of FCC integration into the NICU/PICU should compel clinicians and managers to consider its implementation in our

health delivery system. The anticipation was that FCC implementation would reduce the workload on the already stressed workforce in intensive care. This was because families could support the clinicians by providing basic care for the sick children, including bathing and feeding. The families also provided valuable information that assisted the clinicians in decision making for quality child healthcare.

4.14 SUMMARY

This chapter presented a description of the contextual meaning of FCC, participants' experiences as well as the concepts of FCC in Ghanaian NICU/PICUs. The description of FCC in the Ghanaian context is a shared decision making process between the clinicians and families using a multi-disciplinary approach to provide child health. It provided contextual applications of the four main concepts of FCC into the ICU. Families feel respected and dignified when they see their needs addressed promptly. Families were poorly involved in ICU care, as they were occasionally involved in purchasing medicines and supplies, and running errands. Lack of communication and funding were major barriers of FCC. Clinicians should adopt communication strategies to enhance family participation. Theoretical sampling was to construct the thematic areas and specific items that emerged from the qualitative study. These findings developed the quantitative survey tool for the next stage of the research project presented in Chapter Five.

CHAPTER FIVE

STEP THREE: RESULTS OF THE QUANTITATIVE STUDY

5.1 INTRODUCTION

This chapter is the final part of the exploration phase (Step 3). The purpose of the quantitative stage was to triangulate, complement, confirm, expand, and quantify the perceived family needs, involvement, barriers, and facilitators of FCC that emerged from the qualitative study for the model development. This led to the development of quantitative tool for FCC in the NICU/PICU per the perspectives of families and clinicians in the Ghanaian NICU/PICU. For this reasons, the main findings of the qualitative study were to develop, and pilot test a questionnaire for the quantitative study. The quantitative step also recruited families, clinicians, and health managers in the NICU/PICU.

Firstly, this chapter outlined the processes leading to development of the quantitative questionnaires in a pilot study for the quantitative study using the findings from the qualitative study. The researcher then used the validated questionnaire as the tool to conduct the quantitative survey. This chapter details the results of the pilot study and the main quantitative study. The pilot study data was only to purposely test and modify the tool, and was not included in the main study. There was an exploratory factor analysis performed to arrive at the tool for FCC from the Ghanaian context. The developed FCC tool from the factor analysis became the Delphi questionnaire to develop the model with an expert's panel in the Phase 2 of the project. The next section detailed the pilot study that led to the questionnaires used for the quantitative study.

5.2 USING THE QUALITATIVE FINDINGS TO DEVELOP THE QUANTITATIVE TOOLS FOR FCC STUDY IN GHANAIAN CONTEXT

The development of a survey tool for data collection is most widely used among the positivists school of research (Hong and Kang, 2020). The researcher used the findings from the scoping literature review in Chapter Two together with the results of the qualitative findings in Chapter Four to modify the CCFNI tool and SAI tool of FCC to reflect the context

of FCC as practiced in the Ghanaian NICU/PICU. The researcher adapted the processes of questionnaire development by DeVellis (2016) to construct the survey tool for the quantitative step of this project. A three-stepped approach was used, i.e. conceptual framework and item generation, piloting the drafted tool, and evaluation of the tool (Ricci *et al.*, 2018; Ayoubi *et al.*, 2020; Hong and Kang, 2020).

5.2.1 Conceptual Framework and Item Generation

As discussed earlier, the conceptual framework that underpinned this research is the FST. Thus, the researcher in framing the items of the survey tool lends the construction to the contents of the FST. Again, the items in the questionnaire hinged on the findings of the scoping literature review and that of the qualitative study. The basis for the scoping review was the constructs of the FST and the study objectives. The specific aspects of the literature findings relative to FCC adapted in this item generation are the CCFNI (Leske, 1992; Wetzig and Mitchell, 2017) and the SAI tool (www.ipfcc.org, 2021). These tools centred on the four main concepts of FCC, i.e., dignity and respect, information sharing, participation, and collaboration. These, in different settings, have assessed FCC and have yielded good psychometric properties. Therefore, the modifications adapted include family needs-respect and dignity, communication-information sharing, family involvement-participation ad partnership, facilitators of FCC-collaboration, barriers of FCC, and benefits of FCC. The item generation was backed by the contextual evidence from the CGT qualitative study involving 84 (n = 84) participants (both family and clinicians) presented in Chapter Four of this project. All these were to enrich the tool and make it reflective of the practices of FCC in the Ghanaian context.

Finally, the specific objectives of the study including family needs at NICU, family involvement, barriers of FCC, and the facilitators of FCC implementation in the NICU/PICU, guided the tool development. The drafted survey tool has seven (7) components: 1) biodata of participants, 2) respects and dignity, 3) information sharing, 4) participation, 5) collaboration, 6) barriers of FCC, and 7) benefits of FCC. There was a 4-point Likert scale used for each item in the drafted tool: 1= strongly disagree, 2= disagree, 3= agree, and 4= strongly agree. The supervisor and four other researchers reviewed the drafted tool. The reviewers, three associate professors (two nursing, one health sciences), and two senior lecturers (one with nursing background and one with health research

background), examined the content and face validity of the tool (Heale and Twycross, 2015; Masuwai Azwani, Nor'ain Mohd Tajudin and Noor Shah Saad, 2016; Taherdoost, 2018; Arslan *et al.*, 2019; Ayoubi *et al.*, 2020).

5.2.2 Piloting the Drafted Tool.

A pilot study, also called pre-testing, involves administering a survey instrument to a small sample of the population of interest (Ayoubi *et al.*, 2020). The primary purpose of piloting the drafted tool is to test the validity of items constructed and to remove redundant and/or reframe unclear statements before the main study. The pilot study used a sample of 60 participants involving clinicians, researchers, and parents. The tool was in an electronic format, using RedCap's online development support for research tools. The 60 participants received the tool electronically via an email. After receiving the responses and making the necessary modifications, the researcher and the primary supervisor reached an agreement of the final survey. Some modifications made included the reframing the items to reflect personal responses; for example, "psychological support" was reframed as "I need psychological support during the ICU phase of care."

5.2.3 Evaluation of the Tool

Finally, the researcher evaluated the psychometric properties of the survey tool of FCC by calculating the Cronbach's alpha for internal consistency of the items in the tool. A test-retest reliability was estimated calculating the interclass correlation coefficient (ICC) of the items; the agreement was set at 0.61 to 0.80 and the Cronbach's alpha was set at 0.78 (Devon *et al.*, 2007; Himuro *et al.*, 2015; Taherdoost, 2018; Hong and Kang, 2020). The quantitative analysis of the pilot study used the SPSS version 20.

From the pilot study, Cronbach's alpha examined the internal consistency reliability of the quantitative tool. The Cronbach's alpha of the family scale was 0.91, with a mean range of items as 2.72-3.2, the mean score of the scale was 145.41 and the standard deviation was 13.46. The Cronbach's alpha of the clinicians' scale was 0.97, with a mean range of items as 3.03-3.53, the mean score of the scale was 154.53 and the standard deviation was 22.44. The observation was that the descriptive statistics and the reliability of clinicians' tool was

a bit higher than the family tool. This indicated excellent psychometric properties of the tool, albeit the clinicians' tool was better. **Table 5.1** presents further details of the pilot study.

Table 5.1: Mean, standard deviation and Cronbach's alpha of the items in the two scales for FCC in the Neonatal and Paediatric Intensive Care Units

Item Scale	Mean ranges		Mean for scale		Standard deviation		Cronbach's alpha	
	Family	Clinicians	Family	Clinician	Family	Clinicians	Family	Clinicians
Respect & dignity	3.13-3.40	3.13-3.67	19.60	20.57	2.30	2.96	0.70	0.82
Communication	3.10-3.47	2.90-3.63	33.10	34.77	3.32	4.52	0.81	0.91
Participation	2.67-3.33	2.70-3.67	24.57	26.87	3.72	4.14	0.76	0.86
Collaboration	2.97-3.48	3.17-3.57	28.97	30.03	3.13	5.81	0.77	0.94
Barriers of FCC	2.70-3.07	2.70-3.07	20.40	22.00	3.89	4.77	0.78	0.88
Benefits of FCC	3.03-3.20	3.27-3.50	18.73	20.30	2.32	2.83	0.87	0.87
Family perspectives of FCC survey tool	2.72-3.21	-	145.41	-	13.46	-	0.91	-
Staff perspectives of FCC survey tool	-	3.03-3.53	-	154.53	-	22.44	-	0.97

Source: Pilot data

5.3 DATA ANALYSIS

STATA version 15.0 analysed the data from the family and clinicians' scales. Descriptive statistics were estimated for participant demographics for continuous variables, checks were conducted on their distribution using the Shapiro Wilk tests for normality; if normally

distributed, means and the standard deviations was reported and if not, the median and inter-quartile range was calculated (Razali and Yap, 2014). The reporting of the categorical data was as frequencies and percentages. To assess the internal consistency of the items that made up each of the six subscales, i.e., how well the items measured the subscale of interest, there was a Cronbach alpha coefficient calculated for each of the six sub-scales. A Cronbach alpha coefficient of ≥0.70 indicated strong internal consistency (Roaldsen *et al.*, 2016). To compare the level of agreement on the items of each of the subscales, a t-test compared means and a Mann Whitney Wilcoxon test compared medians (Harerimana and Mtshali, 2020; Lamash and Josman, 2020). All statistical tests were at the 5% significance level. The data was finally reduced using factor analysis to arrive at the six sub-scales of FCC. To assess whether the data were suitable for factor analysis, a Kaiser-Meyer Olkin (KMO) Measure of sampling adequacy and Bartlett's test of Sphericity were used (Balasundaram, 2009). Data were considered suitable for analysis if the KMO measure was ≥0.80, $p<0.005$. For the factor analysis, factor extraction was based on Kaiser's criteria, i.e., extracted factors had an Eigenvalue of ≥01(Balasundaram, 2009; Heiss, Timko and Hormes, 2020). In the current analysis, the variables most attributable to the factor, i.e., variables with the highest factor loading, were the items that contributed to the most variance in the subscale and were reported in the results section.

Before conducting the factor analysis, the researcher subjected the data to testing to determine the minimum requirements for PCA, i.e. normally distributed data, and sample >300. Balasundaram (2009) stated that a sample size greater than 300 is adequate for factor analysis. The sample size for this quantitative stage of the project was 446. Kaiser-Meyer-Olkin's (KMO) estimation of sampling adequacy must be greater than 0.65 for the dataset to be adequate for FA. The KMO for this study was 0.95 for family and 0.89 for clinicians. Bartlett's test of Sphericity measures the multivariate normality of a distribution and a significance value of less than 0.05 indicates acceptability of the data for FA. The significance returned from the current data was 0.000. The data produced a Cronbach's alpha of 0.97 reliability in both datasets, albeit there was one item deleted for the family dataset because its deletion increased the Cronbach's alpha to 0.97; usually, Cronbach's alpha > 0.78 is a reliable dataset for FA (Niranjan, 2004; De Los Campos and Gianola, 2007; Balasundaram, 2009; Li *et al.*, 2020). The next section presents the descriptive analysis of the two scales of FCC prior to the data reduction using the factor analysis.

5.4 DATA ANALYSIS: RESULTS AND FINDINGS

This section was to done to triangulate the findings for the development of an instrument or tool for the Delphi study in Phase 2 of the project. The respondents (N= 446) were conveniently sampled from the NICU/PICUs of Hospital T in the northern and the Hospital K in the southern setting. The main study findings were organised into three parts. The first part was the demographics of the participants. The second part was descriptive statistics of the family questionnaire and that of the clinician's questionnaire that were developed. The third aspect was the findings from the factor analysis that took place to reduce the concepts to explainable components using communalities rule in principal component analysis (PCA) (factor load >0.50); which congregated into the FCC tool for the Delphi in Phase 2 of the research. The following sections present the family demographic data and the clinician's demographic data.

5.4.1 Family Demographic Data

Table 5.2 Demographic characteristics of family (n = 346)

Variable	Frequency	Percent (%)
Gender of family		
Male	59	17.1
Female	287	82.9
Relationship with family		
Father	52	15.0
Mother	278	80.3
Spouse/partner	2	0.6
Sibling	6	1.7
Other relative	8	2.3
Religion		
Christian	186	53.8
Moslem	159	46.0
Traditional	1	0.3
Education		
No education	73	21.1
Basic education	99	28.6
Secondary education	109	31.5
Tertiary education	65	18.8
Occupation of family		
Public employment	34	9.8
Private employment	42	12.1
Self-employed	197	56.9
Unemployed	73	21.1

Delivery level		
Single	315	91.0
Multiple	31	9.0
Mode of delivery		
Safe vaginal delivery	223	64.5
Assisted vaginal delivery	18	5.2
Caesarean section	108	30.3
Breast feeding		
No	191	55.2
Yes	155	44.8
Gender of child		
Male	173	50.0
Female	173	50.0
Type of delivery		
On-delivery	165	47.7
Emergency	20	5.8
Transfer-in	131	37.9
OPD	30	8.7
Age (in years)		
<19	13	3.8
20 to 29	163	47.1
30 to 39	146	42.2
40 to 49	23	6.6
>49	1	0.3
Parity		
Single	108	31.2
Multi-parity (2 – 5)	216	62.4
Grand multi-parity (>5)	22	6.4
ANC Visits		
Poor visits (0-3)	43	12.4
Good visits (>6)	188	54.3
Very good visits (>6)	115	33.2
Gestational		
<28	48	13.9
29-32	86	24.9
33-35	29	8.4
36-42	173	50.0
>42	10	2.9
Birth weight		
Extremely low birthweight (<1kg)	16	4.6
Very low birth weight (1.1 – 1.5kg)	45	13.0
Moderate low birth weight (1.51 – 2.0kg)	108	31.2
Low birth weight (<2.5kg)	12	3.5
Normal (2.5 – 4.0kg)	152	43.9
Macrosomia (>4.0 kg)	13	3.8

The majority of families in the ICUs were mothers (80.3%). Only 21.1% of the families had no form of education, 28.6% had basic education, and about 50.5% of the families had secondary education and above. The families were largely self-employed (56.9%), with about 21.1% unemployed. The mean income of families was 478.34 Ghana cedis (USD 83.00), with modal income of 200 Ghana cedis (USD 34.70), and minimum and maximum income of 50 Ghana cedis (USD 8.68) and 3000 Ghana cedis (USD 520.52), respectively (refer to **Table 5.2** for details)

Table 5.2 illustrates a good number of mothers who participated in the study had more than six ANC visits (33.2%) and 12.4% had as low as three visits. The majority of the families (62.4%) were multi-parous and about 31% of them were first-time families in the ICU with their sick child. Most families with sick children in the ICU had more than 36 weeks of gestation (52.9%) and about 39% had a gestational age of 32 weeks and below. The majority (52.3%) of the babies born had their birth weight less than 2.5Kg.

Table 5.3 Descriptive statistics of families at the NICU/PICU (n=346)

Statistics	Age (years)	Parity	ANC Visits	Gestation age (weeks)	Birth weight (Kg)	Duration of stay	Income
Mean	29.33	2.52	5.76	34.80	2.39	6.45	478.34
Median	29.00	2.00	6.00	36.00	2.40	5.00	200.00
Mode	30	1	6	38	2	3	200
SD	6.67	1.39	2.09	5.00	94	5.77	587.35
Minimum	14	1	0	24	1	1	50
Maximum	54	8	10	47	5	60	3000
Percentiles							
25%	25.00	1.00	4.00	31.00	1.70	3.00	200.00
50%	29.00	2.00	6.00	36.00	2.40	5.00	200.00
75%	34.00	4.00	7.00	38.00	3.10	7.00	500.00

Table 5.3 illustrates the mean age of families who participated in the study was 29.33 ± 6.67, and the modal age was 30 years. The mean antennal visits were 5.76 ± 2.09, with six modal visits. The first quartile of gestational age was 31 weeks, and the third quartile 38 weeks. Mean birth weight of babies admitted in the NICU was 2.39 ± .94.

5.4.2 Clinicians' Demographic Data

Table 5.4 Demographic characteristics of clinicians (n = 100)

Variable	Frequency	Percent (%)
Age (in years)		
20 to 29	34	34.0
30 to 39	54	54.0
40 to 49	11	11.0
>49	1	1.0
Gender		
Male	31	31.0
Female	69	69.0
Religion		
Christian	70	70.0
Moslem	30	30.0
Marital status		
Single	40	40.0
Married	60	60.0
Educational qualification		
Certificate	8	8.0
Diploma	46	46.0
Degree	35	35.0
Masters	5	5.0
Doctoral	6	6.0
Profession		
Nursing	81	81.0
Midwifery	8	8.0
Medicine	10	10.0
Nutrition	1	1.0
Specialisation		
Paediatrician	7	7.0
Neonatal intensive care nurse	4	4.0
Paediatric nurse	8	8.0
Midwife	17	17.0
Opthalmic nurse	2	2.0
ENT nurse	2	2.0
Nutritionist	1	1.0
Physician assistant	1	1.0
No speciality	58	58.0
Years of practice		
1 to 5	63	63.0
6 to 10	27	27.0
11 to 15	7	7.0
16 to 20	2	2.0
>20	1	1.0

The mean age of clinicians was 31.93 ± 5.204, minimum age 23 years, and maximum age 53 years with majority (69%; n = 69) being females. The clinicians had on average 5.67 years of experience, a minimum of 2 years and maximum of 28 years clinical working experiences. Most of the clinicians (63%) had less than 5 years working experience. The majority of the clinicians (81%) were nurses, with the remainder belonging to other professions including medicine, midwifery, and nutrition. A significant number (58%) of the professionals at the NICU/PICU had no specialisation in intensive care, neonatal, and paediatric care; only 7% were paediatricians, 4% neonatal intensive care nurses, and 8% paediatric nurses (See **Table 5.4**).

5.5 RESULTS ON THE FCC QUESTIONNAIRES

5.5.1 Family Perspectives of FCC

5.1.1.1 Dignity and Respect

Table 5.5 Descriptive statistics from family for the dignity and respect subscale

Item	**Levels of agreement**	
	Median	IQR
I feel accepted by staff in the ICU regardless of sociocultural backgrounds	3	3-4
I feel my privacy and confidentiality is ensured by ICU staff		
	Mean	**SD**
I want the staff to respond positively to my psychological needs and that of my family in the NICU/PICU	3.32	0.47
I want the staff to communicate positively with me and my family in a respectful manner	3.4	0.49
I want the facility to provide comfortable furniture in the waiting room/area in the ICU for me and my family	3.39	0.49
I want the staff in ICU to provide care that respect my religion and culture	3.32	0.52

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The dignity and respect subscale has six items. Overall, the family members had positive experiences relating to the healthcare providers dignity and respect in their approach to them (level of agreement ≥3) (refer **Table 5.5).**

The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show that there was strong internal consistency in the items that make up the Dignity and Respect subscale (Cronbach alpha coefficient=0.89)) **(**refer **Table 5.11).**

5.5.1.2 Communication

Table 5.6 Descriptive statistics from family for the communication subscale

Item	**Levels of agreement**	
	Median	IQR
I want to know about the types of medical staff taking care of my patient	3	3-4
I want to know how my child is being treated medically	3	3-4
I want to be orientated on the ward environment and protocols	3	3-4
I want to be told about transfer plans while they are being made	3	3-4
I want the staff to provide me regular information on the progress of my child's condition	3	3-4
	Mean	**SD**
I want the staff to effectively communicate with me and my family at all the time	3.38	0.49
I want the staff to answer questions honestly	3.36	0.48
I want the staff to explain my child's condition and ICU care processes to me in simple terms	3.39	0.5
I want the staff to educate me on my childcare including feeding and clothing during hospitalisation at the ICU	3.39	0.5
I want the staff to build rapport and reassure my family in all phases of care in the ICU	3.36	0.49

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Communication subscale has nine items. Overall, the family members had positive experiences relating to the healthcare providers communication (level of agreement ≥3). (**Table 5.6**).

More than 98% of the family members agreed to the items in the Communications subscale showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show that there was strong internal consistency in the items that make up the Communication subscale (Cronbach alpha coefficient=0.92) (**Table 5.11**).

5.5.13 Participation

Table 5.7 Descriptive statistics from family for the participation subscale

Item	**Levels of agreement**	
	Median	IQR
I want the staff to involve me in the feeding, bathing and clothing of my critically ill child	3	3-4
I want to be supported financially by the hospital for my childcare through the social welfare department	3	3-4
I want to accommodation and food to be provided for me and my family whilst my baby is at NICU/PICU	3	3-4
I want to be involved in all stages of decision making about my childcare in the NICU/PICU	3	3-4
I need more space in the NICU for me and my family to bond and practice Kangaroo Mother Care (KMC)	3	3-4
I want the facility to provide me and my family with adequate PPEs to participate in the care of our critically ill child	3	3-4
	Mean	**SD**
I want a well-stocked in-house pharmacy and laboratory services at the NICU/PICU for prompt care of my child.	3.42	0.49
I want the staff to provide regular education and counselling sessions for me and my family in the NICU/PICU	3.34	0.49

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Participation subscale had eight items. Overall, the family members had positive experiences relating to the healthcare providers encouragement of family members participation (level of agreement ≥3) (**Table 5.7**).

More than 92% of the family members agreed to the items in the Participation sub-scale showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show there was strong internal consistency in the items that made up the Participation subscale (Cronbach alpha coefficient=0.87) (**Table 5.11**).

5.5.1.4 Collaboration

Table 5.8 Descriptive statistics from family for the collaboration subscale

Item	**Levels of agreement**	
	Median	IQR
I want the curriculum for training doctors, nurses and midwives to have FCC incorporated	3	3-4
I want the NICU/PICU to be designed into sub-units based on my child's condition	3	3-4
I want NICU/PICU to have adequate logistics including ventilators, SPO2, monitors, flow meters, and phototherapy machines and consumables	3	3-4
I want my baby to be immunised (if allowed) during our stay in the NICU	3	3-4
	Mean	**SD**
I want the facility to have guidelines and policy on FCC that addresses my needs and respect me as expert in the care of my child	3.32	0.47
I want government set up a National Chid Health Fund to support quality child healthcare services in the country	3.43	0.5
I want the NICU/PICU to be family friendly and inclusively spaciously designed	3.31	0.48
I want the staff to have regular training on newborn and infant care and the concepts of FCC	3.39	0.49
I want the ICU to have adequate specialised professionals, including neonatal nurses, paediatric nurses, paediatricians, and intensive care nurses and doctors to meet our needs	3.39	0.49

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Collaboration subscale has nine items. Overall, the family members had positive experiences relating to the healthcare providers encouragement of family members collaboration (level of agreement ≥3) (**Table 5.8**).

More than 99% of the family members agreed to the items in the Collaboration subscale showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this sub-scale show there was strong internal consistency in the items that made up the Collaboration subscale (Cronbach alpha coefficient=0.93) (**Table 5.11**).

5.5.1.5 Barriers of FCC

Table 5.9 Descriptive statistics from family for the barriers of FCC subscale

Item	**Levels of agreement**	
	Median	IQR
Lack of financial support for families for funding the expensive ICU services	3	3-4
Lack of guidelines, policy, and protocols on FCC at the ICU	3	2-4
Families may be a source of infection to critically ill children at the ICU	3	3-4
	Mean	**SD**
Inadequate space in the intensive care to accommodate families and implement FCC	3.05	0.72
Inadequate logistics including ventilators, incubators, bilirubinometer, phototherapy machines, and SPO2 monitors	3.04	0.71
Inadequate specialised personnel in intensive care, neonatal care, paediatrics, and psychologist at the NICU/PICU	2.92	0.75
Some families abandon their babies in the ICU	2.88	0.94

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Barriers of FCC subscale has seven items. Overall, the family members had positive experiences relating to the healthcare providers encouragement of family members collaboration (level of agreement ≥3) (**Table 5.9**).

More of the family members agreed to the items in the Barriers to FCC (≥66%) subscale than disagreed, showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this sub-scale show there was strong internal consistency in the items that made up the Barriers of FCC subscale (Cronbach alpha coefficient=0.84) (**Table 5.11**).

5.5.1.6 *Benefits of FCC*

Table 5.10 Descriptive statistics from family for the benefits of FCC subscale

Item	**Levels of agreement**	
	Median	IQR
FCC practices serves as a school for me and my family to learn and continue out childcare at home after discharge	3	3-4
FCC practices reduce my anxiety and motivates us psychologically to support/participate in care of our critically ill children	3	3-4
FCC practices promote bonding and initiates good parenting between me and my critically ill child	3	3-4
FCC practices reduces legal infractions as I am well informed by staff on the care processes	3	3-4
	Mean	**SD**
FCC practices promote early recovery and shorten the length of hospitalisation of my child and family at the intensive care unit	3.36	0.49
I play significant roles in providing timely information and resources to support clinical care of my critically ill child	3.36	0.49

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Benefits of FCC subscale has six items. Overall, the family members had positive experiences relating to the healthcare providers encouragement of family members collaboration (level of agreement ≥3) (**Table 5.10**).

More of the family members agreed to the items in the Benefits of FCC (≥66%) subscale than disagreed showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show there was strong internal consistency in the items that made up the Benefits of FCC subscale (Cronbach alpha coefficient=0.94) (**Table 5.11**).

Table 5.11: Family Perspectives of Family-Centered Care in NICU/PICU questionnaire sub-scales: reliability testing and assessment for exploratory factor analysis

Subscale	Cronbach alpha	Kaiser-Meyer Olkin	Chi-Square	p-value
Dignity and respect	0.89	0.85	1138.98	<0.001*
Communication	0.95	0.92	2750.25	<0.001*
Participation	0.82	0.87	824.08	<0.001*
Collaboration	0.93	0.93	1933.27	<0.001*
Barriers of FCC	0.84	0.88	1067.51	<0.001*
Benefits of FCC	0.94	0.91	1676.25	<0.001*

Key: * = statistically significant

Results from the Kaiser-Meyer Olkin (KMO) measure of sampling adequacy and Bartlett's test of Sphericity show that the data were suitable for factor analysis (M=KMO≥0.8; p<0.05) (Tripathi and Singal, 2019)

5.5.2 Clinicians Perspectives of Family Centered Care

5.5.2.1 Dignity and Respect

Table 5.12 Descriptive statistics from clinicians for the dignity and respect subscale

Item	**Levels of agreement**	
	Median	IQR
To have staff in the ICU accept regardless of sociocultural backgrounds	4	3-4
To ensure privacy and confidentiality of families and their children in the NICU/PICU	4	3-4
To have staffs respond positively to the psychological needs of families in the NICU/PICU	3	3-4
To have staff communicate positively with family in a respectful manner	3	3-4
To have comfortable furniture in the waiting room/areas	3	3-4
To have staff provide care that respect the religion of the child and family in the NICU/PICU	3	3-4

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Dignity and Respect subscale has six items. Overall, the clinicians had positive experiences relating to dignity and respect in their approach to family members (level of agreement ≥3) (**Table 5.12**). More clinicians (≥95%) agreed to the items that make up the Dignity and Respect subscale. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show that there was strong internal consistency in the items that make up the Dignity and Respect Subscale (Cronbach alpha coefficient=0.86) (**Table 5.18**).

5.5.2.2 *Communication*

Table 5.13 Descriptive statistics from clinicians for the communication subscale

Item	**Levels of agreement**	
	Median	IQR
To provide information about the types of staff members taking care of the patient to the families	3	3-4
To have families orientated on the ward environment and protocols	3.5	3-4
To inform families about transfer plans while they are being made	3	3-4
To inform families about transfer plans while they are being made	3	3-4
To provide regular information on the progress of child's condition to family	3	3-4
To explain child's condition and ICU care processes to families in simple terms	**3.5**	3-4
To educate families on newborn and infant care including feeding and clothing during hospitalisation at the NICU/PICU	3	3-4
	Mean	**SD**
To have staff communicate effectively with families all the time	3.45	0.50
To know how the patient is being treated medically	3.40	0.49
To have questions answered honestly sought by family	3.42	0.49
To build rapport and reassure family in all phases of care in the NICU/PICU	3.40	0.49

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Communication subscale has eleven items. Overall, the clinicians had positive experiences relating to their communication with the family members (level of agreement ≥3) (**Table 5.13**).

More than 93% of the clinicians agreed to the items in the Communications subscale showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show that there was strong internal consistency in the items that make up the Communication Subscale (Cronbach alpha coefficient=0.88) (**Table 5.18**).

5.5.2.3 Participation

Table 5.14 Descriptive statistics from clinicians for the participation subscale

Item	**Levels of agreement**	
	Median	IQR
To allow family to be fully involved and participate in the feeding, bathing and clothing of critically ill children	3	3-4
To have available financial support systems in the hospital for needy families and their children	3	3-4
To have family involved in all stages of decision making about childcare in the NICU/PICU	3	3-4
To have an in-house pharmacy and laboratory service in the ICU for prompt care	4	3-4
To have more space for families to be involved in Kangaroo Mother Care (KMC) in the NICU	4	3-4
To provide regular education and counselling sessions for families in the NICU/PCIU	3	3-4
To provide adequate PPEs and ensure strict IPC for parents involved in the care of critically ill children	4	3-4
	Mean	**SD**
To provide accommodation and food for families and children at the NICU/PICU	3.05	0.73

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Participation subscale has eight items. Overall, the clinicians had positive experiences relating to the healthcare providers encouragement of family members participation (level of agreement ≥3) (**Table 5.14**).

More than 76% of the clinicians agreed to all the items in the Participation subscale showing positive experiences except for the item: "To provide regular educational and counselling sessions for families in the NICU/PICU," where 69% of the clinicians disagreed with the statement. The results from the Cronbach alpha test for assessing the internal consistency in

the items of this subscale show there was strong internal consistency in the items that make up the Participation Subscale (Cronbach alpha coefficient=0.80) (**Table 5.18**).

5.5.2.4 *Collaboration*

Table 5.15 Descriptive statistics from clinicians for the collaboration subscale

Item	**Levels of agreement**	
	Median	IQR
To have a guideline and policy on FCC implementation a the NICU/PICU	3	3-4
To have national child health fund to support quality child healthcare services	3	3-4
To have a revised curriculum on FCC incorporated into the training of doctors, nurses and midwives	3	3-4
To have a family friendly and inclusively spacious designed NICU/PICU	3	3-4
To have the NICU.PICU designed into sub-units based on the needs of children and their families including preterm and congenital anomaly	**3**	3-4
To have regular training of staffs on newborn and infant care and the concepts of FCC	4	3-4
To have adequate logistics in ICU including ventilators, SPO2 monitors, flow meters, and phototherapy machines	4	3-4
To have community health nurses immunise well babies and conduct follow ups	3	3-4
To have adequate specialised professionals in the ICU including neonatal nurse, paediatric nurse, paediatricians, and intensive care nurses and doctors.	4	3-4

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Collaboration subscale has nine items. Overall, the clinicians had positive experiences relating to the healthcare providers encouragement of family members collaboration (level of agreement ≥3) (**Table 5.15**).

More than 96% of the clinicians agreed to the items in the Collaboration subscale showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show there was strong internal consistency in the

items that make up the Collaboration Subscale (Cronbach alpha coefficient=0.84) (**Table 5.18**).

5.5.2.5 Barriers of FCC

Table 5.16 Descriptive statistics from clinicians for the barriers of FCC subscale

Item	**Levels of agreement**	
	Median	IQR
Inadequate space in the intensive care to accommodate families and implement FCC	4	3-4
Inadequate logistics including ventilators, incubators, bilirubinometers, phototherapy machines, and SPO2 monitors	4	3-4
Lack of financial support for families for funding the expensive ICU service	3	3-4
Families may be a source of infection o critically ill children at the ICU	**3**	3-4
	Mean	**SD**
To have the NICU/PICU designed into sub-units base onto the needs of children and their families including preterm and congenital anomaly	3.25	0.61
Some families abandon their babies in the ICU	2.87	0.90
Lack of guidelines, policy, and protocols on FCC at the ICU	3.25	0.63
Families may be a source of infection to critically ill children at the ICU	2.92	0.75

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Barriers of FCC subscale has eight items. Overall, the clinicians were more likely to agree to statements regarding barriers of FCC (level of agreement ≥3) (**Table 5.16**).

More of the clinicians agreed to the items in the Barriers to FCC (≥69%) subscale than disagreed, showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show there was poor internal consistency in the items that made up the Barriers of FCC subscale (Cronbach alpha coefficient=0.61) (**Table 5.18**).

5.5.2.6 Benefits of FCC

Table 5.17 Descriptive statistics from clinicians for the benefits of FCC subscale

Item	**Levels of agreement**	
	Median	IQR
FCC practices serves as a school for me and my family to learn and continue out childcare at home after discharge	3	3-4
FCC practices reduce my anxiety and motivates us psychologically to support/participate in care of our critically ill children	3	3-4
FCC practices promote bonding and initiates good parenting between me and my critically ill child	3	3-4
FCC practices reduces legal infractions as I am well informed by staff on the care processes	3	3-4
	Mean	**SD**
FCC practices promote early recovery and shorten the length of hospitalisation of my child and family at the intensive care	3.36	0.49
I play significant roles in providing timely information and resources to support clinical care of my critically ill child	3.36	0.49

Scale 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree (1 & 2=negative practice; 3 & 4 = Positive practice)

The Benefits of FCC subscale has six items. Overall, the clinicians had positive experiences relating to benefits of FCC (level of agreement ≥3) (**Table 5.17**).

More of the clinicians agreed to the items in the Benefits of FCC (≥95%) subscale than disagreed, showing positive experiences. The results from the Cronbach alpha test for assessing the internal consistency in the items of this subscale show there was strong internal consistency in the items that made up the Benefits of FCC subscale (Cronbach alpha coefficient=0.82) (**Table 5.18**).

Table 5.18: Clinicians Perspectives of Family-centered Care in NICU/PICU questionnaire subscales: reliability testing and assessment for exploratory factor analysis

Subscale	Cronbach alpha	Kaiser-Meyer Olkin (KMO)	Chi-square	p-value
Dignity and respect	0.86	0.86	243.87	<0.001*
Communication	0.88	0.80	469.36	<0.001*
Participation	0.80	0.83	266.26	<0.001*
Collaboration	0.84	0.84	333.16	<0.001*
Barriers of FCC	0.61	0.69	139.52	<0.001*
Benefits of FCC	0.82	0.85	185.65	<0.001*

Key: * = statistically significant

Results from the Kaiser-Meyer Olkin (KMO) measure of sampling adequacy and Bartlett's test of Sphericity show the data were suitable for factor analysis ($M=KMO\geq0.8$; $p<0.05$). (Tripathi and Singal, 2019)

5.6 PRINCIPAL COMPONENT ANALYSIS RESULTS: FACTOR EXTRACTION BASED ON INITIAL EIGENVALUES

A Principal Component Analysis (PCA) was performed and variables were retained based on Eigenvalues greater than one rule, and Varimax Orthogonal rotation factor loading of component above 0.50 (Balasundaram, 2009). The rationale for the Varimax orthogonal rotation was to influence factors to correlate with the concepts of the theoretical underpinnings of the study, i.e. the FST and FCC concepts (Wood, Gnonhosou and Bowling, 2016). Based on these rules, seven factors were retained from the 46 components (Eigenvalues>1). The seven retained factors are factor 1: family acceptance; factor 2: privacy, and confidentiality; factor 3: psychosocial needs; factor 4: respectful communication; factor 5: family and ICU spaces; factor 6: respect religion of family; and factor 7: effective communication. There was a scree plot (**Figure 5.1**) generated based on **Initial Eigenvalues** values of the components under study. The components with **Initial**

Eigenvalues greater than one show a bend or an elbow in the scree plot depicting the seven components retained **(See Figure 5.1)**.

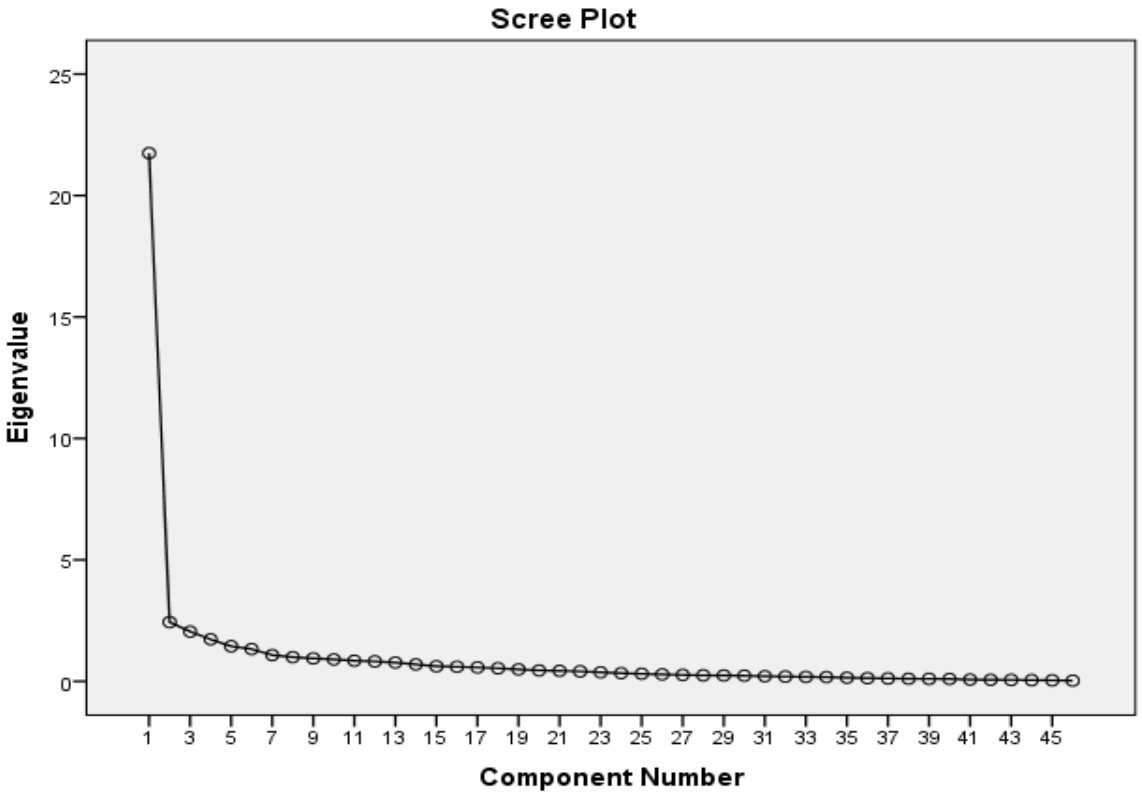


Figure 5.1: Scree plot showing the seven factors retained based on Eigenvalues >1.

Table 5.19 Principal Component Analysis results: Family perspectives of FCC after Rotated Component Matrix[a] (N= 346) - (only factors loading >0.50 are shown)

Name of Characteristics	Retained components based on Eigen values >1 rule						
	Acceptance	Privacy	Psy. need	Resp. comm.	Space	Resp. religion	Effect. comm.
FCC reduces lawsuits	**0.74****						
FCC promotes recovery	**0.73****						
FCC reduces anxiety	0.69						
Inadequate space	0.69						
Provides timely information	0.67						
Specialised professionals	0.65						
Adequate logistics	0.65						
FCC promotes bonding	0.63						
Child immunisation	0.63						
Regular Training for staff	0.62						
Family and ICU Spaces		**0.76****					
Respectful communication		**0.74****					
Information of transfer		**0.73****					
Privacy/confidentiality		**0.71****					
Educate on Childcare		**0.70****					
Explain condition care		0.69					
Types of medical staff		0.66					
Honest responses		0.65					
Information on progress		0.64					
Respect religion		0.62					
Family orientation		0.62					
Inadequate logistics			**0.83****				
Lack of finance			**0.79****				
Inadequate personnel			**0.74****				
Financial support				0.69			
Abandoned babies					0.68		
Lack of FCC guidelines						0.60	
Family acceptance							**0.79****
Eigen Values	21.90	2.29	1.85	1.52	1.31	1.16	1.05
Proportion of variance (%)	20.14	19.68	8.86	6.79	5.48	3.37	3.25
Cumulative Variance Explained (%)	20.14	39.82	48.68	55.47	60.95	64.32	**67.58**

Key: **Weighted factor loads (close to 1) representing FCC concepts per family perspectives (Tripathi and Singal, 2019).

According to **Table 5.19**, the total variance explained from the family perspective of FCC for the 7-component retained based on the **Initial Eigenvalues** rule of greater than 1, was **67.58%.** The variables underwent further, separate subjection to an Orthogonal Varimax Rotation with Kaiser Normalization for family. Components with weighted factor loadings above 0.60 were retained because the cumulative variance explained for the dataset was above 60% (Tripathi and Singal, 2019). Therefore, only variables with weighted factor loads close to 1 were retained from the PCA Varimax rotations (Tripathi and Singal, 2019). Variable characteristics that load well to a retained component provide meaning to that concept under study. The ultimate goal of rotation is to obtain a simple structure of characteristics that can easily be explained (Balasundaram, 2009; Tripathi and Singal, 2019; Harerimana and Mtshali, 2020; Mahmoudi *et al.*, 2020).

Table 5.19 shows results of a PCA with Varimax rotation of the 46 items under study from the family perspectives. Seven retained factors of Eigen values >1 were extracted, which explained **67.58%** of the total variance. The factor scores ranged from 0.827 to 0.60, albeit only factors scoring >0.50 were presented (Balasundaram, 2009). The factor load characterised the underlying concepts of FCC under study. According to the family perspective presented in Table 5.4, factor 1: family acceptance was characterised by 10 different items with factor loadings ranging from 0.74 for reduced lawsuits to 0.62 for regular clinicians training. The Eigen value for the factor 1: family acceptance was 21.90, and these factors accounted for 20.14% of the rated variance.

Table 5.19 further shows that factor 2: privacy and confidentiality was characterised by 11 items with factor loadings ranging from 0.76 for family and ICU spaces to 0.62 for family orientation. The Eigen value for factor 2 was 2.29, which accounted for 19.69% of the rated variance. Factors 1 and 2 (acceptance and privacy) sought to describe the tenets of respects and dignity of the FCC concepts.

Similarly, factor 3: psychological needs, was characterised by three factors after rotation, i.e., inadequate logistics, lack of finance, and inadequate personnel, with factor scores ranging from 0.83 to 0.74. The psychosocial needs of the family explained 8.86% of the

rated variance with an Eigen value of 1.85. Again, respectful communication, the fourth factor, was characterised by one item with 0.69 score for financial support; it had an Eigen value of 1.52 and explained 6.791% of variance. Factor 5: family and ICUs space were characterised by abandoned babies, 0.68, Eigen value of 1.313, and 5.48% accounted variance.

Factor 6: respect religion and sociocultural background was characterised by lack of FCC guidelines with factor score 0.60, Eigen value of 1.165, and 3.37% of accounted variance. Finally, the seventh factor retained was effective communication, which was characterised by only family acceptance into the ICUs; it had a factor score of 0.79, Eigen value of 1.05, and accounted for 3.25% of variance. The cumulative variance explained for the seven extracted factors was 67.58% for the family perspectives of FCC in the Ghanaian context. Overall, 11 factors (**weighted), inadequate logistics -.83 to education of childcare -.70, were the underlying concepts of FCC per the family perspectives. The next section explored the clinician perspective of FCC using the PCA.

Table 5.20 Principal Component Analysis: Clinicians' perspectives of FCC after Rotated Component Matrix[a] (n= 100) (only factors loading >0.50 are shown)

Name of Characteristics	Retained components based on Eigen values >1 rule						
	Acceptance	Privacy	Psy. need	Resp. comm.	Space	Resp. religion	Effect. comm.
Specialised professionals	**0.78****						
Regular Training for staff	**0.75****						
Adequate logistics	0.68						
Education & Counselling	0.66						
Child immunisation	0.65						
NICU design into subunits	0.65						
National Child health Fund	0.63						
Privacy & confidentiality		**0.81****					
Family acceptance		**0.78****					
Psychosocial needs		**0.71****					
Space & Comfortable furniture		0.68					
Respect Religion		0.61					
FCC promotes recovery			0.68				
Provides timely information			0.68				
FCC reduces lawsuits			0.61				
FCC promotes bonding			0.60				
Inadequate logistics				**0.71****			
Inadequate personnel				**0.70****			
Lack of finance				0.67			
Family involvement					**0.75****		
Family as a source of infection						**0.71****	
Eigen Values	21.74	2.44	2.05	1.73	1.44	1.33	1.08
Proportion of variance (%)	16.47	14.06	11.68	8.98	8.02	5.37	4.59
Cumulative Variance Explained (%)	16.47	30.52	42.20	51.19	59.21	64.58	**69.16**

Key: **Weighted factor loads (close to 1) representing FCC concepts per clinicians' perspectives (Tripathi and Singal, 2019).

From **Table 5.20,** seven factors were extracted from the PCA varimax rotation, which accounted for 69.16% of total variance explained, with factor scores ranging from 0.81 for privacy and confidentiality to 0.60 for FCC promotes bonding, albeit only scores >0.50 were presented after. According to the clinicians, they perceived family acceptance to be explained by seven characteristics, with scores ranging from 0.78 for specialised personnel to a score of 0.63 for National Child Health Fund. This factor had an Eigen value of 21.74 and accounted for 16.47% of variance.

The second factor was ensuring privacy and confidentiality in the ICU, characterised by five defined characteristics with factor scores ranging from 0.81 for privacy to 0.61 for respect religion, Eigen value of 2.44, and 14.06% of variance. **Table 5.5** further shows factor 3: psychosocial needs of families, defined by four characteristics, with scores ranging from 0.68 for promotes recovery to 0.60 for promote bonding, Eigen value of 2.05, and 11.68% accounted variance.

Factor 4: respectful communication was also characterised by three factors, with scores ranging from 0.71 for inadequate logistics to 0.67 for lack of finance, Eigen value of 1.73, and 8.98% of accounted variance. Family and ICU space was the fifth factor, characterised by only family involvement with a score of 0.75, Eigen value of 1.33, and 5.37% of variance. Factor 6: respect religion and sociocultural background of family was the only item defined by family as a source of infection, with a score of 0.71, Eigen value of 1.33, and 5.37% of variance. Finally, the seventh factor: effective communication had an Eigen value of 1.08, and accounted for 4.585% of variance, but had no specified defined characteristic after the PCA Varimax rotation. The PCA Varimax rotation matrix of the clinician's data cumulatively explained a much higher percentage variance (69.16%) of the same seven extracted components than the family PCA of 67.58%.

The researcher further explored the two datasets with direct oblimum rotation, which produced similar findings of seven retained components. The SPSS and the PCA imported the clinicians and family datasets, with Varimax orthogonal rotation repeated. The next section presents the results of the PCA of both data sets.

Table 5.21 Principal Component Analysis results: Rotated Component Matrix of Characteristics from Clinicians and Family (N=446) (only factors loading >0.50 are shown)

Name of Characteristics	Retained components based on Eigen values >1 rule						
	Acceptance	Privacy	Psy. need	Resp. comm.	Space	Resp. religion	Effect. comm.
FCC promotes recovery	**0.78****						
FCC reduces lawsuits	**0.71****						
Provides timely information	**0.68**						
FCC reduces anxiety	**0.65**						
FCC promotes bonding	**0.63**						
Inadequate space	0.51						
Adequate logistics		**0.64****					
Regular Training for staff		**0.64****					
Specialised professionals		**0.62****					
NICU design into subunits		**0.60****					
Education and Counselling		0.59					
Child immunisation		0.57					
More space for KC		0.50					
Privacy and confidentiality			**0.83****				
Family acceptance			**0.81****				
Respectful communication			**0.73****				
Space & Comfortable furniture			**0.65****				
Psychological needs			0.59				
Explain condition and care				**0.61****			
Types of medical staff				**0.61****			
Build family rapport				0.59			
Honest responses				0.53			
Family orientation				0.52			
Information on progress				0.51			
Lack of finance					**0.80****		
Inadequate personnel					**0.77****		
Inadequate logistics					**0.77****		
Family as a source of infection					**0.63****		
Decision making						**0.68****	
Financial support						0.55	
Family accommodation						0.54	

Abandoned babies							**0.78****
Eigen Values	19.76	2.24	1.93	1.56	1.28	1.15	1.06
Proportion of variance (%)	11.70	11.52	11.41	10.78	7.97	6.69	2.92
Cumulative Variance Explained (%)	11.70	23.23	34.63	45.41	53.38	60.08	**63.00**

Key: **Weighted factor loads (close to 1) representing FCC concepts per family perspectives (Tripathi and Singal, 2019).

Table 5.21 illustrates the PCA analysis produced the same seven retained components with a much lower cumulative variance explained of 63.00%. Factor one: family acceptance had six characteristics with scores ranging from 0.78 for FCC promotes recovery to 0.51 for inadequate space, Eigen value of 19.76 and accounted for 11.70% of variance. The privacy factor had seven characteristics, with scores ranging from 0.64 for ICU logistics to 0.50 for more space for KC, Eigen value of 2.24 and accounted for 11.52% of variance. The psychological needs had five characteristics with factor scores ranging from 0.83 to 0.59 with an Eigen value of 1.93, and 11.41% proportion of variance.

In the Ghanaian context, the needs of families in the ICUs include acceptance, privacy, and psychosocial needs. These three significant needs had a cumulative percent variance of 34.631%; i.e., accounting for more than half of the cumulative variance explained by all the seven retained components (both datasets). Family acceptance had 11.704%, the highest percentage variance of the three, which perhaps, underscores the need for clinicians and hospitals to accept and integrate FCC into clinical practice at all levels of care. These results illuminate the significance placed by both family and clinicians on the practice of respect and dignity component of FCC concept.

Furthermore, **Table 5.21** depicted that the fourth retained component, respectful communication, was explained by six characteristics notably among which was that the family needed explanations on their child's condition and care processes -0.61, by the clinicians -0.61; the actual factor scores for this respectful communication component ranged from 0.611 to 0.51, with Eigen value of 1.56, and 10.78% of variance. Factor 5: family and ICU space, explained the real barriers of FCC in the Ghanaian context. These defined characteristics of the space barrier were lack of funding -0.80, inadequate personnel

-0.77, inadequate logistics -0.77, and the fear of family bringing infections into the ICUs-0.63. This component had an Eigen value of 1.28 and accounted for 7.97% of variance.

Table 5.21 further depicted that the sixth component retained was also respect for the religion and the sociocultural backgrounds of families in the ICUs. This component was defined by three characteristics, family involvement in decision-making -0.68, financial support -0.55, and provision of family accommodation -0.54. The grouping of this component was to represent the ingredients of participation and partnerships concepts of FCC. Thus, in the Ghanaian context the involvement of family in decision making, providing families with regular funding support to seek care, and providing accommodation in the hospital for them will facilitate their participation and integration of FCC into clinical practice. This component had an Eigen value of 1.15 and accounted for 6.69% of variance.

Finally, the seventh component retained (effective communication) sought to provide one of the possible rationales of another major FCC barrier in the Ghanaian context, i.e., abandoned babies. This component was characterised by only abandoned babies with a factor score of 0.78, suggesting that the use of effective communication as a tool in clinical practice may be helpful in reducing the abandoned baby's menace. This factor had an Eigen value of 1.06 and accounted for 2.92% of the 63.00% of the cumulative variance explained from both perspectives.

5.7 PRINCIPAL COMPONENT ANALYSIS: PARALLEL ANALYSIS

Performing Parallel analysis (PA) is to identify the number of components to be retained, usually after a Principal Component Analysis of Exploratory Factor Analysis. PA minimises the number of factors generated from the data due to chance or based on sampling error (Franklin *et al.*, 1995; Matsunaga, 2011; Helwig, Hong and Polk, 2012; Wood, Gnonhosou and Bowling, 2016; Charpentier, Mussard and Ouraga, 2021). The researcher adopted the Brian O'Connor (2000, developed syntax (parallel.sps) to compute the PA. Normally, a factor or component is retained after PA stimulation when the 95^{th} percentile randomly simulated Eigenvalues are smaller than the raw data Eigenvalue, and vice versa (Wood, Gnonhosou and Bowling, 2016; Charpentier, Mussard and Ouraga, 2021). PA moves merely beyond the ordinary decision rule of retaining factors having Eigenvalue >1 rule, and advances to compare the Eigenvalues of the raw data against the Monte Carlos randomly simulated data. In this research, the 46 items from the 446 raw data of family and clinicians

underwent subjection to PA. The Brian O'Connor (2000), syntax was imputed to SPSS and modified to suit the raw data sample (446) and number of items (46) to run the analysis.

Table 5.22 Parallel Analysis: Raw Data Eigenvalues, & Mean & Percentile Data Random Eigenvalues

Component	Raw data	Randomly generated	
		Mean	95th Percentile
Family acceptance	**19.793****	1.679	**1.751****
Privacy & confidentiality	**2.243****	1.607	**1.657****
Psychosocial needs	**1.930****	1.552	**1.597****
Respectful communication	**1.554****	1.506	**1.546****
Space and comfortable furniture	1.267	1.465	1.499
Respect religion	1.1457	1.429	1.465
Effective communication	1.0609	1.393	1.428

Key: (** the bold scores were the final factors retained after PA). Brian O'Connor (2000), syntax (parallel.sps) was used to compute the PA

Table 5.22 shows Eigenvalues of the raw data (family & clinicians) in the first column compared with the mean Eigenvalues in the second column and Percentiles Eigenvalues from a randomly simulated data presented in the third column. The comparison revealed only four components of the initial seven retained components from the initial PCA solutions should remain. Component 1: family acceptance into the ICU had 19.80 raw Eigenvalue, which was higher than the 95th percentile corresponding randomly generated Eigenvalue of 1.75, and thus retained. Component 2: maintaining privacy and confidentiality of family had a raw Eigenvalue of 2.24, higher than its 95th random Eigenvalue of 1.66 and therefore retained. The retaining of Component 3: psychosocial needs of family in ICU, was because its 1.93 Eigenvalue was greater than the corresponding Eigenvalue of 1.60. The final fourth factor retained was respectful communication, since its Eigenvalue of 1.55 was higher than the corresponding random simulated Eigenvalue of 1.54. The remaining initial three PCA factor solutions had raw Eigenvalues lower than the randomly simulated Eigenvalues.

Therefore, according to the parallel analysis conducted after the PCA, and presented in **Table 5.22**, the key concepts of FCC in the Ghanaian context were family acceptance,

privacy, psychosocial needs, and respectful communication. By extension, the concepts of FCC practiced in Ghanaian NICUs/PICUs were respect and dignity (acceptance, privacy, and psychological needs), and respectful communication.

5.8.1 PRINCIPAL COMPONENT ANALYSIS: COMMUNALITIES

The researcher further examined both datasets for each of the items by comparing the pivot tables for their communalities of PCA. Communalities, similar to regression, represents the percentage of variance explained by the extracted components. Item variance with low communalities depicts unrelated concepts and vice versa (Balasundaram, 2009; Jöresko, 2015; Gibbons, 2016; Tripathi and Singal, 2019; Harerimana and Mtshali, 2020; Mahmoudi *et al.*, 2020). Thus, the closer the factor load of communalities to one the higher the correlation of the defined characteristics to the main concept. The researcher performed PCA communalities and used it to answer the specific objectives of the quantitative study: family needs (respect/dignity concept), family involvement (participation and communication concepts), barriers of FCC, and facilitators of FCC (collaboration concepts of FCC). Below is a detailed description of the communalities for each of the concepts.

Table 5.23 Ranking of important components of FCC after PCA rotations (n= 446)

Components retained based on PCA	Define characteristic	Underlying concepts of FCC	Highest factors score after rotation	Ranking
Factor 1: Family acceptance	Promote recovery and early discharge	Benefits of FCC	0.775	4th
Factor 2: Privacy and confidentiality	Adequate logistics and space	Collaboration	0.642	6th
Factor 3: Psychosocial needs	Maintaining Privacy and confidentiality	Respect & Dignity	0.827	1st
Factor 4: Respectful communication	Explain condition and care processes	Information sharing & Communication	0.611	7th
Factor 5: Family and ICU space	Lack of finance	Barrier of FCC Implementation	0.804	2nd
Factor 6: Respect	Family involvement in decision making	Participation & Partnership	0.678	5th
Factor 7: Effective communication	Abandoned babies	Barrier of FCC Implementation	0.78	3rd

Table 5.23 illustrated the most important concept of FCC in the Ghanaian context, was respect and dignity, ranked first with a highest factor score of 0.83 from both clinicians,

managers, and family perspectives. The defining of this concept was by maintaining privacy and confidentiality of families and their sick children whilst meeting their psychological needs. Thus, the greatest need of a family in the ICU, as perceived by the respondents in the Ghanaian context was psychosocial needs.

The second most important characteristic of FCC was provision of family and ICUs space. The respondents perceived that lack of funding (factor score of 0.80) was the root cause of lack of family and ICUs space, as it constitutes the major barrier to the implementation and integration of FCC in the Ghanaian context. The third priority characteristic was, abandoned babies (factor score of 0.78), which was also a barrier of FCC and seemed to be related to poor communication. The fourth priority characteristic of FCC was by accepting families into the ICUs, it could yield benefits such as promoting recovery and early discharge. The concept of participation and partnership was characterised by the need for family involvement in decision-making, the fifth ranked factor score of 0.678. Provision of adequate logistics in the ICUs was the sixth ranked characteristic, which explained the concept of collaboration of FCC in the Ghanaian context. The least ranked characteristic, as perceived by the families, clinicians, and health managers in the context was explaining the condition and care processes to the family in ICUs; this underpinned the concept of communication. The next section presents the summary of the findings in this chapter.

5.9.1 SUMMARY OF FINDINGS

The researcher performed several iterations of the datasets to arrive at the most succinct components that clearly defined the underlying concepts of FCC in a parsimonious manner. Components with very high factor loadings close to 1, were deemed worthy of representing the underlying concepts of FCC in the Ghanaian context relative to the outcome of the quantitative dimension of the study. The main findings of the quantitative study included:

- The mean age of families with sick children at the ICUs was 29.33 (SD=6.68), and the modal age was 30 years, with majority of them being mothers (80.3%)
- About 74% of families were educated and largely self-employed (57%)
- Majority of the families (62.4%) in the ICUs were multiparous, whilst 31% were first-time families admitted into the ICU with their sick children

- About 53% of babies admitted in the Ghanaian NICUs were born after 36 weeks of gestation and 39% were born before 32 weeks of gestation
- Majority (52.3%) of the babies born had their birth weight less than 2.5kg, i.e., preterm.
- The management of preterm babies was with radiant warmers, incubators, and practice of KMC post ICU care in a separate room with families
- Critically ill babies admitted into the Ghanaian NICUs were largely delivered per vagina (65%) and mainly admitted on-delivery (48%)
- Majority of babies (55.2%) admitted into the NICUs were not initiated on breastfeeding within 24 hours
- The top five causes of admissions in Ghanaian NICU/PICUs were prematurity (41.6%), birth asphyxia (20.5%), neonatal jaundice (15.3%), neonatal infections (6.9%), and congenital abnormalities (5.5%)
- The mean age of clinicians was 31.93 (SD= 5.204), minimum age 23 years, and maximum age 53 years, with majority (69%) being females
- The mean years of working experience of clinicians in a Ghanaian ICUs was 6 years
- Nurses were the majority of clinicians in Ghanaian ICUs (81%), and about 58% of all clinicians in the ICU had no specialisations
- Only 19% of the doctors and nurses were specialised in neonatal, paediatrics, and intensive care
- The main concepts of FCC practiced in Ghanaian NICU/PICUs were respect and dignity through family acceptance and maintaining privacy
- The parallel analysis conducted indicated that the key concepts of FCC in the Ghanaian context were family acceptance, privacy, psychological needs, and respectful communication. By extension, the concepts of FCC practiced in Ghanaian NICUs/PICUs were respect and dignity (acceptance, privacy, and psychological needs), and respectful communication
- The other FCC concepts, i.e., communication, participation, and collaboration were poorly practiced
- Families felt accepted when clinicians addressed their needs, such as timely information on the care and progress of treatments, and psychological needs

- Dignified care in the Ghanaian context is care provided to a family in a respectful manner employing respectful communication and acceptance, regardless of their socio-cultural backgrounds
- One priority need of a family in the ICU is psychological needs; the addressing of this is by providing enough space to ensure privacy, family acceptance, and respectful communications
- Clinicians employed initial socialisation from the day of admission, as well as holding counselling sessions with families in the ICUs to practice the concept of communication and information sharing
- Respectful and effective communication was characterised by information sharing by known clinicians through building rapport and providing honest responses to explain the child's condition
- The practice of concept of participation was by relying on families for information, engaging family in counselling and education sessions, and involving families in Kangaroo Mother Care
- Family involvement in the Ghanaian ICUs was mainly in decision making about financial commitments
- The effective practice FCC was in building trilogic partnerships and collaborations between families, clinicians, and managers
- A multidisciplinary approach can ensure effective collaboration, providing adequate funding, logistics, and specialised personnel to be able to implement and practice FCC at the ICU
- The main barriers of FCC are lack of funding (factor score of 0.804), inadequate space and logistics, and abandoned babies (factor score of 0.780).
- The family as a source of infection in the ICU was correlated with high factor loading of 0.635 after PCA Varimax rotation
- The benefits of FCC in the Ghanaian context are promoting recovery and early discharge (factor score of 0.775) of sick children, reduced family anxiety, and reduced lawsuits against clinicians and the facility

5.10 DEVELOPED DELPHI STUDY QUESTIONNNAIRE

Table 5.24 Final ranked components drawn from the factor analysis for the Delphi Study.

Concepts of FCC	Components (Factors)	Factor loads	Strongly Disagree	Disagree	Agree	Strongly agree	Comments
			(1)	(2)	(3)	(4)	
Benefits of FCC	FCC promotes recovery	.775					
	FCC reduces Lawsuits	.712					
	FCC reduces anxiety	.649					
	FCC promotes bonding	.633					
Respect & Dignity	Privacy and confidentiality	.827					
	Family acceptance	.814					
Communication	Respectful communication	.729					
	Providing timely information	.680					
	Explain condition and care processes	.611					
	Know types of medical staff	.607					
Participation & Partnership	Family involvement in decision making	.678					
	Family space with comfortable furniture	.650					
Collaboration	Adequate logistics	.642					
	Regular Training of staff	.637					
	Specialised professionals	.619					
	NICU/PICU design into subunits	.603					
Barriers of FCC	Lack of finance	.804					
	Abandoned babies	.780					
	Inadequate personnel	.772					
	Inadequate logistics	.765					
	Family source of infection	.633					

The researcher used the PCA with Varimax rotation and cut off value of 0.50 to obtain a simplified version of items that best explain the various concepts of FCC in the Ghanaian context from the 46 initial items. These ranking of these variables was according to the factor loadings, and the grouping according to the concepts of FCC under study. This then developed a Delphi study questionnaire for expert's review to arrive as the most succinct components for the model. **Table 5.24** presents these results.

5.11 SUMMARY

This chapter presented results of the quantitative stage, the last stage of the exploratory phase of the thesis. The conducting of this was to triangulate the qualitative findings to develop an instrument of FCC in the NICU/PICU. Tables and Figures presented the analysed data, showing frequencies, means, standard deviations, minimum, maximum, inter quartile range, and factor loadings. Detailed descriptions of factor analysis illustrated how it reduced the variables. Based on the highest (>0.5) loaded factors and the parallel analysis, the retained components after orthogonal Varimax rotation matrix from both families and clinicians developed a Delphi questionnaire 21 items instrument.

The instrument has six subscales as per the concepts of FCC practices in the Ghanaian NICU/PICU. The subscales of the FCC instrument are benefits of FCC, respect and dignity, participation and partnership, collaboration, and barriers of FCC. Four of the subscales were consistent with the concepts of FCC, as proposed earlier by IPFCC (www.ipfcc.org, 2021), and the remaining two subscales (barriers and benefits) are context specific to the Ghanaian setting. Conceivably, the findings reflect the context perspectives of FCC practices in the Ghanaian setting. The instrument can assess FCC practices in the NICU/PICU. This set the platform for the Delphi study and model development presented in Chapter Six.

CHAPTER SIX

PHASE TWO: DELPHI STUDY AND THE MODEL DEVELOPMENT

6.1 INTRODUCTION

This chapter presents a detailed description of how experts in clinical nursing, research, medicine, and family modified the outcomes of the factor analysis for the development of the NICU/PICU FCC model.

The researcher used the outcome of the factor analysis from the quantitative study as the basis for the Delphi study. The quantitative study was based on scoping literature review and qualitative studies involving family, clinicians, and managers at the intensive care setting. Thus, this Delphi was modified and the consensus set at Inter-Quartile Range (IQR) </= 1, with agreement of more than 80% among the experts (Keeney, Hasson and Mckenna, 2010; Kleynen *et al.*, 2014; Chalmers and Armour, 2019). The experts received the Delphi questionnaire in an electronic format using Redcap.

The experts had to build a consensus on the extracted concepts of FCC in the Ghanaian setting (Fink *et al.*, 2019). This chapter presents the results from the two round Delphi study, and the relevant demographics of the experts. Kendell's coefficient of concordance and Cronbach's alpha of the scale were performed (Norris *et al.*, 2014). Excel pivot tables calculated the percentage of agreement on each concept of FCC. SPSS calculated the mean and inter-quartile ranges of each item.

After the two rounds of Delphi studies, each item received a ranking based on the percentages and the mean score of agreements among the experts to prioritise the important concepts of FCC according to the experts' panel. These outcomes conceptually developed the model. There was a vivid presentation in diagram form and a table format highlighting the underlying conceptual principles of the model (the 10 key concepts). For easy FCC implementation the proposal for the 10-key concepts was as a dogma. Also presented are the implications of the FCC model for neonatal and paediatric settings to clinical nursing practice, teaching, policy, and research.

6.2 DELPHI STUDY FINDINGS: RELEVANT DEMOGRAPHICS OF EXPERTS

The two rounds Delphi study had a participation of 24 experts with a mean age of 38.83 ± 5.58, and modal age of 43years; the minimum age was 30 years and the maximum age 51years. The mean years of experience in their various professions was 13.92 years, minimum experience was 5 years and 23 years maximum. This shows the experts involved in this Delphi study were highly experienced, matured, and well composed to add validity to the outcome of the Delphi study.

Table 6.1 Experts' relevant demographic data (n=24)

S/N	Highest qualification	Years of practice	Current job rank/grade	Name of Institution & Department	Expert category
1	Certificate	8	Principal Enrolled Nurse	Ministry of Health. Ghana Health Services	Family member
2	Bachelor's degree	20	DDNS (Matron of ICU)	Korlebu _PICU	Nursing expert (Paediatrics)
3	Bachelor's degree	11	Senior Nursing Officer (Paediatrics)	Korle bu	Nursing expert (Paediatrics)
4	Diploma	21	Midwifery officer	Maamobi General Hospital	Family member
5	Master's degree	5	Advanced Practice Nurse (ICU)	Department of Nursing, Wits	Nursing expert (Intensive care)
6	PhD	23	Dean, Professor of Nursing	University of Ghana	Nursing expert (Clinical research)
7	Bachelor's degree	7	Nursing officer	Kumbungu Health Centre	Family member
8	Master's degree	11	Specialist paediatrician	Tamale Teaching Hospital, Paediatrics and Child Health Department	Medical expert (Paediatrician)
9	Master's degree	15	Consultant paediatrician	Korle Bu, Department of Child Health	Medical expert (Paediatrician)
10	Master's degree	16	Principal Nursing Officer	Korle bu Child health	Nursing expert (Paediatrics)
11	Master's degree	11	Nurse Specialist	Tamale Teaching Hospital/Paediatric ward	Nursing expert (Neonatal nurse)
12	Diploma	10	Senior Nursing Officer (Critical care)	Korle-bu Teaching Hospital, Child Health Department	Nursing expert (Intensive care)
13	Membership	9	Neonatal Nurse Specialist	Tamale Teaching Hospital, Child Health.	Nursing expert (Neonatal nurse)

Table 6.1 Experts' relevant demographic data (n=24) (continued
)

S/N	Highest qualification	Years of practice	Current job rank/grade	Name of Institution & Department	Expert category
14	Bachelor's degree	16	Specialist paediatrician	KBTH/NICU	Medical expert (Paediatrician)
15	Bachelor's degree	21	Neonatal nurse specialist	Tamale Teaching Hospital/NICU	Nursing expert (Neonatal nurse)
16	Bachelor's degree	21	Neonatal nurse specialist	Tamale Teaching Hospital/NICU	Nursing expert (Neonatal nurse)
17	Bachelor's degree	21	Neonatal nurse specialist	Tamale Teaching Hospital/NICU	Nursing expert (Neonatal nurse)
18	PhD	16	Lecturer/ Consultant ICU/Anesthesia	University for Development Studies	Medical expert (Intensive care & Anaesthesia)
19	Bachelor's degree	9	Nurse specialist	Tamale Teaching Hospital/Paediatrics	Nursing expert (Paediatrics)
20	Bachelor's degree	7	Nursing officers	Ayawaso central, RCH	Family member
21	Master's degree	12	Nurse Specialist (Paediatrics)	Tamale Teaching Hospital. Child Health Department	Nursing expert (Paediatrics)
22	Master's degree	20	Principal Nursing Officer (Paediatrics)	KBTH/Child Health	Nursing expert (Paediatrics)
23	PhD	14	Senior Lecturer/ Nursing consultant	Wisconsin International University College, Ghana	Nursing expert (Clinical research)
24	Master's degree	10	Neonatal Nurse Specialist	Tamale Teaching Hospital/NICU	Nursing expert (Neonatal nurse)

T**able 6.1** provides the demographic characteristics of the experts in the first and second round Delphi. The least qualification of the expert was certificate (family), and the highest qualification was PhD. Most of the excerpts had professional membership qualifications in intensive care and paediatrics. The study had participation from neonatal nurses, paediatric nurses, paediatricians, intensive care specialist (paediatric), nursing consultants, and the family, and from one international ICU expert from South Africa.

Table 6.2 Frequency distribution of Delphi experts' relevant demographics (n=24)

Characteristics	Frequency	Percent
Age (in years)		
30 to 35	10	41.7%
36 to 40	4	16.7%
41 to 45	9	37.5^
>45	1	4.2%
Years of experience		
5 to 10	8	33.3%
11 to 15	6	25.0%
16 to 20	5	20.8%
21 to 25	5	20.8%
Marital status		
Single	4	16.7%
Married	19	79.2%
Widow	1	4.2%
Religion		
Christianity	19	79.2%
Islam	5	20.8%
Qualification		
Certificate	1	4.2%
Diploma	2	8.3%
Bachelor's degree	10	41.7%
Master's degree	8	33.3%
PhD	3	12.5%
Profession		
Family	4	16.7%
Nursing	16	66.7%
Medicine	4	16.7%
	4	16.7%
Position		
Consultant	4	16.7%
Specialist	13	54.2%
Managers	3	12.5%
Family	4	16.7%
Institution		
Clinical care	16	66.7%
Training & Research	4	16.7%
Experts Category		
Paediatrician	3	12.5%
Neonatal Nurse Specialist	6	25.0%
Paediatric Nurse	6	25.0%
Intensive Care	3	12.5%
Nursing research	2	8.3%
Family	4	16.7%

From **Table 6.2**, neonatal specialist and paediatric nurses (50%) constituted the largest group of experts who participated in the two round Delphi; the rest were paediatricians (12.5%),

intensive care specialists (12.5%), clinical nursing consultants (8.3%), and family (16.7%). Approximately 12.5% of the experts were health managers, 16.7% were consultants, 54.2% were specialists, and 16.7% were family. The experts came from family (16.7%), nursing (66.7%), and medicine (16.7%) who worked in a clinical setting, training and research setting, and the rest were family of critically ill children admitted at the NICU/PICU in Ghana.

6.3 DELPHI RESULTS OF EXPERTS ON THE FCC CONCEPTS AT THE NICUS/PICUS

Table 6.3 Delphi results: Descriptive Statistics of the FCC concepts per experts' review

Concept	Mean	Std. Deviation	Percentiles (Quartiles)			Inter-Quartile Range (IQR)
			25th (QI)	50th (Median)	75th (Q3)	
FCC promotes recovery	3.79	.41	4.00	4.00	4.00	0.00
FCC reduces lawsuits	3.50	.78	3.00	4.00	4.00	1.00
FCC reduces anxiety	3.75	.44	3.25	4.00	4.00	0.75
FCC promotes Bonding	3.79	.41	4.00	4.00	4.00	0.00
Privacy & confidentiality	3.54	.51	3.00	3.00	4.00	1.00
Family acceptance into ICU	3.75	.44	3.25	4.00	4.00	0.75
Respectful communication	3.67	.48	3.00	4.00	4.00	1.00
Timely information	3.75	.44	3.25	4.00	4.00	0.75
Explain condition & care processes	3.75	.44	3.25	4.00	4.00	0.75
Know types of medical clinicians	3.29	.69	3.00	3.00	4.00	1.00
Family involvement & decision making	3.75	.44	3.25	4.00	4.00	0.75
Family and ICU Space	3.63	.49	3.00	4.00	4.00	1.00
Adequate logistics	3.21	.78	3.00	3.00	4.00	1.00
Regular clinicians training	3.50	.66	3.00	4.00	4.00	1.00
Specialisation of clinicians	3.38	.65	3.00	3.00	4.00	1.00
ICU subunits	3.38	.65	3.00	3.00	4.00	1.00
**Lack of finance	2.88	.85	2.00	3.00	3.75	1.75**
Abandoned babies	3.17	.70	3.00	3.00	4.00	1.00
Inadequate personnel	3.21	.66	3.00	3.00	4.00	1.00
Inadequate logistics	3.42	.58	3.00	3.00	4.00	1.00
Family as a source of infection in ICU	2.92	.05	2.25	3.00	3.00	0.75

Key: Consensus reached at IQR≤1, except lack of finance where IQR>1(**)

According to **Table 6.3**, the researcher calculated the means, standard deviation, percentiles (quartiles) and the inter-quartile of the experts' responses. The mean ranges from 2.88 to 3.79, modal score was 3, and the inter-quartile range (IQR) of each concept was estimated and presented in **Table 6.3**. Ideally, consensus is reached in a Delphi response when IQR is ≤1 (Fink *et al.*, 2019; Gossler *et al.*, 2019). In the two-round Delphi, all concepts under study had an IQR of ≤1, except lack of finance (IQR=1.75), IQR>1, as shown in **Table 6.3**.

Table 6.4: Ranking of experts' agreement based on the means of the items (concepts)

S/N	Concept	Mean	Group priority
1	FCC promotes recovery	3.79**	1st
2	FCC Promotes bonding	3.79**	
3	Family acceptance	3.75**	2nd
4	Timely information	3.75**	
5	FCC reduces anxiety	3.75**	
6	Explain condition & care processes	3.75**	
7	Family involvement & decision making	3.75**	
8	Respectful communication	3.67**	3rd
9	Family and ICU Space	3.63*	4th
10	Privacy and confidentiality	3.54**	5th
11	Regular clinicians training	3.50	6th
12	FCC reduces lawsuits	3.50	
13	Inadequate logistics	3.42	7th
14	ICU subunits	3.38	8th
15	Specialisation of clinicians	3.38	
16	Know types of medical clinicians	3.29	9th
17	Adequate logistics	3.21	10th
18	Inadequate personnel	3.21	
19	Abandoned babies	3.17	11th
20	Family as a source of infection in ICU	2.92	12th
21	Lack of finance	2.88	13th

Key: **Priority concepts based on means close to strongly agree (4)

Table 6.4 shows the ranked mean scores of each concept to identify the priority concepts according to the experts. After the two round Delphi, the experts ranked the concepts of respect and dignity, communication, participation, and benefits of FCC as the most important concepts of FCC practices in Ghana, as shown in **Table 6.4**. The least priority concepts of FCC per the experts mean rankings were, lack of finance affecting FCC practices (13^{th}), family as a source of infection in the ICU (12^{th}), and abandoned babies affecting FCC practices (11^{th}). Thus, these items, according to the experts should ideally not constitute enough barriers to prevent the participation and involvement of families in the care of their critically ill children.

Table 6.5 Test Statistics of the two round Delphi study of Experts (n=24)

Test Statistics	Score
Kendall's W[a]	.269
Chi-Square	128.208
Df	20
Asymp. Sig.	.000
Cronbach's Alpha	.845
Cronbach's Alpha Based on Standardised Items	.861
a. Kendall's Coefficient of Concordance (KW=0.3, weak agreement after 1^{st} round)	

Even though it seems a decision had been reached after the first round Delphi, the agreement of the experts on the concepts was rather weak as the Kendell's W score was 0.3 (Norris *et al.*, 2014), as shown in **Table 6.5**. Additionally, **Table 6.5** also presents the reliability statistics of the Delphi questionnaire to demonstrate the statistical soundness of the Delphi results. The Cronbach's Alpha of the scale was 0.86 and that of the standardised items was 0.87, indicating a high reliability of the data. The significance was 0.000 with $x^2=117.882$, *and df=19.* Since the agreement among the experts was weak *(KW=0.3),* the researcher took the decision to go for a second round.

The researcher calculated the percentages agreement of each item using Excel pivot tables to identify the items that did not reach the 80% set consensus agreement. Consequently, five items failed to reach the 80% consensus by the experts.

Table 6.6: Round 1 Delphi results (n=24)

No	Question	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	% Agreement (3+4)	Remarks (80% agreement or disagreement signifies consensus)
	Section 1: Benefits						
1	FCC promotes recovery	0	0	20.83	79.17	100	Consensus reached
2	FCC reduces lawsuits	4.17	4.17	29.17	62.5	91.67	Consensus reached
3	FCC reduces anxiety	0	0	25	75	100	Consensus reached
4	FCC promotes bonding	0	0	20.83	79.17	100	Consensus reached
	Section 2: Respect & Dignity						
5	Privacy & confidentiality	0	20.83	41.67	37.5	79.17**	No consensus
6	Family acceptance into ICU	0	0	25	75	100	Consensus reached
	Section 3: Communication						
7	Respectful communication	0	0	33.33	66.67	100	Consensus reached
8	Timely information	0	0	25	75	100	Consensus reached
9	Explain condition & care processes	0	0	25	75	100	Consensus reached
10	Know types of medical clinicians	0	12.5	45.83	41.67	87.5	Consensus reached
	Section 4: Participation & Partnership						
11	Family involvement & decision making	0	0	25	75	100	Consensus reached
12	Family and ICU space	4.17	25	33.33	37.5	70.83**	No consensus
	Section 5: Collaboration						
13	Provision of logistics	4.16	8.33	50	37.5	87.5	Consensus reached
14	Regular training	0	8.33	33.33	58.33	91.66	Consensus reached
15	Specialisation of clinicians	0	8.33	45.83	45.83	91.66	Consensus reached
16	ICU subunits	0	8.33	45.83	45.83	91.66	Consensus reached

Key: ** No consensus since agreement <80% (Chalmers and Armour, 2019)

Table 6.6 Round 1 Delphi results (n=24) (continued)

No	Question	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	% Agreement (3+4)	Remarks (80% agreement or disagreement signifies consensus)
	Section 6: Barriers of FCC						
17	Lack of finance	0	25	58.33	16.67	75**	No consensus
18	Abandoned babies	4.17	29.17	50	16.67	66.67**	No consensus
19	Inadequate personnel	0	12.5	54.17	33.33	87.5	Consensus reached
20	Inadequate logistics	0	4.17	50	45.83	95.83	Consensus reached
21	Family as a source of infection in ICU	8.33	16.67	58.33	16.67	75**	No consensus

Key: ** No consensus since agreement <80% (Chalmers and Armour, 2019)

According to **Table 6.6**, the researcher estimated the percentage of agreement or disagreement among experts established consensus on the concepts of FCC. Rating 1 and 2 are negative practices, and 3 and 4 are positive practices of FCC. Therefore, agreement or disagreement were defined as a cumulative rating of 1 and 2 > 80%, or cumulative rating of 3 and 4 >80% (Chalmers and Armour, 2019).

From **Table 6.6**, the experts were unable to reach the set 80% consensus on five of the concepts of FCC. There were 21 concepts presented to the experts, five of which did not reach consensus after round one. The five concepts were maintaining privacy and confidentiality (79.17%), family and ICU space (70.83%), lack of finance (75%), abandon babies (66.67%), and family as a source of infection in ICU (75%).

There was consensus reached for all the concepts under benefits of FCC, communication, and collaboration concepts of FCC by experts as all items under each of those domains were >80%. The researcher then used the five concepts without consensus to develop a second round Delphi questionnaire for the same experts to review, with the results presented in the next section.

6.4 ROUND TWO DELPHI STUDY RESULTS

All the experts who participated in the first round took part in the second-round expert review. Thus, 24 experts responded to the five concepts of FCC presented in the second-round experts' review.

Table 6.7 Round Two Delphi results (n=24)

No	Question	Strongly disagree (1)	Disagree (2)	Agree (3)	Strongly agree (4)	% Agreement (3+4)	Remarks (80% agreement or disagreement signifies consensus)
	Section 2: Respect & Dignity						
5	Privacy & confidentiality	0	0	45.83	54.17	100	Consensus reached
12	Family and ICU Space	0	0	37.5	62.5	100	Consensus reached
	Section 6: Barriers of FCC						
17	Lack of finance	4.17	29.17	41.67	25	66.67**	No consensus
18	Abandoned babies	0	16.67	50	33.33	83.33	Consensus reached
21	Family as a source of infection in ICU	0	25	58.33	16.67	75**	No consensus

Key: ** No consensus since agreement <80% (Chalmers and Armour, 2019)

According to **Table 6.7,** there was consensus reached for three of the five FCC concepts re-rating by the experts. Only two of the concepts failed to meet the 80% agreement or disagreement by consensus from the experts, i.e., lack of finance (66.67%), and family as a source of infection (75%). The researcher terminated the Delphi sessions since the experts had reached consensus on the majority of the concepts (90.48%).

Table 6.8 Round two Delphi study results experts' priority FCC Concepts

No	Question	Agree (3)	Strongly Agree (4)	% Agreement (3+4)	Remarks (80% agreement or disagreement signifies consensus)	Experts' Priority FCC Concepts
1	FCC promotes recovery	20.83	79.17	100	Consensus reached	Benefits of FCC
3	FCC reduces anxiety	25	75	100	Consensus reached	
4	FCC promotes bonding	20.83	79.17	100	Consensus reached	
5	Privacy & confidentiality	47.83	52.17	100	Consensus reached	Respect & Dignity
6	Family acceptance into ICU	25	75	100	Consensus reached	
7	Respectful communication	33.33	66.67	100	Consensus reached	Effective Communication
8	Timely information	25	75	100	Consensus reached	
9	Explain condition & care processes	25	75	100	Consensus reached	
12	Family and ICU space	39.13	60.87	100	Consensus reached	Participation & Partnerships
11	Family involvement & decision making	25	75	100	Consensus reached	
20	Inadequate logistics	50	45.83	95.83	Consensus reached	Barrier of FCC
14	Regular training of clinicians	33.33	58.33	91.66	Consensus reached	Collaboration
15	Specialisation of clinicians	45.83	45.83	91.66	Consensus reached	
16	ICU design into subunits	45.83	45.83	91.66	Consensus reached	
2	FCC reduces lawsuits	29.17	62.5	91.67	Consensus reached	Benefits of FCC
10	Know types of medical clinicians	45.83	41.67	87.5	Consensus reached	Effective Communication
13	Provision of adequate logistics	50	37.5	87.5	Consensus reached	Collaboration
19	Inadequate personnel	54.17	33.33	87.5	Consensus reached	Barrier of FCC
18	Abandoned babies	52.17	30.43	82.6	Consensus reached	

Table 6.8 shows, the ranking of 19 out of the 21 concepts of FCC based on the percentage of agreement from the two round Delphi. Respect and dignity were characterised by family acceptance into ICU and maintaining privacy and confidentiality of families. The experts also reached consensus on effective communication, which was characterised by respectful communication, timely information, explaining the condition and care processes, and knowing the types of medical staff attending to the sick child in the ICU. Incidentally, respect/dignity and effective communication were the key concepts that earlier emerged from the quantitative factor analysis presented in Chapter Five. Additionally, the experts reached 100% consensus for the concept of participation and partnership, which were characterised by family involvement in decision-making, and provision of adequate family and ICU spaces. The least priority concept of FCC per the experts' review was collaboration, albeit it had 92% to 88% agreement. Collaboration was characterised by regular training of clinicians, specialisation of clinicians, design of ICU into subunits, and provision of adequate logistics.

Furthermore, **Table 6.8** depicted that the priority benefits of FCC were, promotes recovery, reduces family anxiety, and promotes bonding between the sick child and the family. According to the experts, the top priority barrier of FCC in the Ghanaian context is inadequate logistics in the ICU. Other barriers of FCC, as per the experts' perspectives, were inadequate personnel, and abandoned babies in the NICUs/PICUs.

The researcher earlier set the ratings of 1 and 2 for the concepts to imply negative FCC practices. The experts' failed to reach consensus on lack of finance (66.67%) and family as a source of infection in the ICU (75%); thus, from the experts' point of view, lack of finance on the part of families should not prevent their participation and involvement in the care processes of their sick child. Again, they vehemently rejected the notion that the involvement of family in the ICU would cause infections. The experts relished the significance of FCC in the management of critically ill children in the NICU/PICUs by giving 100% agreement to its benefits, as shown in **Table 6.8**; these findings corroborate the earlier findings presented in this study. However, the experts proposed family participation as an additional concept of FCC for inclusion in the model.

Table 6.9 Delphi response rate

Delphi rounds	Experts' Emailed	Experts' Responded	Response Rate (%)
Round 1	25	24	96.00
Round 2	25	24	96.00

According to **Table 6.9**, the two round Delphi received a very high response rate of 96% from the experts, even though one expert out of the 25 experts contacted did not respond to the Delphi questionnaires. This high response rate could be due to succinct clarity of the questionnaires, as it came from outcomes of qualitative and quantitative studies in the previous chapters. Also, the researcher established a good relationship with the experts in his field of study and maintained high ethical standards throughout the research. Conceivably, the experts participated because of the relevance of the study and its possible impact on their daily work in the ICU.

From Figure 6.1, the experts who participated in the Delphi study described the FCC study as good initiative, elaborate, and covered a wide range of issues regarding family nursing that are worth incorporating into our ICUs. They called for family involvement and participation on a daily basis.



Figure 6.1 Word clouds of experts' comments on the concepts of FCC presented in the Delphi.

6.5 SUMMARY OF RESULTS FROM THE DELPHI STUDY

- The two round Delphi engaged 24 multidisciplinary experts in neonatal care, paediatric care, intensive care, family, and nursing research.
- The mean age of the 24 experts was 38.83years (SD=5.58), with a modal age of 43years. The minimum age was 30 years and the maximum age 51years.
- The mean years of experience in their various categories was 13.92 years; minimum experience was 5 years and 23 years maximum.
- About 62.5% of the experts were specialised in neonatal and paediatric care, 12.5% were intensive care specialists, and 16.7 were family members.
- Overall, the majority of the experts were nurses (66.7%) with two of them at nursing consultancy level with PhD.
- Three paediatricians and one intensive care consultant (PhD) also participated in the two-round Delphi study.
- The two-round Delphi received a very high response rate of 96% from the experts, even though one out of the 25 experts contacted did not respond to Delphi questionnaires.
- The Cronbach's alpha of the scale was 0.862 and that of the standardised items was 0.873, indicating a high reliability of the data. The significance was 0.000 with a $x^2=117.882$, *and* $df=19$.
- After the first round Delphi, five of the 21 concepts presented to the experts had not reached the 80% consensus set: maintaining privacy and confidentiality (79.17%), family and ICU space (70.83%), lack of finance (75%), abandon babies (66.67%), and family as a source of infection in ICU (75%).
- There was consensus reached in the first round for all the concepts under benefits, communication, and collaboration concepts of FCC by experts as all items under each of those domains were >80%.
- After the two round Delphi, the experts ranked the concepts of respect and dignity, communication, participation, and benefits of FCC as the most important concepts of FCC practices in Ghana as they attained 100% full consensus from the experts.
- The least priority concepts of FCC per the experts mean rankings were lack of finance affecting FCC practices (13^{th}), family as a source of infection in the ICU (12^{th}), and abandoned babies affecting FCC practices (11^{th}).

- Respect and dignity were characterised by family acceptance into ICU and maintaining privacy and confidentiality of families.
- The experts also reached consensus on effective communication, which was characterised by respectful communication, timely information, explaining the condition and care processes, and knowing the types of medical staff attending to the sick child in the ICU.
- The experts reached 100% consensus for the concept of participation and partnership, which were characterised by family involvement in decision-making, and provision of adequate family and ICU spaces.
- The least priority concept of FCC per the experts' review was collaboration, albeit it had 92% to 88% agreement. Collaboration was characterised by regular training of clinicians, specialisation of clinicians, design of ICU into subunits, and provision of adequate logistics.
- The priority benefits of FCC are promoting recovery, reduces family anxiety, and promotes bonding between the sick child and the family.
- The top priority barrier of FCC in the Ghanaian context is inadequate logistics in the ICU, while other barriers according to the experts' perspectives were inadequate personnel, and abandoned babies in the ICU.

6.6 DISCUSSION OF THE DELPHI STUDY FINDINGS

This current Delphi review aimed to seek consensus of the quantitative findings by engaging experts in neonatal, paediatric, intensive care, and nursing to add more reliability to the study findings and arrive at a parsimonious FCC model. The Delphi study's participants were multi-disciplinary experts with a mean age of about 38 years, minimum age of 30 years and maximum age of 51 years, from nursing, medicine and research with an average working experience about 14years of clinical practice. The inclusion of heterogeneous and matured experts in building consensus has been widely reported in the literature to increase the validity and reliability of study findings (Kleynen *et al.*, 2014; Birko, Dove and Özdemir, 2015; Lai *et al.*, 2015; Grime and Wright, 2016; Massaroli *et al.*, 2017; Roth, Brewer and Wieck, 2017; Ahmad and Yew, 2019; Allen *et al.*, 2019; Fink *et al.*, 2019; Gossler *et al.*, 2019; Shi *et al.*, 2020). It is possible the researcher established relationships with the experts in his field of study and maintained a high ethical standard throughout the research. It is

plausible the experts participated because of the study's relevance and possible impact on their daily work. This will add credence and visibility to the new model since most of these experts are among the key drivers of policy and guidelines implementations in clinical and research institutions in the country. Thus, the selection of these experts occurred carefully and purposefully to psyche them about an upcoming model in their field that required their commitment for its full implementation and integration into the health system.

Most of the Delphi study findings reaffirm earlier findings in this thesis, as discussed in previous stages of the study. For example, the Delphi review by the experts builds full consensus on the concepts of respect and dignity and effective and respectful communication between clinicians and families in the ICU. These were the key concepts of the quantitative study presented above. Despite this, respectful communication is contextual to this setting as others only reported mutual trust between families and the staff (Hassankhani *et al.*, 2019)). Columbia, the Republic of Korea, and the United States have employed education and provision of information to families in the ICU to improve FCC practices (Hernández, Grillo and Lovera, 2016; Butler *et al.*, 2019; Uhm and Kim, 2019). The consistency of the findings from the various stages points to the rigorous nature of the methodology adopted. These findings have re-echoed the need for clinicians to accept families into the ICU, established and maintain effective communication with them, and maintain their privacy and confidentiality.

Furthermore, the experts reached 100% consensus for the concept of participation and partnership, which were characterised by family involvement in decision-making and the provision of adequate family and ICU spaces. Family involvement in care, such as kangaroo care and decision-making, has been reported in Canadian and New Zealand NICUs (Benzies, 2016; Serlachius, Hames, Juth, Garton, Rowley and Keith J. Petrie, 2018; Clarkson, Bc *et al.*, 2019). It is possible Kangaroo Care is the most common means of family involvement in decision-making in the Ghanaian setting, which might have accounted for these findings. This underscored the need for clinicians to engage families fully in the care of their sick children in the ICU, as buttressed by the experts in the Delphi review.

The experts also had a consensus on the collaboration concept of FCC, which was characterised by regular training of clinicians, specialisation of clinicians, design of ICU into subunits, and provision of adequate logistics. Similarly, ICU designs per international

standards and training of nurses and doctors have been effective in implementing FCC in Europe (Van Den Berg *et al.*, 2017; Kjellsdotter, Lantz and Ottosson, 2018). Contrary to these findings, clear visual information and family support enhanced mother-nurse collaboration in Japan (Shimizu and Mori, 2018). The low literacy level of mothers in the study setting makes it impossible to build and sustain effective communication and partnerships between clinicians and families. Further studies need conducting to explore the appropriate strategies to build and maintain partnerships and collaboration among clinicians and families in the ICU.

The priority benefits of FCC are promoting recovery, reduces family anxiety, and promotes bonding between the sick child and the family, which are again consistent with earlier findings in this study. Similarly, according to the American Academy of Paediatrics, these benefits are congruent with other studies findings elsewhere (Eichner *et al.*, 2012). Perhaps the experts' understood the importance of FCC in our setting even though no guidelines or model exist to push its full implementation into practice. Paediatricians, neonatal, and intensive care experts must embrace this new FCC model and use the key concepts developed out of this rigorous evidence-based study to facilitate the implementation for its full benefits for clients, families, clinicians, and the health system.

Finally, according to the experts, the top priority barrier of FCC in the Ghanaian context was inadequate logistics in the ICU. Meanwhile, in the developed world, such as the Netherlands, it was the mind-sets of the healthcare professionals that hindered the implementation of FCC (Oude Maatman *et al.*, 2020). Also, in Iran, the implementation of FCC was challenged by healthcare providers cultural, legal and operational challenges (Mirlashari *et al.*, 2020). It is conceivable the experts made inadequate logistics the main barrier because of their daily challenges, trying to improvise in poor resource settings like Ghana. Lack of resources was evident in the research setting, as presented earlier in this thesis. However, the experts disagreed on FCC's financial and socio-cultural barriers, such as lack of finance and abandoned babies. The experts believed the mere fact that government, institutions, and families lacked the financial capabilities to support the care of their critically ill should not warrant the lack of implementation of FCC in the ICUs. Again, experts maintained that even though some families abandon their babies in the NICUs or PICUs, it should not constitute enough grounds to impede further family involvement and participation in childcare. It is possible the experts are arguing from professional and human rights points of view, but the

fact on the ground is that these challenges do exist, which add to the burden of staff in taking care of the clients as they commit personal funds in most cases to support the care of the abandoned babies in the ward.

6.7 DEVELOPMENT AND DESCRIPTION OF THE FCC MODEL FOR NICU/PICUs

The framework for model development has been proposed by researchers to include the definition, indication, goal (purpose), theoretical foundations (assumptions), underlying concepts, and context of the model (Levac, Wright and Leahey, 1997; Davies, 2005; Jacqueine Fawcet, 2006; Meleis, 2009; Fawcett *et al.*, 2015). The explanation of the frameworks in this section is to properly describe and contextualise the NICU/PICU FCC model.

6.7.1 Definition of the NICU/PICU FCC model

The definition of this model is as a multidisciplinary approach to managing families and their critically ill children in the ICU, building partnerships for effective communication and involvement in decision making among family, clinicians, and managers for a quality respectful and dignified care in a family inclusively designed ICU environment.

6.7.2 Indications for the NICU/PICU FCC model

Ideally, families should spend more time with their children to promote their physical, emotional, and cognitive development. The enhanced restrictions of families to their sick children in the ICU manifest in anxiety, depression, and interrupted family processes, as well as thwart the speedy recovery. Hence, a multidisciplinary approach is necessary to comprehensively develop care plans and manage these situations.

6.7.3 Purpose of the FCC Model for NICU/PICUs

The primary purpose of this model is to promote quality child healthcare at the NICU/PICUs. The anticipation is that the birth of this model will also illuminate and strengthen the integration and practices of family nursing into the health system via health policy. Overall,

the FCC model will aid the advancement of FCC in child health practices to optimise the health outcomes for sick children and their families.

6.7.4 Theoretical Inspirations of the FCC Model Development

The application of FCC in nursing practice, especially at the neonatal and paediatric care has become a contextual issue with unclear pathways even though there was earlier identification of its components by the Institute of Patient and Family-centered Care. To this extent, the researcher set out to study the practices of FCC in Ghanaian NICU/PICUs to develop a model of FCC. The researcher lends the development of the model to various existing theories and models to give the FCC model sound theoretical foundations. The entire project was guided by the FST (Webster, 2009) as it was used as the glue for the three phases of this research. The FST is a blend of the Newman systems theory (Neuman and Reed, 2001), Bowen's family theory (Bowen, 1974, 1990), and the family care theory (Hohashi and Honda, 2015; Beer and Brysiewicz, 2019; Schmollgruber, 2019). FST enjoins the 21st century nurse to treat the patient as a whole and not in parts whilst focusing on their family and the disease condition (Ray, 2018). The researcher drew on this inspiration of "putting family in childcare," especially in the intensive care setting for the FCC model development (Bamm and Rosenbaum, 2008; Tomlinson, Peden-mcalpine and Sherman, 2011; Paredes *et al.*, 2018). Moreover, there is scientific evidence to suggest the positive impact of family on patient care and this cemented the researcher's inspirations to develop the FCC model (Bamm and Rosenbaum, 2008; Smith, 2018; Kelley, Godfrey and Young, 2019). There are calls from nursing scholars to identify and remove the barriers of FCC for its implementation to foster families and patient satisfaction and promote quality care, especially in the neonatal and paediatric intensive care (Malusky *et al.*, 2011; Mikkelsen and Frederiksen, 2011; Holditch-davis *et al.*, 2013; Toivonen *et al.*, 2019).

Again, the Charmaz CGT was used to qualitatively explore the contextual practices of FCC in the ICUs from the participants perspectives for the emergence of the Ghanaian FCC concepts from the data (Charmaz, 2008; Albert, Mylopoulos and Laberge, 2019). The CGT doctrines paved way for the researcher to be part of the data collection processes to socially study and construct the concepts of the FCC phenomenon from the participants and the researcher's perspectives as a Registered Nurse in a natural real world situation (Charmaz, 1997, 2006, 2008; Charmaz and Liska, 2015; Albert, Mylopoulos and Laberge, 2019). This

dictated the qualitative aspect of the research project whilst marrying the concepts of the FST to carefully construct the real phenomenon of FCC in the Ghanaian context (Charmaz, 2008). A pragmatic paradigm approach was therefore used to answer the various research questions, which provided valid responses for the FCC model development (Mackenzie and Knipe, 2006; Weaver and Olson, 2006; Rapport and Braithwaite, 2018). Finally, the six-step intervention model development processes (Squires *et al.*, 2016) were adapted to construct the model. The fusion of these theories and models inspired the researcher to construct and develop the FCC model walking through the three phases of the research employed in this thesis (Mackenzie and Knipe, 2006). These further justified the choice of mixed methods as the research methodology for this thesis (Creswell, 2007; Hesse-Biber and Johnson, 2015; Hunter and Brewer, 2015; Chen, Lewis and Squire, 2016; Coid *et al.*, 2016; Power *et al.*, 2016).

6.7.5 Context of the FCC Model for Hospitalized Children

In current child health practice, one cannot overlook the role of NICU/PICUs. The NICU/PICU are specialised units that address the health needs of fragile babies and sick children with life threatening health problems (Lavoie-Tremblay *et al.*, 2016; Sanabria and de Rodríguez, 2016; Priya Govindaswamy *et al.*, 2019). In Ghana, both units are under the Department of Child Health that dispense critical care to sick children and their families. The population of children with these critical illnesses are increasing daily and needs particular attention (El Halal *et al.*, 2012; Kurek Eken *et al.*, 2017; Synnes *et al.*, 2017; Ibiebele *et al.*, 2018). In the development of child health interventions however, there is usually the downgrading of the significant role of the family, especially parents. In the Ghanaian context, sick persons mostly go to the hospital as a last resort, after all traditional remedies have proven futile. Mothers in most Ghanaian contexts usually provide first aid for their fragile babies and sick children, yet as soon as they enter the hospital with the sick child, especially in the NICU, the same parents who initiated the care are separated from their loved babies and children. The psychological toll on both ends might even surpass the current pathological problem (Schmollgruber, 2019; Ocampo, Tinero and Rojas-Ashe, 2020); often this is ignored, and the child is treated with little involvement and consultation with the family. The concepts of FCC admonished healthcare providers to adhere to its key tenets of respect, communication, partnership, and collaboration. The researcher conceptualised the development of the FCC model based on these backdrops.

The development of the FCC model was in the NICU/PICUs in the Department of Child Health in two tertiary teaching hospitals. A three-dimensional approach was adopted, i.e. families, clinicians (nurses, midwives, doctors), and managers of the departments. Counselman *et al.* (2017), used three-dimensions of patients, physician tasks, and medical knowledge in the development of the Emergency Medicine model. The researcher contended there is an inter-relation between these three dimensions, with a common goal of patient safety through quality and timely care to promote patient satisfaction. Thus, this FCC model seeks to project family as experts in the care of their sick children to promote recovery and foster continuity of care at home after discharge. In the end, this blend of triangular stakeholders' engagement will make the FCC model stand the test of time in its implementation in a family friendly NICU/PICU environment. The next section presents the description of the model underlying characteristics.

6.8 CHARACTERISTICS OF THE FCC MODEL FOR NICU/PICUs

There are four main core concepts of FCC practiced in the Ghanaian setting that emanated from both family and clinicians' perspectives; these are family acceptance into the ICU, maintaining privacy and confidentiality of families, respectful communications, and addressing the psychosocial needs of families in the ICU. The building of these four core principles should be on a trilogic partnership between the family, clinicians, and health managers to implement FCC in an ideal NICU/PICU environment **(see Figure 6.2**). The researcher identified 10 major key conceptual principles after the exploratory and the Delphi studies. These principles were born out of the extensive interactions with families, clinicians, managers, and nursing researchers. The researcher then used these principles as the dogma to construct the model.

The FCC model for NICU/PICUs could be the first evidence-based extensive model of FCC for all sick children and their families in the intensive care. This model is unique because it has triangulated data and existing theories in the field of family health nursing and research methodology to develop the model conceptually. This proposed model could become the bedrock of practicing FCC at the neonatal, and paediatric units in Ghana. It has magnified the four key concepts of FCC into 10 key principles for easy implementations and integrations at all settings of childcare for an improved quality and satisfactory care for sick children and their families. The model holds the position that the technical basis for the

practice of FCC in the Ghanaian setting are on respect/dignity, effective communication, and family participation in an ideal NICU/PICU environmental design whilst recognising the Families, Clinicians, and Health Managers as the stakeholders and experts. The clinicians should provide respectful and dignified care through accepting families into the intensive care using respectful effective communications, privacy, and psychosocial care as the strategies. By so doing, they will be able to fully explain the care processes to the families as well as involve the families in decision making for their optimum participation in the NICU/PICU phase of care.

This has the benefits of promoting family-child bonding, providing timely essential information, reducing family anxiety, promoting recovery of the sick child, and reducing the possibility of lawsuits from families since they are well informed and involved in the care processes. The health managers have the responsibilities of ensuring the provision of adequate space (family and ICU) via ICU design into subunits/cubicles, adequate logistics, and regular training and provision of adequate specialised personnel to empower the clinicians to deliver their optimum best of quality and satisfactory care. The pinnacle of this model is that it posits a trilogic multidisciplinary approach to family-centered care, advocating for families, clinicians, and manages as the major partners' central to the successful implementation of FCC in an ideal ICU environment. Therefore, the researcher proposed a trilogic partnership model of Family-Clinicians-Managers approach to addressing the barriers of FCC and facilitating its implementation in clinical practice in the Ghanaian context (**see Figure 6.2**). Thus, the four key conceptual characteristics of the proposed model are the family, clinicians, health managers, and the NICU/PICU environment, as explained below:

6.8.1 Family of the Sick Child

The management of sick children should revolve around the sick child and their family. The family in the Ghanaian context is the parents, child, siblings, and significant others. The clinicians should build partnerships with families in the healthcare setting through respectful, effective communications, family acceptance, and ensuring privacy irrespective of their socio-economic backgrounds. This will stimulate their full involvement and participations in the care processes for early discharge and continuity of care at home and the community.

6.8.2 Clinicians in ICU

These are the nurses, midwives, doctors, social welfare, and all specialists, including psychologists and allied health professionals, who play diverse significant roles in the management of critically ill children at the ICUs. The researcher considers the clinicians as the second key pillar in the trilogic partnership of the patient engagement model. The clinicians should work hand in hand with the families whilst recognising them as experts in the management of their children in the healthcare settings. Thus, the family and the sick child should be the fulcrum of care rendered by the clinicians. This will pave the way for the clinicians to manage the physical, mental, and social aspects of their illness holistically, as recommended by the WHO, to restore family health and promote speedy recovery.

6.8.3 Health Managers

The managers are the third pillar of the model. Manager in this context refers to persons who are responsible for and manage the resources for the provision of health services and include, but are not limited to, the heads of facilities, heads of departments, unit heads, Ministry of Health, Ghana Health Services, private, quasi-government, and religious faith facility managers. For instance, the managers should ensure the design of a spacious ICU to allow full family participation. Managers should also provide the needed logistics and specialised personnel to promote the quality delivery of child health services. There is the need for managers to conduct regular clinical satisfaction surveys with clinicians and families to identify and address the barriers of care for holistic and quality satisfactory health services. The engagement of the managers will facilitate the acceptance and implementation of the NICU/PICU FCC model.

6.8.4 NICU/PICU Environment

Finally, the Ghanaian FCC model posits that all these concepts can be operationalised in an ideal NICU/PICU environment. From this context, the participants described an ideal ICU environment to include subunits/cubicles including KC rooms, counselling rooms, ICU information desk, an in-house pharmacy and laboratory, mini store and more importantly, family areas with comfortable furniture and amenities to serve as family comfort zones (**see Figure 6.2**).

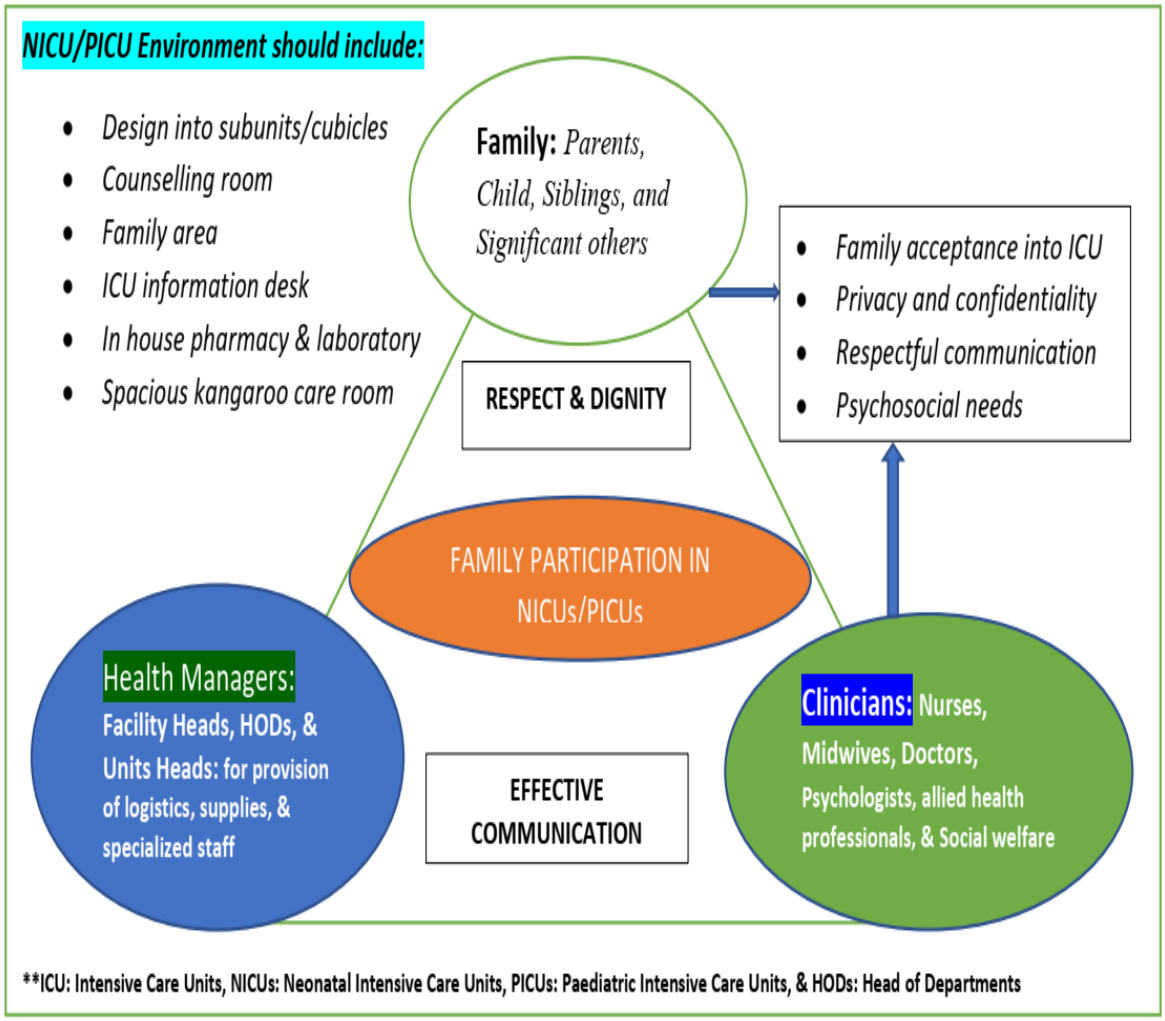


Figure 6.2 Family-Centered Care model for Neonatal and Paediatric ICUs

Table 6.9 Synopsis of the key Conceptual Principles of the FCC Model for NICU/PICUs

No.	Key principles of FCC Model for NICU/PICUs	Focal Person(s)
1	Ensure family acceptance through respectful communication, building family socialisation, and involvement in decision-making	Clinicians & Managers
2	Ensure privacy and confidentiality of children and their families through nursing sick children in separate cubicles and obtaining informed consent	Clinicians & Managers
3	Build a triangle of partnership involving Families-Clinicians-Managers (FCM) approach to implement FCC and motivate clinicians to assist family's transit into home care using Community Health Nurses and social welfare	Clinicians, Families & Managers
4	Provide family friendly and inclusive NICU/PICU design including enough ICU space in subunits, Kangaroo care rooms, and family areas	Managers & Government
5	Provide psychological support for families and clinicians through clinical psychologists at the ICUs in a secured counselling room to reduce anxiety	Clinicians & Managers
6	Provide ICUs with an information desk for effective communication with families and orientation to build initial rapport and socialisation	Managers & clinicians
7	Ensure continuous education of families in the ICUs to regularly update them on the care processes and build collaborative partnerships	Clinicians & Managers
8	Set up National Child Health Fund to provide financial support for families and provide adequate logistics, specialised training, and research	Government & Managers
9	Strengthen the Institutional Social Welfare Departments to handle the Abandoned Babies Syndrome and other psychosocial concerns of care	Clinicians, Managers & Government
10	Promote family visitations via 7-Schedule Family Visits Approach in 24 hours: minimum of four visits for mothers (3-hour interval), two visits for fathers (8-hours apart), and one visit for significant others to promote participation, bonding, and early discharge	Clinicians, Families & Managers

Key: Clinicians refers to Healthcare Professionals in the ICU; Managers refers to Head of facility, Department Head, Unit Head, and Ministry of Health

6.9 RELATIONSHIP BETWEEN THE FCC CONCEPTS AND THAT OF THE NICU/PICUs FCC MODEL

The researcher used a multiphase mixed methods triangulation design to develop the NICU/PICUs FCC model. The four main thematic characteristics of the model are family of a sick child, clinicians in ICU, health managers, and the design of NICU/PICU environment. These themes of the model are in the four key concepts of FCC, as identified in the scoping review.

T**able 6.9** presents a synopsis of the model key conceptual principles that emerged from the Ghanaian context. The following sections detail the descriptions of these key concepts, the main themes, and their applications in the earlier FCC concepts of respect/dignity, communication, partnerships, and collaboration.

6.9.1 Respect and Dignity

In the sociocultural context of Ghana, both families and clinicians described respectful and dignified care as care that addresses the *psychosocial needs* of families at the Intensive Care Unit, including meeting their emotional needs, respecting their religion, involving them in the care, provision of *family space/area* and accommodation, and *funding support* (**see Figure 6.2** and **Table 6.9**).

Additionally, families can better participate in the care of their sick children as experts' when clinicians and managers ensure their privacy and confidentiality and accept them irrespective of their religious and sociocultural backgrounds. This may enhance *family satisfaction* and quality healthcare. There has to be conscious efforts made to set up counselling units in the ICUs with clinical psychologists, nurses, and doctors as part of each counselling session to provide adequate information for families to address their psychosocial and pathological concerns of their children's illness and care processes. There could be scheduling of seven visitations for family into the ICUs to meet families halfway and reduce family frustrations. Handing over of patients to Community Health Nurses from the NICU/PICU should be encouraged to help family's transit from ICU phase of care into home and community care. This would promote immunisations, health education, rehabilitations, and follow-ups of children discharged from the ICUs. These activities would complement and sustain the gains

made during the ICUs phase of care and promote full recovery of the sick child even after discharge.

6.9.2 Triangle of Experts' Partnerships/Participation

Building partnerships with families is another key concept of FCC that would promote full family participation. The researcher posits that the integration and implementation of FCC requires a *Triangle of Families-Clinicians-Managers (*FCM) approach (**see Figure 6.2**).

The FCM approach demands healthcare professionals and managers to see families as experts in the provision of care to sick children in an ideal design of NICU/PICU environment. It further encouraged professionals to have a *multidisciplinary approach* to the implementation of FCC by involving *specialists* in the care of sick children in the Intensive Care Unit, including psychologists, social welfare, paediatricians, nurses, midwives, neonatal intensive care nurses, and paediatric nurses, as well as families. This would promote a holistic approach to addressing the needs and health problems of a sick child and their families for a best outcome and *quality care.* By adopting the *FCM approach, the healthcare professionals can assist families to plan and transit from ICU phase of care into home and community care using social welfare, and community health nurses to conduct follow-ups. There should be consideration of seven-scheduled visits (SSV) at the ICUs to build partnerships and participation between families, clinicians, and managers.* Thus, mothers should have at least four scheduled visits (3-hour interval), two scheduled visits (8-hours apart) for fathers, and one scheduled visit for a designated (approved) significant other member of a family. These scheduled visitations would pave the way for optimum family involvement and participation in the decision making and care processes in the ICUs to foster family satisfaction, bonding, early discharged, continuity of care, and quality service delivery.

6.9.3 Respectful and Effective Communication

Information sharing regarding the *care processes and explaining the condition* of child to families is vital in the implementation and integration of FCC at the NICU/PICU (**see Figure 6.2**).

This is achievable by having *respectful communication* and education with families' right from the day of admission (*building initial socialisation*), holding *regular counselling sessions,* and having an *information desk* in the ICUs environment for families. Respectful communication will foster partnerships between families, clinicians, and the managers at the NICU/PICU, which can promote the best outcomes of service delivery, including early discharge and quality childcare at the ICUs. New families could have *schooling* on proper childcare, especially feeding and temperature control of sick neonates, via the education and counselling sessions in the proposed counselling rooms for *continuity of care at home.*

6.9.4 Broad Conceptual Collaborations

Previous models on FCC either focused on preterm babies, such as the POPPY model (Staniszewska *et al.*, 2012), or need's assessment of families in the intensive care, such as the Calgary Family Assessment model (Zimansky *et al.*, 2020). Most studies of FCC focus on family involvement at the neglect of family outcomes and satisfaction (Smith, 2018). The researcher utilised *several theories* and models including the FST, CGT, and the six steps model development processes in intervention studies to develop this broad conceptual model. There was *triangulation of data* from participants in two tertiary NICU/PICUs to develop this model with the view of approaching and resolving the *barriers of FCC* implementation at the ICUs, irrespective of the child's condition. The uniqueness of this NICU/PICU FCC model in part, is the fact it has derived data and sought inputs from all *stakeholders* in the care of sick children, including clinicians (nurses, doctors, and midwives), health managers, nursing consultants, ICU consultants, paediatric consultants, and families so as to give it strong validity and reliability.

The model recommends the strengthening of institutional social welfare departments by health managers and government to address the psychosocial concerns, such as funding gaps in childcare. For instance, there should be more attention given to the barriers of *abandoned babies' menace* in the ICUs, especially NICUs in the study context. Some of the identified undercurrents of the abandoned babies included teenage motherhood, religious-socio-cultural factors, congenital anomaly and physical disability, and lack of funding. Governments could set up a *National Child Health Fund* via legislation to take the financial burden off families with sick children and reduce the abandoned baby syndrome, especially in the ICUs.

Furthermore, health managers and government could take concrete steps to provide adequate spaces in future designs of the ICUs, especially NICUs and PICUs, for clinical work as well as family comfort zones for effective participation. For instance, adequate funding support could assist in the design and develop the NICUs in particular to have subunits for special cases, such as preterm, asphyxia, and congenital abnormalities, and create family areas with optimum amenities. More efforts are necessary to re-integrate the concepts of family health nursing into the training of health professionals, especially nurses and doctors, at all levels. The anticipation is that the integration of this FCC model will not only address the family needs and improve quality health outcomes at the Neonatal and Paediatric ICUs, but may also become useful in adult healthcare settings.

6.10 SUMMARY

This chapter presented the results of the Delphi study, its discussions, and the subsequent development of the NICU/PICU FCC model. Overall, 24 experts in neonatal, paediatrics, intensive care and nursing research helped to build the consensus of the concepts of FCC that emanated from the quantitative findings in a two-round Delphi study. The experts identified respect and dignity, effective communication, and participation as the most important concepts of FCC. The use of the agreed concepts and their defining characteristics, as ranked and prioritised by the experts, conceptually developed the FCC model. The researcher presented a synopsis of the main findings from the qualitative, quantitative and Delphi studies deemed relevant for the conceptualisation of the model. These main findings then conceptually developed the NICU/PICU FCC model. The presentation of the detailed description of the context specific model was in the form of a model diagram supported by its 10 FCC key underlying concepts for easy implementation in the ICUs. A five-stage iterative research processes, including the Scoping literature review, Qualitative (constructivism), Quantitative study, Modified Delphi study, and Evaluation was the initial design to develop the NICU/PICUs FCC model in the Ghanaian context. Therefore, Chapter Seven focuses on the evaluation of the model to complete the model development processes as planned.

CHAPTER SEVEN

PHASE THREE: EVALUATION OF THE NICU/PICUs FCC MODEL

7.1 INTRODUCTION

The third and final phase of this thesis was to evaluate the validity and reliability of the NICU/PICU FCC model. This chapter therefore presents the findings of the model evaluation. The final model was sent to families, clinicians, and managers for their evaluation employing methodological design approach (Bernal, Cummins and Gasparrini, 2017; Minary *et al.*, 2019; Gaglio *et al.*, 2020). The content validity index and reliability (Cronbach's alpha) (Gaglio *et al.*, 2020) of the model were estimated and presented in this chapter, as was the discussion of the findings.

7.2.1 EVALUATION OF THE NICU/PICUs FCC MODEL

The researcher used the 10 key contextual principles of FCC developed from the earlier phases and the model diagram to conduct the model evaluation via a methodological design. The development of an electronic questionnaire was by using the 10 key concepts of FCC and the model diagram attached for the evaluation. The end users of the model, i.e., clinicians, health managers, family, and health policy, were tasked to rate the model based on a five-point Likert scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree).

The questionnaire was delivered to the evaluation team via Redcap (Project Redcap, 2018). They had to rate and comment on each of the concepts and the general presentation of the model. Subsequently, there was a presentation of the face validity, percentage agreement, content validity index, Cronbach's alpha, Inter-Class Correlation, and word clouds of the experts' comments (**Figure 7.1**).

7.2.1 Relevant Demographic Backgrounds of Experts

Table 7.1 Relevant demographics of experts sampled for model evaluation.

Qualification	Experience (Years)	Position	Institution	Expert Category
Diploma	10	Senior staff Midwife	Grater Accra Regional Hospital (Ridge)	Nursing expert
Certificate	10	Principal Enrolled Nurse	Ghana Health Services/Nursing, Kumbungu Tolon District	Family member
Degree	20	Assistant Director 1	Ghana Education Service (GES)	Family member
Degree	15	Midwifery officer	Tema General Hospital	Nursing expert
Degree	9	Nurse specialist	TTH, child health/paediatric	Nursing expert
Degree	23	Nurse specialist	Tamale Teaching Hospital, NICU	Nursing expert
Degree	26	DDNS	KBTH NICU	Health Manager (Director)
Degree	7	Nursing officer	Maamobi	Family member
Master's	7	IT officer	Nursing and Midwifery Council	Family member
Master's	14	Deputy Director	Northern Regional Health Directorate	Policy expert
Bachelor's Degree	16	Specialist	KBTH NICU	Medical Expert (Paediatrician)
Master's	22	PNO	TTH / Pediatric	Health Manager
Certificate	10	Principal	Kaneshie Polyclinic RCH	Family member
Degree	20	DDNS	Korlebu _PICU	Health Manager (Director)
Degree	12	Principal CHN	Ghana Health Service	Family member
Master's	12	Programme Coordinator	Nursing and Midwifery Council of Ghana	Nursing Expert (Policy level)

Table 7.1 Relevant demographics of experts sampled for model evaluation (continued)

Qualification	Experience (Years)	Position	Institution	Expert Category
Degree	7	Nursing Officer	University of Ghana Hospital	Family member
Master's	15	Consultant	Korle Bu, Department of Child Health	Health Manager (Paediatrician)
Doctorate	7	Consultant	South Africa	Nursing & Policy expert
Master's	7	Senior Health Tutor	College of Nursing and Midwifery, Nalerigu	Nursing Expert (Education & Research)
Degree	14	Snr PA.	TTH/paediatric depart	Medical Expert
Diploma	10	Senior staff Midwife	Greater Accra Regional Hospital	Nursing expert
Master's	15	Technical Advisor	World Health Organization	Policy expert
Master's	11	Lecturer	University for Development Studies, Tamale, Ghana	Nursing Expert (Education & Research)
Master's	14	Principal Operations Officer	Nursing and Midwifery Council of Ghana	Nursing Expert (Policy level)

According to **Table 7.1**, there was heterogeneous sampling of the experts recruited in the model evaluation, from family (7), clinicians (7), health managers (4), research and model evaluators (3), and health policy (4). The researcher employed purposive and snowball sampling techniques to recruit the 25 experts with primary inclusion criteria of more than 5 years working experiences in nursing, medicine, health management, and health policy. The expert's evaluators had working experience ranging from 7-26 years. Families who participated in the evaluation were educated and had their children admitted in the Intensive Care Units in Ghana. The clinicians comprised five nurses and

two doctors, one paediatrician, and one medical doctor, all currently stationed at the NICU/PICU. The health managers included in the evaluation were one Head of Department of Child Health, and three Heads of Nursing NICU and PICU at the two study settings.

Again, the researcher recruited experienced nursing researchers who were into model and framework development and evaluation, one of whom was an external expert from South Africa. Finally, the researcher also included four policy experts, two of whom were nursing experts at national level at the Ministry of Health (MOH), a regional director of health services, Ghana Health Services (GHS), and one external policy expert at the World Health Organization (WHO). Overall, nurses and midwives in clinical, management, health research, and policy portfolios constituted the majority (14; 56%) of the experts in the evaluation, the rest were medical practitioners, consultants, and policy experts (4;16%), and the family accounted for 7 (28%) of the experts. **Table 7.1** presents the details**.**

7.3 FACE VALIDITY OF THE MODEL

The experts had to comment on the wording of the concepts and the diagram of the model. The experts described the model as *clear*, *sound*, *well thought and conceptualised, and practicable* as it reflects the *contextual practices* of FCC. Families in particular were excited to see the issues of visitations and counselling directly highlighted in the key concepts of the model. The extracts comments below codify experts' statements of face validity:

> *"The concept is clear and straightforward. And it is highly acceptable, and we are anticipating its quick implementation in the country (Clinician- Neonatal Nurse Specialist)"; "The framework is user friendly and very relevant (Nursing expert, Health Research & Nursing education)"; "The diagram comprehensively conceptualises the components of FCC model (Clinician, medical expert)"; "This model is well thought of… (Nursing expert, South Africa)"; "The conceptual model is sound and practicable (Expert in Health Policy, WHO-Africa)"; & "I think the concept is generally good. This is because it gives room for families to visit their loved children at the hospital. Moreover, providing facilities for counselling sessions will also aid families to spend quality time together with their children (Family, Parent of critically ill in ICU)."*

However, one of the experts (health manager and paediatrician) called for the modification of the frequency of visits in the PICU. He maintained that the proposed seven scheduled

family visitations approach in the NICU was practicable but disagreed with the same for the PICU. Another two experts also recommended the removal of the setting up of the Child Health Fund, whilst one of the experts (Nursing expert in health education) commented that the funding aspect is outside the scope of FCC even though a relevant suggestion, and the other expert (Health policy, WHO-Africa) argued that fragmentation of health financing is unsustainable. The overall agreement on these items among all experts was high, hence the retaining in the model. The extracts below illuminate their recommendations:

> *"Family visitation in the PICU cannot be that frequent but in the NICU the mother may need to visit that often because they will have to breastfeed… (Health Manager, Consultant Paediatrician)"*
> *"… I may be wrong, but I think point 19 (Setup National Child Health Fund) is outside the scope of the model and does not fit well into family-centered care in a NICU/PICU. Though, the idea is an excellent one (Nursing expert, Health Research & Nursing education)," and "… I only have a concern about setting up a separate earmarked funding for child health. The same argument has been made for all disease areas and programmes. From a health financing perspective, this has shown to be unsustainable for any country to set up parallel funding mechanisms for specific programmes and/or diseases. A comprehensive health financing strategy that adequately address all diseases and programmes is always recommended (Expert in Health Policy, WHO-Africa)."*

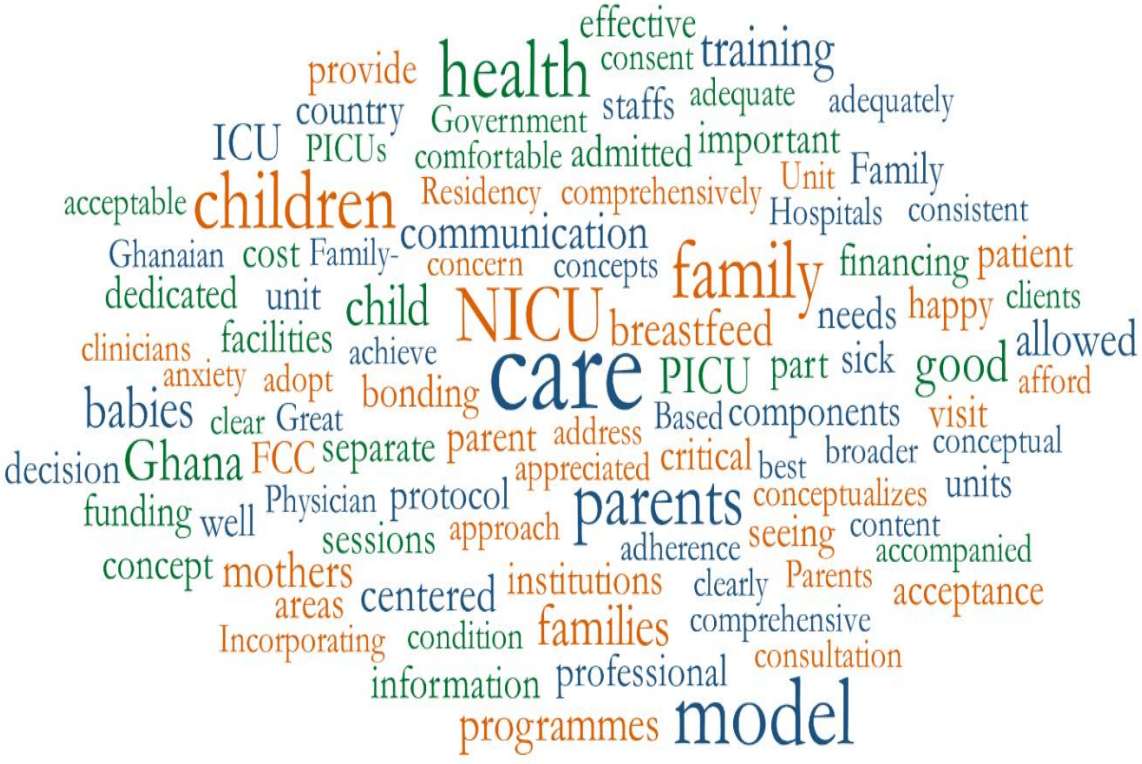


Figure 7.1 Word cloud of evaluation comments from experts.

7.4 DESCRIPTIVE STATISTICS OF THE MODEL

Table 7.2 Descriptive statistics of the model evaluation (n=25)

No.	**The 10 Key principles of the NICU/PICUs FCC Model** Cronbach's alpha=0.95 KMO=0.75	Expert Ratings					Descriptive				
		1	2	3	4	5	Mean	Min (Q1)	Median (Q2)	Max (Q3)	IQR (Q3-Q1)
1	Family acceptance	1	0	0	6	18	4.64	4.50	5.00	5.00	0.50
2	Privacy	1	0	2	12	10	4.16	4.00	4.00	5.00	1.00
3	Building trilogic Partnerships	0	0	1	10	14	4.52	4.00	5.00	5.00	1.00
4	Spacious ICU design in subunits	1	0	0	8	16	4.52	4.00	5.00	5.00	1.00
5	Psychosocial support	1	0	1	8	15	4.48	4.00	5.00	5.00	1.00
6	ICU Information desk	1	0	0	8	16	4.56	4.00	5.00	5.00	1.00
7	Constant Information sharing and education	1	0	2	8	14	4.4	4.00	5.00	5.00	1.00
8	NCH Fund	1	2	0	8	14	4.32	4.00	5.00	5.00	1.00
9	Strengthen Social Welfare	1	0	1	6	17	4.52	4.00	5.00	5.00	1.00
10	Seven Scheduled Family Visitations	1	1	0	12	11	4.24	4.00	4.00	5.00	1.00

Ratings: I=Strongly disagree, 2=Disagree, 3=Neutral, 4=Agree, & 5=Strongly agree, KMO= Kaiser-Meyer-Olkin Measure of Sampling Adequacy.

Table 7.2 shows the descriptive statistics of the evaluation instrument including Cronbach's alpha, Meyer-Olkin Measure of Sampling Adequacy, median, and Inter-quartile range of the experts' ratings. The Cronbach's alpha is 0.95 and KMO=0.75 reflects excellent internal consistency and good sampling adequacy respectively of the experts' evaluation of the model. T**able 7.2** displays further details the descriptive statistics including mean, median, and IQR scores.

7.5 PERCENTAGE OF AGREEMENT AMONG THE EXPERTS

Percentage of agreement is one of the easiest ways of eliciting expert judgement on a scale or model. The researcher used Excel to compute the percent agreement of each item among the 25 experts. Excel pivot tables counted responses from the experts for each of the five-point Likert scale. The agreement for each item among experts was defined as the score of 4 and 5 on the scale (Zamanzadeh *et al.*, 2015). Therefore, the number of agreements was a sum of 4 and 5 on each item. The estimation of the percentage agreement was the score for agreement divided by the number of experts in the evaluation. Usually, percentage score of ≥80% is considered excellent (Keeney, Hasson and Mckenna, 2010; Kleynen *et al.*, 2014; Chalmers and Armour, 2019).

Table 7.3 Estimation of percentages of agreement of the model among the experts (n=25)

Item's description	**Strongly disagree (1)**	**Disagree (2)**	**Neutral (3)**	**Agree (4)**	**Strongly agree (5)**	**Experts item agreement (Sum 4+5)-I^a**	**Item proportionate agreement (P_a)**	**% of expert agreement/item (E^a)**
Family acceptance	1	0	0	6	18	24	0.56	96
Privacy	1	0	2	12	10	22	0.37	88
Partnerships	0	0	1	10	14	24	0.45	96
Spacious ICU design	1	0	0	8	16	24	0.49	96
Psychosocial support	1	0	1	8	15	23	0.44	92
ICU Information desk	1	0	0	8	16	24	0.49	96
Information sharing	1	0	2	8	14	22	0.40	88
NCH Fund	1	2	0	8	14	22	0.40	88
Strengthen Social Welfare	1	0	1	6	17	23	0.50	92
Seven Scheduled Family Visitations	1	1	0	12	11	23	0.40	92
Total	9	3	7	86	145			
Proportionate agreement of Category (PAC)	0.04	0.012	0.028	0.344	0.58			
Overall Expert Agreement for model (EAM)							0.92	92.4

P_a = (item proportionate agreement by experts) = (∑square of categories)-N/N-1; where N=Number of Experts (Arat *et al.*, 2016)

E^a= (item Percentage per expert) = Number of agreement (I^a)/Number of experts by 100

PAC= Total agreement per category/ (Number of items by Number of Experts)

EAM= Average of item proportionate agreement or Percentage of item agreement

From **Table 7.3**, the percentage score of all items ranged from *88% to 96%,* and that of the model is *92.4%,* indicating an excellent rating by the experts. Thus, the experts agreed with the model and its 10 key concepts presented to them.

7.6 CONTENT VALIDITY OF THE MODEL

This measures the accuracy of the model from the expert's perspectives. Experts received the model diagram and the key concepts, as well as a detailed information sheet and background of the FCC study at the ICU that led to the birth of the new model. This was necessary to inform them about the backdrops and provide adequate understanding of the contextual relevance of FCC in ICU practice. The experts had to study the model diagram and the key concepts that underpinned the model and then rate their level of agreement using the 5-point Likert rubrics delivered via Redcap. The downloading of the results was onto an Excel spreadsheet, and cleaning took place for analysis. Content validity index is used to measure the internal accuracy of the ratings among the experts in a scale or model evaluation (Polit and Beck, 2006; Zamanzadeh *et al.*, 2015; Arat *et al.*, 2016; Arora *et al.*, 2019; Yusoff, 2019; Han, 2020; Irawan and Wilujeng, 2020). Lynn (1986) and Polit and Beck (2006) reported there are three forms of content validity index, namely, Item content validity index (I-CVI), Average Scale content validity index (S-CVI/Ave), and Universal content validity index for scale (S-CVI/UA).

The researcher employed quantitative estimation of content validity to evaluate the accuracy of the model in measuring FCC in the Ghanaian context. Firstly, the number of agreements (i.e., 4 and 5 score) for each item were estimated from their corresponding item agreement among all 25 experts. The second part of the validity was estimation of the content validity index (CVI), performed in three folds, i.e., Individual content validity index (I-CVI), Average scale/model content validity index (S-CVI/Ave) and Universal content validity index of Scale (S-CVI/UA). I-CVI is the proportion of experts giving an item ratings of 4 or 5, S-CVI/Ave is the summation of item content validity index provided by the experts for all the concept items in the model, and S-CVI/UA is the proportion of items in the model that achieved an important rating of 4 and 5 (Polit and Beck, 2006; Arat *et al.*, 2016; Yusoff, 2019).

Table 7.4 Content validity estimates of the NICU/PICUs FCC Model (N=25)

Item Description	Agree (4)	Strongly agree (5)	Number of agreements	Item-Content Validity Index (I-CVI[a])	Evaluation Remarks (E_r)
Family acceptance into ICUs	6	18	24	0.96	Excellent
Privacy & confidentiality	12	10	22	0.88	Excellent
Partnerships	10	14	24	0.96	Excellent
Spacious ICU design in Subunits	8	16	24	0.96	Excellent
Psychosocial support	8	15	23	0.92	Excellent
ICU Information desk	8	16	24	0.96	Excellent
Information sharing(education)	8	14	22	0.88	Excellent
NCF Fund	8	14	22	0.88	Excellent
Strengthen Social Welfare	6	17	23	0.92	Excellent
Seven Scheduled Family Visitations	12	11	23	0.92	Excellent
Average Model Content Validity Index (AVE-S-CVI[b])				**0.92**	**Excellent**
Total agreement among experts (T[a])				**4**	**Good**
Universal agreement among experts(S-CVI/UA[c])				**0.4**	**Good**

I-CVI[a]= Item Content Validity Index = Number of agreement (∑ (4 n 5))/N; Where N= Number of Experts (Yusoff, 2019)
AVE-S-CVI[b]= Average Scale/Model Content Validity= ∑ (I-CVI); ∑=average, I-CVI= Item Content Validity Index (Yusoff, 2019)
T[a]= Total agreement among experts= ∑ (similar agreements among experts) (Yusoff, 2019)
S-CVI/UA[c]= Scale Universal agreement= ∑ (similar agreements among experts)/Number of items in scale; UA≥0.4=Good (Polit and Beck, 2006)

Er=Evaluation remarks = Lynn (1986) and Polit and Beck, 2006, >9 experts with I-CVI>0.78= Excellent

The detailed results and the formulas for estimating all types of content validity index appear in the footnote of **Table 7.4**. Statistically, a score of CVI ≥0.78 for at least nine experts in the evaluation of a model or scale is interpreted as excellent (Polit and Beck, 2006; Arat *et al.*, 2016; Arora *et al.*, 2019; Liljequist, Elfving and Roaldsen, 2019; Han, 2020). In this current model evaluation, the I-CVI scores was 0.88-0.96, and S-CVI/Ave score was 0.924; indicating excellent validity rating of the model by the experts, even though the S-CVI/UA was 0.4, with only four total agreements among the experts. Refer to **Table 7.4** for the details.

7.7 RELIABILITY OF THE MODEL

Internal reliability estimates and descriptive statistics of the model were calculated and presented in **Table 7.5**. Thus, the researcher estimated the internal consistency among the expert's agreements for the items constructs of the model and the overall model. In addition, the estimation of the inter-rater reliability of the model was by calculating the item statistics and intra-class correlation coefficient (ICC) of the model.

Table 7.5 Descriptive and Reliability statistics of the FCC Model for NICU/PICUs

Item-Total Statistics & Reliability Statistics								Experts' Evaluation Remarks
Item description	Mean Ratings	Standard Deviation	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted	
Family acceptance	4.60	0.87	39.6	46.58	0.85	0.91	0.94	Excellent
Privacy	4.20	0.91	40.00	46.25	0.83	0.78	0.95	Excellent
Partnerships	4.52	0.59	39.68	51.39	0.68	0.71	0.95	Excellent
Spacious ICU design	4.52	0.87	39.68	46.14	0.89	0.89	0.94	Excellent
Psychosocial support	4.44	0.92	39.76	45.44	0.90	0.86	0.94	Excellent
ICU Information desk	4.52	0.87	39.68	46.14	0.89	0.91	0.94	Excellent
Information sharing	4.36	0.95	39.84	45.72	0.84	0.88	0.95	Excellent
NCF Fund	4.28	1.10	39.92	47.16	0.60	0.84	0.96	Excellent
Strengthen Social Welfare	4.52	0.92	39.68	46.39	0.81	0.86	0.95	Excellent
Seven Scheduled Family Visitations	4.24	0.97	39.96	46.29	0.77	0.87	0.95	Excellent
Cronbach's Alpha of model							0.95	Excellent
Cronbach's Alpha on Standardized items							0.96	Excellent

7.7.1 Item statistics and Cronbach's Alpha of the NICU/PICU FCC Model

From **Table 7.5**, the Cronbach's alpha for the model was 0.95 and that of the standardised items was 0.96, indicating a high degree of internal consistency among the items in the model. The means of the individual items ranged from 4.20 to 4.60, with a mean on the total model 44.20 ±7.58, and 57.42 variance. Generally, the expert's responses on the model showed an excellent reliability of the model of FCC for NICU/PICU developed for the Ghanaian context. **Table 7.5** presents the details of the means, standard deviations, and the various forms of Cronbach's alphas of the model.

7.7.2 Intra-Class Correlation Coefficient (ICC) of the NICU/PICU FCC Model

The researcher performed ICC to assess the test-retest and inter-rater reliability of the model (Bobak, Barr and O'Malley, 2018; Liljequist, Elfving and Roaldsen, 2019). Statistically, ICC is based on the theory of analysis of variance (ANOVA) and is a known statistical method for assessing the correlation within a particular dataset, especially in a model or scale evaluation (Kintner and Sikorskii, 2008; Tiku and Pecht, 2009; Ghazali, 2016; Roaldsen *et al.*, 2016; Bobak, Barr and O'Malley, 2018; Bohman *et al.*, 2018; Liljequist, Elfving and Roaldsen, 2019; Randrianarivony, Ravelomanantsoa and Razanamihaja, 2020). By employing ICC, the researcher was able to isolate any systematic differences between and among the expert's agreements during the model evaluation to judge the test-retest and inter-rater reliability (Roaldsen *et al.*, 2016; Bobak, Barr and O'Malley, 2018; Bohman *et al.*, 2018; Liljequist, Elfving and Roaldsen, 2019).

The researcher used SPSS version 20 to conduct the ICC analysis of the model. There are three types of models in SPSS used to assess ICC of scales or models to accomplish error variances, One-Way-Random, Two-Way Random, and Two-Way Mixed (Koo and Li, 2016). In the One-Way-Random model, the random effect of agreement is either on the experts or the subject, in the Two-Way Random model the subjects and the experts are randomly chosen from a population with similar characteristics so the effect can be from any of them, and in Two-Way Mixed model, the experts are fixed, and the subjects are chosen randomly (Koo and Li, 2016). In this evaluation, the Two-Way Random effect model was used because the experts with at least 7 years working experience were randomly selected

to be able to generalise the reliability of the new FCC model for clinical practice (Field, 1995; Gupta, 2002; García, Seco and Pol, 2013; Koo and Li, 2016; Yockey, 2016).

There two types of analysis in performing ICC based on a chosen model: consistency analysis and absolute agreement analysis. The consistency analysis type (similar to Pearson Correlation) is only capable of establishing a linear relationship among the expert's agreements during the evaluation. In this current model evaluation, the researcher used the absolute agreement analysis type to establish the consistency of agreement among all the experts in the FCC model evaluation to offer enough grounds for generalisation of the model (Field, 1995; Gupta, 2002; Koo and Li, 2016; Yockey, 2016). The reference range of ICC for interpretation is between 0 and 1, with an ICC value ≥ 0.75 = good model; ICC ≥ 0.91= excellent model, and ICC=1 means a perfect model (Bobak, Barr and O'Malley, 2018; Bohman *et al.*, 2018; Liljequist, Elfving and Roaldsen, 2019; Randrianarivony, Ravelomanantsoa and Razanamihaja, 2020).

Table 7.6: Intra-class Correlation Coefficient

Types of ICC	Intra-class Correlation[b]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.661[a]	0.525	0.798	21.135	24	216	.000
Average Measures	0.951	0.917	0.975	21.135	24	216	.000

Two-way random effects model where both people effects and measures effects are random

a. The estimator is the same, whether the interaction effect is present or not

b. Type A intra-class correlation coefficients using an absolute agreement definition

There was ICC analysis calculated for each single item in the model as well as the average measure of the model from the experts. In this current model evaluation, there was an excellent degree of reliability found amongst the 25 experts in the 10-item measurement of the FCC key concepts. The average measure of ICC was 0.951 with a 95% confidence interval from 0.917 to 0.975 and the F-test at {(24, 216) =21.135), p<.001}. **Table 7.6** presents the details.

7.8 DISCUSSION OF THE EVALUATION FINDINGS

The concluding part of this pragmatic multi-phased thesis set out to conduct a preliminary evaluation of the new FCC model for NICUs and PICUs through a methodological design to estimate the validity and reliability of the model. Experts purposely sampled from clinical, management, policy, and family, evaluated the model. A heterogeneous group of experts with at least 7 years working experience participated in the model evaluation, which perhaps contributed to the high validity and reliability exhibited by the new model (Ahmad and Yew, 2019; Allen *et al.*, 2019; Fink *et al.*, 2019; Gossler *et al.*, 2019; Shi *et al.*, 2020). The experts described the model as *clear, sound, well thought and conceptualised and practicable* as it reflects the *contextual practices* of FCC. Arat *et al.* (2016) reported a good judgement of face validity in the preliminary evaluation of their illness perception questionnaire for healthcare professionals in Belgium. Conceivably, the direct representation of the actual practices of FCC that emerged mainly from the constructivist qualitative stage of the study, together with the succinct presentation of the model, accounted for the finding. This gives some high sense of accuracy or validity to the model developed and echoes the need to integrate the model into ICU practices.

Moreover, the total score achieved for all items ranged from *88% to 96%* and *92.9%* for the model, thus indicating an excellent rating by the experts. Thus, the experts agreed with the model and the 10 key concepts presented to them. Similarly, there has been a high percentage of agreement among experts' tool and model evaluations reported by some health science researchers (Kleynen *et al.*, 2014; Burton *et al.*, 2015; Arat *et al.*, 2016; Chalmers and Armour, 2019; Randrianarivony, Ravelomanantsoa and Razanamihaja, 2020). These findings may be attributable to the careful selection of experts with similar nursing and intensive care practice levels. The researcher also provided enough background on the study through an information sheet to the experts, who had a week to study the content and diagram of the model together with its key concepts before submitting their ratings. These findings may signify a maximum likelihood of accepting and integrating the new model into clinical practice since the experts were heterogeneous from medicine, nursing, health management, and policy.

Additionally, there was an examination of the content validity of the model, which revealed excellent validity of model. In this evaluation, the I-CVI scores were 0.88-0.96, and S-

CVI/Ave score was 0.924, indicating an excellent validity rating of the model by the experts, even though the S-CVI/UA was 0.4 with only four total agreements among the experts (**Table 7.4**). Similarly, the new model exhibited a high degree of internal consistency (Cronbach's alpha of 0.953) with an excellent mean item score of 4.20. (**Table 7.5**) (Polit and Beck, 2006; Zamanzadeh *et al.*, 2015; Arat *et al.*, 2016; Arora *et al.*, 2019; Liljequist, Elfving and Roaldsen, 2019; Han, 2020). Finally, a Two-Way-Random effect model with absolute agreement at 95% estimation of ICC conducted with SPSS version 20 equally resulted in excellent reliability of the model. The average measure of ICC was 0.951 with a 95% confidence interval from 0.917 to 0.975 and the F-test at {(24, 216) =21.135), p<.001} (**Table 7.6**) (Kintner and Sikorskii, 2008; Kvist and Persson, 2009; Arat *et al.*, 2016; Koo and Li, 2016; Roaldsen *et al.*, 2016; Wind *et al.*, 2016; Bobak, Barr and O'Malley, 2018; Bohman *et al.*, 2018; Arora *et al.*, 2019; Han, 2019).

Perhaps, using a mixed method design to arrive at the model and its key concepts may have also contributed to these almost perfect model presented. This further highlights the methodological benefits of using multiple methods in the development of tools and model. Such tools and models may be more accurate and reliable to meet the optimum operational generalisation of the model in clinical practice.

However, the limitation of such methodological pathways may be the inaccuracies in the efficient and proper understanding and the applications of these varied methodologies in a single research project since one cannot effectively know each of the methods. Thus, researchers at the doctoral level, especially those in health sciences, must endeavour to learn and be conversant with at least three of the methodologies deployed in their research projects to clothe their findings with sound academic rigour. Therefore, the recommendation is that doctoral students, particularly in other fields of studies, consider adopting the FCC model development processes to achieve similar, near perfect models in their research works. However, the immediate generalisation of these findings should be with some reservations since the evaluation was only a preliminary one. Future research should consider full-scale testing and evaluation of the NICU/PICU FCC model in our setting and other settings with similar characteristics to rip the full benefits of this new model.

7.9 SUMMARY

This chapter presented the validity and reliability of the model. The model has acceptable high psychometric properties, which underscores the efficiency of the mixed method design used in the model development. Chapter Eight discusses the results from all the phases of the research.

CHAPTER EIGHT

INTEGRATIVE DISCUSSION OF THE RESULTS

8.1 INTRODUCTION

This chapter presents the overall results of the study in three phases and an integrative discussion highlighting the strengths, uniqueness, and limitations of the NICU/PICU FCC model. Also highlighted, was the contributions of the study. The integrative discussions focus on the key themes and the contextual principles of the model. Thus, the integrative discussions are on the most significant findings of the study relative to the model developed. This chapter details the similarities and differences of the NICU/PICU FCC model to other models. The following three sections present the overall findings, specific contributions of the study to knowledge, integrative discussions, and conclusions of the chapter.

8.2 SUMMARY OF THE STUDY

The primary objective of this thesis was to investigate FCC in the intensive care setting, develop and evaluate a model of FCC for NICU/PICUs. This main objective gave rise to seven specific research questions answered in three phases of exploration (executed in three steps), model development and model evaluation. The researcher adopted a mixed methods triangulation design with the Family Systems Theory (FST) theoretical application to answer the various research questions. The rationale for adopting mixed methods was an attempt to cure the methodological weaknesses of each method, and more importantly, produce diverse multiple-based concretes perspectives of FCC practices from family, clinicians, and health managers in the Ghanaian ICUs.

This section presents a summary of the main findings from the scoping, qualitative, quantitative, Delphi, and evaluation studies used as the underlying principles to conceptualise the Ghanaian NICU/PICU FCC model. The purpose of this section is to drive home the evidence from the research that gave birth to this context specific model for ICU practices. The seven specific objectives of the study were to:

1. Describe the key concepts of FCC through scoping review

2. Explore family needs at the NICU/PICUs
3. Describe how family can be involved in care at the NICU/PICUs
4. Explore the barriers of FCC integration at the NICU/PICUs
5. Describe the facilitators of FCC integration at the NICU/PICUs
6. Develop an FCC model for the NICU/PICUs
7. Evaluate the validity and reliability of the NICU/PICU FCC model

The following sections present a summary of the various phases and stages of the thesis relative to the methodological processes and the triangulation of the main finding of each phase to the birth of the model.

8.2.1 Phase One: Exploration Studies

This section presents a summary of the methodological processes and the most significant findings of all the three stages of the exploration phase.

8.2.1.1 Exploration Step 1: scoping literature review

The first step of the exploration phase was to identify the key concepts of FCC practices at the NICU/PICUs through a scoping literature review. For this reason, the researcher developed a search string in consultation with a certified university librarian, scoping review researcher, and the supervising professor. The conducting of the scoping literature review was from five databases, Scopus, PubMed, CINAHL, Google scholar, and Willey Library online for published studies on FCC, from January 2015 to December 2019. The researcher followed the JBI methodology for scoping reviews. The final report conforms to the PRISMA-ScR guidelines (Peterson *et al.*, 2017). In total, there were 881 articles retrieved and systematically reduced to 52 full articles for content analysis. The 52 articles were charted into a tabular data matrix consisting of the authors, objectives/setting, methods/paradigms, and major findings; these were imported into MAXQDA version 2020 software for content analysis for the concepts of FCC to emerge.

The evidence from the content analysis identified respect/dignity (Brødsgaard *et al.*, 2017; Amorim *et al.*, 2019; Hassankhani *et al.*, 2019; www.ipfcc.org, 2021), communication (Hernández, Grillo and Lovera, 2016; Hill *et al.*, 2019c; Uhm and Kim, 2019), participation

(Benzies, 2016; Clarkson, Bc *et al.*, 2019), and collaboration (Denis-Larocque *et al.*, 2017; Van Den Berg *et al.*, 2017; Shimizu and Mori, 2018) as the four main concepts of FCC. There was adoption and implementation of these concepts across different settings based on their contextual preferences, except for Europe and the American continent, which integrated all these four concepts into ICUs. In contrast, other parts of the world contextualised their implementations. The review showed very little evidence of FCC practices at the NICU/PICU in the African context, especially in West Africa. It was also evident that most of the studies adopted more qualitative approaches to study FCC at the expense of other research methods, such as quantitative and Delphi studies involving experts, which might have given a broader contextualised meaning to FCC. Again, most of the reviewed studies were more about the perspectives of nurses and doctors with occasional engagements of families and health managers. These stakeholders, especially the health managers' participation in such studies, could pave the way for easy integration and implementation into the ICUs. These outcomes set the research agenda and motivated the researcher to broaden the scope of this current study to include clinicians, families, and health managers whilst adopting a mixed methods design to study FCC in the NICU/PICU in the Ghanaian context.

8.2.1.2 Exploration phase Step 2: a qualitative study

At the second stage of the exploration phase, the researcher set out a qualitative study to explore family needs, describe how family can be involved, explore the barriers of FCC integration, and describe the facilitators of FCC integration into the NICU/PICUs in the Ghanaian context. The CGT qualitative design was appropriate to study FCC in this context to meet these objectives. The rationale for adopting the CGT design was to offer the prospect to explore family needs, family involvement, barriers, and facilitators of FCC from the perspectives and lived experiences of families, clinicians, and health managers at the NICU/PICU, with the researcher being part of the entire process (Charmaz, 2006; De Beer and Brysiewicz, 2017; Albert, Mylopoulos and Laberge, 2019; Rieger, 2019). The researcher purposefully selected 84 participants to participate voluntarily in 24 individual interviews and 12 focus group discussions (five-members each). Each focus group was separate, and comprised five family members or clinicians and lasted for approximately 45 minutes; the individual interviews lasted at least 30 minutes. Data collection was from two tertiary teaching hospitals, NICU/PICUs, after obtaining ethical clearance from each hospital and an

additional ethical clearance from the university's Human Ethics Committee. Information sheets and consent for participation were obtained from all the participants Before data collection began, participants received information sheets and had to give consent to participate. The interviews were in a secure room in the hospitals to minimise any interference for the audiotaping.

The audio versions underwent verbatim transcription into text, with some transcripts returned to the participants to ensure the data represented their perspectives. There was also a comparison between the field notes and the transcripts to enrich the data. The researcher repeatedly read all 36 transcripts (24 individual and 12 FGDs) for immersion into the data before content analysis. There were patterns of the relevant concepts of the FST looked for in the transcripts, and manual coding conducted to develop themes and sub-themes. The supervisor also conducted some sample coding and compared them to the researcher's themes, thus developing a final codebook with code definitions, themes, and sub-themes developed. The researcher then imported all the 36 transcripts into MAXQDA version 2020 qualitative software for thorough analysis. The analysis used the lexical search, word clouds, comparison of retrieval patterns, and code/subcode models functions of the qualitative software. The researcher employed CGT analysis to conducted initial open coding, focused coding, and advanced coding for the concepts of FCC to emerge.

Contextually, FCC at the NICU/PICU is partly practice, and it refers to shared decision making and respect between the families, clinicians and managers using a multidisciplinary approach to prioritise the provision of quality and satisfactory childcare. Technically, it is impossible to provide holistic quality child healthcare, especially in the ICU without the family. The family is the primary source of strength and support for a child, and their participation will only clarify the care processes provided by the health professionals (Eichner *et al.*, 2012). The qualitative study identified contextual family needs at the ICUs, including acceptance, information (communication), privacy/confidentiality, and psychological needs. Thus, ICU clinicians and managers should strive to meet these needs of families in the NICU/PICU to maximise the provision of quality ICU services for families and their critically ill children. Families were involved in the Ghanaian NICUs and PICUs, notably during breastfeeding sessions, Kangaroo Care (KC), and running errands, such as purchasing drugs and taking samples for laboratory investigations. However, the families yearned for involvement in the care processes, including feeding, bathing, and decision-

making, which occurred sparingly as they watched helplessly. These events culminated in their anxieties, with some families observed crying and reporting insomnia.

The contextual barriers of FCC practices that emerged included lack of communication between clinicians and families, lack of space, inadequate logistics and specialised personnel, lack of finances on the part of families, and the phenomenon of abandoned babies at the NICU/PICUs. To facilitate FCC implementation, the participants illuminated the need for building collaborative partnerships among the three stakeholders, clinicians, families, and health managers at the NICU/PICUs. The participants called for strengthening social welfare and providing reliable funding sources to support needy families. Also, to train more intensive care professionals and paediatricians, build spacious family friendly NICUs and PICUs, use of available clinical psychologists, inclusion and expansion of FCC concepts into the training of doctors and nurses, and developed tailor-made FCC guidelines for NICUs and PICUs. These significant qualitative findings were theoretically sampled, as per the CGT doctrines, and used to develop a contextual quantitative FCC tool further to explore these findings with a larger sample for generalisation. The following section presents a synopsis of the quantitative study.

8.2.1.3 Exploration phase Step 3: a quantitative study

The final part of the exploration phase (Stage 3) was a descriptive quantitative study that sought to quantitatively compare, triangulate, and quantify the contextual practices of FCC, among a sample of families, clinicians (doctors, nurses, and midwives), and health managers (n = 446) at the NICU/PICUs for generalisation. The main qualitative findings, together with existing tools of FCC, SAI (www.ipfcc.org, 2021) and the CCFNI (Leske, 1992), were then used to develop quantitative tools and pilot test with 60 participants (30 for each family and clinicians) in populations of similar characteristics. The pilot testing yielded high psychometric properties for the quantitative tools: Cronbach's alpha of the family tool was 0.91, and that of the clinicians was 0.97. The researcher conveniently recruited 50 (n = 50) clinicians from Hospital K and 50 clinicians from Hospital T to answer the questionnaire using Redcap (Project Redcap, 2018) electronic data capture sheet. An estimated sample of 346 (n = 346) families who stayed more than 48 hours in the ICU were randomly recruited from the two settings. The inclusion criteria for the clinicians were ICU working experience of at least two years. There was adherence to all protocols of quantitative research to ensure

data credibility and academic rigour. Prior to analysis, there was the retrieval of the quantitative data from the Redcap and cleaning for incomplete responses. The coding and entering of the data into SPSS version 20 was for statistical analysis. Means, standard deviations, mode, minimum, maximum, histograms, and bar chart of the results were presented (refer to Chapter Five for details).

Before conducting factor analysis, there was a check of the data to determine the minimum requirements for PCA, i.e. normal distributed data and sample ≥ 300. Balasundaram (2009) stated that a sample size ≥ 300 is adequate for factor analysis. The sample size for this quantitative stage of the project was 446 (n = 446). Kaiser-Meyer-Olkin's (KMO) estimation of sampling adequacy must be greater than 0.65 for the dataset to be deemed adequate for FA (Niranjan, 2004; De Los Campos and Gianola, 2007; Balasundaram, 2009; Li *et al.*, 2020). The KMO for this study was 0.95 for family and 0.89 for clinicians' datasets. Bartlett's test of Sphericity measures the multivariate normality of distribution, and a significance value of less than 0.05 indicates the acceptability of the data for FA. The significance returned from the current data was 0.000. The data produced a Cronbach's alpha of 0.97 reliability in both datasets, albeit there was one item deleted for the family dataset because its deletion increased the Cronbach's alpha to 0.97. Usually, Cronbach's alpha > 0.78 is a reliable dataset for FA (Niranjan, 2004; De Los Campos and Gianola, 2007; Balasundaram, 2009; Li *et al.*, 2020). Afterwards, factor analysis and principal component analysis with varimax orthogonal rotations occurred to reduce the variables to explainable concepts. The researcher then used the Brian O'Connor syntax to conduct parallel analysis (Franklin *et al.*, 1995; Matsunaga, 2011; Helwig, Hong and Polk, 2012; Wood, Gnonhosou and Bowling, 2016) to finally retain only four variables that explained the contextual practices of FCC in the Ghanaian context. The outcome of Stage 3 was to produce the key contextual concepts of FCC practices at the Ghanaian NICUs and PICUs.

The quantitative study initially retained seven key concepts of FCC practices, which accounted for 63% of the total variance. A parallel analysis retained only family acceptance, privacy, psychological needs, and respectful communication. Thus, the main concepts of FCC practiced in Ghanaian NICU/PICUs were respect/dignity and effective communication through family acceptance (λ=19.79, factor score-0.81, & 95th λ=1.75), maintaining privacy/confidentiality (λ =2.24, factor score-0.83, & 95th λ=1.66), psychosocial needs (λ=1.93, factor score-0.60, & 95th λ=1.60), and respectful communication (λ =1.55, factor

score-0.729, & 95th λ=1.54). The main barriers of FCC in Ghana were lack of funding (factor score of 0.80), inadequate space and logistics (factor score-0.76), and abandoned babies (factor score of 0.78). The finding also pointed to some possible benefits of the FCC integration into NICU/PICUs, including promoting recovery and early discharge (factor score of 0.77) of sick children, promoting bonding (factor score of 0.63), reduced family anxiety (factor score of 0.65), and reduced lawsuits (factor score of 0.71) against clinicians and the facility.

There was poor practice of the other FCC concepts, i.e., communication, participation, and collaboration. In Ghana, families feel accepted when there is the addressing of their needs, such as timely information on the care and progress of treatment and psychological needs, by ICU clinicians. One priority need of a family in the ICU is psychological need, the addressing of which can be by providing enough space to ensure privacy, family acceptance, and respectful communications. Dignified care in the Ghanaian context is respectful care provided to a family employing respectful communication, acceptance, and confidentiality, regardless of their socio-cultural backgrounds. Finally, the facilitation of such FCC practices in this context can be through effective collaboration and a multidisciplinary approach, providing adequate funding, logistics, and specialised personnel. Based on the factor loadings from the orthogonal varimax PCA and parallel analysis, 21 key concepts were synthesised into a Delphi questionnaire, which set the stage for Phase 2 of the study, as presented in the next section.

8.2.2 Phase 2: Model Development

The purpose of the second phase was to develop an FCC model for the NICU/PICUs. To achieve this objective, the researcher employed a Delphi study to engage experts in intensive care, neonatal, paediatrics, and family who had critically ill children admitted in the NICU/PICU in Ghana. This phase was guided by the six steps of model development in intervention research (Wight *et al.*, 2015; Squires *et al.*, 2016), as well as the Dewey's model of pragmatism since the underpining philosophy was that of pragmatism (Morgan, 2014, 2017; Kaushik and Walsh, 2019). Concepts with high factor loadings after varimax rotations in the PCA presented in Chapter Five were ranked and used to develop a Delphi questionnaire. The experts were invited to participate via the letter of invitations sent by email. A list of experts who agreed to participate was compiled, and the Delphi questionnaire

sent to them via Redcap (Project Redcap, 2018) for their review. Subsequently, the researcher conducted a two-round Delphi (two weeks apart) to seek the expert's perspectives of the priority concepts included in the model and for heuristic purposes. The decision rule of consensus among experts in the Delphi was based on 80% agreement on a 4-point Likert scale and inter-quartile range ≤ 1 (Keeney, Hasson and Mckenna, 2010; Kleynen *et al.*, 2014; Chalmers and Armour, 2019). The researcher further calculated Kendell's coefficient of concordance and KW ranking of the items to present the priority concepts of FCC per the experts' perspectives.

The experts who participated in the two-round Delphi included those in neonatal and paediatric care (62.5%), intensive care specialists (12.5%), and family members (16.7%). Their mean age was 39 years (SD=5.58), with an average of about 14years of working experiences in intensive care and paediatrics. The two-round Delphi received a high response rate of 96% from the 24 experts. There was consensus reached in the first round for benefits, communication, and collaboration concepts of FCC by experts. All items under each of those domains were ≥ 80%. Consequently, the experts reached consensus on 19 out of the 21 concepts after the two-round modified Delphi study, but failed to reach the 80% consensus decision rule on two barriers of FCC: lack of finance as a barrier of FCC (66.67%) and family as a source of infection in ICU (75%). The experts ranked the concepts of respect and dignity, communication, participation, and benefits of FCC as the most important concepts of FCC practices in Ghana as they attained 100% full consensus. According to the experts, the least prioritised concept of FCC in the Ghanaian context was a collaboration (88%). The main barrier of FCC, per the expert's perspective, was inadequate logistics in the ICU. Overall, it is worth noting that the experts reaffirmed the earlier findings presented, albeit they recommended family participation to be included in the model as a key concept of FCC in the Ghanaian context. The researcher used these findings to conceptually develop the FCC model for NICUs and PICUs as well as the 10 key contextual principles to facilitate its easy implementation, as presented in Chapter Six (see **Figure 6.2** and **Table 6.9**).

The researcher developed a trilogic FCC model of Family-Clinicians-Managers with 10 synthesised key contextual principles addressing the barriers of FCC and facilitating its implementation at the NICUs and PICUs in the Ghanaian context. The model theorises a trilogic multidisciplinary partnership between families, clinicians, and health managers in a well-designed NICU/PICU environment to promote respect/dignity, effective

communication, and family participation to facilitate the integration and implementation of FCC in the Ghanaian ICUs for critically ill children and their families. The model defined family to consist of the father, mother, grandparents, or senior sibling older than 18years, or any person(s) who plays a significant role in the patient's life, and not necessarily the client's legal or biological parent. Clinicians are the nurses, midwives, doctors, clinical psychologists, and allied health professionals, such as nutritionist/dieticians and physiotherapists, and social welfare staff. Health managers include facility heads, heads of child health/ICU departments, Heads of NICUs and PICUs. A well-designed NICU/PICU environment is one in subunits/cubicles, with family comfort zone or area, KC room, in-house pharmacy/laboratory, counselling room, and ICU formation desk. Central to the triangle of these stakeholders are the contextual concepts of FCC, which are respect/dignity, family participation in NICU/PICU care, and effective communication. These triangular themes are placed in a box representing the NICU/PICU environment, which is consistent with current international recommended designs of ICUs (Thompson *et al.*, 2012). Refer to **Figure 6.2** in Chapter Six for the conceptual model. Thus, this model has expanded the concept of FCC as proposed by IPFCC and CCFNI to include environmental designs, ICU information desk, counselling rooms, KC rooms, seven-schedule ICU visitations, and a multidisciplinary approach, among others, to improve the provision of quality healthcare for critically ill children and their families. These contextual principles developed an evaluation tool (see Appendix T) to send with the model diagram to experts for the model evaluation. The next phase described the evaluation of the model.

8.2.3 Phase 3: Model Evaluation

The third and final phase of the thesis was set out to evaluate the validity and reliability of the developed NICU/PICU FCC model. The researcher employed a methodological design to evaluate the face validity, content validity, and reliability of the model (Mitchell *et al.*, 2016; Moallemi, Elsawah, and Ryan, 2018; Grove, Burns, & Gray, 2013). The adoption of this design was because it allowed the researcher to send an evaluation questionnaire to experts at different locations. Invitations went to experts, and those who agreed to participate received an information sheet to study. The questionnaire consisting of the model diagram was sent to the experts via Redcap (Project Redcap, 2018), requesting their experts' comments and evaluation of the model. The developed model and its 10 key contextual principles constituted the evaluation tool presented to 25 experts, including neonatal nurse

specialists, paediatricians, intensive care specialists, health managers, and families whose sick children were admitted into the NICU/PICU for the evaluation. The responses of the panel of experts were indicated on a five-point Likert scale using "strongly disagree-1, disagree-2, neither disagree or agree-3, agree-4, and strongly agree-5" using Redcap (Project Redcap, 2018). The experts had five working days to study and submit their individual objective ratings of the model. They were encouraged to comment on the relevance of the model as well as its clarity of presentation to evaluate the face validity (refer to **Figure 7.1** showing word clouds of experts' comments).

The content validity of the model was examined by calculating the item content validity index (I-CVI), scale average content validity index (S-CVI/Ave), and universal content validity index (S-CVI/UA) (Polit and Beck, 2006; Zamanzadeh *et al.*, 2015; Arat *et al.*, 2016; Yusoff, 2019). To measure the reliability of the model, internal consistency and test-retest reliability were calculated: Cronbach alpha coefficient and Intra-Class correlation Coefficient (ICC (Devon *et al.*, 2007; Taherdoost, 2018) (refer to Chapter Seven for details). In this current model evaluation, the I-CVI score was 0.88-0.96, and S-CVI/Ave score was 0.924, indicating an excellent validity rating of the model by the experts, even though the S-CVI/UA was 0.4 with only four total agreements among the experts. The average measure of ICC was 0.951 with a 95% confidence interval from 0.917 to 0.975 and the F-test at {(24, 216) =21.135), p<.001}. Thus, the evaluation of the model showed excellent psychometric properties. This outcome could be attributable to the strength of this pragmatic mixed methods triangulation design with its ability to collect extensive multiple forms of data from literature, nurses, doctors, midwives, intensive care experts, neonatal nurses, paediatric nurses, paediatricians, nursing consultants, families, and health managers across two major hospitals from the southern and northern zones of the setting. These research actions have provided rich meaning and enough credence, validity, reliability, methodological rigour, and academic rigour to the NICU/PICUs FCC model.

8.3 INTEGRATIVE DISCUSSION OF FINDINGS

The primary design of this thesis was to study FCC in the Intensive Care setting, and develop and evaluate a model of FCC for NICU/PICUs in Ghana. This was achieved in a five-stage research processes including Scoping review, Qualitative (CGT design), Quantitative study, Modified Delphi study, and Evaluation (SCoQME) to develop the FCC model for

NICU/PICUs in the Ghanaian context. This multi-phase study was comprehensive to link and corroborate the findings from the multiple perspectives of the participants in the Ghanaian context. These research processes engaged families, clinicians, and health managers in two Ghanaian public tertiary ICUs to triangulate data and allow the findings of each stage to inform one another culminating into the model.

The researcher proposed that a Trilogic Multidisciplinary Partnership (TMP) between families, clinicians, and health managers in a well-designed NICU/PICU environment could promote respect/dignity, effective communication, and family participation in the ICU phase of care and facilitate the integration and implementation of FCC in the Ghanaian context. Such collaborative partnerships may promote quality satisfactory care for children and their families in the NICU/PICUs. There are 10 underlying context specific concepts of FCC that emerged from the study and used for the NICU/PICU FCC model development. These are family acceptance into ICUs, ensuring privacy and confidentiality, respectful communication, addressing the family psychosocial needs, designing spacious NICU/PICU into sub-units including KC rooms that will address the specific needs of sick children and their families, using available space to setup an information desk, counselling by a clinical psychologist in a secured room, family area with amenities, provision of in-house pharmacy/laboratory and specialised clinicians, and seven-schedule flexible visiting times to allow full family participation. Contextually, these principles have formed four thematic concepts of the NICU/PICU FCC model as family of the sick child, clinicians in the ICU, health managers, and a well-designed NICU/PICU environment. Aspects of these findings corroborate with previous models and research on FCC in different settings, whilst others are contextual to the Ghanaian NICU/PICUs.

Several studies on FCC have recommended various models for the practices of FCC in different context (Levac, Wright and Leahey, 1997; Staniszewska *et al.*, 2012; Hill *et al.*, 2019a; Kokorelias *et al.*, 2019; www.ipfcc.org, 2021). For illustration, the hospital self-assessment inventory tool developed in the United States advocated for a comprehensive assessment of the needs of families in the healthcare system (www.ipfcc.org, 2021). Further, Kynoch *et al.* (2019), in their development of family needs model in the ICU, used the Leske's CCFNI tool to identify psychological factors as one main predictor of ICU patients' needs. Their work is consistent with the findings of this study as the model also proposed the assessment of family needs, including psychosocial needs, communication needs, and

privacy and confidentiality. Perhaps, the consistency in both recommendations is born out of the fact that the researcher used the IPFCC concepts and the CCFNI were as a sensitising concept during the qualitative aspect of the study upon which the model was developed, and built.

Furthermore, the Calgary Family Assessment Model (CFAM) developed in Canada recommended a multi-dimensional framework of structural, developmental, and functional assessment for practitioners to comprehensively assess families and identify their needs to plan care (Levac, Wright and Leahey, 1997). The CFAM recommendations are slightly different from this current model as this model recommends a series of interventions to plan specific care for families, which perhaps may be attributable to the contextual variations. However, the lesson from these previous models is that addressing family needs in the intensive care is significant in promoting the recovery of critical ill children in the NICU/PICU. As such, clinicians and managers of these units should employ tactful and compassionate ways to address family needs. The FST recognises the family as the basic unit of life. Perhaps, the recommendations by the researcher to place family and the sick child at the fulcrum of care may holistically manage these fragile children and help families navigate the complex ICU phase of care (Ray, 2018). Therefore, there is the need to train clinicians including nurses and doctors on these FCC concepts in the form of in-service training and curriculum review to facilitate its integration in daily clinical practice to inure quality healthcare for children and their families.

The Neonatal Integrative Care model provided seven neuroprotective interventions for the management of preterm infants in the NICU (Altimier and Phillips, 2016). This model only focused on the neurological assessment and care of preterm babies in the NICU, whilst the NICU/PICU FCC model is a holistic model for the care of all categories of sick children and families in both NICU and PICU. However, the two models share similarities in their recommendations of partnering with families, and having a healing environment for skin-to-skin contact as a key intervention in the care of preterm in the intensive care. The NICU/PICU FCC model proposed the provision of spacious KC rooms for the management of preterm babies in the NICU. Correspondingly, the design of appropriate ICU environment has been reported in the guidelines for Intensive Care Units (Thompson *et al.*, 2012). The environmental and contextual design of the NICU/PICU is crucial to the implementation of FCC as it will accommodate evolving care practices including patient support zones, clinical

support zones, unit support zones, and family support zones (Thompson *et al.*, 2012). Conceivably, the role of families as well as the provision of ICU space and environmental designs in the care of sick children in any setting or context remains paramount. Therefore, the recommendation is that the design of the ICU environment should be into separate sub-units or cubicles with kangaroo rooms inclusive; This will allow more space, and promote privacy and confidentiality, as well as facilitate family involvement in the care of their critically ill in the NICU/PICUs.

Another main finding of the study is building collaborative partnerships and respecting the socio-cultural background of families. Partnership model and respecting the socio-cultural differences have been reported in some studies in other setting (Dennis *et al.*, 2017; Franck and O'Brien, 2019b; Vasey *et al.*, 2019). The researcher extends this partnership of care to include a multidisciplinary approach involving the family, clinicians, and health managers in the ICU. For example, the inclusion of clinical psychologist in the daily care of ICU may be helpful in reducing the psychological toll on families and their children as well as the staff during ICU phase of care. Contextually, fathers are seldom involved in the care of the critically ill children due to socio-cultural and religious reasons. As such, most mothers are alone with very little family support during the ICU phase of care. Such situations heightened the anxiety and psychological stress of the ICU stay on the mothers. The recommendation is to use available clinical psychologists to attend to families in this regard routinely. Further research should qualitatively examine the barriers and facilitators of fathers' involvement in the NICU/PICU phase of care. The researcher's recommendation may be valid as some Australian researchers in their model of family needs in ICU found a positive correlation between the psychological factors of family including anxiety and the needs of ICU patients (Kynoch *et al.*, 2019).

Additionally, the study found that collaboration with stakeholders' families and clinicians is important for FCC implementation and integration into the ICUs. The researcher identified training and specialisation of professionals, and family involvement in decision making as prudent interventions for the integration of FCC into the NICU/PICUs. Similarly, a scoping review of 55 articles on previous models of FCC also identified collaboration between family and healthcare providers, family as a context, policies, and procedures, as well as patient, family, and healthcare professional education as the main themes that emanated from those studies (Kokorelias *et al.*, 2019). The NICU/PICU FCC model is even more specific and

broader to address the issues of privacy and confidentiality of families, which was identified as the gaps in the said scoping review (Kokorelias *et al.*, 2019). Peradventure, the similarities between the NICU/PICU FCC model and these models is because they all arose from the four thematic areas of FCC as proposed by IPFCC. There is therefore the need for healthcare providers and managers to develop care plans that are holistic and yet family-centered to address the needs of critically ill children and their families in the ICUs.

The involvement of health managers in the implementation and integration is a major message from this study. Contrarily to this, previous models were developed based on the perspectives of either families and/or nurses and also illness specific (Staniszewska *et al.*, 2012; Hudson *et al.*, 2016; Enke *et al.*, 2017; Paredes *et al.*, 2018). Significant among these previous models is the POPPY model for NICUs that was specifically developed to support the care of preterm babies in the NICUs from the perspectives of parents of preterm babies and staff (Staniszewska *et al.*, 2012). However, the NICU/PICU FCC model has consistently triangulated data from varied perspectives of families, clinicians, and health managers in a five-stage research processes. The robust nature of the data collected from the participants in NICU and PICU have provided the comprehensive findings proposed in the 10 conceptual principles of the model for its implementation. Contextually, it is worth noting that the clientele of NICU and PICU is from birth to 12 years, with some neonates with special conditions requiring surgical interventions and/or re-admission, for example, into the PICU. This perhaps may appear to have skewed some aspects of the findings to reflect the population of neonates. This however, does not change the setting of the study as the focus of the data gathered was on the family as recommended by the concepts of FCC (www.ipfcc.org, 2021). It is however, recommended to further research same phenomenon in other context with same methodology as well as test the model and its recommendations in cohort studies and randomised control trials for generalisation.

In addition, the study found that respectful communication, respect/dignity, and participation in care could also facilitate the implementation of FCC in the ICU. Communication models have proven to be effective in other settings (Enke *et al.*, 2017; Butler *et al.*, 2019). Patient and family satisfaction was improved in Italian NICUs due to FCC models implementation (Oglio *et al.*, 2014; Kokorelias *et al.*, 2019). Anecdotally, information sharing, respectful care, and education of patient and family is part of nursing care processes at all settings. Healthcare providers should develop interventions that focus on empathetic communications

to educate families on the care processes in the NICUs and PICUs. This will go a long way to allaying their anxiety and promote participation. The care plans should undergo testing in other settings for a broader generalisations to be drawn.

Moreover, one other unique feature of the NICU/PICU FCC model is that its development was from a generic point of view to address the needs of sick children and their families in the ICU. This may attempt to resolve the challenges healthcare providers face in integrating and implementing the several illness-specific existing models in the ICUs (Kokorelias *et al.*, 2019), because there are multifactorial causes of admission into the ICU. Meanwhile, most of the models of FCC are just recommendations without pointing out the implementation benefits. Tentatively, the NICU/PICU FCC model is possible to improve outcomes of families and their sick children, including shorten the length of stay, reduce anxiety, and reduce lawsuits against the healthcare providers. The recommendation is for the evaluation of this model on a larger scale in this context as well as other settings with similar characteristics to verify the consistency of these findings in the NICU/PICU setting and pave the way for its holistic implementation. This model has indicated the need for healthcare professionals to ensure privacy and confidentiality, which some models in the paediatric populations ignored. However, there is the need for further research to explore patient privacy protocols and legislations in our setting to grant families full access to information about their sick children in the ICU for their full participation in care plan decision-making. Future researchers should also consider testing these findings in other contexts and populations towards a universal model of Family-centered Care to foster quality healthcare for sick children and their families across settings.

Although FCC has been widely researched across many settings, especially in the developed world, its practices in the Ghanaian setting lack a context specific model. This thesis has therefore produced a context specific model to support its integration into the NICU/PICU and promote quality healthcare services for children and family satisfaction. These discussions illustrate that the study rigorously engaged several stakeholders in the development of the model. This has backed the findings and recommendations of the study culminating to the model. There is a proper link to existing literature and further directions of research indicated. The preliminary evaluation of the model indicated sound psychometric properties, which perhaps is an indication of the readiness of the stakeholders including families, clinicians, and the managers to embrace the model and integrate it into the daily

practice of NICU/PICU. The researcher plans to disseminate the findings and recommendations of the model in workshops and conferences as well as publish the findings in peer review journals for global consumption. This will create the opportunity to highlight the specific recommendations to experts in neonatal, paediatrics, ICU, and the managers about the model. This will set the pace for a possible full acceptance of the model into the NICU/PICU in Ghana. It is also anticipated that the will serve as framework for teaching, research, and education relative to the practices of the model of FCC, especially in the nursing training institutions in Ghana. The inclusion of this model to daily nursing practices may also serve as a boost to nursing as a profession, since a model is a building block of a theory that is the dogma of measuring the standards of a profession globally.

In spite of the forgoing discussions, it is worth noting that this model may be limited as it was born out of just two ICUs. Perhaps the inclusion of more ICUs would have further broadened the contextual concepts of FCC. There was a skewing of recruited families towards mothers due to the socio-cultural poor attendance of other family members including fathers in ICU phase of care. Again, nurses are the main clinicians in the Ghanaian ICUs and as such constituted the majority of the participants in this model development. This was due to the inadequate personnel especially specialist and consultants in the Ghanaian public health delivery system. Consequently, these findings should be subjected to correlational and experimental studies with larger diverse samples before generalisation.

8.4 SUMMARY

This chapter presented the discussions of results from all the three phases of the thesis and linked them to intensive care literature. The chapter highlighted and discussed the contextual findings of FCC. Most of the findings were similar to other published studies on FCC in intensive care literature. Some of the findings were contextual, and the possible reasons for those findings are illuminated. The researcher presented the clinical nursing implications of the overall findings and made recommendations on how to improve FCC practices in the ICUs. Also presented were the proposals for further research on issues that emerged relative to the study domain. The next chapter presents the summary, conclusions, and recommendations of the entire thesis.

CHAPTER NINE

SUMMARY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSIONS OF THE STUDY

9.1 INTRODUCTION

This chapter presents a summary evaluation of the entire study with specific emphasis on the meeting of the objectives as well as the strengths and specific contributions of the developed NICU/PICU FCC model, recommendations, limitations, and the conclusions of the study. The first section outlines the evaluation of the entire study in line with the set objectives of the thesis and how they were met.

9.2 EVALUATION OF THE STUDY

The primary objective of this thesis was to investigate FCC in the Intensive Care setting, and develop and evaluate a model of FCC for NICU/PICUs. This goal was met as the model was developed and evaluated by experts. This main objective gave rise to seven specific study objectives fulfilled in three phases of exploration (executed in three steps), model development, and model evaluation. The researcher adopted a mixed method design with the FST theoretical application to answer the various research questions. The researcher gathered detailed qualitative (36 transcripts; n=84) and quantitative (n=446) data and then examined it to conceptually develop the model. The accomplishment of the study was in nine chapters.

The first chapter presented the background, problem statement, objectives/research questions, concept definitions, and an overview of the study methodology.

Chapter Two presented the definition, history, models, barriers, facilitators of FCC practices as well as overview of the research methodology. This part of the study presented an overview of the entire research to help the reader see the direction of the study.

Chapter Two also presented a scoping review of existing literature using the JBI methodology to explore the literature in NICU/PICUs to identify the main concepts of FCC, which set the research agenda. The researcher performed this critical literature review to help contextualise the study and provide a detailed background to the key areas of the study, including FCC and model development processes. This aspect of the study met the first objective of the study; designed as Step 1 of the exploration phase.

Chapter Three outlined the methodological processes used to address the seven research questions of the study. In the methods chapter, the researcher justified using pragmatism and mixed method design for the study. Presented are the setting, sampling techniques, sample size estimation, data analysis, methodological rigour, reliability, validity, and ethical considerations. The methodological discussions and illuminations of the procedures used were to clarify and justify the methods used and help other researchers to repeat the methodology in other settings.

In Chapter Four (Phase 1 Step 2), the researcher used the CGT qualitative design to study FCC at the NICU/PICU, recruiting family (father, mother, senior sibling, and a significant other), clinicians (nurses, midwives, and doctors), and managers (department and unit heads) as participants (n = 84). The objectives of this step were to explore family needs, family involvement, barriers of FCC, and the facilitators of FCC integration into the Ghanaian NICU/PICU. This step was critical to explore and describe the contextual FCC practices from the perspectives of families and clinicians within the Ghanaian NICU/PICU setting. This led to the outlining of the contextual perspectives of FCC practices in the Ghanaian setting. The theoretical sampling of the findings was as per the CGT approach. The development of the quantitative tools (family questionnaire, and clinician's questionnaire), 46 items each, came from the qualitative findings. Vivid discussions of the contextual findings were to give better illuminations and recommendations for clinical nursing practice and for further research.

In Chapter Five (Phase 1 Step 3), the researcher triangulated the findings of the qualitative research to expand, confirm, and quantify the contextual practices that emerged from the qualitative step. To achieve this, the researcher conducted a pilot study using the developed questionnaire prior to the quantitative survey, the detailed results are illustrated in this chapter. Subsequently, a sample of families (n= 346), and clinicians (n=100) participated in

a survey to achieve this goal. The researcher employed factor analysis; Principal Component Analysis (PCA) to reduce the initial 46 items questionnaire into a 21 items instrument; however, parallel analysis was later used to pin the concepts to only four. This aspect of the study provided more rigour, validity, and reliability to the final model.

In Chapter Six, the objective was to develop the model via a Delphi panel. The researcher recruited 24 experts in clinical nursing, medicine, intensive care, paediatrics, and neonatal care to examine the outcome variables from the quantitative findings as presented in Chapter Five. The developed 21 items instrument from the factor analysis became the Delphi questionnaire for the expert review. The experts gave priority rankings of the concepts of FCC in the Ghanaian context. After a two-round Delphi, the experts failed to reach consensus (80%) on three of the 21 items presented to them; these then developed the model (Chapter Six for details). This aspect of the study was necessary to allow the expert's inputs into the model to give it more validity, reliability, and more importantly, acceptance into the ICUs since it included all the stakeholders (family, doctors, nursing, and health managers).

The final objective of the study was to evaluate the model, which was executed in Chapter Seven. The researcher recruited 25 experts in nursing, neonatal care, paediatric care, intensive care, health management as well as families of sick children in the NICU/PICU to evaluate the model. The experts received the developed model diagram and its 10 contextual principles to comment on its validity. A five-point Likert scale (1= Strongly disagree; 2= Disagree; 3=Neutral; 4= Agree; & 5= Strongly agree) was provided to rate each principle of the model. Subsequently, there was an estimation of the validity (content validity index and face validity) and reliability (Cronbach's alpha and Intra class correlation coefficient) of the model were estimated. This chapter provides the details of these results and brief discussions. This was necessary to provide evidence of the psychometric properties of the model.

In Chapter Eight, the researcher presented an integrative discussion of the findings of all the phases of the study. This part was necessary to present the main findings as well as compare the NICU/PICU FCC model with other models and to show the uniqueness of this model.

The final chapter, Chapter Nine, presented the summary, conclusions, recommendations, further research, and the study limitations.

Overall, the model has four thematic areas. Firstly, the family needs considering as an integral part of clinical practice in the ICU. This family should encompass the father, mother, and significant other of the sick child placed at the fulcrum of ICU care to facilitate participation, and decision-making. Secondly, experts' multidisciplinary collaborative partnerships with clinicians i.e., nurses, midwives, and doctors, and allied health professionals, are weighed to the care of critically ill in the ICU. The third unique theme of the model is health managers, i.e., heads of NICU, PICU, and the Department of Child Health/paediatrics. The fourth and final theme is the NICU/PICU environment including KC room, ICU information desk, counselling room, in-house pharmacy and laboratory, and family area with amenities. These themes find themselves at anchor on 10 key underlying principles of the FCC model, which the researcher considers as the care plan interventions for critically ill children and their families in the ICUs:

1. Family acceptance to participate in ICU
2. Ensuring privacy and confidentiality of families and their sick children in ICU
3. Respectful communication and information sharing for families
4. Addressing the family psychosocial needs including strengthening social welfare for funding support to handle abandon babies
5. Designing spacious NICU/PICU into sub-units including KC rooms that will address the specific needs of sick children and their families
6. Using available space to setup ICU information desk for regular dissemination of information to families,
7. Provide counselling by a clinical psychologist in a secured room in the ICU setup,
8. Provide family area with amenities including washrooms, and comfortable furniture,
9. Provision of in-house pharmacy and laboratory, specialised clinicians by health managers
10. Have seven-schedule flexible visiting times into the NICU/PICU to allow full family participation.

The presentation of these themes and the concepts is in a diagram and table format as the NICU/PICU FCC model (see **Figure 6.2** and **Table 6.9**).

9.3 STRENGTHS AND SPECIFIC CONTRIBUTIONS OF THIS STUDY TO KNOWLEDGE

At the time of putting this thesis together, the researcher was unaware of any model of FCC for NICUs and PICUs in Ghana that had triangulated data extensively from multiple perspectives, including family, nurses, midwives, doctors, managers, and policy experts. Existing models of FCC at the NICU/PICU in academic literature only focused on specific conditions such as preterm, like the POPPY model for NICUs (Staniszewska *et al.*, 2012), the Calgary Family Assessment Model (Zimansky *et al.*, 2020), and the Self-Assessment Inventory tool (www.ipfcc.org, 2021) that is focused on the need's assessment of families in the ICU. The evidenced-based findings of this thesis have backed the scientific proposal of the researcher to recommend the context-specific model of FCC for NICU/PICU.

This model proposed a collaborative partnership with families, clinicians, and health managers to practice FCC at the NICUs and PICUs in the Ghanaian setting in an ideal family inclusively designed NICU/PICU environment (**see Figure 6.2**). Such collaborations will help clinicians and managers to see the sick child and their family as the fulcrum of care and therefore strive to meet their needs to address their physical, social, and mental health and not merely the disease conditions presented at the ICU. The researcher has provided concrete pathways in the 10 key contextual practices of FCC (see **Table 6.9**) to facilitate the implementation and integration of the model for NICUs/PICUs. Notable among these key principles are the calls on clinicians and managers to set up an information desk in the ICUs to reduce the solidarity invasion of families in the context into the NICUs/PICUs and to help provide simple basic information regarding the admission of their loved ones into the ICUs.

The NICUs and PICUs should adopt the seven-schedule family visitations recommended by the model to allow full participation of families into the NICUs/PICUs (see **Table 6.9**). Again, the practice of FCC from a multidisciplinary approach was yet another significant finding birthed by this thesis. The researcher proposed the inclusion of community health nurses, clinical psychologist, nutritionist, and other health professionals to augment and support the families, clinicians, and health managers to provide quality and satisfactory

healthcare in the NICUs and PICUs. The design of future NICUs and PICUs must have subunits/cubicles to create enough ICU space and family areas to allow full family participation in the care of their critically ill children.

Contextually, health professionals fear the acceptance and implementation of FCC due to the lack of logistics, space, and adequate specialised professionals. For instance, the study found that more than 70% of the 3000 annual admissions into the ICUs were attributable to preterm, birth asphyxia/respiratory distress, and neonatal jaundice. In Ghana, NICUs and PICUs are in the main cities, to the neglect of some regional facilities. These few units lack the necessary logistics, including ventilators, phototherapy machines, radiant warmers, bilirubin meters, pulse oximeters, and oxygen flow meters. Participants illuminated the need for the government to set up a National Child Health Fund (NCH Fund) similar to the Ghana Educational Trust Fund (GET Fund) to support the provision of the needed logistics, establish more NICUs/PICUs, support professional training, and support needy families access intensive care services with their sick children across the country. Achieving this can be through collaboration between the Ministry of Health, and the Ministry of Children, Gender and Social Protection via an Act of parliament. This fund may go a long way to reduce the abandoned babies menace in the NICUs and PICUs as some families abandon their babies in the ICUs due to financial constraints. Finally, the embracement and acceptance of the FCC model into NICU/PICU practices will further bolster the care provided by the clinicians, improve family involvement in care, reduce family and child anxiety, promote bonding and psychological wellbeing, promote recovery and early discharge, reduce lawsuits, and foster continuity of care after discharge for a full recovery of ICU patients. The model will support clinical practice, research, and training in neonatal, paediatrics, and intensive and critical care. The next section presents the limitations of the study.

9.4 LIMITATIONS OF THE STUDY

Although this research had shown the important role that FCC could play in the effective management of critically ill children, some limitations are worth noting. The study setting was only in the Intensive Care Unit; perhaps the inclusion of other child health settings, such as paediatric emergency, could have enriched the findings. The study had some limitations in respect of the participants recruited. Firstly, mothers largely represented the families, as

fathers do not usually accompany their wives to hospital in our context due to socio-cultural reasons. The management of the Intensive Care settings in Ghana is generally by general nurses and doctors with few specialists, and as such, the majority of the participants were nurses. The health managers recruited at the qualitative stage were few as there are not many staff in the ICU setting. As such, the researcher recruited additional managers in the other phases, especially the Delphi and evaluation studies, to address these limitations.

It was difficult obtaining access to the ICUs even with the institutional ethical clearance due to the Covid-19 pandemic. The researcher had to procure and supply nose masks and hand sanitisers for each participant during the qualitative interviews and FGDs to manage the situation. There were several meetings held with the units' heads to schedule appropriate timing for the recruitment of participants. Some participants, especially the families, were unwilling to participate, which delayed the qualitative data collection processes. The researcher procured and provided snacks for participants to win their acceptance and participation. There was a good relationship established between the researcher, units' managers, and some staff in the ICU, facilitating the data collection in the other stages of the study. Some of the qualitative interviews were in local Ghanaian languages ("Twi and Dagbani") and translated with the help of a language expert into English to help keep the participants' accurate reflections on the contextual practices of FCC in the NICUs and PICUs. However, these events did not affect the quality of data collected or alter the original study methodology.

Furthermore, the rating scales for the questionnaire were four-point Likert scale because those tools were born out of existing tools on FCC with high psychometric properties that had 4-Likert scales; perhaps, a 5 or 7-point Likert scale would have added more variation to the data collected. Financial and time constraints also limited the study to the two selected settings; conceivably, data collection from all regional ICUs may have presented more reflective, socio-cultural perspectives of FCC in the Ghanaian NICUs and PICUs. Mixed method methodological pathways may have some inaccuracies in the efficient and proper understanding, and in the applications of these varied methodologies in a single research project since one cannot comprehensively know each of the methods. Therefore, the model's generalisation should be with caution since findings are only from two hospitals and the evaluation presented is only a preliminary one with a small statistical sample. The next section outlines the recommendations of the study.

9.5 RECOMMENDATIONS ARISING FROM THE FINDINGS OF THIS STUDY

In this section, the researcher outlined the nursing implications of the model and presented some specific recommendations to improve clinical practice, education, management, and further research.

9.5.1 Clinical Nursing Practice

Adopting the NICU-PICU FCC model should promote the best outcomes of care for sick children and their families through early discharge and family satisfaction. It will improve family acceptance, respectful communication, and participation as experts in the care of children by clinicians in the ICUs. This model is multi-disciplinary in nature and points to the essence of teamwork, a key dogma of clinical nursing practice. The NICU-PICU FCC model may rejuvenate the interests of health professionals, especially nurses, to study and apply family nursing concepts in the care of their patients. Therefore, healthcare facilities may adopt this model and its 10 key principles (see **Table 6.9**) as the guidelines to train their clinicians on FCC for its implementation and integration into NICU/PICU practices. This may contribute to quality child healthcare in any setting, especially those with similar contextual characteristics like Ghana.

Specifically, health managers and clinicians in the ICUs should provide ICU information desks for effective communication with families to provide education, manage their fears and psychological stress. Similarly, there should be a clinical psychologist assigned to the ICUs to help both clinicians and families manage the emotional and psychological stressors, including anxieties associated with the ICU phase of care. Clinicians and managers of NICU/PICUs should adopt an open-door policy to grant full access to family involvement and participation in the NICU/PICUs to promote satisfactory quality ICU services. This could be through the seven scheduled family visitations approach. Thus, there should be at least four scheduled visits (3-hour interval) allowed for mothers, two scheduled visits (8-hours apart) for fathers, and one scheduled visit for a designated (approved) significant other member of a family. Health managers, units, and departmental heads should ensure that families in ICUs have basic needs such as washrooms, water, accommodation, and food during their stay in the ICU.

Furthermore, facility, units, and departmental managers in ICUs should provide enough storage facilities, such as refrigerators, to preserve infant feeds, especially breast milk in the NICUs. This will help reduce the stress clinicians, and families go through to obtain infant feeds to meet the nutritional needs of critically ill children in the ICUs. There should be more effort made to establish a collaborative relationship with community health nurses to improve the referral system in Ghana. Health managers should also ensure there is the integration of community health nurses into follow-ups of children and their families discharged from the ICUs. This may help immunise the babies, prevent vaccine-related diseases, and facilitate continuity of care.

9.5.2 Nursing Education

This NICU-PICU FCC model could be a scientific foundation for the teaching and training of health professionals, including nurses, midwives, and doctors especially in specialisations such as Family Health Nursing, Family Health Medicine, and Intensive Care. Thus, there is the need to ingrain FCC concepts and principles into the training of health professionals under a curriculum of family nursing/family health to training basic, post-basic and specialist programmes in intensive care, neonatal care, and paediatrics.

Therefore, the recommendation is that the Nursing and Midwifery Council (NMC) for Ghana, the Ghana College of Nurses and Midwives (GCNM), universities and other health training institutions consider modifications of the curricula of training nurses and midwives to developing Family Health Nursing curriculum as a major content area for all nursing and midwifery programmes. Additionally, the National Accreditation Board (NAB) of the Ghana Tertiary Education Commission (GTEC) should add Family Health Nursing as a course evaluation requirement to train basic, post-basic and specialist health programmes, including intensive care and paediatrics.

9.5.3 Management and Health Policy

Government and health managers should provide adequate logistics, including incubators, ventilators, pulse oximeters, bilirubin meters, flow meters, radiant warmers, and also train and provide specialised professionals in the NICUs and PICUs, including neonatal nurses, paediatric nurses, paediatricians, intensive care specialists, and family health nurses to foster

the provision of quality child health. Government and health managers should ensure the design of future NICUs/PICUs into cubicles with enough clinical working area and family space and comfort zones to facilitate FCC implementation. Health managers, MOH, and GHS, should conduct in-service training about the model and relationship communication for clinicians to augment their assertive communication strengths and emotional intelligence. Again, facility managers and GHS should provide an in-house pharmacy and laboratory for the NICU/PICU for prompt provision of such services. The facilities should have stock of emergency medicines and supplies to facilitate the quick delivery of critical care services. Health facility managers and departmental heads should ensure the digitisation of the delivery of ICU services, including documentation, pharmacy, and the laboratory, to remove the bottlenecks and promote quality child health and intensive care services. It is further recommended that the government should set up a National Child Health Fund via MOH as well as strengthen the social welfare department via the Ministry of Children and Social Welfare to provide direct funding support to needy families, provide logistic for the ICUs, establish more NICUs/PICUs, support staff specialisation, and research. Finally, the Health Facility Regulatory Authority (HeFRA), Ghana Health Services (GHS), and Ministry of Health (MOH) should also adopt the model and its 10 contextual principles in the certifications of new and old health facilities to foster family-friendly hospital settings and promote family safety, satisfaction, and quality healthcare service provisions.

9.5.4 Recommendations for Further Nursing Research

Nursing practice is a science that is directed by research and training to inform clinical practice. The birth of this model will add to the knowledge of existing FCC models to guide further research into the domain of family health nursing, paediatrics, and intensive care. Future researchers can adopt the mixed methods designs utilised in this model development as the scientific underpinnings of their research. The researcher relishes the opportunity to work locally and globally with researchers, individuals, institutions, and organisations to conduct further studies relative to the implementation and evaluation of this NICU-PICU FCC model. Usually, the next phase of complex research is implementing the outcome on a broader scale to determine the effectiveness of that developed; therefore, future research should test the FCC model for NICUs/PICUs. For instance, the specific recommendations with increased samples from regional hospitals and other teaching hospitals in a randomised controlled trial (RCT) and cohort studies can give room for its more comprehensive

implementation in ICU practices. There should be a repeat of such studies every five years to review and update the model to reflect the contextual practices of FCC in the ICUs.

Again, researchers and clinicians should employ a mixed method design to develop a feeding criterion/protocol for critically ill children in the NICU/PICU that is family inclusive. This may facilitate the full participation of families in the feeding of their critically ill during the ICU phase of care and after discharge. Researchers should explore contextual correlates of morbidities and mortalities in the NICU and PICU to help clinicians' better plan care for critically ill children. Further studies could assess the effectiveness of the Kangaroo Care practices, especially the combined neonatal interventions for the improvement of child health outcomes for preterm babies in the NICUs in our context. Furthermore, there should be a qualitative exploration into the barriers and facilitators of fathers' involvement in the ICU phase to address the missing link of fathers' participation in NICU/PICU care processes in our setting. Finally, researchers should adopt a mixed method design to identify the specific barriers of family-clinicians communications in the ICUs and develop clinical guidelines for enhanced family-clinicians communication. This will help build sustained communication and collaborative partnerships between families and clinicians in the ICUs.

9.6 CONCLUSION

A model of FCC for NICU/PICUs has been developed and presented in this thesis. The strength and uniqueness of the model is that it has triangulated data from clinicians, families, and managers and experts in neonatal, paediatric, intensive care, and nursing. The model has families, clinicians, managers, and the NICU/PICU environmental design as its main themes underpinned by 10 contextual principles of FCC for its straightforward implementation in the ICUs. The recommendation of developing a Family Health Nursing curriculum in our context is to adequately train and enrich the professional aptitude of healthcare providers to build collaborative partnerships with families to provide child health and intensive care services. The staff especially nurses and doctors working in the ICU should receive training in FCC using this model as a starting point. Future research should test the model and its recommendations with a large sample within and outside the setting in Randomised Control Trial (RCT) and cohort studies for its full-scale implementations as well as conduct 5-year periodic reviews for validation and possible revision.

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APPENDIX A

Critical literature and scoping review matrix

S/N	Citation/ Country	Title	Purpose/ Aim	Paradigm/ Method /Design	Findings/Conclusion (Main concepts of FCC)
1	(Brødsgaard, Zimmermann and Petersen, 2015) Denmark	A preterm lifeline: Early discharge programme based on FCC	To present an Early Discharge Programme model for preterm infants based on FCC, and to describe its impact on the infants and families.	Mixed Methods: quantitative longitudinal and qualitative synthesis	The study found that family experience of FCC implementation and integration into the NICU resulted in the early discharge of infants and their families.
2	(Li *et al.*, 2016) China	Breaking down barriers: enabling care-by-parent in NICU in China	To provide evidence that it is feasible for parents to participate in their infant's NICU care through rooming-in with them	Quantitative retrospective cohort comparative study.	The study concluded that allowing parents' access to their infant in the NICU is feasible and safe in China since there was no evidence of infection due to family involvement in the NICU.
3	(Enke *et al.*, 2017) Germany	Communicating with parents in NICUs: The impact on parental stress	To identify groups of parents in the NICU who are particularly at risk of experiencing stress, and to explore the effects of clinicians' communication on parental stress.	Mixed models multicenter study	Empathetic communication and parental involvement in care by clinicians from the beginning of a child's stay in the NICU was responsible for reducing parental stress and good prognoses especially for young parents with severely ill neonates
4	(Clarkson, Bc, *et al.*, 2019) USA	A cross-sectional survey of factors associated with paternal involvement in the NICU	To describe factors associated with father involvement in the NICU.	A cross-sectional exploratory study	The involvement of fathers in kangaroo care at NICUs produced positive outcomes in the United States.

5	(Kurtulus, Yıldız and Ozyazicioglu, 2018) Turkey	Determination of Paediatric Nurses' Attitudes on FCC	To determine the attitudes of nurses working in paediatric clinics regarding FCC.	Descriptive quantitative study	Training of ICU nurses on FCC resulted in coordination of family visits to increase their active involvement in childcare.
6	(Skene *et al.*, 2019a) UK	Developing family-centered care in a NICU: An action research study	To develop, implement, and evaluate family-centered interventions to promote parental involvement in caregiving in a NICU.	The participatory action research approach in three phases of Exploration, Intervention, and Evaluation.	The acknowledgment of parents as main caregivers in ICUs during the implementation of the four FCC concepts improved positive health outcomes in the United Kingdom.
7	(Sigurdson *et al.*, 2018) USA	Disparities in NICU quality of care: a qualitative study of family and clinician accounts	To identify how family advocates and clinicians describe disparities in NICU quality of care in narrative accounts	Qualitative analysis of a narrative account	The barriers of family involvement at the NICU include social inequalities, race, and ethnicity.
8	(Vasli *et al.*, 2015) Iran	The dominance of paternalism in FCC in the paediatric intensive care unit (PICU): an ethnographic study	This article examines the culture of FCC in the PICU using focused ethnography	Focused Ethnographic study	Even though there is a wide gap between theory and clinical practice in FCC implementation, Iranian fathers were experts in the care of their neonates in the PICU. Modification of staff attitudes towards family needs may bridge the gap.
9	(Hsieh *et al.*, 2017)	FCC Improved Neonatal Medical and Neurobehavioral	To examine whether a family-centered intervention program	Quantitative multicenter, single-	The involvement of parents with preterm babies in FCC promoted

	Taiwan	Outcomes in Preterm Infants: Randomized Controlled Trial	(FCIP) could improve the short-term medical and neurobehavioral outcomes in preterm infants with very low birth weight in Taiwan over the outcomes seen with a usual care program (UCP)	blind, randomized controlled trial study.	earlier full enteral feeding and hospital discharge, greater weight gain, and better neurobehavioral performance.
10	(Felipin *et al.*, 2018) Brazil	FCC in NICU/PICU: nurse's vision	To meet the nursing vision of a NICU/PICU about FCC	Qualitative descriptive study	Education of both clinicians and families ensured easy integration of FCC in the ICU to narrow the theory and practice gap in Brazil.
11	(Valizadeh, Mirlashari, *et al.*, 2018) Iran	Fathers: The Lost Ring in the Chain of FCC	To understand NICU nurses' lived experiences of family participation in FCC	Interpretative Phenomenology using Heideggerian philosophy.	Fathers' participation in NICU was limited due to traditional attitudes, cultural-religious background, and difficulties relating to the hospitals' organizational rules.
12	(Noergaard *et al.*, 2017) Denmark	Fathers' Needs and Masculinity Dilemmas in a NICU in Denmark	To describe fathers' needs when their infants are admitted to a NICU and to discuss these needs within a theoretical framework of masculinity to advance understanding and	Grounded Theory Qualitative study	The desire of fathers' involvement in the care of their sick infants was affected by cultural and social norms in Danish ICUs.

			generate meaningful knowledge for clinical practices.		
13	(Kjellsdotter, Lantz and Ottosson, 2018) Sweden	Healthcare Professionals' Views on Parental Participation in the NICUs	To examine the associations between age, gender, and profession in relation to the perceived importance of parental participation in NICUs.	Quantitative cross-sectional design	Training of nurses, physicians, and family on parental participation resulted in family integration of family into NICUs in Sweden.
14	(Hadian *et al.*, 2016) Iran	Lived Experience of Caregivers of Family-Centered Care in the NICU: "Evocation of Being at Home"	The present study aimed at the description and interpretation of the FCC experience in two NICU at Shiraz University of Medical Sciences.	A hermeneutic phenomenological approach, analysed through van Manen's methodology.	Managers and clinicians provided proper support to parents to implement FCC resulted in meeting family needs and building therapeutic relationships.
15	(Shimizu and Mori, 2018a) Japan	Maternal perceptions of family-centered support and their associations with the mother–nurse relationship in the NICU	To evaluate maternal perceptions of family-centered support with hospitalized preterm infants and their relationship between mothers and nurses in the NICU.	Quantitative cross-sectional study using path analysis and multiple group analysis	The main concepts of FCC practiced in Japan are support, clear visual information, and mother–nurse collaboration.
16	(Hassankhani *et al.*, 2019) Iran	Mutual trust in infant care: the nurses and mothers experiences	To explore mothers' and nurses' experiences of trust in one another around	Focused ethnographic qualitative research	Mutual trust was a key concept of FCC practice between parents and clinicians which

			the caregiving of the hospitalized infant in the NICU.		promoted maternal participation in Iranian NICUs.
17	(Priya Govindaswamy *et al.*, 2019b) Australia	Needs of parents in a surgical NICU	To identify the parental needs of newborns admitted to the NICU for general surgery and whether healthcare professionals meet these needs.	A quantitative prospective cohort study using Neonatal Family Needs Inventory (NFNI).	In Australia, reassurance is the most significant need for parents in the implementation of FCC in the NICU.
18	(Amorim *et al.*, 2019) Europe (France, Portugal)	Needs of parents of very preterm infants in NICUs: A mixed-methods study	To explore the needs of parents of very preterm infants hospitalized in NICU Units according to their socioeconomic position, obstetric history, and infant's characteristics.	Sequential explanatory mixed methods study	In Europe, parental needs such as privacy, family-friendly environment, information and education, and emotional support regardless of the socioeconomic and socio-demographic background of families are the key tenets of FCC implementation in the NICUs.
19	(Boztepe and Kerimoğlu Yıldız, 2017a) Turkey	Nurses' perspective on barriers to implementing FCC in a paediatric setting: A qualitative study	To explore the views of nurses regarding the practice of FCC	Qualitative study	Implementation of FCC in the NICU require sufficient resources, appropriate education, and support from their managers. Families' cultural characteristics were an obstacle.

20	(Denis-Larocque *et al.*, 2017) Canada	Nurses' perceptions of caring for parents of children with Chronic Medical Complexity (CMU) in the PICU	To explore nurses' perceptions of caring for parents of children with CMC in PICU.	Qualitative interpretive descriptive design	Building partnerships with parents through communication and trust over time are key pillars of FCC implementation in Canadian PICUs. The challenges of FCC were addressed via educational sessions, discussion of mutual expectations, and engaging in an open and transparent dialogue with parents to enhance the partnership with parents.
21	(Shahul S, Tung A, Minhaj M, Nizamuddin J, Wenger J, Mahmood E, Mueller A, Shaefi S, Scavone B, Kociol R D, Talmor D, Rana S, 2017) USA	Nurses' Reflections on Benefits and Challenges of Implementing FCC in PICUs	To describe nurses' perceptions of the benefits and challenges of providing FCC in PICUs	Qualitative descriptive using Hsieh and Shannon content analysis approach.	FCC implementation is beneficial for families, hence policy is required support its integration in the PICUs..
22	(Hill *et al.*, 2019b) USA	Parent perceptions of the impact of the PICU the environment on delivery of FCC	To examine parent perception of how the physical and cultural environment of the PICU impacted the implementation of	Qualitative descriptive design	The core concepts of FCC in United States are information sharing, participation, and respect and dignity, and physical and cultural environment.

			FCC as outlined by the Institute for Patient and Family-Centered Care		
23	(Serlachius, Hames, Juth, Garton, Rowley and Keith J Petrie, 2018) New Zealand	Parental experiences of FCC from admission to discharge in the NICU	To examine parental experiences of FCC during both the admission and discharge time points to examine differences in parents' experiences and identify areas for improvement.	Mixed-method study	Parents identified support in the NICU as the main concept of FCC. Hence, supporting parents of high-risk neonates from admission to discharge will address barriers of FCC and family needs in the NICU and improve FCC practices.
24	(Hagen *et al.*, 2019) Norway	Parental satisfaction with NICUs: a quantitative cross-sectional study	We used the Neonatal Satisfaction Survey (NSS-8) to collect data to explore associations between parental satisfaction and socio-demographic variables and, associations between parents' satisfaction and NICU care services.	Quantitative study using nonparametric analyses and logistic regression.	Family satisfaction and their involvement in decision making are the key concept of FCC in Norwegian NICUs for continuity of care.
25	(Mol, Argent and Morrow, 2018) South Africa	Parental satisfaction with the quality of care in a South Ghanaian PICU	To explore parents' satisfaction with care in a PICU in South Africa	Quantitative perspective descriptive survey	In South Africa, parents were satisfied with the professional attitude of PICU clinicians, quality care, family involvement, and provision of adequate

					information in the PICU in practicing FCC
26	(Dahav and Sjöström-Strand, 2018) Sweden	Parents' experiences of their child being admitted to a PICU: a qualitative study like being in another world	To describe parents' experiences of having their child admitted to a PICU.	Qualitative design using content analysis.	Family involvement in PICU resulted in managing the stress and anxiety associated with their child's illness.
27	(Oxley, 2015) USA	Parents' experiences of their child's admission to PICU	To explore the lived experiences of parents whose children have been admitted to a PICU.	Heidegger's school of interpretative phenomenology	Provision of support, and information and communication will help reduce parental stress, anxiety, post-traumatic stress syndrome associated with transfer and admission into the PICU
28	(Raiskila *et al.*, 2017) **Europe** Finland, Estonia, Sweden, Norway, Italy, and Spain	Parents' presence and parent-infant closeness in 11 NICUs in six European countries vary between and within the countries	To explore physical parent-infant closeness in six European NICUs	Quantitative survey 11 NICUs in Finland, Estonia, Sweden, Norway, Italy, and Spain.	The most important factor supporting parent-infant closeness was the opportunity to stay overnight in the NICU.
29	(Maree *et al.*, 2017) South Africa	Quality Improvement Initiative for FCC in the NICU of a Tertiary Hospital in South Africa	To develop and implement a quality improvement initiative to foster FCC in a tertiary	Mixed methods	Bonding and attachment between the infants and their parents increased with FCC practice in the NICU and this is perceived to have

			NICU from birth onward		consequential long-term positive outcomes.
30	(Brødsgaard *et al.*, 2017) Denmark	Rallying the Troops: How Sharing Knowledge With Grandparents Supports the Family of the Preterm Infant in NICU	To describe the effect of having premature infants' extended families participating in FCC groups in the NICU.	Qualitative content analysis	Accepting the individuality, FCC group interventions, involving extended family are useful strategies to helping new families' with preterm in NICUs.
31	(Benzies, 2016) Canada	Relational Communications Strategies to Support FCC NICU	To briefly describe interventions designed to support the philosophy of FCC in NICUs and offer an evidence-based clinician's education strategy to facilitate relational communications in NICUs.	Intervention study using a qualitative appreciative inquiry approach to develop and qualitatively evaluate	The philosophy of FCC in NICUs include parental involvement, communication, and shared decision making to improved outcomes for infants and families.
32	(Dall'Oglio *et al.*, 2019) Italy	The current practice of FCC in Italian NICUs: A multi-center descriptive study	To explore FCC practices in Italian NICUs and describe areas for improvement.	Quantitative cross-sectional, multi-center, survey	FCC is considered important by Italian neonatology healthcare professionals who called for continuing education and training programmes for ICU clinicians to implement and support high-quality FCC practices in Italian NICUs.

33	(Heo and Oh, 2019) South Korea	The effectiveness of a parent participation improvement program for parents on the partnership, attachment infant growth in a NICU: A randomized controlled trial	To develop a Parent Participation Improvement Program for parents in NUCUs, and to evaluate its effects on parents' partnerships with nurses, attachment to infants, and infants' body weight	Randomized controlled trial in two phases using the Methods King's theory of goal attainment as the theoretical framework	Partnerships, attachment, and communication as important concepts of FCC for families which improved their participation and newborn outcomes in the NICU.
34	(Benzies *et al.*, 2019) Canada	The health care system is making 'too much noise' to provide family-centered care in NICUs: Perspectives of health care providers and hospital administrators	To describe the perspectives of health care providers and hospital administrators on their experiences of providing care for infants in NICUs and their families.	Qualitative study using a descriptive interpretive approach.	Improvements in staffing models, enhancing professional development, providing tools to deliver consistent care, optimize parental capacity to be involved in care, strengthening continuity of care, supporting families to be with their infant, and designing family-friendly environments are key to FCC implementation in NICUs.
35	(Hadian Shirazi *et al.*, 2015) Iran	The Obstacles against Nurse-Family Communication in FCC in the NICU: a Qualitative Study	To recognize the obstacles against nurse family communication in the FCC in the NICU.	Qualitative study using inductive content analysis.	Identification of the obstacles against nurse-family communication helps managers of healthcare systems to plan and eliminate the challenges of effective communication.

36	(Van Den Berg *et al.*, 2017) Sweden	Transition to a New NICU: Positive Effects on Clinicians Working Environment and How the Physical Environment Facilitates FCC	To evaluate the effects of a purpose-built neonatal ward on clinicians' perceptions of job strain, the psychosocial climate, and the appropriateness of the physical environment	Longitudinal cohort intervention study	NICU design according to national and international recommendations provided a more suitable working environment in terms of less trained personnel, and a more caring physical and psychosocial environment for infants, and family members
37	(Frechette *et al.*, 2019) Canada	When the PICU becomes home: A hermeneutic-phenomenological study	To examine PICU nurses' lived experience of caring for families following a major hospital transformation project, which included the construction of a new unit and quality improvement changes.	Hermeneutic-phenomenological design	Nurses negotiating spaces with families resulted in making families feel at home and improved outcomes in PICUs.
38	(Austin, Downing, and Hastings-Tolsma, 2019) South Africa	Experience of NICU nurses in providing developmentally-supportive care: A qualitative study	This study aimed to explore and describe compliance in adhering to developmentally-supportive care principles implemented in one NICU in South Africa	Exploratory qualitative design	Development and revision of policies and practices, are crucial to implementing developmentally supportive care, particularly in resource-poor settings where challenges are magnified.

39	(Skelton *et al.*, 2019) Australia	Facilitating closeness between babies with congenital abnormalities and their parents in the NICU: A qualitative study of neonatal nurses' experiences	To explore the experiences of neonatal nurses with facilitating closeness between parents and babies with congenital abnormalities in the NICU	Qualitative interpretive description study	Individualized supportive care for parents is needed for families with congenitally abnormal child in NICU.
40	(Stefana *et al.*, 2018) Italy	Fathers' experiences with their preterm babies admitted to NICU: A mixed method study	To investigate fathers' emotional experiences of their infant's preterm birth and subsequent stay in the NICU.	Mixed method approach	Provision of varied family support for families with critically ill babies is an important concept for FCC implementation in the NICU.
41	(Uhm and Kim, 2019) Republic of Korea	Impact of the mother–nurse partnership programme on mother and infant outcomes in the paediatric cardiac ICU	To identify the effects of a mother–nurse partnership programme based on the core components of information sharing, negotiation, and participation in care.	Quasi-experimental study	Collaboration and information sharing between nurses and mothers positively influence mothers' emotional and cognitive outcomes, parental satisfaction, parental self-efficacy, perceived partnership, and anxiety.
42	(Sanabria and de Rodríguez, 2016) Colombia	Needs of parents in caring for their children in a PICU	To describe the needs of parents to participate in caring for their children hospitalized in a PICU)	Qualitative study based on the ethno-nursing research method proposed by Leininger.	Knowledge on the cultural perspective of parents with children hospitalized in PICU are vital input to plan and develop care actions to meet their needs.

43	(Tandberg *et al.*, 2018) Norway	Parent-Infant Closeness, Parents' Participation, and Nursing Support in Single-Family Room and Open Bay NICUs	To prospectively measure and compare parent-infant closeness as parental presence and Skin-Skin Contact.	Quantitative prospective study	Support from nurses for parents with critically ill children will facilitate their participation in the care processes
44	(Foster *et al.*, 2018) Australia	Parents' and Clinicians Perceptions of Parental Needs During a Child's Hospital Admission: An Australian Study	To describe and examine the relationship between the clinicians and parents' perception of parents' needs within one Australian hospital.	Quantitative cross-sectional descriptive design	FCC practice should be aligned to the needs of children and their family in the ICUs.
45	(Widding, Hägglöf and Farooqi, 2019) Sweden	Parents of preterm children narrate constructive aspects of their experiences	To explore how parents of preterm infants express then constructive aspects of their experiences.	Qualitative study Using thematic analysis.	Assisting parents to understand their child's illness will activate appropriate social support in the ICUs.
46	(Lundqvist, Weis and Sivberg, 2019) Denmark	Parents' journey caring for a preterm infant until discharge from hospital-based neonatal home care: A challenging the process to cope with	To present parents' lived experience of having a preterm infant cared for at the NICU discharge from hospital-based neonatal home care	Descriptive phenomenological study .	Healthcare providers need to help parents clarify their individual needs and values in caring for a preterm infant to help them achieve parental and family well-being.
47	(Saria, Mselle and Siceloff, 2019)	Parents and nurses telling their stories: the perceived needs of parents caring for critically ill children at the Kilimanjaro	To describe the needs of parents caring for hospitalized critically ill children, as	Descriptive qualitative research design	Nurses in ICU should continuously support, inform, and engage parents as well as understand their needs to integrate them into the

	Tanzania	Christian Medical Centre in Tanzania	perceived by parents and nurses.		daily care via flexible visiting times.
48	(Discenza, 2018) United States	Providing Equal Family-Centered Care in Every NICU	To support parents and ease the family-centered care strain on NICUs	Qualitative study	Increased family teaching through online engagements will promote support to families in the NICU.
49	(Hernández, Grillo and Lovera, 2016) Colombia	Strategies for neonatal developmental care and family-centered neonatal care	To evaluate neonatal developmental care and FCC in a NICU	Participatory action research	Strategies for proving FCC in the NICU include education and communication.
50	(Fowler *et al.*, 2019) United Kingdom	The forgotten mothers of extremely preterm babies: A qualitative study	To explore the experiences of mothers of extremely premature babies during their NICU stay and transition home.	Qualitative interpretive description method	Families are at risk of post-traumatic stress symptoms and/or other mental health issues in the NICU if they are neglected. Hence psychological needs of families must be addressed by ICU clinicians.
51	(Abuidhail *et al.*, 2017) USA	The Lived Experience of Jordanian Parents in a NICU: A Phenomenological Study	To describe the lived experiences, needs in relation to care, and support systems of parents whose neonates were admitted to the NICU	Qualitative design using a phenomenological approach	NICUs Nurses must develop interventions and strategies that decrease the stress and provide emotional support of parents to deal with the stress
52	(Vasey *et al.*, 2019)	Tokenism or true partnership: Parental involvement in a child's acute pain care	To explore parental involvement in the child's acute pain care and establish ways in which parental	Qualitative study using an ethnographical approach	Parental involvement in their child's acute pain care can improve the child's pain experience, reduce parental anxiety,

	UK		preferences for involvement in their child's care can be identified, facilitated, and enhanced by nurses.		and increase parents' satisfaction in care.

APPENDIX B

Overview of model development processes

Author, date Country	Model	Purpose	Methodology	Development process	Strengths and weaknesses
1. (Nastasi *et al.*, 1998) Sri Lanka	The Participatory Intervention Model	To develop a participatory intervention model for mental health programming	Qualitative Participatory Action Research	Engagement of stakeholders in discussions for the themes of the model to emerged	Participant driven but lack clear cut methodological steps. Only qualitative techniques employed.
2. (Overland *et al.*, 2009) Australia	Model of Care (MoC)	To outline the processes used in developing a model to improve service delivery	Mixed methods	Five stage: 1. Project Initiation: Identify services for review, 2. Diagnostic: Define the extent of the problem 3. Solution Design: Develop and select solutions. 4. Implementation: Support the health system to deliver the changes needed 5. Sustainability: Optimize use of the MoC, monitor the results and evaluate the impact	The methodology is extensive but require capital as well as project management team skills over a long period to execute.
3. (Staniszewska *et al.*, 2012) United Kingdom	The POPPY Model for Neonatal Units	To develop the first international model of family-centred care based on strong parental collaboration in the synthesis of robust research evidence to generate the philosophy,	Multi-method	Seven Steps: 1. Step 1: systematic review 2. Step 2: qualitative study 3. Step 3: identifying the philosophy and principles. 4. Step 4 identifying the key stages. 5. Step 5 populated the POPPY model of care. 6. Step 6: developing the indicators of family-centred care; and	Systematically developed but rather illness specific and lack proper data triangulation especially quantitatively.

		principles, model, and indicators for implementation.		7. Step 7: initial testing.	
4. (Kidholm *et al.*, 2012) Denmark	Model of Assessment of Telemedicine (MAST)	To develop an assessment model for telemedicine application	Systematic review	Steps: 1. Systematic review on assessment models 2. Series of stakeholders' engagement in workshops for the model to emerged.	A general framework for assessment has been developed but it lacks rigour in the methodological processes e.g., empirical testing process
5. (Beeson *et al.*, 2020) United States	The Emergency Medicine Model for clinical practice	To develop a model of clinical care for emergency medicine speciality	Clinical Case studies	Two steps: Step 1: Extensive data collection from clinical practice Step 2: Expert panel review of the data collected	Model emerged from direct patient care in clinical practice, however, the methodological pathways are unclear.
6. (Salisbury *et al.*, 2015) United Kingdom	Conceptual model of Telehealth for Chronic disease intervention	To develop a conceptual model for effective use of telehealth in the management of chronic health conditions, and to use this to develop and evaluate an intervention for people with two exemplar conditions: raised cardiovascular	Mixed Method	Five steps: 1. Metareview and realist synthesis 2. Qualitative study 3. Quantitative survey of patients 4. Model comparisons 5. Analysis of national guidelines.	Evidenced-based conceptual model provides framework for interventions and evaluation in disease management. However, stakeholder consultation and expert engagement particularly in Delphi was lacking, and does not crate room

		disease risk and depression			for the testing of the model.
7. (Starling, 2018) United Kingdom	Model of Care for programming	To develop a model of care for programming health care.	Qualitative	Steps: 1. Interviews with stakeholders 2. Systematic review.	Showed possible evidence of model development from only interviews but lack proper methodological regour.
8. (Huybrechts *et al.*, 2021) United States	Primary Health care Implementation Model	To identify the core building blocks of existing implementation frameworks and models, which can be used as a basis to further develop a framework for the implementation of complex interventions within primary care practices.	Narrative review	A narrative review was conducted, searching for papers that describe models for implementation by means of various search terms, and a snowball approach	Provided the building blocks of a model but the methodology is weak.
9. (Sampaio, Sequeira and Lluch Canut, 2018) Portugal & Spain	Nursing models	To explore the aspects set forth as the minimum set of features that should integrate a psychotherapeutic intervention model in nursing	Qualitative study	Focus group discussions were conducted and analysed for the themes of nursing models.	Identified features to be included in nursing models. But the process is not iterative.

10. (McGuire, Schultz and Kelly, 2021) Australia	Model of Care for new design	To develop a model of care using Delphi study	Delphi study	Two round Delphi of recovery nurses from 13 countries	A model of care to ensure safety and quality is developed but lacks regour and iterations in methodology.
11. (Squires *et al.*, 2016) United Kingdom	Conceptual Intervention model framework	To develop an intervention model through an iterative methodological processes	Mixed method	Six steps: 1. Defining and understanding the problem, 2. Identifying the causal factors and the contextual factors that can be modified or changed, 3. Identifying the mechanism of change, 4. Clarifying how the change was delivered or achieved, 5. Testing and adapting the intervention or model on a small scale, and 6. Evaluation and implementation of the model.	This model development processes are iterative with room for testing and evaluation of the model for sound academic rigour but requires expertise and time. Decision: adapted
12. (Minkman, Ahaus and Huijsman, 2009) Netherlands	Integrated care Development Model	To explore how local integrated care services are developed in the Netherlands, and to conceptualize and operationalize a development model of integrated care	Mixed method	Four phases: 1. Phase 1: Literature synthesis 2. Phase 2: 3 round Delphi study 3. Phase 3: Qualitative study 4. Phase 4: Quantitative survey	The process is iterative but lacks testing and evaluation of the model for generalization.
13. (White *et al.*, 2017)	New care Model for hospitalized children	To develop a new care model for hospitalized children	Mixed method	Two phases: Phase 1: qualitative study Phase 2: Quantitative study	A multidisciplinary team was employed in the model development; however, the development process

United States					lacks testing and evaluation for validity and reliability.
14. (Morgan, 2017) United States	Dewey's Model of inquiry	To develop a model of pragmatism	Mixed method	Dewey's five steps: 1. recognizing a problem 2. problem reflection 3. suggested solution, which is, developing a possible line of action as a response to the problem by recognizing possible outcomes that will address the problem 4. evaluating potential actions regarding their likely consequences, and 5. taking actions that will likely address the problem identified	The model accommodates mixed method and hence is robust for the development of models. It is however useful for research that belief in pragmatism alone. Decision: adapted

APPENDIX C

INFORMATION SHEET FOR INDIVIDUAL INTERVIEW

Introduction

My name is Abukari Alhassan Sibdow, a Registered Nurse from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I am conducting research that will culminate in the development of a model of family-centred care at the intensive care for Ghana.

Why am I doing the study?

Family-centred Care (FCC) is an approach of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients'. Quality and safe healthcare can be improved by allowing collaborative involvement of the family in the care of their clients especially when they are children. Until you have one of your own admitted at the Neonatal Intensive Care Unit (NICU), you will think NICUs are the custodians of FCC. The NICU is a complex clinical setting where less attention is given to the family and more emphasis placed on the clinical needs of the patient. The FCC has not clearly been described as a model but rather an approach of involving family members in patient care. There is, therefore, a wide theory-practice gap in FCC for sick children especially infants at the NICU, and that calls for more research in the area to foster family satisfaction and quality childcare, after all, they will continue the child's treatments at home for a full recovery. The primary purpose of this research is to study Family-centred Care (FCC) at the intensive care settings and develop and evaluate a model on FCC for hospitalized children. This study will be conducted at the paediatric/neonatal intensive care unit of the hospital.

What am I asking you to do?

I am inviting you to participate in the study as a key informant in the area of paediatric/intensive/critical care/nursing and give your inputs on family-centred care in the intensive care setting in Ghana. The discussion will take about 30 minutes. I am interested in your views and experiences on the subject so there is no right or wrong answer. Your participation is purely voluntary. You will be required to give additional comments at the concluding part of this interview.

How do you know that the information you give to me will not get out to others?

The information that you give in the interview will be kept confidential. All the questionnaires will be assigned codes. The information from all the questionnaires will be analysed and reported as key informant data.

What about permission to do the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics Committee (Medical) and the ethics committee of Korlebu Teaching Hospital, Accra and that of the Tamale Teaching Hospital, Tamale.

Are there any benefits and risks of participation?

Participation in this study is voluntary. There will be no direct benefits or compensation for anyone who completes the interviews. Similarly, there will be no negative consequences for individuals who do not wish to participate in the interview.

Whom do you contact if you want more information?
For more information or queries regarding the study, please contact me on:
Tel: +233 242888091/ + 233 208726254 Email: 2103642@students.wits.ac.za
Or my supervisor: Prof. Shelley Schmollgruber Tel. +27 114884270

Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):
Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za

Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za
And Rhulani.Munkansi@wits.ac.za

Yours faithfully,



_____
ABUKARI ALHASSAN SIBDOW
(RESEARCHER)

APPENDIX D

INFORMED CONSENT FOR KEY INFORMANTS

I have been given the information sheet on the project entitled: **model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.** I have read and understood the Information Sheet and all the questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Participants signature/initials: …… Date…….

Interviewer's Signature ……. Date……..

APPENDIX E

INFORMED CONSENT FOR VOICE INFORMED CONSENT FOR VOICE RECORDING OF INDIVIUDAL INTERVIEWS

I have been given the information sheet on the project entitled "**model of Family-centred Care in the paediatric and neonatal intensive care setting in Ghana***".* I have read and understood the Information Sheet and all my questions have been answered satisfactorily.

I understand that I can decide whether or not the interview should be voice-recorded and that there will be no consequences for me if I do not want the interview to be recorded.

I understand that voice-recorded information will be transcribed, and transcripts will be given a code and my name will not be mentioned. I understand that the device used for the voice recording will be destroyed two years after publications of the findings.

I understand that I can ask the person interviewing me to stop voice-recording and to stop the interview altogether, at any time.

I can also call to inquire anything concerning this study from Prof Penny, Chair of the Human Research Ethics Committee (HREC), the University of the Witwatersrand at Email: Clement.Penny@wits.ac.za.

I consent voluntarily for the researcher to record the interview.

Participants signature/initials:	……	Date…….
Interviewer's Signature	…….	Date……..

APPENDIX F

QUALITATIVE INTERVIEW GUIDE FOR PHASE ONE STAGE TWO

Date of interview……..

Name of facilitator…….

Name of facility…….

Language used……..

Duration of Interview…….

NB: The discussion is on Family-Centred Care (FCC) at the Neonatal/Paediatric Intensive Care Unit (NICU) and is defined in this context as a philosophy and method of service delivery for sick children and their parents which emphasizes on a partnership between parents and service providers, focuses on the family's role in decision-making about their child, and recognizes parents as experts on their child's health status and needs.

Interview probes:

1. *Socio-demographic factors: age, profession, years of work, babies' condition etc*
2. *Individual experiences: What are your lived experiences of family involvement in the NICU/PICU?*
3. *Family needs: What will you consider as the needs of families at the NICU/PICU?*
4. *Family involvement: how do you involve families in the care of their babies at NICU/PICU?*
5. *FCC Barriers: What will you say are the challenges/barriers of family involvement in the NICU/PICU?*
6. *Dignity & respect: How do you handle the dignity and respect (privacy & confidentiality) of families and their babies at NICU/PICU?*
7. *NICU Communication: Describe how you communicate (share information) to families in the NICU/PICU?*
8. *NICU Participation: what can be done to support family participation (involvement) in the care at the NICU/PICU?*
9. *Collaboration in care: How do you collaborate (team up) with families at the NICU especially in relation to; assessment, decision making, and care delivery during admission at the NICU/PICU?*
10. *Benefits of FCC: In your opinion, describe the importance of FCC implementation in the NICU/PICU?*
11. *General comments: What are your suggestions/recommendation on how to get the FCC model part of the daily NICU/PICU services?*

APPENDIX G

PARENTS INFORMATION SHEET FOR FOCUS GROUP DISCUSSIONS

Introduction

My name is Abukari Alhassan Sibdow, a Registered Nurse from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I am conducting research that will culminate in the development of a model of family-centred care at the intensive care for Ghana.

Why am I doing the study?

Family-centred Care (FCC) is an approach of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients'. Quality and safe healthcare can be improved by allowing collaborative involvement of the family in the care of their clients especially when they are children. Until you have one of your own admitted at the Neonatal Intensive Care Unit (NICU), you will think NICUs are the custodians of FCC. The NICU is a complex clinical setting where less attention is given to the family and more emphasis placed on the clinical needs of the patient. The FCC has not clearly been described as a model but rather an approach of involving family members in patient care. There is, therefore, a wide theory-practice gap in FCC for sick children especially infants at the NICU, and that calls for more research in the area to foster family satisfaction and quality childcare, after all, they will continue the child's treatments at home for a full recovery. The primary purpose of this research is to study Family-centred Care (FCC) at the intensive care settings and develop and evaluate a model on FCC for hospitalized children. This study will be conducted at the paediatric/neonatal intensive care unit of the hospital.

What am I asking you to do?

I am inviting you to participate in the FGDs as a parent and give your inputs on family-centred care in the intensive care setting in Ghana. The discussion will take about 30-45 minutes. I am interested in your views and experiences on the subject so there is no right or wrong answer. Your participation is purely voluntary. You will be required to give additional comments at the concluding part of this interview.

How do you know that the information you give to me will not get out to others?

The information that you give in the interview will be kept confidential. All the questionnaires will be assigned codes. The information from all the questionnaires will be analysed and reported as key informant data.

What about permission to do the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics Committee (Medical) and the ethics committee of Korlebu Teaching Hospital, Accra and that of the Tamale Teaching Hospital, Tamale.

Are there any benefits and risks of participation?

Participation in this study is voluntary. There will be no direct benefits or compensation for anyone who completes the interviews. Similarly, there will be no negative consequences for individuals who do not wish to participate in the interview.

Whom do you contact if you want more information?
For more information or queries regarding the study, please contact me on:
Tel: +233 242888091/ + 233 208726254 Email: 2103642@students.wits.ac.za
Or my supervisor: Prof. Shelley Schmollgruber Tel. +27 114884270
.
Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):
Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za

Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za
And Rhulani.Munkansi@wits.ac.za
Yours faithfully,



_____
ABUKARI ALHASSAN SIBDOW
(RESEARCHER)

APPENDIX H

PARENT INFORMED CONSENT FOR FOCUS GROUP DISCUSSIONS (FGDs)

I have been given the information sheet on the project entitled: a **model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.** I have read and understood the Information Sheet and all the questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else.

I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Participants signature/initials: …… Date…….

Interviewer's Signature ……. Date……..

APPENDIX I

PARENT INFORMED CONSENT FOR VOICE-RECORDING OF FOCUS GROUP DISCUSSIONS (FGDs)

I have been given the information sheet on the project entitled "**model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana***".* I have read and understood the Information Sheet and all my questions have been answered satisfactorily.
I understand that I can decide whether or not the interview should be voice-recorded and that there will be no consequences for me if I do not want the interview to be recorded.

I understand that voice-recorded information will be transcribed, and transcripts will be given a code and my name will not be mentioned. I understand that the device used for the voice recording will be destroyed two years after publications of the findings.

I understand that I can ask the person interviewing me to stop voice-recording and to stop the interview altogether, at any time.

I can also call to inquire anything concerning this study from Prof Penny, Chair of the Human Research Ethics Committee (HREC), the University of the Witwatersrand at Email: Clement.Penny@wits.ac.za.

I consent voluntarily for the researcher to record the interview.

Participants signature/initials: …… Date…….

Interviewer's Signature …… Date……..

APPENDIX J

INFORMATION SHEET FOR SURVEY

Introduction

My name is Abukari Alhassan Sibdow, a Registered Nurse from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I am conducting research that will culminate in the development of a model of family-centred care at the intensive care for Ghana.

Why am I doing the study?

Family-centred Care (FCC) is an approach of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients'. Quality and safe healthcare can be improved by allowing collaborative involvement of the family in the care of their clients especially when they are children. Until you have one of your own admitted at the Neonatal Intensive Care Unit (NICU), you will think NICUs are the custodians of FCC. The NICU is a complex clinical setting where less attention is given to the family and more emphasis placed on the clinical needs of the patient. The FCC has not clearly been described as a model but rather an approach of involving family members in patient care. There is, therefore, a wide theory-practice gap in FCC for sick children especially infants at the NICU, and that calls for more research in the area to foster family satisfaction and quality childcare, after all, they will continue the child's treatments at home for a full recovery. The primary purpose of this research is to study Family-centred Care (FCC) at the intensive care settings and develop and evaluate a model on FCC for hospitalized children. This study will be conducted at the paediatric/neonatal intensive care unit of the hospital.

What am I asking you to do?

I am inviting you to participate in the FGDs as a relevant resource person in the area of paediatric/intensive/critical care/nursing and give your inputs on family-centred care in the intensive care setting in Ghana. The discussion will take about 30-45 minutes. I am interested in your views and experiences on the subject so there is no right or wrong answer. Your participation is purely voluntary. You will be required to give additional comments at the concluding part of this interview.

How do you know that the information you give to me will not get out to others?

The information that you give in the interview will be kept confidential. All the questionnaires will be assigned codes. The information from all the questionnaires will be analysed and reported as key informant data.

What about permission to do the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics, the ethics committee of Korlebu Teaching Hospital, Accra, and the ethics committee of the Tamale Teaching Hospital, Tamale.

Are there any benefits and risks of participation?

Participation in this study is voluntary. There will be no direct benefits or compensation for anyone who completes the interviews. Similarly, there will be no negative consequences for individuals who do not wish to participate in the interview.

Whom do you contact if you want more information?
For more information or queries regarding the study, please contact me on:
Tel: +233 242888091/ + 233 208726254 Email: 2103642@students.wits.ac.za
Or my supervisor: Prof. Shelley Schmollgruber Tel. +27 114884270
.
Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):
Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za

Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za
And Rhulani.Munkansi@wits.ac.za

Yours faithfully,



_____
ABUKARI ALHASSAN SIBDOW
(RESEARCHER)

APPENDIX K

INFORMED CONSENT FOR SURVEY

I have been given the information sheet on the project entitled: a **model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.** I have read and understood the Information Sheet and all the questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Participants signature/initials: …… Date…….

Interviewer's Signature ……. Date……..

APPENDIX L

FAMILY: DATA COLLECTION INSTRUMENT FOR SURVEY

Confidential

FAMILY: Family centered Care At The Neonatal And Paed

Record ID _____

Record ID _____

INFORMED CONSENT

Information: This survey is about Family-Centred Care (FCC) at the Neonatal/Paediatric Intensive Care Unit (NICU/PICU). FCC is defined in this context as an approach of service delivery for sick children and their parents which emphasizes a partnership between parents and service providers. It focuses on the family's role in decision-making about their child and recognizes parents as experts on their child's health status and needs.
The survey tool is in two sections; section A is your biodata and section B is on the concepts of Family-Centered Care in the intensive care. Section B is in 6 sub-sections of dignity/respect, participation, communication, collaboration, barriers of FCC, and Benefits of FCC.
Participant' code is a letter-numeric code that you will be given to ensure anonymity. It will consist of a letter (use the first letter of your name) followed by a case number (referring to the order that participants surveyed). For example, if your name is YASIR and you are the first participant, the "Participant Code" in this case will be Y01

Informed Consent for survey
I have been given the information sheet on the project entitled: a model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.
I have read and understood the Information Sheet and all the questions have been answered satisfactorily.
I understand that it is up to me whether I would like to participate in the survey and that there will be no negative consequences if I decide not to participate.
I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the survey at any time.
I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else.
I understand that selecting "Yes", I consent voluntarily to participate in the survey for this study.

◯ Yes
◯ No

SECTION A: Demographic Data of Staff **Please choose the options applicable to you for each of the following demographics**	
Name of Hospital	◯ Korlebu Teaching Hospital ◯ Tamale Teaching Hospital
Age (Years)	_____
Gender	◯ Male ◯ Female ◯ Other
Relationship to patient	◯ Father ◯ Mother ◯ Spouse/partner ◯ Sibling ◯ Other
Ethnic group	_____
Religion	◯ Christian ◯ Moslem ◯ Traditional ◯ Others
Marital status	◯ Single ◯ Married ◯ Co-habitation ◯ Divorce ◯ Widow ◯ Other
Education	◯ No education ◯ Basic education ◯ Secondary education ◯ Tertiary education
Occupation	◯ Employed (public sector) ◯ Employed (private sector) ◯ Self-employed ◯ Unemployed
Parity	_____
Number of Antenatal Clinic visits during pregnancy	◯ 0 ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10

Admission type	◯ On-delivery ◯ Emergency ◯ Trans-in ◯ OPD
Gender of child	◯ Male ◯ Female
Gestational age at birth (weeks)	_____
Birth weight	_____
Delivery level	◯ Single ◯ Multiple
Mode of delivery	◯ Safe vaginal delivery ◯ Assisted vaginal delivery ◯ Caesarian section
Breastfeeding initiated after birth	◯ Yes ◯ No
How will you describe the child's condition?	_____
Duration of stay (days)	_____
Treatment(s) provided for baby (Choose all applicable)	☐ Antibiotics ☐ Glucose ☐ Phototherapy ☐ Resuscitation ☐ Ventilator ☐ Incubator care ☐ Surgery ☐ Others
Average monthly income of the family	_____

SECTION B: CONCEPTS OF FAMILY-CENTRED CARE IN THE INTENSIVE CARE
Instruction: Please indicate your level of agreement by inputting the corresponding number
1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree
(1 & 2 = Negative practice; 3 & 4 = Positive practice)

SUB-SECTION 1 (6 items)

Dignity & Respect: It implies the health care providers listen to and honour patient and family perspectives and their needs, choices, values, beliefs, privacy, and confidentiality

1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree (1 & 2 = Negative practice; 3 & 4 = Positive practice)

	Strongly disagree	Disagree	Agree	Strongly agree
I feel accepted by staff in the ICU regardless of sociocultural backgrounds	○	○	○	○
I feel my privacy and confidentiality is ensured by ICU staff	○	○	○	○
I want the staff to respond positively to my psychological needs and that of my family in the NICU/PICU	○	○	○	○
I want the staff to communicate positively with me and my family in a respectful manner	○	○	○	○
I want the facility to provide comfortable furniture in the waiting room/area in the ICU for me and my family	○	○	○	○
I want the Staff in ICU to provide care that respect my religion and culture	○	○	○	○

SUB-SECTION 2 (10 items)

Communications: Implies the health care providers communicate and share complete and unbiased information with patients and families

1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree (1 & 2 = Negative practice; 3 & 4 = Positive practice)

	Strongly disagree	Disagree	Agree	Strongly agree
I want the staff to effectively communicate with me and my family at all the time	○	○	○	○
I want to know about the types of medical staff taking care of my patient	○	○	○	○
I want to know how my child is being treated medically	○	○	○	○

I want to be orientated on the ward environment and protocols	○	○	○	○
I want the staff answer my questions honestly	○	○	○	○
I want to be told about transfer plans while they are being made	○	○	○	○
I want the staff to provide me regular information on the progress of my child's condition	○	○	○	○
I want the staff to explain my child's condition and ICU care processes to me in simple terms	○	○	○	○
I want the staff to educate me on my childcare including feeding and clothing during hospitalization at the ICU	○	○	○	○
I want the staff to build rapport and reassure my family in all phases of care in the ICU	○	○	○	○

SUB-SECTION 3 (8 items)
Participation (Involvement): Patients and families are encouraged and supported in participating and involving in care and decision-making about their child's health
1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree (1 & 2 = Negative practice; 3 & 4 = Positive practice)

	Strongly disagree	Disagree	Agree	Strongly agree
I want the staff to involve me in the feeding, bathing, and clothing of my critically ill child	○	○	○	○
I want to be supported financially by the hospital for my childcare through the social welfare department	○	○	○	○
I want accommodation and food to be provided for me and my family whilst my baby is at NICU/PICU	○	○	○	○
I want to be involved in all stages of decision making about my childcare in the NICU/PICU	○	○	○	○
I want a well-stocked in-house pharmacy and laboratory services at the NICU/PICU for prompt care of my child	○	○	○	○

I need more space in the NICU for me and my family to bond and practice Kangaroo Mother Care (KMC)	○	○	○	○
I want the staff to provide regular education and counselling sessions for me and my family in the NICU/PICU	○	○	○	○
I want the facility to provide me and my family with adequate PPEs to participate in the care of our critically ill child	○	○	○	○

SUB-SECTION 4 (9 items)
Collaboration: Patients, families, and providers collaborate (team-up) in care, training, policy, and program development to implement FCC

	Strongly disagree	Disagree	Agree	Strongly agree
I want the facility to have guidelines and policy on FCC that addresses my needs and respect me as expert in the care of my child	○	○	○	○
I want government set up National child health Fund to support quality child health care services in the country	○	○	○	○
I want the curriculum for training doctors, nurses, and midwives to have FCC incorporated	○	○	○	○
I want the NICU/PICU to be family friendly and inclusively spaciously designed	○	○	○	○
I want the NICU/PICU to be designed into sub-units based on my child's condition	○	○	○	○
I want the staffs to have regular training on newborn & infant care and the concepts of FCC	○	○	○	○
I want NICU/PICU to have adequate logistics including ventilators, SPO2 monitors, flow meters, and phototherapy machines, and consumables	○	○	○	○

I want my baby to be immunized (if allowed) during our stay in the NICU	○	○	○	○
I want the ICU to have adequate specialized professionals including neonatal nurses, pediatric nurses, Paediatricians, and intensive care nurses and doctors to meet our needs	○	○	○	○

SUB-SECTION 5 (7 items)

Barriers of FCC: These are factors that hinder the effective implementation and integration of the FCC concepts in the intensive care units

	Strongly disagree	Disagree	Agree	Strongly agree
Inadequate space in the intensive care to accommodate families and implement FCC	○	○	○	○
Inadequate logistics including ventilators, incubators, bilirubinometer, photo machines, and SPO2 monitors	○	○	○	○
Inadequate specialized personnel in intensive care, neonatal care, paediatrics, and psychologist at the NICU/PICU	○	○	○	○
Lack of financial support for families for funding the expensive ICU services	○	○	○	○
Some families abandon their babies in the ICU	○	○	○	○
Lack of guidelines, policy, and protocols on FCC at the ICU	○	○	○	○
Families may be a source of infection to critically ill children at the ICU	○	○	○	○

SUB-SECTION 6 (6 items)

Benefits of FCC: These are the importance of family involvement in the care of critically ill neonates and infants in the intensive care units

	Strongly disagree	Disagree	Agree	Strongly agree

FCC practices serves as a school for family especially new families to empower them to continue appropriate childcare at home after discharge	○	○	○	○
FCC practices reduce anxiety and motivates psychologically stressed families to support/participate in care of critically ill children	○	○	○	○
FCC practices promote bonding and initiates good parenting for critically ill children	○	○	○	○
FCC practices promote early recovery and shorten the length of hospitalization of child and family at the intensive care	○	○	○	○
I play significant roles in providing timely information and resources to support clinical care of my critically ill child	○	○	○	○
FCC practices reduces legal infractions as they are well informed of the care processes	○	○	○	○

APPENDIX M

STAFF: DATA COLLECTION INSTRUMENT FOR SURVEY

Confidential

STAFF: Family-Centered Care at the neonatal and paediatric intensive care

Record ID _____

INFORMED CONSENT

Information: This survey is about Family-Centred Care (FCC) at the Neonatal/Paediatric Intensive Care Unit (NICU/PICU). FCC is defined in this context as an approach of service delivery for sick children and their parents which emphasizes a partnership between parents and service providers. It focuses on the family's role in decision-making about their child and recognizes parents as experts on their child's health status and needs.
The survey tool is in two sections; section A is your biodata and section B is on the concepts of Family-Centered Care in the intensive care. Section B is in 6 sub-sections of dignity/respect, participation, communication, collaboration, barriers of FCC, and Benefits of FCC.
Participant' code is a letter-numeric code that you will be given to ensure anonymity. It will consist of a letter (use the first letter of your name) followed by a case number (referring to the order that participants surveyed). For example, if your name is YASIR and you are the first participant, the "Participant Code" in this case will be Y01

Informed Consent for survey
I have been given the information sheet on the project entitled: a model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.
I have read and understood the Information Sheet and all the questions have been answered satisfactorily.
I understand that it is up to me whether I would like to participate in the survey and that there will be no negative consequences if I decide not to participate.
I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the survey at any time.
I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else.
I understand that selecting "Yes", I consent voluntarily to participate in the survey for this study.

◯ Yes
◯ No

SECTION A: Demographic Data of Staff
Please choose the options applicable to you for each of the following demographics

Name of Hospital

◯ Korlebu Teaching Hospital
◯ Tamale Teaching Hospital

Age (Years) _____

Gender	◯ Male ◯ Female ◯ Other
Ethnic group	_____
Religion	◯ Christian ◯ Moslem ◯ Traditional ◯ Others
Marital status	◯ Single ◯ Married ◯ Co-habitation ◯ Divorce ◯ Widow ◯ Other
Qualification	◯ Certificate ◯ Diploma ◯ Degree ◯ Masters ◯ Doctoral
Profession	_____
Specialization	_____
Years of practice	_____

SECTION B: CONCEPTS OF FAMILY-CENTRED CARE IN THE INTENSIVE CARE
Instruction: Please indicate your level of agreement by inputting the corresponding number
1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree
(1 & 2 = Negative practice; 3 & 4 = Positive practice)

SUB-SECTION 1 (6 items)

Dignity & Respect: It implies the health care providers listen to and honour patient and family perspectives and their needs, choices, values, beliefs, privacy, and confidentiality

1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree (1 & 2 = Negative practice; 3 & 4 = Positive practice)

	Strongly disagree	Disagree	Agree	Strongly agree
To have staff in the ICU accept family regardless of sociocultural backgrounds	◯	◯	◯	◯

To ensure privacy and confidentiality of families and their children in the NICU/PICU	○	○	○	○
To have staffs respond positively to the psychological needs of families in the NICU/PICU	○	○	○	○
To have staff communicate positively with family in a respectful manner	○	○	○	○
To have comfortable furniture in the waiting room/area	○	○	○	○
To have staff provide care that respect the religion of the child and family in the NICU/PICU	○	○	○	○

SUB-SECTION 2 (10 items)
Communications: Implies the health care providers communicate and share complete and unbiased information with patients and families
1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree (1 & 2 = Negative practice; 3 & 4 = Positive practice)

	Strongly disagree	Disagree	Agree	Strongly agree
To have staff communicate effectively with families all the time	○	○	○	○
To provide information about the types of staff members taking care of the patient to the families	○	○	○	○
To know how the patient is being treated medically	○	○	○	○
To have families orientated on the ward environment and protocols	○	○	○	○
To have questions answered honestly sought by family	○	○	○	○
To inform families about transfer plans while they are being made	○	○	○	○
To provide regular information on the progress of child's condition to family	○	○	○	○
To explain child's condition and ICU care processes to families in simple terms	○	○	○	○

To educate families on newborn and infant care including feeding and clothing during hospitalization at the NICU/PICU	○	○	○	○
To build rapport and reassure family in all phases of care in the NICU/PICU	○	○	○	○

SUB-SECTION 3 (8 items)
Participation (Involvement): Patients and families are encouraged and supported in participating and involving in care and decision-making about their child's health
1= Strongly disagree; 2= Disagree; 3= Agree; & 4= Strongly agree (1 & 2 = Negative practice; 3 & 4 = Positive practice)

	Strongly disagree	Disagree	Agree	Strongly agree
To allow family to be fully involve and participate in the feeding, bathing, and clothing of critically ill children	○	○	○	○
To have available financial support systems in the hospital for needy families and their children	○	○	○	○
To provide accommodation and food for families and children at the NICU/PICU	○	○	○	○
To have family involved in all stages of decision making about childcare in the NICU/PICU	○	○	○	○
To have an in-house pharmacy and laboratory services in the ICU for prompt care	○	○	○	○
To have more space for families to be involved in Kangaroo Mother Care (KMC) in the NICU	○	○	○	○
To provide regular educational and counselling sessions for families in the NICU/PICU	○	○	○	○
To provide adequate PPEs and ensure strict IPC for parents involved in the care of critically ill children	○	○	○	○

SUB-SECTION 4 (9 items)
Collaboration: Patients, families, and providers collaborate (team-up) in care, training, policy, and program development to implement FCC

	Strongly disagree	Disagree	Agree	Strongly agree
To have a guideline and policy on FCC implemented at the NICU/PICU	○	○	○	○
To have a National child health Fund to support quality child health care services	○	○	○	○
To have a revised curriculum on FCC incorporated into the training of doctors, nurses, and midwives	○	○	○	○
To have a family friendly and inclusively spacious designed NICU/PICU	○	○	○	○
To have the NICU/PICU designed into sub-units based on the needs of children and their families including preterm and congenital anomaly	○	○	○	○
To have regular training of staffs on newborn & infant care and the concepts of FCC	○	○	○	○
To have adequate logistics in ICU including ventilators, SPO2 monitors, flow meters, and phototherapy machines	○	○	○	○
To have community health nurses immunize well babies and conduct follow ups	○	○	○	○
To have adequate specialized professionals in the ICU including neonatal nurse, pediatric nurses, paediatricians, and intensive care nurses and doctors	○	○	○	○

SUB-SECTION 5 (7 items)
Barriers of FCC: These are factors that hinder the effective implementation and integration of the FCC concepts in the intensive care units

	Strongly disagree	Disagree	Agree	Strongly agree

Inadequate space in the intensive care to accommodate families and implement FCC	○	○	○	○
Inadequate logistics including ventilators, incubators, bilirubinometer, photo machines, and SPO2 monitors	○	○	○	○
Inadequate specialized personnel in intensive care, neonatal care, paediatrics, and psychologist at the NICU/PICU	○	○	○	○
Lack of financial support for families for funding the expensive ICU services	○	○	○	○
Some families abandon their babies in the ICU	○	○	○	○
Lack of guidelines, policy, and protocols on FCC at the ICU	○	○	○	○
Families may be a source of infection to critically ill children at the ICU	○	○	○	○

SUB-SECTION 6 (6 items)

Benefits of FCC: These are the importance of family involvement in the care of critically ill neonates and infants in the intensive care units

	Strongly disagree	Disagree	Agree	Strongly agree
FCC practices serves as a school for family especially new families to empower them to continue appropriate childcare at home after discharge	○	○	○	○
FCC practices reduce anxiety and motivates psychologically stressed families to support/participate in care of critically ill children	○	○	○	○
FCC practices promote bonding and initiates good parenting for critically ill children	○	○	○	○
FCC practices promote early recovery and shorten the length of hospitalization of child and family at the intensive care	○	○	○	○

Families play significant roles in providing timely information and resources to support clinical care of critically ill children	○	○	○	○
FCC practices reduces legal infractions as they are well informed of the care processes	○	○	○	○

APPENDIX N

INVITATION LETTER TO EXPERTS

Wisconsin International University College
P. O. Box LG 751, Legon
Greater Accra Region-Accra.

Dear Sir/Madam,

INVITATION TO PARTICIPATE AS A CLINICAL EXPERT IN AN EXPERT REVIEW

My name is Abukari Alhassan Sibdow, a Registered Nurse from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I am conducting research that will culminate in the development of a model of family-centred care at the intensive care for Ghana.

Why am I doing the study?

Family-centred Care (FCC) is an approach of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients'. Quality and safe healthcare can be improved by allowing collaborative involvement of the family in the care of their clients especially when they are children. Until you have one of your own admitted at the Neonatal Intensive Care Unit (NICU), you will think NICUs are the custodians of FCC. The NICU is a complex clinical setting where less attention is given to the family and more emphasis placed on the clinical needs of the patient. The FCC has not clearly been described as a model but rather an approach of involving family members in patient care. There is, therefore, a wide theory-practice gap in FCC for sick children especially infants at the NICU, and that calls for more research in the area to foster family satisfaction and quality childcare, after all, they will continue the child's treatments at home for a full recovery. The primary purpose of this research is to study Family-centred Care (FCC) at the intensive care settings and develop and evaluate a model on FCC for hospitalized children. This study will be conducted at the paediatric/neonatal intensive care unit of the hospital.

What about permission to do the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics, the ethics committee of Korlebu Teaching Hospital, Accra, and the ethics committee of the Tamale Teaching Hospital, Tamale.

Whom do you contact if you want more information?

For more information or queries regarding the study, please contact me on:
Tel: +233 242888091/ + 233 208726254 Email: 2103642@students.wits.ac.za
Or my supervisor: Prof. Shelley Schmollgruber Tel. +27 114884270

Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):

Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za

Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za and Rhulani.Munkansi@wits.ac.za

Yours faithfully,



_____

ABUKARI ALHASSAN SIBDOW
(RESEARCHER)

APPENDIX O

INFORMATION SHEET FOR EXPERTS IN DELPHI STUDY

Introduction

My name is Abukari Alhassan Sibdow, a Registered Nurse from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I am conducting research that will culminate in the development of a model of family-centred care at the intensive care for Ghana.

Why am I doing the study?

Family-centred Care (FCC) is an approach of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients'. Quality and safe healthcare can be improved by allowing collaborative involvement of the family in the care of their clients especially when they are children. Until you have one of your own admitted at the Neonatal Intensive Care Unit (NICU), you will think NICUs are the custodians of FCC. The NICU is a complex clinical setting where less attention is given to the family and more emphasis placed on the clinical needs of the patient. The FCC has not clearly been described as a model but rather an approach of involving family members in patient care. There is, therefore, a wide theory-practice gap in FCC for sick children especially infants at the NICU, and that calls for more research in the area to foster family satisfaction and quality childcare, after all, they will continue the child's treatments at home for a full recovery. The primary purpose of this research is to study Family-centred Care (FCC) at the intensive care settings and develop and evaluate a model on FCC for hospitalized children. This study will be conducted at the paediatric/neonatal intensive care unit of the hospital.

What am I asking you to do?

I am inviting you to participate in the study as an expert in the area of paediatric/intensive/critical care/nursing and give your inputs on family-centred care in the intensive care setting in Ghana. I am interested in your views and experiences on the subject so there is no right or wrong answer. Your participation is purely voluntary. You will be required to give additional comments at the concluding part of this interview.

How do you know that the information you give to me will not get out to others?

The information that you give in the interview will be kept confidential. All the questionnaires will be assigned codes. The information from all the questionnaires will be analysed and reported as key informant data.

What about permission to do the study?

I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics, the ethics committee of Korlebu Teaching Hospital, Accra, and the ethics committee of the Tamale Teaching Hospital, Tamale.

Are there any benefits and risks of participation?

Participation in this study is voluntary. There will be no direct benefits or compensation for anyone who completes the interviews. Similarly, there will be no negative consequences for individuals who do not wish to participate in the interview.

Whom do you contact if you want more information?
For more information or queries regarding the study, please contact me on:
Tel: +233 242888091/ + 233 208726254 Email: 2103642@students.wits.ac.za
Or my supervisor: Prof. Shelley Schmollgruber Tel. +27 114884270
.
Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):
Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za
Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za
And Rhulani.Munkansi@wits.ac.za

Yours faithfully,



_____
ABUKARI ALHASSAN SIBDOW
(RESEARCHER)

APPENDIX P

INFORMED CONSENT FOR EXPERT IN DELPHI STUDY

I have been given the information sheet on the project entitled: **model of Family-centred Care in the paediatric and neonatal intensive care setting in Ghana.** I have read and understood the Information Sheet and all the questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Participants signature/initials:	……	Date…….
Interviewer's Signature	…….	Date……..

Confidential

Delphi questionnaire

Please complete the survey below.

Thank you!

A DELPHI STUDY OF EXPERTS' TO IDENTIFY THE KEY CONCEPTS OF FAMILY-CENTERED CARE IN GHANAIAN INTENSIVE CARE UNITS

The primary purpose of this research is to study Family-centred Care (FCC) in intensive care settings and develop and evaluate a model on FCC for hospitalized children. This empirical study was conducted at the paediatric/neonatal intensive care unit of the hospital.
I am inviting you to participate in the Delphi as an expert in the area of paediatric/intensive/critical care/nursing or a family member of an ICU patient to give your inputs on family-centered care in the intensive care setting in Ghana. The questionnaire will take about 10 minutes to complete. I am interested in your views and experiences on the subject so there is no right or wrong answer. Your participation is purely voluntary.

Hello Colleagues, please see the information sheet attached in pdf format.

[Attachment: "Information sheet.pdf"]

1) INFORMED CONSENT FOR EXPERT IN DELPHI STUDY

I have been given the information sheet on the project entitled: a model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.
I have read and understood the Information Sheet and all the questions have been answered satisfactorily.
I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.
I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Please select "yes" if you are willing to participate

- ◯ Yes
- ◯ No

2) Please input your age age

_____

3) Please select your gender

- ◯ Male
- ◯ Female
- ◯ Other

4)	Please indicate your marital status	◯ Single ◯ Married ◯ Divorce ◯ Separated ◯ Co-habitation ◯ Widow
5)	Please indicate your religion	◯ Christianity ◯ Islam ◯ African Traditional Religion ◯ Other
6)	Highest qualification	◯ Certificate ◯ Diploma ◯ Bachelor's degree ◯ Master's degree ◯ PhD
7)	Please insert your profession	_____
8)	Cumulative years of practice in the profession	_____
9)	Current job rank/grade	_____
10)	Name of Institution and Department	_____
11)	Please select your best classfication	◯ Family member ◯ Medical expert ◯ Nursing expert

SECTION B: Concepts of FCC (Benefits of FCC)

Kindly indicate your level of agreement with the following concepts of Family-Centered Care (FCC)

1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

		Strongly disagree	Disagree	Agree	Strongly agree
12)	FCC promotes recovery	◯	◯	◯	◯
13)	FCC reduces Lawsuits	◯	◯	◯	◯
14)	FCC reduces anxiety	◯	◯	◯	◯
15)	FCC promotes bonding	◯	◯	◯	◯

SECTION C: Concepts of FCC (Respect & Dignity)

Kindly indicate your level of agreement with the following concepts of Family-Centered Care (FCC).

1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

		Strongly disagree	Disagree	Agree	Strongly agree
16)					

	Privacy and confidentiality	○	○	○	○
17)	Family acceptance	○	○	○	○

SECTION C: Concepts of FCC (Communication)
Kindly indicate your level of agreement with the following concepts of Family-Centered Care (FCC).
1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

		Strongly disagree	Disagree	Agree	Strongly agree
18)	Respectful communication	○	○	○	○
19)	Providing timely information	○	○	○	○
20)	Explain condition and care processes	○	○	○	○
21)	Know types of medical staff	○	○	○	○

SECTION C: Concepts of FCC (Participation & Partnership)
Kindly indicate your level of agreement with the following concepts of Family-Centered Care (FCC).
1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

		Strongly disagree	Disagree	Agree	Strongly agree
22)	Family involvement in decision making	○	○	○	○
23)	Family space with comfortable furniture	○	○	○	○

SECTION C: Concepts of FCC (Collaboration)
Kindly indicate your level of agreement with the following concepts of Family-Centered Care (FCC).
1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

		Strongly disagree	Disagree	Agree	Strongly agree
24)	Adequate logistics	○	○	○	○
25)	Regular Training of clinician	○	○	○	○
26)	Specialized professionals	○	○	○	○
27)	NICU/PICU design into subunits	○	○	○	○

SECTION C: Concepts of FCC (Barriers of FCC)
Kindly indicate your level of agreement with the following concepts of Family-Centered Care (FCC).
1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

		Strongly disagree	Disagree	Agree	Strongly agree
28)	Lack of finance	○	○	○	○
29)	Abandoned babies	○	○	○	○
30)	Inadequate personnel	○	○	○	○
31)					

Inadequate logistics and space	○	○	○	○
32) Family as a source of infection	○	○	○	○

33) Please insert any comment you have regarding the questionnaire and the study _____

Confidential

Delphi questionnaire

Please complete the survey below.

Thank you!

A DELPHI STUDY OF EXPERTS' TO IDENTIFY THE KEY CONCEPTS OF FAMILY-CENTERED CARE IN GHANAIAN INTENSIVE CARE UNITS

The primary purpose of this research is to study Family-centred Care (FCC) in intensive care settings and develop and evaluate a model on FCC for hospitalized children. This empirical study was conducted at the pediatric/neonatal intensive care unit of the hospital.

This a second-round Delphi based on the aggregate scores of all experts in the first round. You are required to compare the mean scores and ranking of the concepts from the first round to re-score/rate the items. You are kindly encouraged to provide a comment about any of the concepts or the entire study at the end of the ratings.

I am therefore inviting you to participate in the second-round Delphi as an expert in the area of pediatric/intensive/critical care/nursing or a family member of an ICU patient to give your inputs on family-centered care in the intensive care setting in Ghana. The questionnaire will take about 10 minutes to complete. I am interested in your views and experiences on the subject so there is no right or wrong answer. Your participation is purely voluntary.

Hello Colleagues, please see the information sheet attached in pdf format.

[Attachment: "Information sheet.pdf"]

Please see attached the results of the first round Delphi

[Attachment: "Delphi round 1 results.docx"]

34) INFORMED CONSENT FOR EXPERT IN DELPHI STUDY

I have been given the information sheet on the project entitled: a model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.
I have read and understood the Information Sheet and all the questions have been answered satisfactorily.
I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.
I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Please select "yes" if you are willing to participate

- ◯ Yes
- ◯ No

35) Please input your age age

_____

36) Please select your gender

- ◯ Male
- ◯ Female
- ◯ Other

37) Please indicate your marital status

- ◯ Single
- ◯ Married
- ◯ Divorce
- ◯ Separated
- ◯ Co-habitation
- ◯ Widow

38) Please indicate your religion

- ◯ Christianity
- ◯ Islam
- ◯ African Traditional Religion
- ◯ Other

39) Highest qualification

- ◯ Certificate
- ◯ Diploma
- ◯ Bachelor's degree
- ◯ Master's degree
- ◯ PhD

40) Please insert your profession

_____

41) Cumulative years of practice in the profession

_____

42) Current job rank/grade

_____

43) Name of Institution and Department _____

44) Please select your best classfication
- ◯ Family member
- ◯ Medical expert
- ◯ Nursing expert

SECTION C: Concepts of Respect & Dignity

Kindly rate your level of agreement with the following concepts of Respect & Dignity in the African Ghanaian context at the ICU.

1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

	Strongly disagree	Disagree	Agree	Strongly agree
45) Family need Privacy and confidentiality in the ICU	◯	◯	◯	◯

SECTION C: Concepts Participation & Partnership

Kindly rate your level of agreement with the following concepts of participation & partnership with a family in the ICU in our African Ghanaian context.

1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

	Strongly disagree	Disagree	Agree	Strongly agree
46) More ICU space including family area must be provided with comfortable furniture in the ICU	◯	◯	◯	◯

SECTION C: Concepts of Barriers of FCC

Kindly rate your level of agreement regarding the barriers of Family-Centered Care (FCC) implementation in the African Ghanaian context.

1= Strongly disagree; 2=Disagree; 3=Agree; and 4=Strongly agree

	Strongly disagree	Disagree	Agree	Strongly agree
47) Lack of family finance is a major barrier of family involvement in the ICU	◯	◯	◯	◯
48) Some families abandoned their babies in the ICU which burdens staff in the provision of care	◯	◯	◯	◯
49) Family involvement may be as a source of infection in the ICU	◯	◯	◯	◯

50) Please provide additional comments about any of the concepts and general comments about the development of a model of family-centered care for the neonatal and paediatric intensive care units. _____

APPENDIX S

INVITATION LETTER TO EXPERT IN EVALUATION

Wisconsin International University College

P. O. Box LG 751, Legon

Greater Accra Region-Accra.

Dear Sir/Madam,

INVITATION TO PARTICIPATE AS A CLINICAL EXPERT IN AN EVALUATION

My name is Abukari Alhassan Sibdow, a Registered Nurse from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I am conducting research that will culminate in the development of a model of family-centred care at the intensive care for Ghana.

Why am I doing the study?
Family-centred Care (FCC) is an approach of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients'. Quality and safe healthcare can be improved by allowing collaborative involvement of the family in the care of their clients especially when they are children. Until you have one of your own admitted at the Neonatal Intensive Care Unit (NICU), you will think NICUs are the custodians of FCC. The NICU is a complex clinical setting where less attention is given to the family and more emphasis placed on the clinical needs of the patient. The FCC has not clearly been described as a model but rather an approach of involving family members in patient care. There is, therefore, a wide theory-practice gap in FCC for sick children especially infants at the NICU, and that calls for more research in the area to foster family satisfaction and quality childcare, after all, they will continue the child's treatments at home for a full recovery. The primary purpose of this research is to study Family-centred Care (FCC) at the intensive care settings and develop and evaluate a model on FCC for hospitalized children. This study will be conducted at the paediatric/neonatal intensive care unit of the hospital.

What about permission to do the study?
I have obtained permission to conduct this research from the University of Witwatersrand Human Research Ethics, the ethics committee of Korlebu Teaching Hospital, Accra, and the ethics committee of the Tamale Teaching Hospital, Tamale.

Whom do you contact if you want more information?
For more information or queries regarding the study, please contact me on:
Tel: +233 242888091/ + 233 208726254 Email: 2103642@students.wits.ac.za
Or my supervisor: Prof. Shelley Schmollgruber Tel. +27 114884270
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Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):
Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za

Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za and Rhulani.Munkansi@wits.ac.za

Yours faithfully,



_____

ABUKARI ALHASSAN SIBDOW
(RESEARCHER)

APPENDIX T

INFORMATION SHEET FOR EXPERTS IN EVALUATION

Introduction

My name is Abukari Alhassan Sibdow, a Registered Nurse from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I am conducting research that will culminate in the development of a model of family-centred care at the intensive care for Ghana.

Why am I doing the study?

Family-centred Care (FCC) is an approach of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person and in which all the family members are recognized as care recipients'. Quality and safe healthcare can be improved by allowing collaborative involvement of the family in the care of their clients especially when they are children. Until you have one of your own admitted at the Neonatal Intensive Care Unit (NICU), you will think NICUs are the custodians of FCC. The NICU is a complex clinical setting where less attention is given to the family and more emphasis placed on the clinical needs of the patient. The FCC has not clearly been described as a model but rather an approach of involving family members in patient care. There is, therefore, a wide theory-practice gap in FCC for sick children especially infants at the NICU, and that calls for more research in the area to foster family satisfaction and quality childcare, after all, they will continue the child's treatments at home for a full recovery. The primary purpose of this research is to study Family-centred Care (FCC) at the intensive care settings and develop and evaluate a model on FCC for hospitalized children. This study will be conducted at the paediatric/neonatal intensive care unit of the hospital.

What am I asking you to do?

I am inviting you to participate in the study as an expert in the area of paediatric/intensive/critical care/nursing and give your inputs on family-centred care in the intensive care setting in Ghana. I am interested in your views and experiences on the subject so there is no right or wrong answer. Your participation is purely voluntary. You will be required to give additional comments at the concluding part of this interview.

How do you know that the information you give to me will not get out to others?

The information that you give in the interview will be kept confidential. All the questionnaires will be assigned codes. The information from all the questionnaires will be analysed and reported as key informant data.

What about permission to do the study?

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Are there any benefits and risks of participation?

Participation in this study is voluntary. There will be no direct benefits or compensation for anyone who completes the interviews. Similarly, there will be no negative consequences for individuals who do not wish to participate in the interview.

Whom do you contact if you want more information?
For more information or queries regarding the study, please contact me on:
Tel: +233 242888091/ + 233 208726254 Email: 2103642@students.wits.ac.za
Or my supervisor: Prof. Shelley Schmollgruber Tel. +27 114884270
.
Should you have any concerns about this research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):
Chairperson: Professor Clement Penny Tell: 0117172301 or email Clement.Penny@wits.ac.za
Secretary: Zanele Ndlovu Tell: 117172700/1234 or email Zanele.Ndlovu@wits.ac.za
And Rhulani.Munkansi@wits.ac.za
Yours faithfully,



_____
ABUKARI ALHASSAN SIBDOW
(RESEARCHER)

APPENDIX U

INFORMED CONSENT FOR EXPERT IN EVALUATION

I have been given the information sheet on the project entitled: **model of Family-centred Care in the paediatric/neonatal intensive care setting in Ghana.** I have read and understood the Information Sheet and all the questions have been answered satisfactorily.

I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.

I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Participants signature/initials:	……	Date…….
Interviewer's Signature	…….	Date……..

APPENDIX V

EVALUATION OF FCC MODEL FOR NICU/PICUs

Confidential

EVALUATION OF FCC MODEL FOR NICU/PICUs

Please complete the survey below.

Thank you!

EVALUATION OF A MODEL OF FAMILY-CENTERED CARE FOR NICU/PICUs IN GHANA

My name is Abukari Alhassan Sibdow a Registered Nurse and lecturer from Ghana. I am pursuing a Ph.D. in nursing at the Department of Nursing Education at the University of the Witwatersrand, South Africa. As part of the study, I conducted research that led to the development of a model of family-centered care for neonatal and pediatric intensive care units in Ghana.

I am inviting you to participate in the model evaluation as an expert in the area of pediatric/intensive/critical care/nursing/policy or a family member of an ICU patient to give your inputs on the new model of family-centered care developed for the intensive care setting in Ghana.

The primary purpose of this part of the research is to evaluate the model of FCC for neonatal and pediatric ICUs. The previous phases were conducted at the pediatric/neonatal intensive care units of the Korle Bu Teaching Hospital and the Tamale Teaching Hospital. The questionnaire will take about 10 minutes to complete.

I am interested in your views and experiences on the new model so there is no right or wrong answer. Your participation is purely voluntary.

Kindly provide comments on the model and its ten blueprints from your expert opinion.

Hello, please see the information sheet attached in pdf format.

[Attachment: "Information sheet.pdf"]

1) INFORMED CONSENT FOR EXPERT IN MODEL EVALUATION

I have been given the information sheet on the project entitled: a model of Family-centred Care in the pediatric/neonatal intensive care setting in Ghana. I have read and understood the Information Sheet and all the questions have been answered satisfactorily.
I understand that it is up to me whether or not I would like to participate in the interview and that there will be no negative consequences if I decide not to participate. I also understand that I do not have to answer any questions that I am uncomfortable with and that I can ask for clarification or stop the interview at any time.
I understand that the researchers involved in this project will make every effort to ensure confidentiality and that my name will not be used in the study reports, and that comments that I make will not be reported back to anybody else. I consent voluntarily to participate in the interview for this study. I have been given telephone numbers that I may call if I have any questions or concerns about the research.

Please select "yes" if you are willing to participate

- ◯ Yes
- ◯ No

Kindly open the pdf file attached to view the Model diagram of Family-Centered Care for NICUs and PICUs in Ghana

[Attachment: "FCC MODEL FOR NICU &PICUs (Evaluation).pdf"]

2) Please input your age age

_____

3) Please select your gender

- ◯ Male
- ◯ Female
- ◯ Other

4) Please indicate your marital status

- ◯ Single
- ◯ Married
- ◯ Divorce
- ◯ Separated
- ◯ Co-habitation
- ◯ Widow

5) Please indicate your religion

- ◯ Christianity
- ◯ Islam
- ◯ African Traditional Religion
- ◯ Other

6) Highest qualification

- ◯ Certificate
- ◯ Diploma
- ◯ Bachelor's degree
- ◯ Master's degree
- ◯ PhD

7) Please insert your profession

_____

8) Cumulative years of practice in the profession

_____

9) Current job rank/grade _____

10) Name of Institution and Department _____

11) Please select your best classfication

- ◯ Family member
- ◯ Medical expert
- ◯ Nursing expert
- ◯ Policy expert

SECTION B: TEN BLUEPRINTS OF THE FCC MODEL FOR NICU/PICUs

The blueprints are the conceptual underpinnings that emerged from this empirical research and used to developed the model.

Kindly rate your level of agreement with the following developed conceptual blueprints of Family-Centered Care (FCC) to facilitate its implementation in the Ghanaian context.

Please note that the bracket after each statement indicates the focal person (s) responsible.

1= Strongly disagree; 2=Disagree; 3=Neutal; 4=Agree; and 5=Strongly agree

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
12) To ensure family acceptance through respectful communication, building family socialization, and involvement in decision making (Clinicians, Health Managers).	◯	◯	◯	◯	◯
13) To ensure privacy and confidentiality of children and their families through nursing sick children in separate cubicles and obtaining informed consent (Clinicians, Health Managers).	◯	◯	◯	◯	◯
14) To build a Triangle of partnership involving Families-Clinicians-Managers (FCM) approach in implementing FCC (Family, clinicians, Health Managers).	◯	◯	◯	◯	◯
15) To provide family friendly and inclusive NICU/PICU design including enough ICU space in subunits, and family areas (Government and Health Managers).	◯	◯	◯	◯	◯
16)					

	To provide psychological support for families and clinicians through clinical psychologists at the ICUs to reduce anxiety (Clinicians, Health Managers).	○	○	○	○	○
17)	To provide ICUs information desk for effective communication with families to manage their fears and psychological stress (Clinicians, Health Managers).	○	○	○	○	○
18)	To setup counselling and education units in the ICUs to educate families and provide psychological support (Clinicians, Health Managers)	○	○	○	○	○
19)	To setup National Child Health Fund to provide financial support for families and provide adequate logistics, specialized training, and research (Government, Health Managers).	○	○	○	○	○
20)	To strengthen the Institutional Social Welfare Departments to handle the Abandoned Babies Syndrome and other psychosocial concerns of care (Government, Clinicians, Health Managers).	○	○	○	○	○
21)	To promote family visitations via 7-Schedule Family Visits Approach in 24 hours: minimum of four visits for mothers (3-hour interval), two visits for fathers (8-hours apart), and one visit for a significant other to promote participation, bonding, and early discharged (Clinicians, Families, Health Managers).	○	○	○	○	○

22) Kindly provide your general comments based on the face and content validity of the model diagram attached and or each of the concepts above. _____

APPENDIX W

ETHICAL CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mr Alhassan Sibdow Abukari

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M190980

NAME: (Principal Investigator)	Mr Alhassan Sibdow Abukari
DEPARTMENT:	Nursing Education School of Therapeutic Sciences Korlebu Teaching Hospital and Tamale Teaching Hospital Ghana
PROJECT TITLE:	A model of family-centred care at the paediatric and neonatal intensive care setting in Ghana
DATE CONSIDERED:	27/09/2019
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Shelley Schmollgruber
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	08/12/2020

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions.Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **September** and will therefore be due in the month of **September** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature _____ Date _____

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX X

KORLE BU TEACHING HOSPITAL INSTITUTIONAL CLEARANCE TO CONDUCT RESEARCH

In case of reply the number
And the date of this
Letter should be quoted
My Ref. No. KBTH/NMIMR/93/20
Your Ref. No......

KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

18th February, 2020

MR ALHASSAN A. SIBDOW
WITS UNIVERSITY
SOUTH AFRICA

INSTITUTIONAL APPROVAL: KORLE BU TEACHING HOSPITAL-SCIENTIFIC AND TECHNICAL COMMITTEE/INSTITUTIONAL REVIEW BOARD (KBTH-STC/IRB/000145/2019

Following approval of your study entitled "A Model on Family-Centred Care at the Paediatric and Neonatal Intensive Care" by the Korle Bu Teaching Hospital-Scientific and Technical Committee/Institutional Review Board.

I am pleased to inform you that institutional approval has been granted for the conduct of your study in Korle Bu Teaching Hospital.

Please contact the Head of Department to discuss the commencement date of the study.

Please note that, this institutional approval is rendered invalid if the terms of the Institutional Reviewed Board/Scientific and Technical Committee approval are violated.

Sincere regards.

Dr. Harry Akoto
Ag. Director of Medical Affairs
For: Chief Executive

Cc: The Chief Executive
Korle Bu

APPENDIX Y

KORLE BU TEACHING HOSPITAL IRB ETHICAL CLEARANCE

In case of reply the number
And the date of this
Letter should be quoted
My Ref. No. KBTH/MRS/10849
Your Ref. No......

KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

27th December, 2019

MR. ABUKARI ALHASSAN SIBDOW
UNIVERSITY OF WITWATERSRAND
JOHANNESBURG

SCIENTIFIC AND TECHNICAL COMMITTEE APPROVAL
PROTOCOL IDENTIFICATION NUMBER: KBTH-STC 000145/2019

The Korle Bu Teaching Hospital Scientific and Technical Committee (KBTH-STC), on 27th December, 2019 approved your submitted study protocol.

TITLE OF PROTOCOL: "A model of Family-Centred Care at the Paediatric and Neonatal Intensive Care setting in Ghana"

PRINCIPAL INVESTIGATOR: Mr. Abukari Alhassan Sibdow

This approval requires that you **forward your approved document to Korle Bu Teaching Hospital – Institutional Review Board (KBTH-IRB) for the ethical aspect of the proposal to be assessed before the project can be initiated.**

This STC approval is valid till 30th June, 2022
You may, however, request extension of the approval period, or renewal as the case may be, should the study extend beyond the stated period.

Upon completion, you are required to submit a final report on the study to the STC. This is to enable the STC ensure among others that, the project has been implemented as per the approved protocol. You are also required to inform the KBTH-STC and Research Directorate of any publications that may emanate from the research findings.

Kindly note that, should the need arise, the KBTH-STC or IRB may institute appropriate measures to satisfy itself that study is being conducted according to the highest scientific and ethical standards.

Please note that any modification to the study protocol without Scientific Technical Committee (STC) approval renders this approval invalid.

Sincere regards,

Prof. G. Obeng Adjei
Chairman, KBTH-STC

Cc: The Chairman, KBTH-IRB

APPENDIX Z

KORLE BU TEACHING HOSPIAL INTRODUCTORY LETTER TO COMMENCE STUDY

MEDICAL DIRECTORATE
KORLE BU TEACHING HOSPITAL

18th February, 2020

THE HEAD
CHILD HEALTH DEPT
KORLE BU

LETTER OF INTRODUCTION – MR ALHASSAN A. SIBDOW
"A MODEL ON FAMILY-CENTRED CARE AT THE PAEDIATRIC AND NEONATAL INTENSIVE CARE"

I have the pleasure to introduce to you the above named Investigator from Wits University, South Africa. Mr Alhassan A. Sibdow sought and has been granted approval to conduct a study entitled "A Model on Family-Centred Care at the Paediatric and Neonatal Intensive Care.

He is to contact you to discuss the commencement date of the study.

Please verify his identity with a Government issued National ID card and accord him the needed assistance.

Attached is the Scientific and Technical Committee and Institutional Review Board approval, which specifies the terms.

Sincere regards,

Dr. Harry Akoto
Ag. Director of Medical Affairs
For: Chief Executive

Cc: The Chief Executive, Korle Bu

APPENDIX AA

TAMALE TEACHING HOSPITAL PERMISSION LETTER TO CONDUCT RESEARCH

Department of Research &Development
Tamale Teaching Hospital

TTH/R&D/SR/053
06/05/2020

TO WHOM IT MAY CONCERN

CERTIFICATE OF AUTHORIZATION TO CONDUCT RESEARCH IN TAMALE TEACHING HOSPITAL

I hereby introduce to you **Mr. Abubakari Alhassan Sibdow,** a PhD candidate in Nursing from University of the Witwatersrand, South Africa. The candidate was duly authorized to conduct a study titled **"Model of family-Centred care at the paediatric/Neonatal Intensive care setting in Ghana"** in TTH and it expired on April 3rd, 2020. He is hereby requesting for an extension of his permission to complete the study.

Please accord the candidate the necessary assistance to enable him completes the study. If in doubt, kindly contact the Research Unit on the second floor of the administration block or on Telephone 0209281020. In addition, kindly report any misconduct of the Researcher to the Research Unit for necessary action.

The candidate is required to furnish the hospital a copy of the dissertation/Study upon completion.

Please note that this approval is given for a period of Six months, beginning from 4th of April, 2020 to 3rd of October, 2020.

Thank You.

ALHASSAN MOHAMMED SHAMUDEEN.

(HEAD, RESEARCH & DEVELOPMENT)

Nurse – in-charge, NICU
Pls assist Mr. Sibdow to Cuplete this work.
12/05/2020

APPENDIX BB

APPROVAL OF STUDY TITLE

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

11 October 2019
Person No: 2103642
PAG

Mr AS Abukari
House Number 109
Ghana

Dear Mr Alhassan Abukari

Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled *Model of family-centred care at the Paediatric and Neonatal intensive care setting in Ghana* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX CC

REQUEST FOR PERMISSION TO USE THE SELF ASSESMENT INVENTORY (SAI) TOOL

WITS UNIVERSITY

Alhassan Abukari <2103642@students.wits.ac.za>

PERMISSION TO USE THE SELF ASSESSMENT INVENTORY TOOL

Alhassan Abukari <2103642@students.wits.ac.za> 30 March 2021 at 12:56
To: institute@ipfcc.org

Hello,

I am a Ph.D. A nursing student at the University of the Witwatersrand, Johannesburg, South Africa.

I am conducting a study on Family-Centered care at the pediatric and neonatal intensive care units and need your permission to adapt your SAI tool of PFCC.

I humbly request your permission to use the SAI tool in my project.
I look forward to your approval to enable me to continue my research.

Thank you.

Warm Regards

AS Abukari
Ph.D. Nursing Student

APPENDIX DD

PERMISSION OBTAINED FROM THE DEVELOPER TO USE THE SELF-ASSESSMENT INVENTORY (SAI)

WITS UNIVERSITY

Alhassan Abukari <2103642@students.wits.ac.za>

PERMISSION TO USE THE SELF ASSESSMENT INVENTORY TOOL

Institute - <institute@ipfcc.org> 31 March 2021 at 16:14
To: Alhassan Abukari <2103642@students.wits.ac.za>

Yes, you have our permission to adapt if this tool is being used for educational purposes and not commercial use. Please acknowledge IPFCC in your tool:

> Adapted with permission from the Institute for Patient- and Family-Centered Care (www.ipfcc.org) 2021.

It would be greatly appreciated if you would send us a copy of the adapted tool when it is available.

Thank you.

Marie

Marie Abraham
Vice President, Programming and Publications
Institute for Patient- and Family-Centered Care®
PO Box 6397 McLean, VA 22106-9998
Website: www.ipfcc.org

Join PFCC.Connect, our free online learning network today https//pfcc.connect.ipfcc.org
Expand Knowledge - Connect with Peers - Increase Your Impact

[Quoted text hidden]

APPENDIX EE

PROOFREADING AND LANGUAGE EDITING

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

Work Certificate

To	Dr. Shelley Schmollgruber
Address	Faculty of Health Sciences, University of Witwatersrand
Date	11/01/2022
Subject	Thesis: A Model of Family-Centred Care at the Paediatric and Neonatal Intensive Care Setting in Ghana
Ref	SS/GS/37

I, Gill Smithies, certify that I have proofed the following for language, grammar and style:

Thesis: A Model of Family-Centred Care at the Paediatric and Neonatal Intensive Care Setting in Ghana, by A. S. Abukari,

to the standard as required by the University of Witwatersrand.

Gill Smithies