

Christina Schuler
George E. Ntow
Emmanuel Bansah
Ophelia Gbadago
Barbara Preusse-Bleuler
Riccardo E. Pfister
Faith Agbozo



Families at the heart of health systems change: A Ghanaian perspective on small and sick newborn care along the continuum of care

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Christina Schuler, (✉)
 Institute of Global Health, Faculty of Medicine,
 University of Geneva,
 Geneva, Switzerland
 Email: christina.schuler@etu.unige.ch

Barbara Preusse-Bleuler,
 Institute of Nursing,
 School of Health Sciences,
 Zurich University of Applied Sciences
 (ZHAW), Winterthur, Switzerland

George E. Ntow,
 Implementation Science
 Department, Dodowa Health Research Centre,
 Dodowa, Ghana

Emmanuel Bansah,
 Department of Epidemiology and Biostatistics,
 FN Binka School of Public Health,
 University of Health and Allied Sciences,
 Ho, Ghana

Ophelia Gbadago,
 Volta Regional Hospital, Hohoe, Ghana

Riccardo E. Pfister,
 Neonatal and Paediatric Intensive Care Unit,
 University Hospitals of Geneva and Geneva University,
 Geneva, Switzerland

Faith Agbozo,
 Department of Family and Community Health,
 FN Binka School of Public Health,
 University of Health and Allied Sciences,
 Ho, Ghana

with long-term disabilities^{1,2}. The greatest burden of these conditions is reported from sub-Saharan Africa and Southern Asia³. Unfortunately, the magnitude of neonatal morbidities and disabilities in low- and middle-income countries (LMICs) remains largely under reported and unknown^{4,5}. Families experience significant emotional, social and financial burdens. These challenges have long-lasting impacts on the newborns' developmental, social, and cognitive growth^{1,6}. Meanwhile, some cultural beliefs, myths and misinformation frequently expose small or sick newborns to compromised care⁷. Hence, the inclusion of families' perspectives and cultural beliefs is essential for shaping effective healthcare strategies and policies in LMICs.

For almost a decade now, we have initiated a consultative effort with healthcare professionals (HCPs) in the Hohoe Municipality of Ghana, with the co-created objective of improving care for small and sick newborns along the care continuum from pregnancy through hospital care to home care. Central was to explore the critical role that families can play in changing the health system when they are actively involved as recipients of care and contributors to the process of improving neonatal outcomes. Their involvement is not just beneficial but essential for shaping effective healthcare strategies and policies. This essay reflects on the various dimensions explored in our project, advocating for a partnership between families and care providers to improve neonatal care outcomes in Ghana.

How Our Journey Began: Voices of Families and Healthcare Professionals That Sparked Change

In 2016, a qualitative study was done to explore how mothers in the Hohoe Municipality cared for their low-birth-weight infants (weighing less than 2500g) at home following discharge. While mothers expressed satisfaction with the hospital care received, a critical gap was highlighted: the need for earlier and continuous counseling on neonatal care, starting during antenatal, through in trapartum and continuing postnatal. Findings also revealed conflicting information and ideas related to hospital-recommended care practices versus traditional home-based caring practices for neonates⁸. This contrast in caring practices at home and the need for early counseling prompted another study in 2021, which engaged mothers, their significant family members, and HCPs across various care levels and units, compromis

Introduction

Globally, the challenge of caring for small and sick newborns is significant. In 2020, one in every ten newborns was born prematurely (<37 weeks gestational age), and one in five was born small for gestational age (SGA). Each year, over 30 million newborns worldwide require inpatient hospitalization, with over 1.3 million surviving

compromising secondary care in a hospital to primary and community-based services. A key highlight was the need to promote family involvement throughout the care continuum. This ongoing collaboration between HCPs, researchers, and families led to key insights to enhance family involvement in the health system. The ensuing paragraphs of this essay explain some essential tools recommended by NEST360 and UNICEF⁹ in the care of small and sick newborns and how we contextualized and applied these tools to improve care experience.

Nine Essential Tools for Caring for Small and Sick Newborns

Family-Centered Care

While family-centered care has been widely recognized as a strategy to involve families in the health system, we propose an extension of a more encompassing approach known as family systems care (FSC) based on the Calgary Family Assessment and Intervention Model¹⁰. FSC promotes health, prevention, and illness management by supporting families in a more comprehensive and structured way¹¹. Like family-centered care, FSC views families and HCPs as collaborative partners, fostering dignity, respect, participatory engagement, information sharing, and shared decision-making^{1,10}. What sets FSC apart from family-centered care is its systemic approach and its structured focus on identifying and involving the broader family network¹². FSC enables HCPs to consider the family as an interaction and reciprocity between multiple systems within the family, society, and the health care system¹³. From our conversations with families, they complained of insufficient information regarding the condition/status of their unborn or newborn babies after delivery¹⁴.

However, access to appropriate and timely information, along with the opportunity for bonding, skin-to-skin care, and breastfeeding, is crucial for families to enhance the development of small or sick newborns^{15,16}. Often, HCPs may not fully understand the family dynamics or maybe unsure which family members should be involved in the care of small and sick newborns. Through open conversations, HCPs can identify the family's information and psychosocial needs, providing individualized, long-lasting emotional and cognitive support by offering appropriate information¹⁰. For example, grandmothers, aunts, or neighbors may play critical roles in care giving¹⁷. Family members want to be supportive, but illness in one family member can have a variety of effects on the health, perceptions, and behaviors of the whole family. Based on a systemic understanding, FSC helps find suitable ways to cope with challenges and alleviate suffering with the affected family. The systemic conversation approach utilizes tools like genograms and eco maps to assess family structure and dynamics to enhance collaboration in care by creating a safe space for expressing concerns and needs¹⁸. The FSC approach empowers families to actively participate in the care of their newborns by acknowledging and leveraging their strengths^{19,20} thereby potentially

addressing issues of disrespect and mistreatment often reported in maternity care²¹. In doing so, FSC creates an environment where families can provide continuous neurodevelopmental and nurturing care for small and sick newborns from pregnancy through postnatal care²². Despite the recognized value of family involvement in care, HCPs in the Hohoe Municipality face challenges in effectively integrating families into the care continuum. These challenges include limited space, time constraints, not knowing which family members to involve, the absence of family members, a lack of skills to engage them, and, at times, a lack of family-friendly attitudes²³.

In response, the research team developed a specialized eight-day FSC training program for HCPs across all levels involved in maternal and newborn care. The training equipped HCPs with knowledge and skills to implement FSC and engage families across the care continuum, building on prior lessons. A family participated, sharing lived experiences that demonstrated how to conduct systemic family conversations, providing HCPs with practical insights into meaningful family engagement.

Linkage to Maternal Care

Both families and HCPs in the Hohoe Municipality recognize the importance of FSC for small and sick newborns during antenatal care²⁴. However, in practice, antenatal care is often centered only on mothers²⁵, despite the importance associated with the inclusion of husbands and other family members in the support system²⁶. Barriers such as long waiting times at clinics, work commitments, and financial constraints often prevent family members, particularly men, from attending antenatal visits. To address these gaps, the ongoing FSC training helps HCPs better understand maternal health needs, family dynamics, and the importance of involving family members during antenatal care and throughout the care continuum²⁷. As a result, participating HCPs are now more attuned to assessing family systems and involving the preferred support person and prioritizing maternal mental health. They also explain critical aspects of care, such as the potential need for the neonatal intensive care unit (NICU), to high-risk pregnant women and their family members. This proactive communication reduces misunderstandings between families and HCPs and allows families to emotionally and financially prepare for the possibility of special care for their newborns^{14,25}.

Post-Discharge Follow-Up

Post-discharge follow-up visits in hospitals or at home are vital for providing psychosocial support and education for the whole family, which are essential for promoting the development, health, and well-being of newborns and their families^{28,29}. However, many African countries, including Ghana, are often faced with poor integration of post-discharge services for families into the broader healthcare system^{24,30}. When families bring

their newborns to child welfare clinics, HCPs often lack detailed information regarding the newborn's medical history and illness experience, which hinders the provision of continuous, high-quality care. These discrepancies leave families with inadequate follow-up care, as HCPs seldom conduct home visits despite Ghana's Community-based Health Planning and Services (CHPS) initiative, which emphasizes home visits³¹. The delivery of these services is often constrained by inadequate human resources and infrastructure or financial barriers that prevent families from attending these appointments²⁴.

The ongoing FSC project, therefore, seeks to address this gap by ensuring that vital information—including medical records and family context—is accurately documented in the maternal and child health booklet and, ideally, integrated into the newly implemented Light wave Health Information Management Software (LHIMS). This electronic health record system is expected to provide HCPs with seamless access to essential information at subsequent stages of care, facilitating improved care continuity.

Human Resources

Without adequate human resources at various care levels, achieving optimum family systems care and universal health coverage will be difficult³². HCPs in the Hohoe Municipality expressed concerns about the lack of time and human resources to support families. Nevertheless, appropriate family care interventions can still be delivered efficiently, even within these time constraints. We recommend the systemic conversation approach, which can be applied in 15 minutes or less, is purposeful and effective in engaging and supporting families^{18,33}.

In the Hohoe Municipality, many HCPs have expressed a desire for additional training in neonatal care, which presents an exciting opportunity to enhance their skills further. Despite these challenges, many HCPs reported satisfaction in their work with newborns²⁴, showcasing their dedication and commitment to improving care. Dedicated, well-trained healthcare professionals are essential to providing high-quality small and sick newborn care³². One indicator of high-quality care is the care experience and satisfaction of families^{16,34}. The experiences of families of small and sick newborns during pregnancy, labor, and the postnatal phase are critical to the health and healing process^{1,19}. However, there is limited quantitative data on how families in sub-Saharan Africa experience care during these stages, particularly for small and sick newborns²². Such information is vital to shaping HCP attitudes toward newborns and their families and driving progress in newborn health and survival²². To address this gap, we conducted a survey among families at various stages of the care continuum, including pregnancy, labor, and postnatal care—both in the hospital and after discharge into the community. A total of 442 family members participated in the survey. Our findings revealed that families with higher education levels and those living in more urban areas received

more cognitive and emotional support from HCPs than those with less education and families in rural areas²⁵. While this support was typically directed at mothers and fathers, other family members were often overlooked. The ongoing FSC training aims to equip HCPs with the skills necessary to support all family members more comprehensively.

Leadership and Governance

Having committed leadership and strong political will is crucial for adapting and integrating cutting-edge research evidence to include families in the care of small and sick newborns. This prompted our ongoing project in the Hohoe Municipality to conduct a context analysis to gather HCPs' perspectives on leadership within their wards. The feedback underscored the importance of having supportive leaders³⁵, which is critical for adopting evidence-based interventions³⁶. Over the years, we have consistently observed strong leadership support from hospital, district, university, and midwifery school administrators. Their openness to new approaches and commitment to allowing HCPs to engage in training has been crucial to advancing our project. Participation in research dissemination meetings, where they listen to both researchers and family concerns, has helped integrate family voices into policy discussions. However, while local leadership has been supportive, greater government involvement is necessary to ensure equitable access to quality healthcare for all families³⁷.

Referral System

Our research examined the Hohoe Municipality's referral system, focusing on how families perceive and experience the referral process. Families consistently reported the need for clear and comprehensive explanations regarding why their newborns are referred to higher-level care facilities. Concise information about the referral system is crucial in family systems care as it ensures families are well-informed. However, financial constraints often make referrals challenging. Coupled with improper communication, families may struggle to fully understand the rationale behind these decisions²⁴. Our findings emphasize the importance of having transparent and accessible communication between HCPs and families during referrals. In response to these insights, HCPs are encouraged to clarify referral decisions using appropriate strategies grounded in family systems care. The Hohoe Municipality has also introduced a telecommunication center located at the Volta Regional Hospital that supports active collaboration between different levels of care to achieve an effective referral system for families³⁸.

Equipment and Commodities

Families often face increased financial strain when purchasing hospital equipment for their newborns in the NICU. Healthcare professionals sometimes instruct them to procure medications and intravenous drips from

local pharmacies, further adding to their stress. While essential oxygen is appreciated, its cost can leave families uncertain about covering hospital bills upon discharge^{14,25}. This underscores the need for hospital subsidies and better-regulated insurance policies to help families care for their small and sick newborns. Despite these challenges, there have been notable improvements in neonatal care, particularly with the introduction of advanced NICU equipment, such as monitoring devices, which enhance the safety and effectiveness of care delivered to newborns. Easy access to all necessary equipment remains critical to ensure optimal care for small and sick newborns³⁹.

Infrastructure

The NICU at the Volta Regional Hospital has recently undergone restructuring; however, spatial limitations continue to pose significant challenges for families. The current layout restricts family members from being adequately present at the bedside of their newborns, complicating efforts to engage in skin-to-skin care. A critical area for improvement identified by families is the establishment of live-in family accommodations within or adjacent to the NICU⁴⁰. The lack of such facilities hampers the ability of families to remain close to their newborns during this critical period. Additionally, the NICU environment lacks designated spaces for families who experience the loss of a newborn, which can significantly hinder the grieving process⁴¹. Similar issues are observed in the labor ward, where birthing women face challenges related to privacy and family involvement. Adequate infrastructure is essential for promoting positive birth outcomes and complex postnatal care for small and sick newborns^{42,43}. In light of these findings, hospital management must consider the needs of family members in the design processes for future renovations of the NICU. Families' perspectives can be included on how NICUs should be structured to meet their needs better and enhance the care experience for newborns and their families.

Data System QI

In 2023, as part of the ongoing project, we conducted a context analysis utilizing the Context Assessment for Community Health (COACH) tool, designed for low- and middle-income countries to evaluate context and readiness prior to implementing evidence-based programs⁴⁴. The survey results indicated that over 80% of HCPs receive regular updates on their unit's performance based on collected data and engage in discussions regarding this information. Additionally, they reported that their unit's data are frequently compared to national and international guidelines³⁵. However, regional managers have noted that, for example, the Every Newborn Action Plan (ENAP) in Ghana is not consistently implemented at lower healthcare levels, underscoring the need for the provision and translation of more evidence-based guidelines into practice¹⁴. A significant opportunity for enhancing data quality is

the optimal utilization of the recently implemented Light wave Health Information Management Software (LHIMS). When effectively utilized, LHIMS has the potential to ensure high-quality, accurate health data that is essential to track progress toward ending preventable stillbirths, newborn deaths, and disability^{45,46}.

The Way Forward: Elevating Family Voices in Small and Sick Newborn Care

We are currently in the last stage of our project, which involves follow-up on families from pregnancy through six weeks after the discharge of their newborns. This part of the research aims to gain insights into the care perceptions and experiences of families during systemic conversations with HCPs at various stages: during pregnancy, around the time of birth, and throughout the postnatal phase, both in hospital settings and at home. We apply a mixed-method case study approach to capture the complexities of these conversations over time⁴⁷. The discussions are not solely focused on clinical care; they also prioritize relationship-building, fostering genuine involvement of families in decision-making regarding the care of their small and sick newborns. Our research team will analyze how these conversations are conducted, paying close attention to the quality of communication and the relational dynamics between families and HCPs. By integrating family perspectives into healthcare practices, we aim to shift the paradigm from families being passive recipients of care to becoming active partners in their newborns' care. This research can potentially enhance the healthcare experience for families, ensuring that their voices are heard and that they play a critical role in shaping the decision-making processes surrounding newborn care. Through our findings, we hope to inform and improve the systemic integration of family-centered care principles in clinical practice, ultimately benefiting both families and healthcare professionals.

Conclusion

Families' involvement in the care continuum for small and sick newborns is not merely beneficial but essential. Our research emphasizes that family engagement in the health system significantly impacts outcomes. We acknowledge the complexities and challenges that HCPs encounter, but we also assert that families' voices must be recognized and valued.

When healthcare teams actively listen to families' concerns, involve them in decision-making processes, and communicate with respect and transparency, families experience a profound sense of empowerment and reassurance. Challenges can be transformed into opportunities for healing, resilience, and hope. By prioritizing family involvement, we enhance the potential for small and sick newborns to not only survive but thrive while also ensuring that families remain strong and healthy throughout the journey. This approach advocates for a re

imagined healthcare model that embraces the critical role of families as active participants in the care of their newborns.

Photo 1) Participants from the Family Systems Care training, including healthcare professionals, facilitators (researchers), the Hohoe Municipal Health Director, and the Dean of the F.N. Binka School of Public Health, University of Health and Allied Sciences (August 2024)



Photo 2) Photo healthcare professionals during group work in the family systems care training Hohoe (August 2024)

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