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Feasibility, acceptability and preliminary effectiveness of the Hospital to Home discharge and follow-up programme in rural Uganda: a mixed-methods intervention study

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ABSTRACT

Introduction Over 60% of premature infants are born in Africa or South Asia. Infants born early, small or who become sick after birth have a higher risk of death, poor growth and developmental impairments. Innovative interventions tailored for low- and middle-income countries are essential to help these newborns survive and develop optimally. This study evaluated the feasibility, acceptability and preliminary effectiveness of Hospital to Home (H2H), a discharge and follow-up programme for small and sick newborns in rural Uganda.

Methods We compared two cohorts of high-risk hospitalised neonates in Uganda: a historical-comparison cohort receiving standard facility-based care and an intervention cohort that received the H2H programme, a hospital and community spanning package of interventions designed to improve neurodevelopmental outcomes. We compared 6-month corrected neurodevelopmental, growth, nutritional and vaccination outcomes between the cohorts complemented by qualitative interviews of caregivers, community health workers and health facility staff.

Results We recruited 191 participants: 91 historical-comparison cohort (born between July and September 2018), and 100 intervention cohort (born July 2019 to February 2020). No statistically significant difference was seen in neurodevelopmental outcomes (adjusted OR 0.68; 95% CI: 0.32 to 1.46). Improved vaccination completion (88.5% intervention vs 76.9% comparison, p=0.041), and exclusive breastfeeding rates (42% vs 6.6%, p<0.001) were seen. Caregivers and healthcare workers reported the intervention to be acceptable and feasible in this rural Ugandan setting.

Conclusion The H2H programme was feasible and acceptable to caregivers and healthcare providers. Improved vaccination and exclusive breastfeeding rates were seen in the intervention group when compared with a historical comparison cohort in this rural Ugandan setting. Further investigation on the short and long-term effectiveness of the H2H programme in a government health services setting is warranted.

Trial registration number ISRCTN51636372.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Over 30 million newborns worldwide require hospital care annually. With high-quality inpatient and follow-up care, these infants can survive and thrive.

⇒ There is growing demand to provide high-quality, family-centred inpatient and follow-up care to high-risk newborns in low- and middle-income countries.

WHAT THIS STUDY ADDS

⇒ This study demonstrated that a hospital and home-based follow-up programme designed to improve outcomes for high-risk newborns in low-income countries is feasible and acceptable, and shows some evidence of improved health outcomes including improved vaccination and breastfeeding rates.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings imply that health personnel and community health workers in low-income countries can acquire the knowledge and skills specific to small and sick newborns and can work together to improve health outcomes for high-risk newborns.

⇒ With this combination of hospital and home intervention, community perceptions about the care and survivability of premature infants can change.

⇒ High-quality, family-centred inpatient and follow-up care may improve breastfeeding and immunisation rates in children in our resource-limited rural Ugandan setting.

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INTRODUCTION

Every year, over 2.4 million newborns die during their first month of life—most of whom reside in low-income countries (LIC).[1 2] Small and sick newborns experience a higher burden of morbidity and mortality than their healthy peers. With increasing recognition of the importance of high-quality facility-based newborn care in reducing mortality, there is now greater survival of infants at high-risk of long-term neurodevelopmental disability.[3] However, despite calls from the global health community, there is no universally recommended 'best-practice', neonatal discharge and follow-up package for use in resource-limited settings.[4–6] Postnatal follow-up visits are rare or not appropriately designed for high-risk infants, often due to resource constraints.[7] With 90% of the estimated 15.1 million high-risk neonates residing in low resource settings,[5] there is increased recognition that the global health community must broaden its focus beyond survival to consider how best to improve long-term outcomes for these infants and to provide outpatient care following hospital discharge.[8]

Little is known about the survival, health and developmental trajectory of small and sick infants after discharge because of the multitude of barriers preventing return to health facilities.[6 9–11] Significant challenges exist for families of high-risk infants in many resource-limited settings: a lack of relevant targeted services, weak referral systems, transport and other care-related expenses, lack of parental support from spouses and peers and lack of knowledge of when care is required for their infant.[10 12 13] The WHO and UNICEF have identified the development and evaluation of relevant discharge and follow-up care packages as a key priority.[8]

To address this gap, Adara Development and its partners developed the Hospital to Home (H2H) programme to support small and sick newborns both during their admission to a neonatal unit, and after discharge when transitioning to home in the community. The programme aims to promote neuroprotective care and nutrition to optimise neurodevelopment and growth.

The primary aim of this study was to evaluate the feasibility and acceptability of the H2H programme. Secondary aims included collecting data on the programme's impact on early childhood neurodevelopment and nutrition.

METHODS

Overview of study design

This was a cohort comparison study comparing developmental and nutritional outcomes between a cohort of newborns at high risk for mortality and developmental delay receiving the H2H programme with a historical-control comparison cohort receiving standard facility and community-based care. We used quantitative and qualitative methods to compare outcomes. The primary outcome was feasibility and acceptability. On discharge from the neonatal unit, we used routine inpatient neonatal data to report infant weight gain (grams per kilo per day) during hospitalisation. At 6 months of adjusted age, we measured neurodevelopmental outcomes, growth, exclusive breastfeeding, completed immunisations and parent–caregiver attachment. Through in-depth interviews, we explored the views and experiences of caregivers, neonatal unit staff and community health workers (CHWs) related to H2H programme feasibility and acceptability.

Setting

The H2H programme commenced in April 2019, at Kiwoko Hospital, in the central region of Uganda and the three surrounding districts—Nakaseke, Luwero and Nakasongola. Kiwoko Hospital is not-for-profit and provides comprehensive obstetrical, neonatal, paediatric and adult healthcare. The hospital includes a well-established neonatal unit considered a Centre of Excellence by the Ministry of Health of Uganda.[3] See[14] for further details on settings.

Objectives

The objectives of this study were to evaluate the feasibility and acceptability of the H2H programme and to explore preliminary effectiveness on infant growth and neurodevelopment outcomes. In the previously published study protocol, we had established that feasibility would be demonstrated if:

1. 70% of infants met discharge criteria (see online supplemental appendix 1),
2. 70% of caregivers received the discharge teaching topics (see online supplemental appendix 2),
3. The infants received 60% of the recommended at-home follow-up visits (see online supplemental appendix 3) and
4. 60% of infants sought medical care at a health facility if referred by a CHW.[14]

We further stipulated that acceptability would be demonstrated if 15% or fewer caregivers declined the home visit component of the intervention.[14] Additionally, although the study was not powered to detect an effect on neurodevelopmental outcomes, we planned an exploratory multivariable analysis to preliminary effectiveness.

Description of intervention

H2H is a family-centred programme of facility-based ('hospital') care and at-home ('home') follow-up care of high-risk newborns discharged from a neonatal unit.[14] The H2H 'hospital' package includes neurodevelopmentally supportive care, lactation and breastfeeding support, a cue-based feeding approach, parent education and strengthened hospital discharge processes including discharge criteria and a discharge checklist. To facilitate programme delivery in the facility, the roles of a neonatal therapist and discharge coordinator were introduced. Two external specialists with expertise in neonatal therapy and lactation and breastfeeding spent several weeks mentoring and training these staff before implementation. On their departure, the unit-based neonatal

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therapist prioritised neurodevelopmental supportive care as well as lactation and breastfeeding.

In the H2H programme, discharge preparation begins on admission with the education of the mother on the importance of early initiation of breastfeeding and expression of milk. A family-centred approach to discharge planning includes an education programme that prepares the family for the day of discharge and to care for their infant at home. On discharge, the discharge coordinator communicates with a supervising trained community midwife who then contacts a CHW working within the family's geographical area to transfer care and arrange for at-home visits.

The H2H 'home' package includes regularly scheduled at-home follow-up support to families for 6 months after discharge from the hospital. Highest risk patients (those who weigh less than 1800 g or who are considered highest risk by healthcare workers) receive more frequent at-home visits from CHWs (see online supplemental appendix 2). CHWs with specialised training in newborn care provide visits that include monitoring for danger signs, growth and development checks, parent counselling and education and referrals to additional care when necessary. CHWs work in teams of 9–16 led by a 'Chief CHW'. All H2H CHWs are overseen by the community midwife who provides supportive supervision and ongoing education during monthly meetings. CHWs receive a bicycle, supplies to conduct at-home visits and a small monthly payment to offset their transport and mobile phone costs. See[14] for further details.

Participants

For this feasibility study, research participants were neonates that met the following inclusion criteria: (1) admission and discharge from the Kiwoko Hospital neonatal unit and, (2) birth during a specific date range (July 2018 to September 2018 for the historical-comparison cohort and July 2019 to February 2020 for the intervention cohort) and, (3) documentation of gestational age and family contact information in the infants' medical records and, (4) residence in one of the three eligible districts and (5) receiving informed consent from the family. COVID-19 lockdown restrictions in Uganda prolonged recruitment for the intervention cohort and complicated the recruitment process by requiring additional safety protocols. Consequently, we extended the eligibility period for the intervention period, as was common for many researchers in the country during this time.

Infants were excluded if (1) they were not 6 months' corrected age at the time of the final assessment, (2) the child required hospitalisation at the time of the 6-month assessment or (3) the parent or guardian did not speak or understand Luganda or English. A convenience subset of cohort caregiver participants (n=15 historical-comparison cohort, n=15 intervention cohort) attending the assessment clinic on days when the qualitative data collectors were working, as well as hospital staff (n=13) and CHWs (n=15) involved in caring for newborns and implementing the H2H programme were interviewed to provide qualitative data about the programme. Infants in the intervention cohort were assigned risk categories at discharge primarily based on discharge weight (less than 1800 g was considered higher risk and greater than 1800 g was considered lower risk).

Quantitative data collection

Demographic, antenatal, birth and hospitalisation information; Maternal Infant Responsiveness Index (MIRI) scores[15 16]; Griffiths Mental Development Scales-Extended Revised scores[17–22]; and parent-reported health history were collected. Further, anthropometric data collected included weight for age, weight for length, length for age, head circumference for age and mid upper-arm circumference. CHWs collected weight, temperature, respiratory rate, parent-reported signs of illness in the infant and whether families took their infant to the healthcare facility when they were referred for medical care by the CHWs. Quantitative data were collected on paper forms and input into REDCap (Research Electronic Data Capture, V.10.9.4), a data management tool, by trained staff.[23 24]

Qualitative data collection

In-depth interviews were conducted with a diverse representation of H2H programme and hospital staff, CHWs that delivered the programme and caregivers of children in each cohort. In-depth interviews followed an interview guide with probing questions used to gain a deeper understanding of the experience of care provided and received. All interviews were conducted by the local Research Monitoring and Evaluation Officer. Interviews were audio-recorded and transcribed. Those conducted in the local language, Luganda, were transcribed and translated into English by a trained transcriptionist and translator. Data were input into NVivo V.12.00[25] and coded by three members of the monitoring and evaluation team. Coders met regularly to discuss and compare emerging themes to ensure dependability. Data were analysed using an inductive thematic analysis approach and a comprehensive coding process as guided by Braun and Clarke's thematic analysis technique.[26] See online supplemental appendix 4 for details.

Statistical analyses

Stata V.15 was used to compute descriptive statistics, constructing a relative wealth index variable and for regression analyses.[27] Frequencies, means, SD, medians and IQR were used to summarise the data. X^2 tests were used for categorical variables and Mann-Whitney U and 2-proportion z-test statistics were used for proportion comparisons. Although the study was not powered in design to assess the intervention effectiveness, we performed exploratory multivariable logistic regression to model the relationship between neurodevelopmental outcome (using a Griffiths Mental Development Scales

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II cut-off score of <84) and the selected independent factors: sex, maternal age, social economic status, birth weight, maternal education, admission diagnosis, length of stay, district of residence and control/intervention group. These variables thought to be important for the analysis were initially included in the models and then excluded if they had a p value≥0.05. In addition, the length of stay and birth weight variables were tested for interaction and multicollinearity using the variance inflation factor. The model was examined using Hosmer-Lemeshow goodness of fit test.

A relative wealth index was constructed using principal component analysis from a set of 15 questions relating to household characteristics such as type of house walls, floor, rent, number of rooms, the primary fuel used, household size, electricity, net, distance to drinking water, ownership of the following: bed, mobile phone, motorbike, car, radio and television. The index was divided into five quintiles. Based on quintile data, the households were further categorised into three groups—poor (quintiles 1 and 2), moderate (quintiles 3 and 4) and wealthy (quintile 5).

Patient and public involvement

The H2H programme was designed in response to feedback from staff observations and the experiences that patient families shared with staff around the difficulty in returning to the hospital for follow-up care and concerns that patients were not thriving after discharge home. Patient families were included by study design in qualitative interviews to determine programme acceptability.

RESULTS

Cohort recruitment

Of the families eligible for recruitment, 180 families in the historical-comparison cohort and 402 families in the intervention cohort met inclusion criteria and were approached. Of these 91 and 100 consented to participation, respectively. Figure 1 shows the flow of participants through the study (Strengthening the Reporting of Observational Studies in Epidemiology diagram). Primary reasons for non-inclusion were inability to contact family after discharge (phones switched off or did not answer) and change of residence to outside of one of the three eligible districts after discharge (figure 1).

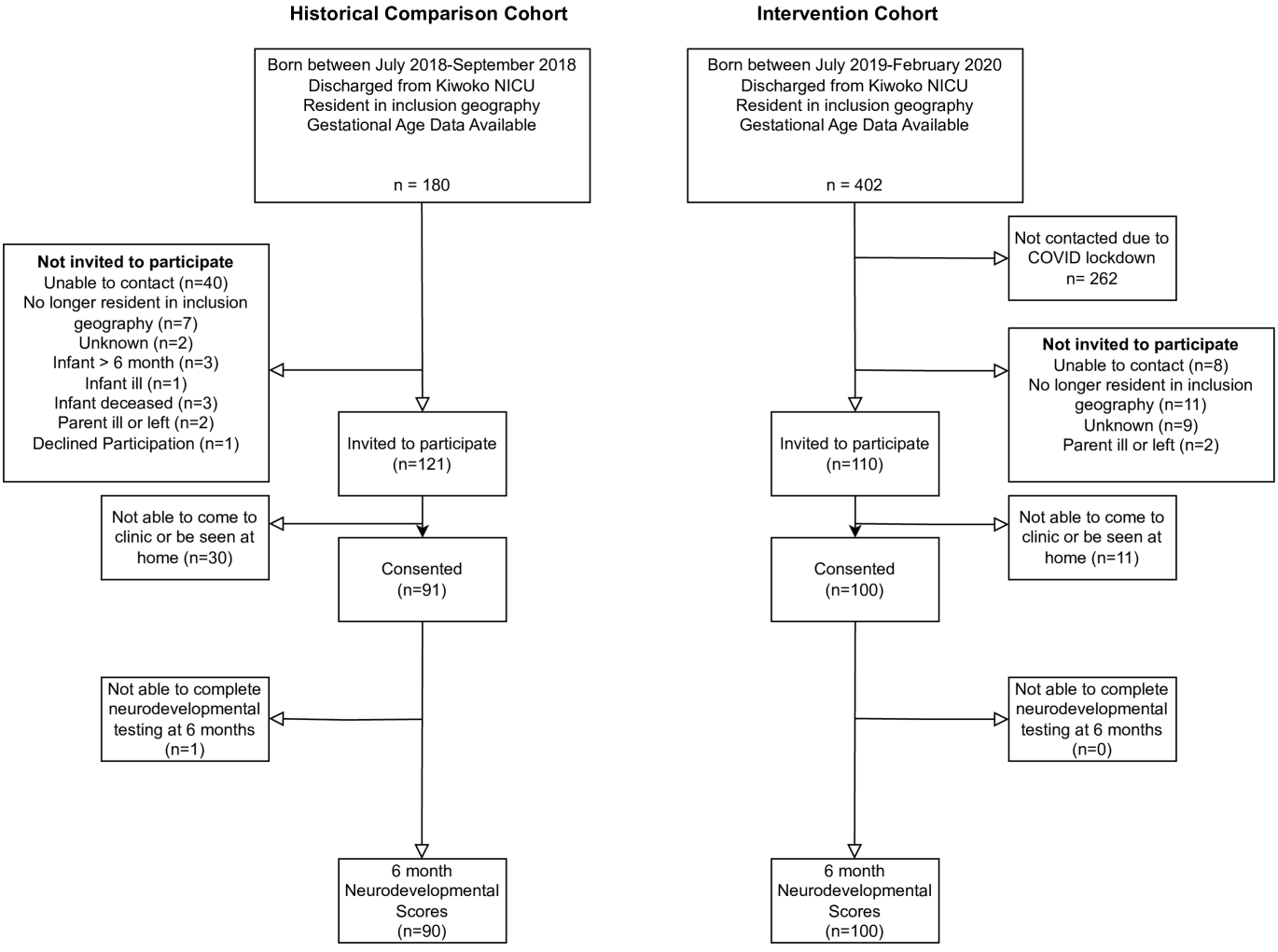

Figure 1 STROBE Diagram.

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Cohort participants' characteristics

Cohort characteristics are shown in table 1. While the groups are similar, the intervention cohort had slightly higher gestational ages and received fewer interventions such as phototherapy and oxygen. See table 1.

Feasibility and acceptability

Patient caregivers in the intervention cohort received discharge education from hospital staff to prepare them to care for their infants independently. 77% of the intervention cohort infants received all required teaching topics, with highest-risk patients having higher completion rates than lower-risk patients (85.2% vs 75.0%) (see online supplemental appendix 5). The intervention also included six required discharge criteria to ensure infants were ready to be discharged. 96% of all intervention cohort infants met all six discharge criteria with little difference between the high-risk and lower-risk infants (100% high-risk infants, 95.8% lower-risk infants). Following discharge, 100% of the intervention cohort received at least one at-home follow-up visit. Nearly 8% (n=7/89) of the intervention cohort infants visited by CHWs during the study period were referred for additional care (data on referrals was available for 89/100 patients in the intervention cohort). The primary reasons for referral were respiratory illness symptoms (fever, cough, etc). Referral rates did not differ based on schedule. Although we had anticipated determining rates of referral completion by families seeking care at a health facility, this data was not able to be obtained due to data collection tool design.

The median duration of stay for the intervention cohort did not change after H2H implementation (median 7.0 days for both cohorts, IQR[5–14] historical-comparison cohort, IQR (5–14.5) intervention cohort). The median discharge weight for all infants increased by 330 g after H2H implementation (median 2050 g (IQR 1610–2970) before H2H, 2380 g (IQR 1840–3150) after H2H). Changes to inpatient growth and duration of hospitalisation varied depending on the birth weight category and can be found in table 2. Very low birth weight (VLBW) neonates gained on average 4.9 and 12.5 g per kilogram per day in the control and intervention groups, respectively.

Health outcomes at 6 months

Although the study was not powered to assess intervention effectiveness, we performed exploratory regression analysis on the risk of neurodevelopmental delay. At 6 months corrected gestational age, one infant was not able to be tested. Considering the other 190 infants, in an underpowered exploratory adjusted logistic regression analysis the intervention cohort did not have statistically different odds of neurodevelopmental delay compared with the historical comparison cohort (adjusted OR 0.68 (95% CI: 0.32 to 1.46)). See table 3. In further analysis excluding neonates with perinatal asphyxia, the results were also similar between the two groups (see online supplemental appendix 6).

Infants who received the intervention displayed improvements in breastfeeding duration and vaccination outcomes. Exclusive breastfeeding rates among 6-month-old infants were six times higher in the intervention group compared with the historical-comparison group (42% intervention vs 6.6% comparison (95% CI: 0.35 (0.25 to 0.46), p≤0.001)) (see table 4). More infants were completely vaccinated in the intervention group compared with the historical cohort (88.5% intervention vs 76.9% comparison, difference 0.12 (95% CI: 0.003 to 0.229, p=0.041) (see table 4). MIRI scores were very similar between the two groups; see online supplemental appendix 7. Anthropometric data for both groups is presented in table 4.

Qualitative data

A total of 43 interviews were conducted with 15 caregivers (from both the historical-comparison and intervention cohorts), 15 CHWs and 13 hospital staff. The data showed several key themes (see online supplemental appendix 8). First, the H2H programme created transformative change in the hospital in the relationships between the neonatal unit staff and the infants' caregivers. Before H2H, data suggested that caregivers were often not involved in discussions about their infant's care because hospital staff believed it was not necessary or that the caregivers would not be able to understand. After implementation, discharge coordinators or staff assigned to assist the infant and caregiver with the discharge process spent time with each caregiver learning more about their home environment and providing in-depth education. This, along with group-based neonatal intensive care unit education classes, one-to-one caregiver education sessions and initiation of cue-based feeding, fostered a family-centred care environment. Over time, staff came to appreciate the caregivers' ability to provide high-quality care to the infant. As Clinician 1 shared, 'It has given us a wider range of topics to discuss, and it has helped me to learn as well how to work with these mothers to know what they go through'.

The second theme to emerge concerned the challenges and fears that caregivers experience during a neonatal unit inpatient stay. Mothers were fearful of machines, especially if they had not spent time in a hospital before or a clear explanation had not been given on the therapeutic purpose of the machines. Over time, caregivers overcame their fears through education, conversations with healthcare workers and bonding with other caregivers whose children were also staying in the unit.

Qualitative data showed strong acceptance from CHWs, hospital staff and caregivers of the role CHWs played in providing home follow-up care after discharge. Staff expressed that it gave them peace of mind to have someone in the community fill the 'critical gap' by providing follow-up care to small and sick infants discharged from the neonatal unit. As Clinician 13 shared, 'We really do our work to see that the babies do survive, but my worry was about their survival when

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Table 1 Characteristics of the study participants

Characteristic	Historical cohort (n=91)	Intervention cohort (n=100)	P value
Infant characteristics			
Sex			0.447*
Male n (%)	55 (60.4)	55 (55.0)	
Female n (%)	36 (39.6)	45 (45.0)	
Birth weight in grams† (mean±SD)	2337.5±807.5	2453.8±825.8	0.247‡
Admit weight in grams (mean±SD)	2332.7±809.6	2409.2±769.7	0.324‡
Estimated gestational age (median (IQR))	35.0 (32–38)	36.5 (33–40)	0.067‡
Discharge diagnoses§			0.472*
Prematurity n (%)	49 (53.8)	45 (45.0)	
Infection n (%)	19 (20.9)	21 (21.0)	
Birth asphyxia n (%)	12 (13.2)	17 (17.0)	
Respiratory distress n (%)	7 (7.7)	6 (6.0)	
Other n (%)	4 (4.4)	11 (11.0)	
Therapies received§			
Phototherapy n (%)	44 (48.3)	32 (32.0)	0.021¶
Oxygen therapy n (%)	9 (9.9)	3 (3.0)	0.049¶
bCPAP†† n (%)	12 (12.9)	9 (9.0)	0.387¶
Maternal characteristics			
Average age of the mother (SD, range)	26.3 (5.9, 17–42)	25.8 (5.9, 15–41)	0.546¶
Maternal age group (years)	n (%)	n (%)	0.698*
<20	12 (13.2)	13 (13.0)	
20–24	26 (28.6)	36 (36.0)	
25–34	42 (46.1)	42 (42.0)	
35+	11 (12.1)	9 (9.0)	
Tribe			0.828*
Muganda	35 (38.5)	40 (40.0)	
Others	56 (61.5)	60 (60.0)	
Religion			0.046*
Christian	28 (30.8)	41 (41.0)	
Pentecostal	13 (14.3)	18 (18.0)	
Catholic	27 (29.7)	12 (12.0)	
Muslim	19 (20.9)	22 (22.0)	
Others	4 (4.4)	5 (5.0)	
Unknown	0.0	2 (2.0)	
Marital status			0.417*
Single	7 (7.7)	9 (9.0)	
Married	82 (90.1)	85 (85.0)	
Divorced/separated	2 (2.2)	6 (6.0)	
Mother's education level			0.331*
None	4 (4.4)	1 (1.0)	
Primary	33 (36.3)	40 (40.0)	
Senior	44 (48.3)	53 (53.0)	
Tertiary	9 (9.9)	6 (6.0)	
Unknown	1 (1.1)	0.0	
Father's education level			0.002*

Continued

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Table 1 Continued

Characteristic	Historical cohort (n=91)	Intervention cohort (n=100)	P value
None	5 (5.5)	5 (5.0)	
Primary	26 (28.6)	41 (41.0)	
Senior	32 (35.2)	45 (45.0)	
Tertiary	24 (26.3)	9 (9.0)	
Unknown	4 (4.4)	0 (0.0)	
Relative household wealth**			0.226*
Poor	31 (34.1)	46 (46.0)	
Moderate	39 (42.8)	37 (37.0)	
Wealthy	21 (23.1)	17 (17.0)	
Place of residence			0.505*
Nakaseke	28 (30.8)	26 (26.0)	
Luwero	47 (51.6)	60 (60.0)	
Nakasongola	16 (17.6)	14 (14.0)	

*X^2 test.
†Two neonates in each group were missing birth weights.
‡Mann-Whitney U test.
§Infants may have received more than one diagnosis or therapy.
¶2-proportion z-test.
**Relative household wealth index was measured using a household characteristics and goods index and divided into groups. See Methods for further details.
††Bubble Continuous Positive Airway Pressure

they are back at home'. CHWs are seen as agents of hope, kindness and generosity by community members grappling with fear and anxiety related to their infants' survival. Caregiver 7 shared, 'Whenever the CHW could come, he used to encourage me. I was always eager for his coming; he was updating me about the current state of my babies, and he was also giving me the next step I should take'. CHWs formed bonds with the infants in their care, which deepened the trust between caregivers and CHWs. As Caregiver 7 continued, 'What made me happy was that the CHW used to come when happy, used to carry the babies, used to play with the babies and that could give me strength as a mother and that was showing me that the CHW was lovely and has a parental heart'. CHW dedication to the H2H programme was boosted by their satisfaction with the training, the supplies they received and the pride they took in learning skills like weighing, temperature reading, breathing assessment and breastfeeding support. They shared that the training has made them 'health workers' and has earned them respect in their communities.

Qualitative data also showed that H2H has influenced the attitudes of both CHWs and communities about the survival of high-risk and preterm infants. Previously, these babies were commonly not perceived as 'real babies' or capable of survival. Although such views are still held by some community members, they are being challenged. H2H has shown communities that these infants can not only survive but thrive. As CHW 15 shared, 'I thought they [high-risk babies] are not supposed to survive, but if they do, they will develop abnormalities. I grew up hearing, that when people give birth to preterm babies, they stay for a short time and die. So, that training helped me so much to know that these babies grow very well, because I have seen them growing'. CHW 11 shares, 'Before H2H when parents had a preterm, they were sure that the baby is to die, but now babies are surviving and the mothers are proud of their babies'.

DISCUSSION

To our knowledge, H2H is one of the very few programmes that have been developed specifically to support high-risk infants in LICs in their transition from health facility to their homes. These initial results suggest that the programme is both feasible and acceptable and may improve exclusive breastfeeding at 6 months and vaccine completion rates among infants.

Our study found that the H2H programme is both feasible and acceptable. A target of 70% of infants meeting discharge criteria and 70% of caregivers receiving discharge teaching was set as a threshold for determining feasibility. Both targets were exceeded (96.9% of infants met discharge criteria; 77.8% of families received required education topics), indicating programme feasibility in this setting. Further, 100% of infants had at least one home visit from a CHW, with most having multiple visits and no families refusing to participate in the home-based component of the programme.

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Table 2 Neonatal participants inpatient length of stay and weight gain

	Historical cohort (n=91)	Intervention cohort (n=100)
Duration of hospitalisation (median (IQR) days in aggregate)	7.0 (5 to 14)	7.0 (5 to 14.5)
Duration of hospitalisation (median (IQR) days disaggregated by birth weight category)		
ELBW* (500–999 g)	(n=2) 68 (66 to 70)	(n=1) 63
VLBW† (1000–1499 g)	(n=9) 25 (18 to 37)	(n=11) 29 (26 to 47)
LBW‡ (1500–2499 g)	(n=44) 7.5 (6 to 14)	(n=40) 6.5 (5 to 14)
Normal (2500–3999 g)	(n=32) 6 (5 to 8.5)	(n=42) 5.5 (3 to 10)
4 kg+ (≥4000 g)	(n=2) 1 (0 to 2)	(n=4) 4.5 (3 to 12)
Missing weight	(n=2) 2 (0 to 4)	(n=2) 8.5 (8 to 9)
Discharge weight in aggregate	(n=91) 2050 (1610 to 2970)	(n=100) 2380 (1840 to 3150)
Discharge weight disaggregated by birth weight category (median (IQR) grams)		
ELBW* (500–999 g)	(n=2) 1765 (1540 to 1990)	(n=1) 1900
VLBW† (1000–1499 g)	(n=9) 1550 (1520 to 1670)	(n=11) 1650 (1520 to 1740)
LBW‡ (1500–2499 g)	(n=44) 1740 (1570 to 2025)	(n=40) 2050 (1695 to 2225)
Normal (2500–3999 g)	(n=32) 3035 (2810 to 3475)	(n=42) 3110 (2640 to 3530)
4 kg+ (≥4000 g)	(n=2) 4080 (3760 to 4400)	(n=4) 3875 (3745 to 4260)
Missing birth weight§	(n=1) 3030	(n=2) 2290 (1660–2920)
Average daily change in weight in aggregate (median (IQR) grams per kilo per day)	(n=81)¶ −1.8 (−8.4 to 3.3)	(n=87)¶ −0.29 (−9.5 to 9.9)
Average daily change in weight disaggregated by weight category (median (IQR) grams per kilo per day)		
ELBW* (500–999 g)	(n=2) 17.9 (17.6 to 18.2)	(n=1) 17.6
VLBW† (1000–1499 g)	(n=9) 4.9 (3.3 to 6.1)	(n=11) 12.5 (8.8 to 13.7)
LBW‡ (1500–2499 g)	(n=44) −5.1 (−11.3 to 0.0)	(n=40) 0 (−7.8 to 4.0)
Normal (2500–3999 g)	(n=32) −0.3 (−10.3 to 3.3)	(n=42) 0.7 (−8.3 to 7.7)
4 kg+ (≥4000 g)	–	(n=4) −7.4 (−14.5 to 0.4)

*ELBW—extremely low birth weight.
†VLBW—very low birth weight.
‡LBW—low birth weight.
§One patient missing both birth and discharge weights.
¶Number of patients differ from starting number due to 23 missing discharge weights or having implausible discharge weight values.

Table 3 Exploratory analysis of risk of any neurodevelopmental delay at 6 months

	OR	OR SE	95% CI	
Control	1			
Intervention	0.68	0.26	0.32	1.46
Male	1			
Female	1.44	0.55	0.67	3.06
Low wealth	1			
Moderate wealth	0.88	0.37	0.38	2.0
High wealth	0.57	0.32	0.19	1.71
Birth weight (grams)	1	<0.01	1.00	1.00
Length of stay (days)	0.93	0.04	0.84	1.00
Birth weight × length of stay	1	<0.001	1.00	1.00
Prematurity	1			
Perinatal asphyxia	2.76	2.08	0.63	12.08
Infection	1.44	0.95	0.39	5.27
Other primary diagnosis	1.43	0.96	0.40	5.11
Intercept	8.19	9.5	0.84	79.45

Qualitative evidence from caregivers, hospital staff and CHWs strongly suggests that the programme was not only acceptable but also resulted in more collaborative health worker-family relationships. CHWs expressed their experience that the programme was making a difference in infants' health in both settings. Healthcare workers reported improvements in relationships with caregivers, who are critical intermediaries for improving infants' health. Family-centred care, one component of H2H, strengthened the involvement of caregivers as well as healthcare workers' respect for the role caregivers can play in the care of their hospitalised infants.

This pilot study was not powered to detect differences in neurodevelopmental outcomes between the comparison and intervention groups, and although in the regression model, infants in the intervention group had lower odds of any neurodevelopmental delay, this was not statistically different from the control group. There are at least three possibilities for these findings. The first possibility is that this pilot study (which was not designed to detect an effect, but rather for feasibility and acceptability) was underpowered to detect a difference. Indeed, based on the magnitude of the odds of any degree of neurodevelopmental delay estimated between these two groups, a study with at least 1000 neonates in each group may be required to detect a statistically significant difference. The second possibility is that the intervention is more effective in a subgroup of patients (ie, small neonates that did not experience perinatal asphyxia) and the effect disappeared when all neonates were considered together. This possibility was tested in a subanalysis (see online supplemental appendix 6) in which we found 23% decreased odds of neurodevelopmental delay which was not statistically significant. The third possibility is

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Table 4 Infant health outcomes at 6 months of age

	Historical-comparison arm	Intervention arm	Difference (95% CI)
Neuro-development risk	n=90	n=100	
Percentage infants with Griffiths Score <84 (any delay—mild, moderate or severe) %	23 (25.6)	21 (21.0)	0.045 (–0.074 to 0.166)
Percentage infants with Griffiths Score <70 (severe delay) %	13 (14.4)	16 (16.0)	–0.015 (–0.118 to 0.086)
Infant exclusively breastfeeding at 6 months (%)	6 (6.6)	42 (42.0)	0.35 (0.245 to 0.463)***
Infant received all eligible vaccinations	**Comparison arm (n=80)**	**Intervention arm (n=99)**	
At birth n (%)	79 (92.4)	98 (98.0)	0.06 (–0.009 to 0.120)
At 6 weeks n (%)	74 (92.5)	95 (96.0)	0.03 (–0.034 to 0.104)
At 10 weeks n (%)	70 (88.6)	92 (94.8)	0.06 (–0.020 to 0.145)
At 14 weeks n (%)	67 (83.7)	90 (90.9)	0.07 (–0.027 to 0.170)
Received all vaccinations from birth to 14 weeks n (%)	60 (76.9)	85 (88.5)	0.12 (0.003 to 0.229)**
Growth at 6 months			
Underweight	n=91	n=100	
Weight for age % (z-score <–2)	12 (13.2)	11 (11)	–0.025 (–0.122 to 0.072)
Weight for age % (z-score >–2 and z-score <–3)	10 (11)	7 (7)	
Weight for age % (z-score <–3)	2 (2.2)	4 (4)	
Missing weight	5 (5.5)	4 (4)	
Wasting	n=91	n=100	
Weight for length % (z-score <–2)	8 (8.8)	6 (6)	–0.029 (–0.109 to 0.050)
Weight for length % (z-score >–2 and z-score <–3)	6 (6.6)	6 (6)	
Weight for length % (z-score <–3)	2 (2.2)	0 (0.0)	
Missing wasting	6 (6.6)	7 (7.0)	
Stunting	n=91	n=100	
Length for age % (z-score <–2)	17 (18.7)	15 (15)	–0.034 (–0.144 to 0.077)
Length for age % (z-score >–2 and z-score <–3)	12 (13.2)	11 (11)	
Length for age % (z-score <–3)	5 (5.5)	4 (4)	
Missing length	3 (3.3)	6 (6)	
Head circumference	n=91	n=100	
Head circumference for age % (z-score <–2)	2 (2.2)	2 (2)	–0.002 (–0.046 to 0.042)
Head circumference for age % (z-score >–2 and z-score <–3)	0 (0.0)	2 (2)	
Head circumference for age % (z-score <–3)	2 (2.2)	0 (0)	
Missing head circumference	8 (8.8)	7 (7)	
Malnutrition	n=91	n=100	
Moderate acute malnutrition % (MUAC† ≥11.0 and MUAC*<12.5)	6 (6.6)	8 (8)	0.013 (–0.062 to 0.089)
At risk of malnutrition % (MUAC† ≥12.5 and MUAC† <13.5)	21 (23.0)	16 (16.3)	–0.075 (–0.191 to 0.039)
Missing malnutrition	3 (3.3)	2 (2.0)	

Anthropometrics based on WHO growth curves. Proportion test statistic, ***1%, **5% and *10% level of significance. †MUAC—mid-upper arm circumference.

that the intervention does not improve neurodevelopmental outcomes. Based on these preliminary data and the evidence from the literature, we are inclined towards an explanatory model based on insufficient power.

Programmes like H2H may improve developmental outcomes due to their focus on (1) neurodevelopmental care and (2) improved feeding practices. Specifically, regarding neurodevelopmental care, the H2H programme emphasised infant positioning and containment as well as avoiding strong stimuli while feeding, handling and sleeping to create a more womb-like environment as well as promoting Kangaroo maternal and paternal care. There is evidence that both reducing noxious stimuli and increasing Kangaroo mother care may improve neurodevelopmental outcomes.[28 29] Feeding practice improvements centred on the introduction and promotion of cue-based feeding which encourages caregivers to feed infants by mouth only when the

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infants are demonstrating feeding cues. When the infant is no longer showing cues, they are fed through the nasogastric tube. The introduction of cue-based feeding may have reduced the number of negative feeding experiences, including aspirations, which likely benefit brain development through decreased associated hypoxaemia. Before H2H, mothers may have inadvertently created stressful situations for the baby in their attempts to wake or feed them.

Additionally, the programme strongly supported lactation and exclusive breastfeeding which likely also improves neurodevelopmental outcomes.[30] Lactating mothers have a short period of time in which they can establish a full milk supply. We believe that the inpatient parent education and lactation support was instrumental in increasing breastfeeding. After the H2H intervention, more than six times more mothers were exclusively breastfeeding at 6 months compared with the comparison cohort. This pilot study was not powered to detect a difference in growth and malnutrition parameters with exclusive breastfeeding for at least 6 months, however, differences in infant growth with exclusive breastfeeding have not been universally found in the studies designed for this outcome.[31 32]

Neonatal developmental care programmes with home follow-up, like H2H, have been prioritised by the global health community and national ministries of health.[8] Since many hospitals in LICs are understaffed, there was concern that the implementation of H2H would result in a longer duration of hospitalisation and subsequent overcrowding of the unit. However, infant hospitalisation lengths were similar for the historical-comparison and intervention cohorts (median 7 days before and after), and in some cases (eg, the LBW category), the duration of hospitalisation decreased by 1 day. For normal-weight babies, the duration of hospitalisation decreased by half a day.

The introduction of cue-based feeding resulted in improved weight gain during infants' hospital stays—most dramatically for the VLBW and LBW infants—helping these smallest babies gain weight and meet discharge criteria sooner. This outcome shows that it is possible to implement cue-based feeding in an LIC hospital when sufficiently resourced with staff. Qualitative data also indicated a reduction in aspirations related to oral feeding, possibly related to the implementation of cue-based feeding. Aspirations can result in respiratory complications, extended duration of hospitalisation, long-term feeding difficulties, neurodevelopmental problems and even death. One staff member shared 'We see that few babies are getting apnoea and stopping to breathe because of feeding issues, and they are going home when they are bigger. And am hearing from people who are in [the hospital follow-up clinic] for seeing these babies coming back, they were coming back when they are weighing more and when they are healthy'. It must be noted, however, that the implementation of a quality cue-based feeding programme requires adequate staffing levels to be consistently present in a neonatal unit. Alternatively, caregivers could implement cue-based feeding for their infants provided they receive strong education and support.

It is important to note that H2H assumes that a certain level of quality care is already being provided in a hospital's newborn care unit. The programme builds on a critical foundation of basic knowledge and resources in newborn care. To appropriately implement the programme requires adequate staffing. The addition of a neonatal therapist and discharge coordinator roles were seen as important for improving the patient and caregiver experience. However, we recognise that these roles may not be possible in all LICs.

The Home component was strongly accepted and supported by programme recipients (caregivers) and deliverers (CHWs). Participation in the H2H programme provided CHWs with greater respect and status in their community. H2H CHWs reported improved knowledge and confidence in caring for infants and more generally about their role as a CHW. This role affirmation resulted in a stronger commitment to the work. CHWs reported feeling supported through the provision of mentorship, ongoing training and the necessary resources to provide care for discharged infants in the community. Supportive supervision by a community midwife was found to be an important component of the performance and satisfaction of CHWs.

Almost all babies in the programme received at least one at-home follow-up visit, with infants receiving an average of nine home visits. Those who did not receive an at-home follow-up had most commonly moved out of the area after discharge, possibly related to a cultural practice of temporary relocation with extended family after the birth of a child. Caregivers felt appreciative for the programme and looked forward to the follow-up visits from the CHWs. One Caregiver shared 'They [H2H CHWs] strengthen you that your baby will be well'. Caregivers and CHWs reported challenges in completing referrals for additional care due to the inability to pay fees associated with transport or health services.

Qualitative data showed a change in attitudes in both CHWs and communities about the survivability of high-risk and preterm infants. Previously, communities and CHWs thought that any infant born sick or small would die; afterwards they perceived that small infants could survive and flourish. This may directly impact the infant's likelihood of receiving additional medical care. Fathers often control financial decisions in the household. If fathers believe in the possibility of survival for their infant, they may be more willing to contribute funds for transport to medical care or costs associated with care.

Based on the findings in this work, an adapted version of the H2H programme for public specialised newborn care facilities in Uganda is under development. Further, we aim to study neurodevelopmental outcomes in larger samples. This work closely aligns with national

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clinical and community health strategies recommending follow-up for high-risk patients.

Limitations

The study has several limitations. First, the impact of the COVID-19 pandemic and the associated lockdown in Uganda on the experience and health of infants is not fully understood.[33] Recruitment for the intervention cohort was impacted by lockdown restrictions, requiring a longer recruitment period. The pandemic and the associated lockdown may have had further impacts on infants who were in utero or born during the COVID-19 pandemic which could have created more differences between the historical-comparison and intervention cohorts. Any differences between groups that may have resulted from the pandemic were not analysed. Second, because this was a pilot study, it was not powered to detect a difference in the risk of neurodevelopmental disability, growth or exclusive breastfeeding. Lastly, the study was conducted in a private hospital rather than a public facility.

CONCLUSION

It is imperative that small and sick newborns receive quality care throughout hospitalisation and after discharge home. The H2H inpatient and follow-up programme for high-risk infants may fill this critical gap. H2H was found to be feasible, acceptable and showed possible improvements in exclusive breastfeeding and vaccination adherence. Despite the similar or shorter length of hospitalisations, discharge weights among VLBW, LBW and normal weight neonates were higher in the intervention group. Qualitative evidence indicated improved relationships between caregivers and healthcare workers, improved knowledge of healthcare workers, improved social standing for H2H CHWs and reduced stigma regarding the survivability of small and sick newborns. Further research is needed on cue-based feeding, programmatic cost-benefit analysis and referral completion barriers for discharged infants who fall ill. Pathways to scale must be identified and key stakeholders engaged to ensure all high-risk infants in LICs can survive and thrive.

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