Family Integrated Care in Uganda: a feasibility study

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ABSTRACT

Objective To determine the feasibility of adapting Family Integrated Care to a neonatal hospital unit in a low-income country.

Design Single-centre, pre/post-pilot study of an adapted Family Integrated Care programme in Uganda (UFICare).

Setting Special Care Nursery at a Ugandan hospital.

Patients Singleton, inborn neonates with birth weight ≥2 kg.

Interventions As part of UFICare, mothers weighed their infant daily, assessed for severe illness ('danger signs') twice daily and tracked feeds.

Main outcome measures Feasibility outcomes included maternal proficiency and completion of monitoring tasks. Secondary outcomes included maternal stress, discharge readiness and post-discharge healthcare seeking.

Results Fifty-three mother–infant dyads and 51 mother–infant dyads were included in the baseline and intervention groups, respectively. Most mothers were proficient in the tasks 2–4 days after training (weigh 43 of 51; assess danger signs 49 of 51; track feeds 49 of 51). Mothers documented their danger sign assessments 82% (IQR 71–100) of the expected times and documented feeds 83% (IQR 71–100) of hospital days. In the baseline group, nurses weighed babies 29% (IQR 18–50) of hospitalised days, while UFICare mothers weighed their babies 71% (IQR 57–80) of hospitalised days (p<0.001). UFICare mothers had higher Readiness for Discharge scores compared with the baseline group (baseline 6.8; UFICare 7.9; p<0.001). There was no difference in maternal stress scores or post-discharge healthcare seeking.

Conclusions Ugandan mothers can collaborate in the medical care of their hospitalised infant. By performing tasks identified as important for infant care, mothers felt more prepared to care for their infant at discharge.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ In hospitals in low-income countries, parents are often the de facto primary caregivers due to healthcare worker shortages, but research on how parents can systematically collaborate with healthcare workers is lacking.
⇒ Parental engagement in the care of their infant in neonatal intensive care units through Family Integrated Care (FICare) improves neonatal and parental outcomes.

WHAT THIS STUDY ADDS

⇒ FICare can be adapted to a neonatal hospital unit in a low-income country. As part of Uganda FICare (UFICare), mothers were able to be engaged in their infant's hospital care and perform specific monitoring tasks.
⇒ Mothers who participated in UFICare felt more prepared to take care of their infant at discharge.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Further research to determine if UFICare improves neonatal outcomes in low-income countries is warranted.

INTRODUCTION

Although global access to hospitals has increased, the neonatal mortality rate in low-income countries remains disproportionately high. In Uganda, births in health facilities increased from 37% in 2000 to 74% in 2016.[1] Nevertheless, infants born in Uganda are still six to seven times more likely to die in the neonatal period than children in high-income countries.[2] Healthcare worker shortages in low-income countries prevent hospitals from providing high-quality neonatal care. Uganda employs less than half of the WHO's recommended 5 healthcare professionals for every 1000 people.[3]

Parents may be a resource for improving the quality of hospital care in low-income countries. Parental engagement is increasingly recognised as a necessary component of neonatal intensive care units (NICUs).[4] Family Integrated Care (FICare) is a model that incorporates parents as partners in the NICU and has been shown to improve outcomes, including weight gain and parental stress.[5 6] FICare includes interventions targeting the physical environment, staff education and support, parent education and support, and parent partnership. Adaption of FICare to low-income countries may allow parents to improve the quality of their infant's hospital care and promote their own confidence at discharge. The current study's objective was to determine the feasibility of implementing a locally adapted FICare programme in a neonatal hospital unit in Uganda (UFICare).[7 8] Specifically, we evaluated whether mothers could engage in their infants' medical care and participate in their monitoring.

METHODS

Setting and participants

We conducted a pre/post-pilot study in the Special Care Unit (SCU) at Jinja Regional Referral Hospital

in Uganda. The SCU is a postnatal ward that cares for sick and premature neonates, has a nurse-to-patient ratio of approximately 1:10 and admits 1500 neonates annually. The most common reasons for admission are prematurity/low birth weight (~50%), asphyxia (~20%) and sepsis (~20%). Bubble continuous positive airway pressure is the highest level of respiratory support, and continuous pulse oximetry is reserved for very ill patients. Kangaroo mother care (KMC) is standard practice for preterm/low birthweight infants. Mothers stay at the hospital when their infant is hospitalised and are provided a bed in an adjacent ward.

Singleton neonates admitted to the SCU and their mothers were eligible for inclusion if the neonate was inborn and weighed ≥2000 g at birth. Birth weight was used as an inclusion criterion due to the risk of inaccurate gestational age assessment.[9] We excluded neonates who were critically ill or expected to be discharged within 48 hours. Mothers were excluded if they were not staying at the hospital with their infant or were too unwell to be with their infant. Caregivers provided written informed consent for participation in the study. Consecutive sampling was used to recruit 50 mother–infant dyads for both the baseline (November 2020–February 2021) and intervention group (February 2021–July 2021).

Procedures

Neonates in the baseline group received routine care in accordance with hospital policy. UFICare began with two focus groups of mothers whose infants were admitted to the SCU and individual interviews of healthcare workers.[10] Results were used to identify tasks that were important for infant care and potentially transferrable to mothers. Healthcare staff were provided with information about the parent training, expectations and how to address maternal concerns. Unit procedures were changed to allow for maternal engagement in the monitoring of their infant. We employed two research nurses who trained and evaluated the participants. Mothers in the intervention group received a 30–45 min educational session. Mothers were taught to monitor and record the presence or absence of clinical features that predict severe illness ('danger signs') twice daily.[11] The danger signs were adapted from the WHO's Integrated Management of Newborn and Childhood Illness and included poor feeding, convulsions, difficulty breathing, weakness, omphalitis and temperature instability (figure 1). Mothers used a sticker that changed colour to indicate hypo/hyperthermia (Thermospot) to evaluate their infant's temperature. Mothers were also taught to weigh and document their infant's weight daily using a digital scale and to document each time their infant fed. The monitoring forms were paper based and designed for the purpose of this study.

Outcomes and analysis

We assessed the feasibility of UFICare through maternal proficiency and maternal completion of monitoring tasks. We evaluated maternal proficiency by auditing the mothers' ability to correctly perform and document each task. Two to 4 days after enrolment, a research nurse observed the mother weigh her infant, evaluate for each danger sign, feed her infant and document all tasks. For each task, the mother was assessed as being 'proficient' or 'not proficient'. The percentage of mothers who were proficient at each task was calculated. We evaluated maternal completion of the monitoring tasks by calculating the completion rates of the documentation forms for the first 7 days following enrolment or until discharge, whichever occurred

Figure 1 Maternal monitoring form. The form was translated to Lusoga for usage in the study.

first. Maternal documentation rates in the intervention group were compared with nursing medical chart documentation in the baseline group. Specifically, we compared the rate of maternal documentation of the infant's weight to the rate of nursing documentation of the infant's weight. We also compared the rate of maternal documentation of dangers signs to the rate of nursing documentation of vital signs given that both assess the infant's clinical status. Nurses do not track patient feeding, so this variable was not compared between groups.

The secondary outcomes examined were maternal stress, discharge readiness and post-discharge health seeking. Maternal stress was measured 2–4 days after enrolment using the Parental Stress Scale (PSS):NICU which assesses stress related to infant appearance and behaviour, communication with staff, altered parenting role, and sights and sounds.[12 13] The parent rates each item from not at all stressful (1) to extremely stressful (5). At discharge, mothers completed the paediatric Readiness for Hospital Discharge Scale which measures five domains: parent's personal status, child's personal status, parental knowledge, parental coping and expected support.[14] Both surveys were translated to the local language (Lusoga) and administered orally if the mother was illiterate. A telephone follow-up 6 weeks after discharge assessed for post-discharge infant mortality, health seeking and readmission.

The characteristics and outcomes of the study population were compared between the baseline and intervention groups using X^2 test for categorical variables and Student's t-test or

Table 1 Maternal and neonatal characteristics

	Control	Intervention	P value
Mother–infant dyads, n	53	51	
Maternal age, years, mean (SD)	26.42 (6.02)	24.92 (5.82)	0.17
First-time mothers, n (%)	23 (43.40)	21 (41.18)	0.82
Education			0.50
No school, n (%)	1 (1.89)	0 (0)	
Less than primary, n (%)	1 (1.89)	0 (0)	
Primary, n (%)	14 (26.42)	20 (39.22)	
Secondary, n (%)	32 (60.38)	26 (50.98)	
Post-secondary, n (%)	5 (9.43)	5 (9.80)	
Antenatal visits, n, mean (SD)	4.53 (1.66)	4.51 (1.75)	0.93
Mode of delivery			0.87
Vaginal, n (%)	32 (60.38)	31 (60.78)	
Caesarean, n (%)	21 (39.62)	20 (39.22)	
Gestational age, weeks, median (IQR)	36 (35–40)	36 (36–40)	0.96
Birth weight, grams, median (IQR)	2900 (2600–3500)	3200 (2750–3650)	0.16
Neonatal sex			0.23
Male, n (%)	24 (45.28)	18 (35.29)	
Female, n (%)	29 (54.72)	33 (64.71)	
Reason for admission			0.33
Asphyxia, n (%)	32 (60.38)	22 (43.14)	
Infection, n (%)	10 (18.87)	11 (21.57)	
LBW/prematurity, n (%)	4 (7.55)	2 (3.92)	
Meconium aspiration syndrome, n (%)	3 (5.66)	7 (13.72)	
Jaundice, n (%)	2 (3.77)	3 (5.88)	
Injury/accident, n (%)	0 (0)	3 (5.88)	
Other, n (%)	2 (3.77)	3 (5.88)	
Age at admission, days, median (IQR)	1 (1–2)	1 (1–2)	0.88
Deaths, n (%)	2 (3.77)	4 (7.84)	0.36
Discharged against medical advice, n (%)	2 (3.77)	1 (1.96)	0.60

LBW, low birth weight.

Mann-Whitney U test for continuous variables with normal or skewed distribution, respectively. Data obtained by the research nurse were collected and managed using REDCap hosted at McGill University Health Centre. Statistical analyses were completed using Microsoft Excel (V.16.60) and R Statistical Software (V.4.0.1).

RESULTS

Fifty-three mother–infant dyads were enrolled in the baseline cohort, and 51 mother–infant dyads were enrolled in the intervention group. There were no differences in the rate of in-hospital mortality or discharge against medical advice between groups. Baseline characteristics did not differ between groups (table 1). Forty-two per cent of mothers were first-time mothers, and 65% of mothers had at least secondary education. The median gestational age was 36 weeks, and the most common reason for admission was birth asphyxia.

When audited 2–4 days after training, 84% (43 of 51) of mothers could correctly weigh their infant and document the weight. Ninety-six per cent (49 of 51) of mothers were proficient in assessing for danger signs and documenting their evaluation. Ninety-six per cent (49 of 51) of mothers knew how to properly track their infant's feeds.

Table 2 Readiness for Hospital Discharge Scale*[11]

Domain	Baseline	UFICare	P value
Parent personal status	7.7	8.1	0.008
Child personal status	7.7	8.1	0.008
Knowledge	5.3	7.4	<0.001
Coping ability	6.7	7.6	<0.001
Expected support	7.3	8.6	<0.001
Total	**6.8**	**7.9**	**<0.001**

*Scores range from 0 to 10 with higher scores indicating a more favourable response.
UFICare, Uganda Family Integrated Care.

Infants in the baseline group were weighed a median of 29% (IQR 18–50) of hospitalised days compared with a median of 71% (IQR 57–80) of hospitalised days in the intervention group (Mann-Whitney U=331.5, p<0.001). Nurses in the baseline group documented vital signs a median of 22% (IQR 12–38) of expected times (ie, twice per day), while mothers in the intervention group documented danger signs a median of 82% (IQR 71–100) of expected times (ie, twice per day) (Mann-Whitney U=73, p<0.001). Mothers in the intervention group documented their infant's feeds a median of 83% (IQR 71–100) of hospitalised days.

There was no difference in the maternal PSS:NICU scores (baseline 3.41 vs intervention 3.57, t(91)=1.99, p=0.06) measured 2–4 days after enrolment. Mothers in the intervention group scored higher on the Readiness for Hospital Discharge Scale compared with mothers in the baseline group (baseline 6.8 vs intervention 7.9, t(88)=1.99, p<0.001). When disaggregated by domain, mothers in the intervention group scored more favourably than mothers in the baseline group in all domains (table 2).

The average length of stay was not different between groups (baseline 7.63 days vs intervention 6.83 days, t(93)=1.34, p=0.18). Telephone follow-up was completed for 99% (94 of 95) of all mother–infant dyads who remained in the study until discharge. All discharged infants were alive 6 weeks following discharge. Twenty-three per cent of mothers (11 of 48) in the baseline group sought medical care for their infant after discharge compared with 11% of mothers (5 of 46) in the intervention group (X^2_1=2.4, p=0.12). There was no difference in the rates of readmission between groups (baseline 18.8%; intervention 13% X^2_1=0.57, p=0.45).

DISCUSSION

FICare was adapted to a Ugandan neonatal hospital unit (UFICare) based on input from mothers and healthcare staff.[10] Mothers in the UFICare group collaborated with healthcare staff in the care of their infant, including weighing their infant, assessing for danger signs and tracking their feeding. After training, mothers were proficient in these tasks and completed the monitoring forms at higher rates than nursing documentation in the medical chart. Mothers in the UFICare group felt more prepared to care for their child after discharge compared with mothers in the baseline cohort.

While parents often serve as the de facto primary caretakers in hospitals in low-income countries due to staff shortages, there is a lack of research on how parents can partner with healthcare providers in these settings. A recent review of parental participation in the medical care of hospitalised neonates (eg, monitoring or medication administration) in

low/middle-income countries (LMICs) identified 18 studies from middle-income countries but none from low-income countries.[15] Our study found that monitoring tasks may be ideal responsibilities for mothers to assume in low-income countries. Nurses infrequently performed these tasks, likely due to the competing demands on their time. Beyond the neonatal period, von Saint Andre-von Arnim *et al* found that trained parents in Kenya could recognise signs of deterioration in hospitalised paediatric patients that correlated with healthcare workers' evaluations.[16] Thus, engaging parents in the important but often neglected patient care tasks may improve the quality of neonatal hospital care in low-income countries. These responsibilities could be combined with other evidence-based interventions, such as KMC.[17]

While FICare was developed in Canada, its structure was adapted from a neonatal unit in Estonia.[18] FICare has undergone other adaptations, including a mobile enhanced FICare[19] and an adaptation for NICUs in China.[6] Although UFICare maintained fidelity to the FICare vision, we adapted the components based on interviews and focus groups. Local healthcare workers and mothers viewed the FICare model as a way to ameliorate the staffing shortage by engaging mothers in tasks traditionally assigned to nurses.[10] Therefore, UFICare emphasised parent education and partnership by teaching mothers to monitor their infants. Our modifications reflect the growing recognition that evidence-based interventions must be adapted to ensure a good fit between intervention and context in order to reproduce effects.[20]

Engaging parents in their infant's care has the potential to improve outcomes even after discharge. Mothers in the UFICare group had higher Readiness for Discharge scores compared with mothers in the baseline group, suggesting increased confidence in their ability to care for their child at home. Post-discharge care is essential in LMICs where post-discharge paediatric mortality may be even higher than in-hospital mortality.[21 22] The majority of post-discharge deaths occur outside of the healthcare system. Hence, efforts to improve post-discharge survival must begin during hospitalisation. While the current study was not powered to determine UFICare's effect on post-discharge outcomes, research examining UFICare's impact on post-discharge survival is warranted.

This study had several limitations. First, we employed two dedicated nurses to teach mothers, which probably contributed to the high level of maternal proficiency. Similar dedicated personnel are not likely to be available in most low-resource settings. Studies using alternative teaching methods, such as audio-visual tools, are needed. There is also the potential for ascertainment bias given that the research nurses enrolled, trained and evaluated the participants. Next, our study included singleton, relatively healthy infants. Maternal comfort in monitoring her children if they are sicker or when she has twins remains unknown. Additionally, we did not track the occurrence of adverse events. While there is a risk that maternal monitoring led to inappropriate management by the medical team, this risk is low given the high level of maternal proficiency. Finally, our study was not powered to determine whether UFICare improves outcomes, However, mothers trained in the UFICare group had higher Readiness for Discharge scores, which has been associated with reduced hospital readmission rates.[14]

In conclusion, the adaptation of FICare in a low-income country is feasible. Parental engagement in tasks traditionally assigned to nurses has the potential to have the greatest impact in settings with the highest healthcare worker shortage. Prior to widespread adoption of UFICare in Uganda, research to determine whether UFICare improves outcomes is needed.

Contributors All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work. JD, NF, KO'B, K-MN, AT and MOW were involved in the study's design, interpreting the data and writing of the paper. OK, JM and EK were involved in acquisition of data and writing of the paper. DB was involved in data analysis and writing of the paper. JD is guarantor.

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval This study involves human participants and ethical approval was obtained from Makerere University (ref: 770), the Uganda National Council for Science and Technology (ref: HS632ES), and the McGill University Health Centre (ref: FICARE/2021-6672). Participants gave informed consent to participate in the study before taking part.

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Data availability statement Data are available upon reasonable request.

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