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Family-centred care in the African Neonatal Network

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Abstract: *Background:* Family-centred care (FCC) fosters collaboration between neonatal healthcare providers and families to improve outcomes. Despite global recognition, FCC implementation in African neonatal intensive care units remains inconsistent due to infrastructural, cultural, and policy-related challenges.
Methods: Fourteen hospitals in the African Neonatal Network responded to an annual facility survey and a health facility survey co-developed by faculty in the African Neonatal Network and Vermont Oxford Network. All analyses use descriptive statistics.
Results: Significant disparities exist in parental access: 29% of hospitals hinder access to mothers and 79% hinder access to fathers. Similarly, visitation policies restrict sibling (93%) and extended family (35%) access, potentially impacting parental stress and bonding. Despite these restrictions, 94% of hospitals expect families to provide daily infant care. Kangaroo Mother Care (KMC) is universally allowed (100%), yet activities such as bathing (52.9%), remain inconsistently permitted. Rooming-in facilities, essential for parental involvement, are available in only 41% of hospitals. Forty seven percent of hospitals provide private counselling spaces. While 71% of hospitals conduct patient satisfaction surveys, only 12% involve family representatives in hospital meetings and protocol developments. Cultural resistance to allowing fathers (29%) and other family members (12%) to participate in KMC further hinders full implementation.
Conclusions: This study underscores the urgent need for policy reforms, enhanced staff education on FCC, and improved infrastructure to facilitate inclusive FCC adoption. Addressing these challenges will help bridge the gap between evidence-based neonatal care and real-world implementation, ultimately improving neonatal outcomes and fostering stronger family engagement in care processes.

Keywords: Family-Centered Care; Patient-Centered Care; Neonatal Intensive Care Units; Infant, Newborn; Premature, Family; Counseling; Patient Satisfaction; Africa South of the Sahara; Global Health

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Résumé: *Contexte:* Les soins centrés sur la famille (SCF) favorisent la collaboration entre les professionnels de santé néonatale et les familles afin d'améliorer les résultatscliniques. Malgré une reconnaissance mondiale, la mise en œuvre des SCF dans les unités de soins intensifs neonatal en Afrique demeure inégale en raison de défis liés aux infrastructures, à la culture et aux politiques.
Méthodes: Quatorze hôpitau membres du Réseau Néonatal Africain ont participé à une enquêteannuelle sur les structures hospitalières ainsi qu'à une enquête sur les établissements de santé, co-développées par des experts du Réseau Néonatal Africain et du Vermont Oxford Network. Toutes les analyses ont été réalisées à l'aide de statistiques descriptives.
Résultats: Des disparités significatives existent concernant l'accès des parents : 29% des hôpitaux restreignent l'accès des mères et 79% celui des pères. De même, les politiques de visite limitent l'accès des frères et sœurs (93%) et des membres de la famille élargie (35 %), ce qui peut affecter le stress parental et le lien affect if. Malgré ces restrictions, 94% des hôpitaux attendent des familles qu'ellesa ssurent les soins quotidiens des nourrissons. Le "Kangaroo Mother Care" (KMC) est universellement autorisé (100%), mais des activitéstelles que le bain (52,9%) restent permises de manière inégale. Les installations de rooming-in, essentielles pour l'implication des parents, ne sont disponibles que dans 41 % des hôpitaux. Quarante-sept pour cent des hôpitaux offrent des espaces de consultation privés. Alors que 71% des hôpitaux réalisent des enquêtes sur la satisfaction des patients, seulement 12% impliquent des représentants familiaux dans les reunions hospitalières et le développement des protocoles. La résistance culturelle à la participation des pères (29%) et d'autres membres de la famille (12%) au KMC entrave encore une mise en œuvre complète.
Conclusions: Cette étude souligne le besoin urgent de réformes politiques, d'une formation accrue du personnel sur les CCF, et d'une amélioration de l'infrastructure pour faciliter l'adoption inclusive des CCF. Aborder ces défis permettra de comblerl'écart entre les soins neonatal fondés sur des preuves et leur mise enœuvre dans le monde réel, améliorantainsi les resultants néonatals et renforçant l'engagement familial dans le processus de soins.

Introduction

Family-centred care (FCC) is an approach that involves collaboration between healthcare providers and families with an emphasis on involving parents in the care process and decision-making of babies in the neonatal intensive care unit (NICU). FCC ensures comprehensive, safe, compassionate, equitable, and culturally sensitive care outcomes for neonates, fostering stronger family bonds, and supporting emotional well-being for both the child and the family.[1] Remaining together with the baby in NICU and being involved in decision making with the healthcare team are key principles of FCC.[1]

FCC can improve health outcomes, patient satisfaction and family well-being.[2] In the context of newborn care, FCC has been associated with higher weight gain, breastfeeding rates, and improved sleep duration for preterm infants in NICUs.[3] A quasi-experimental study demonstrating the positive impact of FCC on very low birth weight (VLBW) infants reported that empowering parents through education and involvement in care improved clinical outcomes and increased parental confidence in managing their infants' needs.[4] This study highlighted a growing trend towards recognizing the efficacy of FCC interventions, though it acknowledged that widespread implementation remains a challenge, particularly in developing regions.

Studies of African countries have highlighted the need for culturally sensitive and context-specific approaches to FCC.[5-10] Although participation is an essential concept in FCC, many health professionals are not familiar with this approach and most hospitals lack FCC policies. Many low- and middle-income countries (LMICs) face challenges in providing adequate healthcare resources.[7-11] While there is an increasing recognition of the importance of family involvement in neonatal care, the implementation of FCC in African NICUs has not been systematically studied.

This paper reviews the extent and impact of family involvement in the care of and decision-making for the small and sick newborn babies in African Neonatal Network NICUs, with a focus on understanding how it can be adapted to local resources, cultural contexts and

healthcare systems.

Methods

Data collection was conducted in 14 African Neonatal Network (ANN) member hospitals across five countries: Ethiopia, Nigeria, Rwanda, Uganda, and Zimbabwe.

Vermont Oxford Network (VON) conducts an annual survey for members that was co-developed with ANN faculty members, which includes information on the hospital setting, number of beds and admissions, staffing, obstetric service, follow-up clinic, resuscitation and essential newborn care, transfers and transport, family-centred care, services provided by the neonatal unit, guidelines in the neonatal unit, quality assurance/ continuous quality improvement, and level of neonatal care. Participation in the membership survey is mandatory. The responses used for this manuscript are from 2023.

In October 2023, the ANN conducted a health facility assessment to collect more detailed information on buildings and facilities, medications, diagnostics and consumables, equipment, staffing, governance, thermal regulation and foetal transition, nutrition, family-centred care and kangaroo mother care, infection prevention and control, and perceived priorities.

Tables of hospital-level measures include data from both the membership survey and the health facility assessment. All analyses are descriptive.

The collaborative QI project and subsequent assessments received individual and hospital institutional research and ethics review approvals at the start of the collaborative and learning initiative.

Results

Collaboration and Information Sharing

All hospitals reported that families participate in decision making for their infants, eleven hospitals (79%) reported that family knowledge, values, and beliefs are incorporated into care delivery and 12 (86%) reported that treatment decisions are aligned with the best interest of the child (Table 1). Almost all of the hospitals reported having a non-discrimination policy for treatment of patients. Seven hospitals (50%) reported having private spaces for counselling within the neonatal unit, five of which were separate rooms.

While eight (57%) hospitals reported that families participated in NICU quality improvement meetings and initiatives and five (36%) reported that families participated in hospital committees, only two hospitals reported that family members participated in unit meetings and protocol development. Eight hospitals (57%) reported having a standard discharge summary for parents and ten hospitals (71%) reported routinely performing parent satisfaction surveys.

Participation

Thirteen hospitals (93%) reported that families were expected to provide daily care to infants. However, only ten (71%) hospitals reported that mothers have unhindered access to infants and only 3 (21%) reported the same for fathers. One hospital (7%) reported that siblings were allowed in the unit and five (36%) hospitals reported that other visitors were allowed. (Table 2) Four hospitals (29%) reported having a rooming-in facility in the neonatal unit.

Infant care activities that may be completed by family members include bathing, feeding, turning, changing diapers, KMC, and other unspecified activities (Fig 1).

Finances

At six (43%) hospitals, families cover 100% of the total cost of care while at three (21%) hospitals, families cover 51% to 99% of care costs; and at 5 hospitals, families cover 0% to 50% of care costs. At hospitals where families cover a portion of the cost of care, they are often financially responsible for buying both medications and tests (Table 3). At nine hospitals (64%), delays in purchasing sometimes cause delays in providing necessary treatment.

Management of Infant Pain

Hospitals were not asked about family involvement in the management of infant pain; however this topic will be a part of future surveys. Five hospitals (36%) reported that the unit has an infant pain policy, and 7 (50%) hospitals reported that nurses and doctors used a standardized pain assessment tool 10% of the time or less. Most hospitals reported that intravenous anaesthesia (71%) and sedation (86%) were available consistently. Provision of pain relief varied by whether the procedure was mild-to-moderately painful (e.g., placing an intravenous cannula or doing a lumbar puncture) or moderately-to-severely painful (e.g., non-emergent chest drain placement) (Fig 2). Fifty percent of hospitals did not use sedation for non-emergent intubations.

Table 1: Incorporation of families reported by 14 African neonatal network hospitals

	#	%
Families participate in decision making for their infant	14	100
Family knowledge, values, and beliefs are incorporated into care delivery	11	79
Families are included in NICU-based quality improvement activities	8	57
Families are included in hospital-wide committees	5	36
Your hospital has a non-discrimination policy for treatment of patients	13	93
Your NICU has guidelines to support staff and families that recommend treatment decisions are aligned with the best interest of the child	12	86
Preterm infants at <28 weeks born breathing and vigorous are offered resuscitation if that is aligned with parent's wishes	14	100

Table 2: Parental access to infants at 14 African neonatal network hospitals

	Mothers		Fathers	
	#	%	#	%
Unhindered access	10	71	3	21
Access only at specific times	4	29	11	79
Visits not allowed	0	0	0	0

Table 3: Payment for medications and pathology tests at 14 African neonatal network hospitals

	Medications		Pathology Tests	
	#	%	#	%
All are free	1	7	3	21
Some are free, some purchased by parents	6	43	3	21
All purchased by parents	7	50	8	57

Fig 1: Infant care activities allowed by family members in 14 African Neonatal Network hospitals

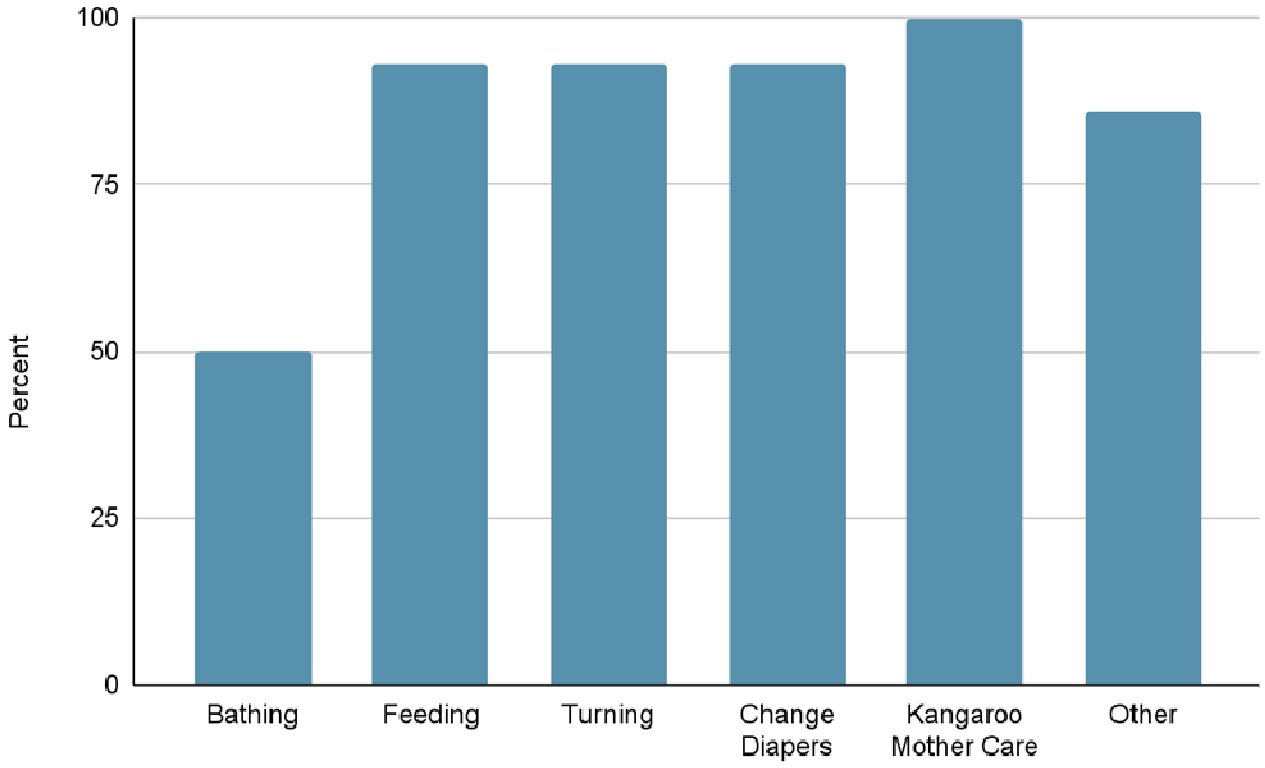

Fig 2: Provision of pain relief during mild/moderately painful and moderately/severely painful procedures at 14 African Neonatal Network hospitals

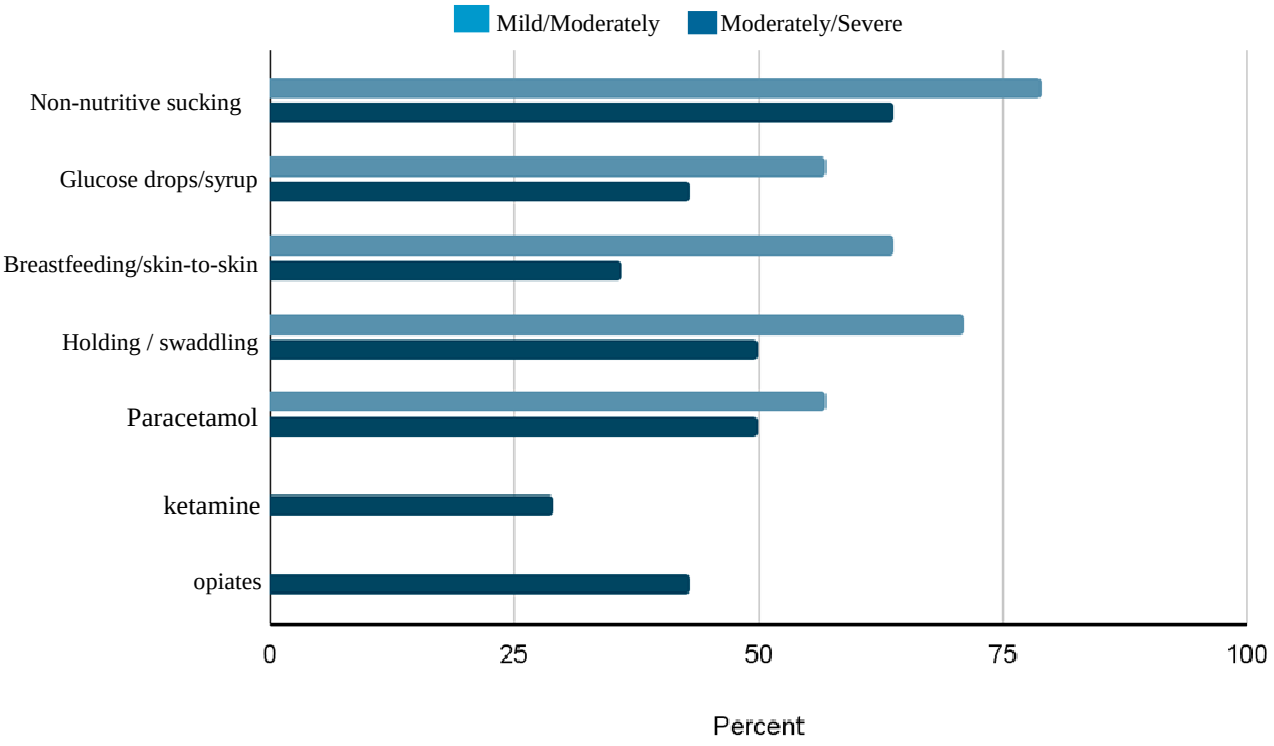

Fig 3: Spectrum of Family Engagement, adapted from: Framework for Family Involvement in QI at VON by Abraham and Nickerson (IPFCC)[16]

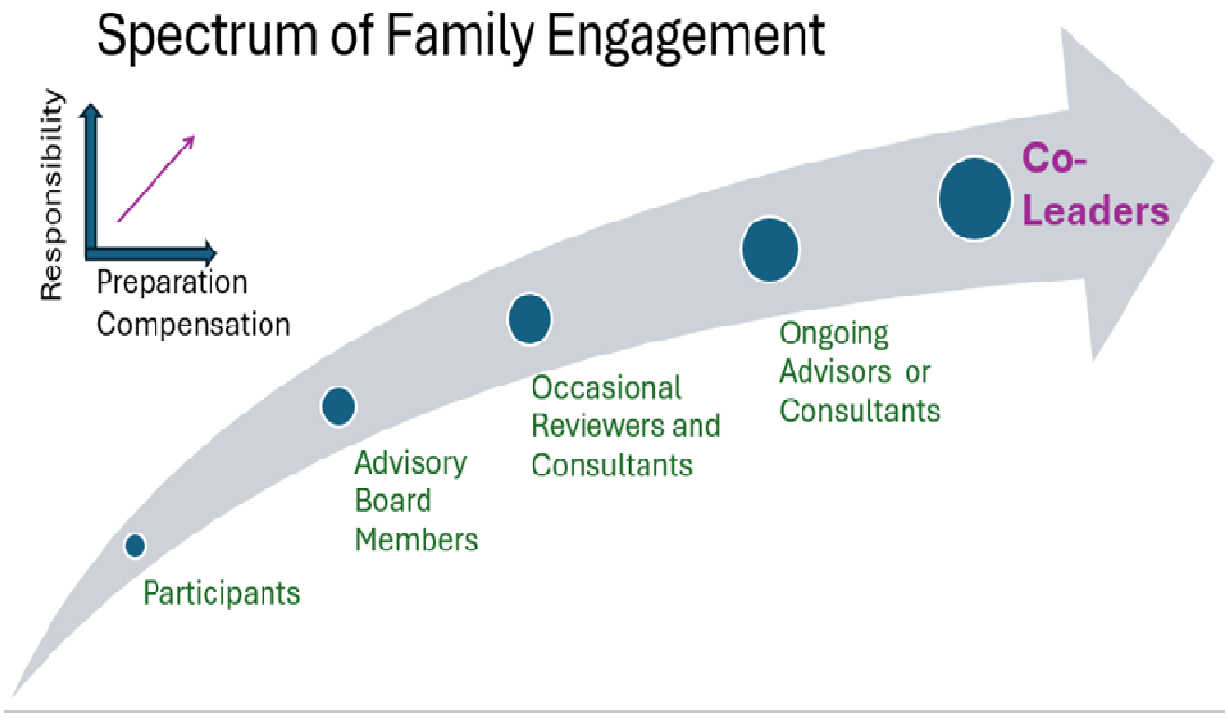

Fig 4: Partnering with Families to Accelerate Change and Improvement Readiness Assessment, adapted from: Partnering with Families to Accelerate Change and Improvement Readiness Assessment (IPFCC) [17]

African Neonatal Network
Partnering with Families to Accelerate Change and Improvement Readiness Assessment

Area	For each item, circle the box best describes your teams perspective and experience			
Data transparency.	Our team is uncomfortable sharing performance and other data with family partners related to the project.	While we have limited or no experience in involving family partners, our team is comfortable sharing performance and other data with family partners related to the project .		Our team has experience and is comfortable sharing performance and other data with family partners.
Flexibility around aims and specific changes for project.	We have limited ability to refine the projects aims or planned changes.	We are open to changing both the aims and planned changes based on family partner team members feedback and perspectives.		We have partnered with our family partner team members to develop the aims and planned changes for this project.
Underlying fears and concerns.	We have identified several concern about involving family partners on project teams and would need assistance in creating a plan to address them.	We have identified several concerns related to involving family partners on project teams but believe we can create a plan to address or manage them		We have no concerns about family partner involvement, and we have experience addressing issues that may arise due to their involvement on our project team.
Perceived value and purpose of family partner involvement.	There is no clear agreement that family partner involvement on our team is necessary to achieve our project goals.	Our team believes family partner involvement will be beneficial to our project but we have limited or no experience with family partner involvement.		There is clear recognition that family partner involvement is critical to achieving our project goals .
Senior leadership endorsement.	Senior leaders in our NICU do not consider family involvement to be a top priority.	Senior leaders in our NICU are aware of and communicate support for family partner involvement in charge and improvement.		Senior leaders in our NICU are committed and provide resources necessary to involve family partners in change and improvement .
Resources available for family partner involvement.	No resources are available and dedicated toward removing barriers for involving family partners.	We have assessed barriers and facilitators for involving family partners and some have received resources.		We have assessed barriers and facilitators for involving family partners and committed sustainable resources.
Experience with family involvement as advisor.	Our NICU has not yet involved families.	Our NICU has implemented family satisfaction surveys or focus groups to obtain family perceptions of care.	Our NICU has family advisors and /or a family advisory council/group.	Family advisors are members of NICU commit and partner with clinicians and staff in making decisions at the program and policy level .
Collaboration and teamwork in care.	Clinicians and staff in our NICU occasionally work in multidisciplinary teams to provide care.	Clinicians and staff in our NICU work effectively across disciplines to provide care.		Clinicians and staff in our NICU are effective at working collaboratively in multidisciplinary teams that include families as valued and essential members of the care team.

1. What supports and resources are available to your team for involving family partners in this project?
2. What challenges do your team anticipate in involving family partners in this project successfully and meaningfully?
3. How confident is your team about successfully and meaningfully involving family partners on your project team (on a 1-10scale with 1=not confident at all and 10= extremely confident?

Discussion

Successful implementation of FCC in African NICUs requires a dedicated commitment from healthcare providers, collaboration with families, and consideration of the unique cultural context needed to create a supportive environment where parents feel actively involved in their newborn's care. In the current study, all 14 hospitals reported that families participate in decision making for their infants but only 11 said that family knowledge, values and beliefs are incorporated into care delivery. To address these challenges, we recommend concentrated team efforts to implement FCC based on a shared culture and defined framework, which can help redistribute power and promote a more equitable relationship between care providers and families.

In the current study, 13 hospitals reported that families were expected to provide daily care to infants, but mothers had unhindered access to infants at 10 hospitals and fathers had unhindered access at three. This finding aligns with work from Sierra Leone[8] and Uganda,[12] both of which noted that parental participation is often used as a tool for overcoming workload challenges for healthcare providers. Wanduru *et al.* acknowledged that in many instances parents are "deployed as assistants rather than as equal partners, contrary to the ideals of family-centred care".[12] Hindered access for fathers was also observed in Ghana, where mothers were allowed to visit any time but fathers could visit only in limited morning hours.[9] In another study from Ghana, mothers could only see their infants every two hours.[10] There is a great need for hospitals to recognise the intrinsic value of FCC and to promote a supportive environment for all family members all of the time.

Having enough physical space for families is often a challenge, especially in resource-limited settings. In the current study, 29% of hospitals had a rooming-in facility in the unit and 50% had private spaces for counselling in the neonatal unit. A study in 10 NICUs in Brazilian public hospitals revealed that seven institutions provided private space for families, either within or outside neonatal units, but in four hospitals, these spaces were reserved for mothers only.[13] In Ghana, mothers had to sleep on the floor in the hospital or outside.[9,10] In Sierra Leone, nursing staff overwhelmingly agreed that the hospital lacked the resources and structures to implement FCC in a way that was feasible and worthwhile.[8]
A study in Ethiopia found that family integrated neonatal care (FINC) was conceptually acceptable and technically implementable.[14] However, integration and adaptability may be constrained by poor organizational infrastructure related to NICU space and infection prevention measures. Opportunities to co-develop a solution *with* families rather than *for* families or healthcare providers should be pursued.

An Ethiopian study on person-centred maternal and newborn care explored women's experiences of care and satisfaction.[15] Most observed consultations scored low on indicators of person-centred care, with satisfaction increasing with more information shared. Women valued respectful and responsive communication from healthcare workers, affecting willingness to disclose psychosocial problems. The study shows that prioritisation of person-centred care could improve women's experience of maternal care and better address psychosocial needs. Acknowledging and addressing these needs positively affect the outcomes of newborns. An aligned and integrated FCC system from maternal to newborn care should be viewed not as a luxury but a necessity that requires immediate attention and action.

The literature on FCC reveals a progression in understanding and applying FCC principles across various contexts.[6,11] FCC is a significant shift in the paradigm of health care delivery, emphasizing the integral role of families in the care of neonates. We recognize the spectrum of family engagement in QI within the ANN, and our opportunity to catalyse progression along this spectrum (Fig 3).[16] The Institute for Patient- and Family-Centered Care in the United States has created a readiness assessment for NICUs as they commit to partnering with families to accelerate change and improvement (Fig 4).[17] Ensuring families have unhindered access to their newborns is crucial for advancing FCC. The current access rate, especially for fathers, is alarmingly low. To bridge this gap hospital teams must prioritise policies and practices that actively promote family involvement, address cultural and societal barriers. (fig 3/4)

This research will contribute to the global body of knowledge on family-centred care, providing insights into the extent and impact of family involvement in care and decision-making for small and sick newborns in low-resource settings. The study can contribute to the advancement of FCC practice providing insights into the complex relationships between family involvement, care and decision-making for small and sick newborns. The study provides insights into the contextual factors that influence family-centred care in LMIC NICUs, highlighting the need for culturally sensitive and context-specific approaches to care. The study's findings can inform healthcare policy, practice, guideline development and funding decisions in Africa highlighting the importance of FCC in improving health outcomes for small and sick newborns.

To provide authentically FCC in the ANN NICUs, it is crucial to prioritise inclusion of pain management indicators in our care survey, ensuring that the unique needs and experiences of the newborn are addressed while honouring the values and preferences of the families. In addition, the study's findings can inform policies that promote intersectoral collaboration between healthcare providers, community leaders and government officials, ensuring that FCC is integrated into all aspects of healthcare.

Conclusion

FCC is a critical component of high-quality neonatal care in the ANN NICUs. This study highlights the need for increased family engagement and FCC. To sustain and spread FCC initiatives ongoing training and education for healthcare providers, infrastructure development and policy support and funding are needed. By prioritising FCC, NICUs can provide compassionate care that supports the unique needs of newborns and their families, ultimately improving health outcomes and saving lives.

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