

**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - QUALITATIVE**

# Experiences of families and health professionals along the care continuum for low-birth weight neonates: A constructivist grounded theory study

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## Abstract

**Aims:** To explore the experiences of health professionals and families concerning supporting low-birth weight (LBW) infants along the continuum of care (CoC) in Ghana with the goal to unveil new strategies to improve the quality of neonatal care.

**Design:** A constructivist grounded theory.

**Method:** Simultaneous data collection and analysis among health professionals alongside families with LBW infants from September 2020 to April 2021. The study used constructivist grounded theory strategies for data collection and analysis.

**Results:** The analysis of 25 interviews resulted in a theoretical model describing 10 themes along the CoC for LBW infants, categorized into health and family systems drivers. In this paper, we focus on the latter. Early bonding and family involvement were empowering. Mothers needed assistance in balancing hope and confidence which enabled them to render special care to their LBW infants. Providing mothers with financial and domestic support as well as creating awareness on newborn health in communities were important.

**Conclusion:** To achieve family involvement, a coordinated CoC must entail key players and be culturally inclusive. It must be applied at all levels in the CoC process in a non-linear fashion. This can help LBW infants to thrive and to reach their full developmental potential.

**Impact:** The theoretical model developed shows the importance of family involvement through family systems care for a comprehensive response in addressing needs of health professionals and families with LBW infants and bridging the fragmentations in the neonatal CoC in Ghana. Context-tailored research on family systems care in the neonatal period is necessary to achieve a quality CoC for LBW infants and their families.

**Patient or Public Contribution:** Caregivers and providers participated by granting in-depth interviews. Care providers further contributed through their feedback on preliminary findings.

## KEYWORDS

continuum of care, ghana, grounded theory, low birth weight, nurses, neonatal nursing, newborn health, family systems care or family-centred care

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## 1 | INTRODUCTION

Over the past few decades, some progress has been made in addressing low birth weight (LBW) (<2500g) in sub-Saharan Africa (SSA), but the pace has been slower as compared with other regions worldwide (Dwomoh et al., 2022). In Ghana, LBW prevalence has decreased from 16.1% in 2000 to the current rate of 14.2% (UN Interagency Group for Child Mortality Estimation, 2022). Despite this reduction, the current rate of LBW deliveries in Ghana is still higher than the rate in SSA.

LBW is attributed to premature birth, small-for-gestational-age or both (Hughes et al., 2017). Infants with LBW are at an increased risk of mortality, long-term developmental problems and disability including adult-onset chronic conditions such as diabetes and coronary heart disease (Blencowe et al., 2019) resulting in the loss of significant human potential (WHO, 2019).

Poor neonatal services for LBW infants can exacerbate socio-economic burden for families and increase health systems and national budgets both in the short and long-term (Enweronu-Laryea et al., 2018; Liu et al., 2015). Moreover, families of LBW infants are at high risk of experiencing long-term psychological burden which can have additional detrimental effects on the infant's physical, social and cognitive developmental (Mathewson et al., 2021; Moxon et al., 2015).

## 2 | BACKGROUND

In the field of maternal, newborn, and child health (MNCH), the continuum of care (CoC) is a commonly used policy goal of governments in low- and middle-income countries (LMICs) to provide timely and quality care (Shibanuma et al., 2021). The CoC concept entailing service integration and appropriate service delivery personnel was first described in 1970 by Liebowitz and Brody (1970) and later modified by Kerber et al. (2007) for the MNCH framework. The MNCH care continuum, referred to as the Kerbers CoC, emphasizes the importance of the linkages and continuity in service delivery during pregnancy, childbirth, and postpartum periods among the different levels of care, namely the hospital, community (primary care) and home care (Kerber et al., 2007). However, the care received by families' after hospital discharge is fragmented and often discontinued abruptly, resulting in readmissions, sub-optimal outcomes or even death (Bahr & Weiss, 2019). Fragmented care can result in inconsistent counselling from health workers, dissatisfaction of patients and their families, and reduction in families' ability for self-care (Bahr & Weiss, 2019).

Theories, models and conceptual frameworks such as the CoC framework allow the integration of observations and findings from research into practice and display the relationships among a range of constructs or variables in relation to health outcomes (Polit & Beck, 2017; Singh et al., 2022).

An increased focus on the CoC framework in healthcare service provision can improve neonatal survival and well-being in LMICs (Kayode et al., 2014). However, the MNCH care continuum is

affected by economic and socio-cultural factors making its effective implementation challenging for many countries, including Ghana (Kikuchi, Ansah, Okawa, Shibanuma, et al., 2015; Okawa et al., 2019).

As part of efforts by the Ministry of Health to achieve a quality CoC in Ghana and strengthen its MNCH healthcare system, it institutionalized measures such as the Community-based Health Planning and Services (CHPS) in 2000 to empower underserved communities to contribute to health governance (Binka et al., 1995; Kushitor et al., 2019). The MNCH services offered through the CHPS such as home visits are intended to ensure care continuity (Shibanuma et al., 2021). In 2014, Ghana adopted and implemented the Every Newborn Action Plan (ENAP), a strategy to strengthen maternal and newborn care during pregnancy, labour, birth and postnatal focusing specially on the care of small and sick newborns. Despite these efforts and extensive improvements in newborn survival, Ghana still faces challenges in ensuring quality and continuity in MNCH healthcare (Okawa et al., 2019; Shibanuma et al., 2021) because of the bottlenecks within and outside the health system that challenge the success of these interventions (Yawson et al., 2016).

Although the importance of an effective CoC is widely recognized, it is least practiced in LMICs (Kikuchi et al., 2021). In Ghana, the care of LBW infants as a continuum is less prioritized (Kayode et al., 2014; Yeji et al., 2015) so is data limited on the CoC practices for LBW and the critical transition between the different levels of care (Engmann et al., 2016; Okawa et al., 2019). A recent study in Ghana outlined the need to better understand how the social determinants of health both at the individual and community levels can affect access to and continuity of postnatal services within the CoC. The authors indicate that women's uptake of postnatal services is influenced by individual factors, such as maternal age, parity and employment alongside community-level factors, such as poverty and illiteracy (Dankwah et al., 2021). Assessing the current postnatal CoC for LBW infants would highlight the gaps and the enablers that influence the care process to facilitate synchronized and harmonious coordination of the transition for LBW infants and their families between the different care services, levels and systems.

## 3 | THE STUDY

### 3.1 | Aims

The aim of the study was to explore the experiences and needs of health professionals and families with LBW infants along the neonatal CoC in Ghana. The insights are likely to (1) unveil new strategies that can improve the quality of care rendered to LBW neonates along the CoC and (2) improve the care coordination between the hospital, primary care and the home.

The following research questions guided the study: (1) what are the experiences and needs of health professionals and families with LBW infants along the CoC in the neonatal transition period; and (2) how can health professionals and families be empowered to provide quality neonatal care for LBW infants?

### 3.2 | Design

The study was conducted using Charmaz's (2014) qualitative constructivist grounded theory. This methodology is suited to study social processes including experiences and needs of both health providers and families of LBW infants. This iterative research process recognizes how interaction between the researcher and participant can influence data construction (Charmaz, 2014). This design creates interpretive theories or theoretical models that go beyond describing to explaining processes grounded in data (Creswell & Poth, 2017; De Vaus, 2001). With a constructivist grounded theory approach, it is possible to examine complex phenomenon such as the delivery of healthcare services, taking into account the perspectives from both clients and providers (Creswell & Poth, 2017). A theoretical model grounded from data might help to explain clinical practice and provide a framework for further research and practice development.

### 3.3 | Sample/participants

The study took place in a municipality in Ghana that has over 200,000 inhabitants with the majority engaged in small-scale trade, agriculture and livestock keeping. In terms of access to healthcare facilities, the municipality has one regional secondary-level referral hospital, 11 health centres and 10 CHPS zones. The referral hospital provides emergency obstetric and essential newborn care in the maternity unit as well as cares for sick and small newborns at the Neonatal Intensive Care Unit (NICU). At the time of data collection, the NICU had a paediatrician, a general practitioner and 10 nurses, one of whom is a paediatric nurse specialist.

The CHPS compounds are run by community health nurses sometimes complemented by midwives and physician assistants and provide basic maternal, neonatal and child healthcare in addition to adult health services at the primary level. The newborn care services comprise breastfeeding counselling, growth monitoring, vaccinations, management of minor ailments and referrals to higher level facilities (Ministry of Health, 2016).

Two groups of participants totalling 27 adults were recruited. The first group was care providers ( $n = 16$ ) comprising nine healthcare professionals (HCPs) who provide direct clinical care in the hospital or public health services in the community plus seven healthcare managers (HCMs) who play key managerial and administrative roles at the hospital, district and regional levels. The second group was care recipients ( $n = 11$ ) comprising seven mothers and other four family members who had LBW infants. The eligibility criteria were admission to the NICU for at least 24 hours and discharge home no longer than 8 weeks prior to the interview. The 24-hour hospital admission time frame was informed by the knowledge that newborns, including LBW infants are often discharged early in LMICs for reasons such as overcrowded neonatal units, mothers' responsibilities for older children at home, inadequate social support and financial constraints (Adama et al., 2017; Enweronu-Laryea et al., 2018).

Besides parents, relatives are often instrumental in caring for LBW infants in Ghana (Adama et al., 2018; Schuler et al., 2019). Therefore, persons mentioned by the mothers as playing important roles in the care of their LBW infant were also recruited. Different groups of participants were to gain a holistic view from the various actors involved either in the care provision and coordination or in policy design and implementation for LBW infants (Creswell & Poth, 2017).

### 3.4 | Data collection

Data collection and analysis were done simultaneously from September 2020 and ended in April 2021. The study used a criterion sampling approach to purposefully select participants who experienced the phenomenon of caring for LBW neonates and who could contribute to the establishment of a model (Creswell & Poth, 2017). Sampling criteria for potential participants were defined and participants who met the pre-specified eligibility criteria were recruited (Creswell & Poth, 2017; Patton, 1990).

One administrative staff from the hospital and another from the primary care facility in the community acted as gatekeepers. They helped with gaining permission from authorities to conduct interviews on-site and assisted the researchers to get access to the appropriate participants in the different care levels. After an initial contact was established with care providers at the hospital through the gatekeeper, the first set of in-depth one-on-one interviews were conducted with HCPs at the NICU. Further interviews at the hospital captured views of other HCPs directly involved in providing clinical (bedside) care for LBW infants. The interviews were then extended to staff holding managerial positions that transcend LBW support. This was followed by interviews with HCPs at four CHPS compounds within the community and with administrators at the district and regional health directorates. Additional HCPs and HMCs at different levels of care were invited after previous interviews revealed that they played a major role in the LBW CoC. Initial sampling was completed when all key actors had been interviewed.

Contacts of families with LBW infants were obtained from the NICU and the delivery records at the labour ward. The families were called and informed about the study. After agreeing to participate, a date and time was fixed.

A theoretical sampling procedure followed the initial sampling to obtain different perspectives and to shed light on additional features of the emerging theoretical model (Conlon et al., 2020; Glaser & Strauss, 1967). After assigning theoretical categories, sampling continued by selecting new participants or re-interviewing previous participants. Theoretical saturation was reached when the extra data collected yielded no new properties of the theoretical categories and provided no further insight into the emerging theory (Charmaz, 2014). Sociodemographic information was gathered during each interview to provide a succinct overview of the participants.

Intensive interviewing, a gently guided open-ended conversation that explores participants' perspectives on their personal experience

with the phenomenon under study, was used (Charmaz, 2014). The interviews were conducted using four different thematized interview guides containing 3–6 main themes and 15–22 sub-themes with a few open-ended questions and probes designed depending on the category of respondents. The interview guides were pre-tested in a neighbouring municipality; that for the care providers was pre-tested with a paediatric nurse while that for the care recipients was pre-tested with a parental of a LBW infant. Experience gathered from the pre-testing exercise led to slight modifications of the interview guides before the actual field work to include for example, questions concerning antenatal care usage and support options for parents. Consistent with grounded theory, questions in the interview guides were further refined as data collection progressed with the aim to develop a theoretical model (Charmaz, 2014; Corbin & Strauss, 2015).

The interviewing started with broad open-ended questions that encouraged interviewees to narrate their experiences and share opinions concerning the care of LBW infants thereby creating a conducive atmosphere to uncover hidden actions, practices and their implications. Example of questions caregivers were asked were: “can you tell me how you experienced your time in the NICU” and for health professionals “can you tell me how it is for you to provide care for LBW infants here in the NICU/community”? For healthcare managers, questions such as “can you tell me ways in which you are engaged in the planning and implementation of care for LBW infants at your institution and/or district/regional level?” were asked.

Where the responses were information-rich, probing questions were used to dive deeper into the discussion point. In the later stage, focused questions were asked to elucidate more detailed discussion about the topic (Charmaz, 2014). Interviews were conducted in the participant's place of choice such as at the neonatal intensive care unit (NICU), CHPS compound, office, or the family's home. All interviews with care providers and administrators were conducted in English whereas interviews with families were held in the local language, Ewe, where communication in English was not feasible.

### 3.5 | Ethical considerations

This study was authorized by an official ethical review committee in Ghana. Permission to conduct the study was granted by the regional and district health directorates as well as the hospital management. Participants were informed about the risks and benefits, voluntary participation, the option to withdraw at any point in time and adherence of the investigators to confidentiality during interviewing and data handling. Before the interviews, written informed consent was obtained from the participants. For those who could not read, the information sheet was read to them in the presence of a witness, usually a relative after which they thumb-printed the consent sheet. Audio files generated from each interview were encrypted and stored to ensure confidentiality.

### 3.6 | Data analysis

Data analysis was an iterative process aimed to develop a theoretical explanation of the CoC built on the views and experiences from both the demand and supply side. Every interview was transcribed verbatim using the f4-transcription program (Dresing & Pehl GmbH, 2020). The interviews held in the local language were directly transcribed into English, analysed and interpreted. An external person, fluent in both languages spot-checked the transcripts to ensure the quality of the translation. The transcripts of all English-held interviews were counterchecked using the dual control principle to ensure its quality and rule out mistakes (Dresing & Pehl, 2015). Immediately after each interview, observations and experiences were documented in a field diary which later supported memo writing.

The qualitative analysis software Atlas.ti version 9.2 was used to analyse the data inductively. In the first step, line by line coding and constant comparison techniques were applied (Glaser, 1978). Focused coding followed in the second step to verify the adequacy and conceptual strength of the initial codes. The selected focused codes were used to form conceptual categories through writing narrative memos, clarifying the content and identifying the relationship between them. Relationships between the categories were delineated using ATLAS.ti's network function which helped to examine linkages between different actors, processes and events (Miles et al., 2014). The third step of conceptualizing categories helped to advance from a purely descriptive level of analysis to a more abstract, theoretical level (Charmaz, 2014). To do this, the technique of sorting and diagramming was used in addition to theoretical coding to verify and saturate the codes and emerging categories. The theoretical model was also discussed with participants during the theoretical sampling stage. This enabled the generation of a theoretical model. Fieldnotes and the constant use of memos facilitated the advancement of the model and the description of the results. The research team had regular meetings during the data collection and analysis stages to critically discuss the memos and the developing categories, reflect on the possible personal biases (reflexivity) and discuss the features of the evolving theoretical model on the CoC for LBW infants.

### 3.7 | Rigour

The research team followed the constructivist grounded theory criteria for rigour: credibility, originality, resonance and usefulness (Charmaz, 2014; Charmaz & Thornberg, 2020). Credibility was achieved by collecting rich data from diverse participants who expressed their unique views, feelings and perspectives and representing the research method transparently. Using fieldnotes that built thick descriptions of the research context ensured credibility (Charmaz, 2014; Phillippi & Lauderdale, 2018). Extensive and constant comparisons between the observations and categories throughout the research process also contributed to establishing

credibility. Originality was attained through in-depth understanding of both the demand and provider-side issues thereby enhancing knowledge in the field of neonatal care in Ghana and in similar contexts. Resonance was realized through member checking to review how well participants agreed with emerging categories. This was done by presenting the preliminary results including the theoretical model with one participant each from the hospital and community to get their reflections, approval and accreditation. Since personal experiences may not be recognized in the summary results and because some memories may trigger anxiety in participants (Birt et al., 2016), preliminary results were not shared with the family members. To achieve usefulness, the study's contributions towards advancing knowledge and optimizing care for families with LBW infants was achieved by presenting the results to the healthcare providers and administrators and receiving feedback.

## 4 | FINDINGS

In all, 27 participants were interviewed in 25 separate interview sessions that produced approximately 24 hours of audio recordings, lasting between 30 to 111 minutes with an average of 56 minutes per interview in addition to hand-written fieldnotes. About 16 (59.3%) health professionals and 11 (40.7%) mothers and their family members were interviewed. The health professionals were in two groups. One group included nine (33.4%) HCPs offering direct care to LBW infants. The remaining seven (25.9%) were those in managerial positions. The second group of participants included seven (25.9%) mothers and four (14.8%) relations of the LBW infant. Coincidentally, all LBW infants included in this study were females. Further demographic information describing the study participants is provided in Tables 1-3.

### 4.1 | Model for continuum of care for LBW infants

The findings herein (Figure 1) is presented as a theoretical model of the CoC for LBW infants in the neonatal period. The model explains the experiences and needs of family members and health professionals along the CoC as well as the organization of the care continuum for LBW newborns in Ghana. At the centre of the CoC is the family with a LBW infant whose life has been shaped by their individual life circumstances and the communal environment. The health and well-being of the LBW infant and the family is influenced by social determinants emanating from the socio-cultural context, demography, economic situation, psychosocial stressors, access to healthcare as well as access to information on their care needs. During the transition from hospital into the community and home care, families with LBW infants encounter numerous contacts with health professionals at the different levels of care and experience varying events. Experiences of the families and health professionals during the transition are influenced by enablers/barriers from both sides thus necessitating the strengthening of postnatal discharge, referral

TABLE 1 Sociodemographic characteristics of the mothers and their family relations

Variable	Frequency (%)	
	Mothers (n = 7) number (%)	Relatives (n = 4) number (%)
<b>Age (years)</b>		
20-25	3 (42.9)	0 (0.0)
26-30	2 (28.5)	0 (0.0)
31-35	1 (14.3)	2 (50.0)
36-40	1 (14.3)	1 (25.0)
41-45	0 (0.0)	0 (0.0)
46-50	0 (0.0)	1 (25.0)
<b>Mean age ± SD</b>	<b>27.4 years ± 6 years</b>	<b>37.0 years ± 7 years</b>
<b>Sex</b>		
Male	0 (0)	2 (50.0)
Female	7 (100.0)	2 (50.0)
<b>Highest educational level attained</b>		
Primary	1 (14.3)	0 (0.0)
Junior High School	3 (42.9)	2 (50.0)
Senior High School	2 (28.5)	0 (0.0)
Tertiary	1 (14.3)	2 (50.0)
<b>Employment status</b>		
Employed (informal sector)	3 (42.6)	2 (50.0)
Employed (formal sector)	1 (14.3)	1 (25.0)
Unemployed	3 (42.6)	1 (25.0)
<b>Marital status</b>		
Single	2 (31.6)	1 (25.0)
Married	5 (68.4)	3 (75.0)
<b>Place of residence</b>		
Semi-urban	5 (47.4)	3 (75.0)
Rural	2 (52.6)	1 (25.0)
<b>Religion</b>		
Muslim	1 (14.3)	1 (25.0)
Christian	6 (85.7)	3 (75.0)

Abbreviation: SD, Standard deviation.

and review systems. The CoC in the neonatal period is also impacted by the wider outer context of the health service structure including the District Health Directorate, Regional Health Directorate and the national Ministry of Health who complement the CoC and influence the care continuum with their decisions and actions.

The themes derived have been broadly categorized into health system and family system drivers. The family system drivers are organized into hospital, community (primary care) and home support intertwined with the health-systems drivers. Due to the lengthy content and richness of the data obtained, in this paper, we focused on the four themes related to family systems: (1) empowering families through bonding and

TABLE 2 Sociodemographic of the low-birth weight (LBW) infants

Variable	Frequency (n = 7)
<b>Sex</b>	Number (%)
Male	0 (0.0)
Female	7 (100.0)
<b>Age at interview (days)</b>	
20–25	0 (0.0)
26–30	2 (28.6)
31–35	0 (0.0)
36–40	2 (28.6)
41–45	1 (14.3)
46–50	1 (14.3)
Above 50	1 (14.3)
<b>Mean age at interview <math>\pm</math> SD</b>	<b>40.57 days <math>\pm</math> 9.05</b>
<b>Delivery mode</b>	Number (%)
Spontaneous vaginal delivery	2 (28.6)
Caesarean section	5 (71.3)
<b>Birth order</b>	
1st child	2 (28.6)
2nd child	1 (14.3)
3rd child	4 (57.1)
<b>Gestational age at birth (weeks)</b>	
32–33	2 (28.6)
34–35	2 (28.6)
36–38	3 (42.9)
<b>Mean gestational age at birth <math>\pm</math> SD</b>	<b>35.14 weeks <math>\pm</math> 2.34 weeks</b>
<b>Birth weight (kg)</b>	Number (%)
1.0–1.4	2 (28.6)
1.5–2.0	4 (57.1)
2.1–2.5	1 (14.3)
<b>Mean birth weight <math>\pm</math> SD</b>	<b>1.66 kg <math>\pm</math> 0.36</b>
<b>Time spent at NICU (days)</b>	Number (%)
0–10	3 (42.9)
11–20	3 (42.9)
21–30	1 (14.2)
<b>Mean length of stay in NICU <math>\pm</math> SD</b>	<b>12.86 days <math>\pm</math> 5.84 days</b>
<b>Time spent at home after discharge (days)</b>	Number (%)
0–10	0 (0.0)
11–20	2 (28.5)
21–30	1 (14.3)
31–40	3 (42.9)
41–50	1 (14.3)
<b>Mean post-discharge days <math>\pm</math> SD</b>	<b>27.71 days <math>\pm</math> 11.61 days</b>

Abbreviations: NICU, Neonatal Intensive Care Unit; SD, Standard deviation.

involvement, (2) balancing hope, confidence and the need for special care, (3) enhancing access to financial and domestic support and (4) creating awareness on newborn health. The other six themes related to health-system drivers are reported elsewhere.

TABLE 3 Sociodemographic characteristics of healthcare professionals

Variable	Frequency (n = 16)
<b>Age (years)</b>	Number (%)
20–25	0 (0.0)
26–30	1 (6.3)
31–35	5 (31.3)
36–40	2 (12.5)
41–45	1 (6.3)
46–50	1 (6.3)
51–55	3 (18.8)
56–60	3 (18.8)
<b>Mean age <math>\pm</math> SD</b>	<b>43.13 years <math>\pm</math> 11.04 years</b>
<b>Sex</b>	Number (%)
Male	7 (43.8)
Female	9 (56.2)
<b>Highest educational level attained</b>	
Certificate	2 (12.5)
Diploma	7 (43.8)
Bachelor	2 (12.5)
Masters	5 (31.2)
PhD	0 (0.0)
<b>Years of work experience</b>	
0–5	1 (6.2)
6–10	6 (37.5)
11–15	2 (12.5)
16–20	0 (0.0)
21–30	5 (31.3)
Above 30	2 (12.5)
<b>Mean <math>\pm</math> SD</b>	<b>16.56 years <math>\pm</math> 10.73 years</b>
<b>Years in the current position</b>	Number (%)
<1	3 (18.8)
1–5	10 (62.5)
6–10	2 (12.5)
11–15	1 (6.2)
<b>Mean <math>\pm</math> SD</b>	<b>2.98 years <math>\pm</math> 3.18 years</b>
<b>Care involvement</b>	Number (%)
Direct care (NICU)	3 (18.8)
Direct care (PHNU)	2 (12.5)
Direct care (CHPS)	4 (24.9)
Indirect care (Hospital level)	3 (18.8)
Indirect care (District level)	2 (12.5)
Indirect care (Regional level)	2 (12.5)

Abbreviations: CHPS, Community-based Health Planning and Services; NICU, Neonatal Care Unit; PHNU, Public Health and Nutrition Unit; SD, Standard deviation.

In summary, we observed that the four family systems drivers within the CoC in the neonatal period influence each other. Empowered families are more confident, better informed and therefore more capable of providing the special care LBW infants need.

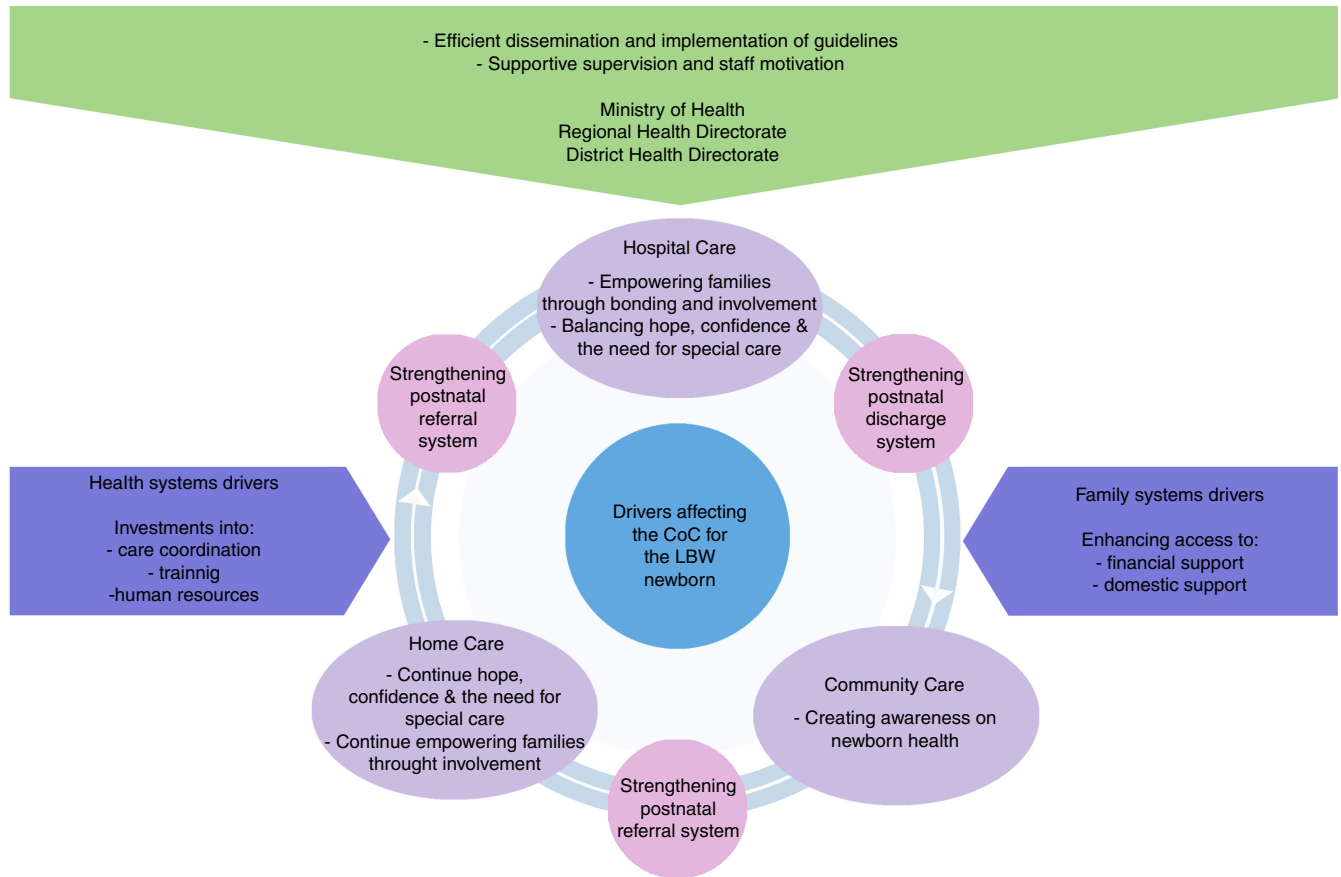


FIGURE 1 Continuum of Care for LBW infants in Ghana displaying family system and health-systems drivers

Through awareness creation among communities, mothers are expected to gain more financial and domestic support to lessen the stigma and serve as a confidence booster both at the early stage in the hospital and later at home and in the community.

In the ensuing thematized sections, we provide a detailed report on experiences about the transition of care for LBW infants and the context in which the experiences occur and the decisions made.

#### 4.2 | Empowering families through bonding and involvement

After birth, LBW infants who needed special care due to their critical health state, such as temperature instability, respiratory distress or feeding inability, were admitted to the NICU and therefore separated from their mothers. Mothers and family members were often not informed immediately where their LBW infants were taken to and for what reason:

*"I heard the doctor saying, they [the nurses] should inform the NICU that they will be bringing a baby to them. (...)They didn't tell me personally but I thought because of the gestation weeks. (...) Maybe they [health professionals] have to send her to a care unit."* [Mother, Birth weight (BW) 1.7 kg, Gestational age (GA) 36]

When information on the state of the LBW infant was not clearly communicated to the families, it created insecurity, fear and anxiety. The families desired for timely information about the well-being and whereabouts of their LBW infants without having to request specifically. Families who had no prior knowledge of an impending LBW delivery and the possible implications had difficulty understanding why treatment at the NICU was indicated. Thus, some HCPs reiterated the need for early education:

*"Once a woman is pregnant, I think they should re-enforce certain education at ANC [antenatal care]. They can invite the paediatrician to come to the ANC to give education to the pregnant women."*

[HCP NICU]

HCPs believed open and straight forward information reduces misunderstandings and tension between families and HCPs thereby helping families to appreciate the necessity of an admission at the NICU.

Once the LBW infant was admitted at the NICU, the mother-infant dyad experienced a time of separation due the small size of the NICU which did not allow for rooming-in. When the mothers' health status or the need for bed rest after caesarean section in the first few days after birth prevented them from visiting their newborns

at the NICU, other family members were assigned to play that role. Knowing the location of their newborn provided mothers with hope and a sense of security about the possible survival of their children:

*"I asked my sibling that when she goes, will she be able to recognize the baby? (...) The moment she [my sister] said, she saw her [the baby] lay there (...) that gave me encouragement that the baby is alive."* [Mother, BW 1.8kg, GA 38]

Once mothers recovered from the delivery process, they were allowed to visit their newborns at the NICU. Some HCPs tried to create time and room for bonding despite the architectural challenges of the NICU:

*"When a baby is delivered, we want this bonding. We don't want the situation whereby baby will be taken away from mother to break that bonding. So when we have this severely ill or critically ill babies, we allow their mothers to come in, they can be around the baby (...) their anxiety level is allayed and they [mothers] become so happy seeing their babies."*

[HCP NICU]

When mothers spent time with their babies, it created closure, enhanced bonding, and bridged the gap between them thereby decreasing mothers' anxiety and stress. Mothers tried to make up for the time they were separated from their infants through diverse approaches:

*"I do go check up on her (the baby) because she wasn't with me. So every second, I go to check up to see how she is (...) Oh, morning, afternoon, every second, I do go, also at night."* [Mother, BW 1.5kg, GA 38]

Regarding the care process, mothers got involved in care activities, such as feeding, kangaroo care and bathing of their LBW infant's. In few exceptions, fathers were partly included into the care as well:

*"They [the fathers] themselves will tell you they can't do but some when you give them the opportunity, you see that they are eager to do the care. (...) We allow them to also do [the care of the baby]. So, when they do, you will see them happy [saying] eei, today I am the one who cleaned you."*

[HCP NICU]

But because fathers often did not have much time to spend at the NICU due to their busy work schedules or simply their absence from the lives of the women and for that matter their LBW infants, chances of involving them were limited. Generally, family members were mainly involved in providing financial support like purchasing medicines and other essentials. The HCPs alleged that when families were asked to

purchase medical commodities needed for the care process and were not informed timely, they were hesitant to spend money:

*"They think that immediately you deliver, the baby is fine. (...) So assuming they come and you explain to them that the baby is having difficulty in breathing, so we need to give oxygen (...). but as at that point you didn't educate the caretaker about the condition or the need for a medication, the person will be feeling reluctant to go [and buy the medication]."*

[HCP NICU]

The more families were well informed and aware of the need for a care activity, the easier it was for them to comply with the instructions given by the HCPs and to also continue the care at home. A father mentioned that he would have appreciated more detailed information to be able to support his wife at home:

*"Since this is the first time [having a LBW baby], I think there should have been more information or education concerning the handling of the baby. Because the information or the education we were given, to me was too shallow if I may say."* [Father, BW 1.7kg, GA 36]

The discharge education given at the NICU was generally provided to mothers alone. Some HCP reported that care at home was often delivered by other female relations whose knowledge and practices on newborn care was sometimes outdated. Where the other caregivers did not receive the same instruction on current caring practices as the mother, it created tension at home. Thus, most HCPs at all levels of care perceived family involvement and education as important. They considered it as supportive because mothers can appreciate and properly carry out caring practices such as kangaroo care at home without being questioned by family members about the unfamiliar practice.

### 4.3 | Balancing hope, confidence and the need for special care

Different health professional and managers mentioned that mothers often faced psychological challenges as result of the birth of the LBW infant. Establishing hope was crucial because in the early days, some mothers had little or no hope, and over time, lost confidence in the chances of the child surviving. Thus, hope was often very faint and needed time to be established. When the mothers saw older babies who were born small became "big", it created a glimmer of hope that their infants would survive and grow too. Sometimes pictures of "success stories" with babies born LBW who reached normal weight were used to encourage the mothers. One HCP said that these stories gave mothers motivation and raised their hope. Further, comforting words from HCPs were helpful when the mothers were sad or fearful about the survival and well-being of their LBW infants. A



HCP stressed that it was also very vital to remain realistic and tell parents the truth about the LBW infants' condition and their risk.

Apart from HCPs, relatives and close friends played complementary roles in establishing hope. A few mothers mentioned their husbands and religious body to be their source of encouragement. A male family member said:

*"As for us, we do say that that is the will of God. That is God who gives you this aspect [the low weight] so you need to take care of her [the baby] special. We do support her [the mother]. She shouldn't feel bad that she she got this baby to be low birth weight. She is more happy because we are all there to support her. [Uncle, BW 1.35 kg, GA 35]"*

Some mothers consoled themselves but often, it was the varied sources of encouragement and hope that facilitated the confidence-building process as exemplified in this statement:

*"I knew definitely she will develop. [smiled] (...) I gave myself that vim before my mothers also came to greet me and said, I shouldn't worry, I shouldn't think. This person [the baby] will turn to obolo [Obolo is a term used to refer to overweight]. Everyone was saying that." [Mother, BW 1.35kg, GA 35]"*

After discharge home of the mother–infant pairs, the HCPs in the community continued the process of maintaining hope through counselling and encouragement. When mothers regained hope, they became joyful and were more likely to provide the necessary and appropriate care to their LBW infants.

One other aspect that created emotional trauma was the physical look of the LBW infant which people made comments about. Mothers often compared their LBW infants to other babies on the ward or in their communities. A HCM explained the psychological effect it can have on a mother, when her baby was smaller than the normal size, and she was faced by comments without receiving professional support:

*"So psychologically, the mother is not comfortable, somebody will come and see her baby (...), [and say] eiii why is it that the baby is small? (...) Or the mother herself, is emotionally down. Why everybody [in the ward] has a big baby, but her own is small. (...) It's a psychological problem that the mother really needs to be taken through a whole lot of counselling. So if there is no psychologist, there is a big problem, there is a big gap. And if you are not careful, it dampens the spirit of the mother."*

[HCM regional health directorate]

Some mothers found it difficult to handle and care for their small baby and when faced with demoralizing comments from family or community members, puts their already fragile self-confidence at risk. Health professionals in the NICU and at the community level emphasized the necessity to build mothers' confidence so as to reduce their

anxiety levels. Mothers appreciated words of praise and encouragement when they provided ample care for the infant. It reassured the mothers that they can carry out the care at home.

About the socio-cultural dimensions of LBW, various descriptions and beliefs prevailed among the general population on the causes. Some allotted medical explanations such as inadequate feeding during pregnancy while others had more abstract, culturally driven beliefs but regardless of the cause attributed, the mothers often faced the blame:

*"Some [mothers] feel it's their fault to give birth to such babies. And the community usually see those babies as I don't know, gods or maybe the fault of the mother. You know that everything they blame the mothers."*

[HCP NICU]

These views and beliefs impacted the mother's feelings negatively. The mothers sometimes faced stigma from their own husbands, family and community members leading to shame and consequently, avoidance of for example child welfare clinic sessions. The stigma influenced the care provided for LBW infants and in the worst case, led to traumatic experiences and neglect. In such situations, mothers' required professional support:

*"Sometimes the mothers, when they have small babies they get some psychological trauma. They feel shy to bring the babies out when people come. So we have to counsel them. Soon the baby will pick up and become a normal baby. So we have to calm down the mothers' nerve to regain confident and be happy with the baby. If not, they won't take care [of the baby]. They wish to leave the baby to die because it doesn't look like a normal baby."*

[HCP CHPS]

HCPs providing primary care in the community followed different counselling approaches to help mothers regain their confidence and lessen the psychological burden. In some cases, family members were involved in the counselling. One HCP stated that when fathers encouraged and supported their wives at home, it aided the mothers to regain confidence and minimized the neglect of the LBW infants. When despite the counselling, the neglect of care by families was observed, then the community health committee came on board to encourage the family to improve care for their LBW infant. Health professionals mentioned the need for professional psychological support in health facilities and communities to provide support to mothers who are psychologically stressed.

Some families believed that their LBW infant would grow like normal weight baby and therefore had fewer challenges with their nurturing. Health professionals needed to let families understand the special care needs of their LBW infant while at the same time keeping up the trust and hope of the infant's survival:

"Most of them [families of LBW infants] don't have the adequate knowledge on how to take care of such babies. (...) So we try to inform them that these babies, they are special, they need extra care. We try to talk to them, counsel them and even psych their mind that the baby is just normal. (...) It does not mean that they are different from the other babies. They are just normal like the other babies but they just need extra care."

[HCP CHPS]

It is important that HCPs maintain families' trust about the survival of their LBW infant by constantly balancing the hope and confidence established with encouragement to render adequate care to their LBW infants. Otherwise, mothers would lose their confidence and hope which could result in the neglect of their LBW infants.

#### 4.4 | Enhancing access to financial and domestic support

Health professionals stressed the importance of involving family members to enable them support the mothers after discharge home. Due to the neonate's small size, there was a greater need for support and for a longer period than with a normal weight infant:

"Now the baby is very low birth weight, you cannot carry that baby to go to the river side and fetch water. So you might need somebody who will fetch for you, ahaa. So you see, there is a difficulty than those who are term baby."

[HCP CHPS]

All HCPs as well as some mothers and family members claimed that there was a general lack of support for mothers with newborns. Sometimes assistance with household chores and childcare and in other cases, financial support were missing. A mother explained why the presence of her husband would not necessarily ease the financial struggles she faced:

"Oh, it's not about coming. Someone [husband] might come but is not having money. If he will be somewhere, working and sending money, that one is rather better than him coming." [Mother, BW 1.4kg, GA 32]

In the quest to make ends meet, mothers in the informal sector were forced to resume work within 6 weeks after delivery leaving the baby at home. A health care manager explained that family systems need to be assessed to identify and involve the major support persons to ensure mothers' care for their LBW infants is secured:

"You have to involve the family. You have to find out from antenatal if all this support ones [people] were enrolled

in the care provision (...) If the woman says the husband or the mother in-law or her mother, all these people, you need to bring them on board. You have to explain the condition of the baby to them. (...) Then if they now understood what you are saying, then now you can tell them the support that they need to give to that woman and the baby."

[HCM regional health directorate]

Early family involvement and counselling created the opportunity to generate holistic understanding about the care LBW infants need and increased the likelihood of mothers getting the necessary support from their families.

#### 4.5 | Creating awareness on newborn health

Another approach to tackle the predominant stigmatization of mother/families with LBW infants in some communities was community durbars where community HCPs educated the public on stigmatization:

"Stigmatization is something that is a common. (...) So we try to educate the public or the community on stigmatization. What we do is that we organise durbar. We involve the opinion leaders. So with that the stigmatization level is coming down a bit."

[HCP CHPS]

Health professionals suggested that health education on newborn and LBW should be done using educational materials and videos in the hospital. They further recommended outreach programs and information sharing on television. Health professional from both the hospital and the community mentioned the intention of establishing a support group that encompassed other community members to provide mothers with a platform to exchange their challenges while offering a source of emotional support.

## 5 | DISCUSSION

This study conducted using a constructivist grounded theory approach aimed to explore the experiences and needs of health professionals and families with LBW infants along the neonatal CoC in Ghana and to pictorialize the emerging model. We identified that family involvement is key for a comprehensive neonatal CoC as it empowers families in the care of LBW infants, allows bonding and enables health professionals to learn how to balance their direct care intervention with counselling and psychosocial support to promote good quality care. The study also revealed that it is necessary to enhance financial and domestic assistance for mothers of LBW infants and that raising awareness on newborn care in the general public is crucial. Our results show that CoC for LBW infants

is influenced by several interconnected factors ranging from economic, cultural to social factors which are important determinants of health (Braveman et al., 2011). These determinants impact life circumstances (Braveman et al., 2011; Marmot et al., 2008) and influence adequacy of postnatal CoC for LBW infants and their families thereby affecting health outcomes. Postnatal care quality can worsen if family members are unaware of and not involved in the care of their LBW infants.

Developing parent–infant bonding and enabling physical contact between them is highly necessary. Bonding facilitates infant neurodevelopment, improves their feeding and growth, reduces mothers' pain, stress, and depression (WHO, 2022a). However, bonding is often times interrupted due to early separation of the infant from the mother right after birth which can impair mother–infant attachment (Ncube et al., 2016). Bonding can further be hampered when admission to the neonatal ward excludes mothers' involvement in the care process which could cause despair, anxiety and uncertainty over the infant's survival (Horwood et al., 2019; Phuma-Ngaiyaye & Welcome Kalembo, 2016). Neonatal healthcare personnel play a key role in establishing and fostering bonding and security during interactions with LBW infant (Horwood et al., 2019). In non-Western environments, infants often have several caregivers and have to establish multiple attachments and relationships in early childhood (Aubel, 2021; Quinn & Mageo, 2013). Therefore, in the unavoidable absence of the baby's biological mother, health professionals could involve other family members to enable early bonding and attachment between the LBW infant and the new caregiver.

Similar to our findings on explicit information sharing, Horwood et al. (2019) described that mothers felt anxious, vulnerable and disempowered when procedures were performed on their babies without prior information. Smith et al. (2012) argued that when families lack understanding of why their infants are hospitalized, they find it difficult comprehending the care processes thereby impairing their ability to recognize the severity of the infant's health status while possible warning signs might be overlooked later at home (Geerlings et al., 2019). Our study and others recommend that antenatal care visits should double as an avenue where families at risk of having LBW infants receive information on the implications of LBW deliveries and the possible need for a postnatal admission (Tekelab et al., 2019; Unsworth et al., 2021). In the absence of a neonatologist, a paediatrician, gynaecologist or a nurse-midwife preferably with an advanced practice background could take over this task.

Effective communication between families and health professionals facilitate empowerment and active involvement of both parties in the care of LBW infants (Horwood et al., 2019). Permitting women and their families in shared decision-making is associated with social independence and higher compliance with MNCH care continuum procedures (Rahman et al., 2021; Tsega et al., 2022). Thus, to achieve better health outcomes and increase family well-being, there is need to promote a family-centred care approach (Franck & O'Brien, 2019). Built on the principles of active encouragement, family-centred care empowers families to develop care

competencies and gain respect as care partners working hand-in-hand with health professionals (Brødsgaard et al., 2019).

Studies have widely discussed the psychosocial traumas faced by mothers whose babies were admitted in neonatal wards (Al Maghaireh et al., 2016; Garti et al., 2021). The risk of neglect due to stigma and shame have been well established (Sakyi et al., 2020; Smith et al., 2017). Like our findings, in Malawi and Ethiopia, the use of success stories had positive impact on families with LBW infants and when complemented with early counselling could change negative perceptions and stigma in communities (Lydon et al., 2018; Usman et al., 2019).

Like Garti et al. (2021), we found that mothers were comforted and encouraged by family members, friends, religion and health professionals and confirm the quest by health professionals to have psychologists complement neonatal care teams and to set up support groups in hospitals and communities. However, in the absence of psychologists, nurses and midwives trained in family systems care (FSC), a care approach where families and healthcare providers are seen as mutually beneficial partners revolving on principles of dignity and respect, information sharing, participation, and collaboration (WHO, 2019) can establish therapeutic relationships with families along the CoC (Wright & Bell, 2021; Wright & Leahey, 2013). Equipped with FSC skills, HCPs are enabled to provide comfort and build trust which in turn helps families to cope with their difficult situation (WHO, 2022b; Wright & Leahey, 2013).

The need for families to maintain hope and optimism has been described by Janvier et al. (2016) who delineated that the right balance between honesty vis-à-vis compassion and reality vis-à-vis optimism is needed. Despite the need to promote hope, false expectation needs to be avoided (Green, 2015) confirming our findings that the balancing act is delicate but an important task for health professionals along the CoC to support mothers and families with LBW infants.

Mothers of LBW infants are often constrained by finances, work and the responsibility of caring for their vulnerable babies. Others have reported on inadequate maternal support and economic challenges faced by mothers post-delivery (Sakyi et al., 2020; Unsworth et al., 2021). Similar to the needs and responsibilities our participants highlighted, in a recent Ghanaian study, women of preterm babies reported on practical (domestic chores/baby care), material, psychosocial and spiritual support (Tibil & Ganle, 2021). Fathers are mostly responsible for financial aspects and decision-making, but a few serve as source of comfort to their wives, corresponding with findings from Adama et al. (2017). Absence of male involvement in newborn care is common despite evidence that it positively impacts newborn health (Mukunya et al., 2019; Tokhi et al., 2018). A major source of support in Ghana and similar settings are older female relations such as mothers-in-law, mothers and aunts who often have significant power, autonomy and influence in the care of newborns (Adama et al., 2018; Mukunya et al., 2019; Schuler et al., 2019). Therefore, involving males in LBW neonatal care needs to be carefully considered to not compromise the autonomy (Aubel et al., 2021). However, if that is the woman's preference and it helps with easing her burden, it should be encouraged.

Where mothers are counselled without including especially the older female caregivers, the mothers are likely to encounter conflicts at home. Adama et al. (2018) noticed comparable scenarios of tension between parents and grandmothers because the grandmothers' caring practices are often outdated. Thus, including these influential family members in timely and inclusive education could reduce the risk of tension among family members and increase the likelihood of applying appropriate care practices.

Similar to our results where health professionals suggested community level activities, Usman et al. (2019) and Kikuchi, Ansah, Okawa, Enuameh, et al. (2015) recommend improving holistic support for families with LBW infants through community involvement focusing on strengthening awareness about LBW infants. A FSC approach offers the opportunity to support families and to include the wider community into the care of LBW infants because it can be implemented in all healthcare levels but needs to be adapted to the local context (Moxon et al., 2015; Phiri et al., 2020). In Ghana, this means within a collectivistic society where an individual is part of a larger social construct within a family, community and cultural system and where decisions are taken collectively (Aubel, 2021). This systemic view has often been overlooked in global health frameworks since the use of linear models of cause and effect has been more common (Rutter et al., 2017). Having the potential to effectively address health problems and inequalities in the neonatal CoC for LBW infants requires urgent implementation and use of systems models (Aubel, 2021; Rutter et al., 2017). Thus, a major conceptual shift in new policies, healthcare planning and appropriate funding is required to incorporate the values and structures of more collectivists non-western societies (Aubel, 2021; Dzamedo et al., 2018; Usman et al., 2019). This shift would contribute towards a more effective newborn health strategy along the care continuum.

## 5.1 | Strengths and limitations

One strength of this study is the inclusion of health professionals at all levels of care plus family members which facilitated an in-depth understanding of the CoC from different viewpoints. The quality of this study was evaluated using Charmaz's (2014), Charmaz and Thornberg (2020) quality criteria. All the criteria were achieved which adds to the strength of the study. Although not generalizable beyond the study context, findings generated new knowledge that integrates well with existing theories and is transferable to similar settings and populations.

This study also has some limitations. It was challenging to interview fathers due to their unavailability or unwillingness to participate. Views from stakeholders like community volunteers, opinion leaders such as elders from the community or queen mothers and health managers at the national level could have provided additional insights to complement the theoretical model of the CoC. The coincidence that the families' LBW infants were all females might have had some implications on the care provision since sex preference could stimulate families to exhibit extra concern with their care.

## 6 | CONCLUSION

A theoretical model of family systems-based care approach has been identified to guide the exploration and improve the care conditions for LBW infants and their families in the neonatal CoC in Ghana. Findings illuminate the importance of FSC that promotes family involvement and stimulates a comprehensive response to addressing the needs of care providers and families with LBW infants along the neonatal CoC. The strategies required to achieve FSC must be multi-sectoral, culturally inclusive, sensitive to the socio-economic status of families and applied non-linearly at all levels in the CoC process (hospital, community and home care).

A FSC approach can equip health professionals to effectively counsel families on LBW care starting from the antenatal period. But knowledge on early bonding, skills to balance families' confidence and hope with the reality, family involvement and creating community awareness on LBW is required to effectively reduce stigma and blame and increase support for mothers with LBW infants in the CoC in Ghana and other resource-constraint countries.

Additional research in the area of stakeholder involvement and FSC in the neonatal period is necessary to inform training, policy development and implementation research on the feasibility of effectively integrating FSC at all levels of care to achieve a well-coordinated and quality care along the CoC for LBW infants and their families. This would potentially minimize the risk of sub-standard care of this vulnerable population along the care continuum thereby optimizing their chances to thrive and reach their full developmental potential.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE [<http://www.icmje.org/recommendations/>]): Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: Christina Schuler, Veronika Waldbboth, George Edward Ntow, Faith Agbozo; Involved in drafting the manuscript or revising it critically for important intellectual content: Christina Schuler, Veronika Waldbboth, George Edward Ntow, Faith Agbozo; Given final approval of the version to be published: Christina Schuler, Veronika Waldbboth, George Edward Ntow, Faith Agbozo; Each author participated sufficiently in the work to take public responsibility for appropriate portions of the content: Christina Schuler, Veronika Waldbboth, George Edward Ntow, Faith Agbozo. Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: Christina Schuler, Veronika Waldbboth, George Edward Ntow, Faith Agbozo.

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## CONFLICT OF INTEREST

The authors declare that they have no competing interests.

## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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