"We give our all": Mothers’ experience of participating in the care of their newborns in newborn care units in Eastern Uganda

Phillip Wanduru (wandulup@gmail.com)
Karolinska Institutet

Claudia Hanson
Karolinska Institutet

Peter Waiswa
Makerere University

Angelina Kakooza-Mwesige
Makerere University

Helle Mölsted Alvesson
Karolinska Institutet

Research Article

Keywords:

Posted Date: January 19th, 2023

DOI: https://doi.org/10.21203/rs.3.rs-2477657/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License. Read Full License

Additional Declarations: No competing interests reported.

Version of Record: A version of this preprint was published at Reproductive Health on July 20th, 2023. See the published version at https://doi.org/10.1186/s12978-023-01649-1.
Abstract

**Introduction:** Mothers’ participation in the care of their sick newborns in newborn care units (NCUs) has been linked to several advantages including earlier discharge, fewer complications, better mother-baby bonding, and an easier transition after discharge. This study aimed to understand mothers’ experiences while participating in the care of their sick newborns in the NCUs to inform interventions promoting mothers’ participation in resource-limited settings.

**Methods:** We conducted an exploratory qualitative study comprised of 18 in-depth interviews with mothers caring for their newborns in two NCUs at a regional referral and general hospital in Eastern Uganda between April and May 2022. The interviews were audio-recorded and then transcribed. For analysis, we used a thematic approach.

**Results:**

Mothers participated in activities ranging from the more basic, like breastfeeding and skin-to-skin care, to the more “clinical”, including tasks such as nasal gastric feeding, and oxygen therapy provision. Mothers were eager to participate in care. The fear of losing their baby was a major underlying sentiment driving their participation. Mothers’ perspectives on i) medical care, ii) the living space in the NCU, and iii) their support system emerged as key themes. Mothers expressed varying degrees of confidence in care, depending on whether or not their baby was improving. Although some mothers needed medical attention, NCU staff only paid attention to the baby. NCU space was crowded, and mothers expressed a lack of control over their personal space. Mothers turned to families to mobilize resources because caring for babies was logistically and financially taxing. Family member support roles and expectation were gendered.

**Conclusion:**

This study indicates that mothers are eager to participate in their babies’ care in the NCU. Many negative experiences, however, taint mothers’ participation in their babies’ care. Interventions to encourage mothers’ participation in the NICU should focus on improving NCU staff-mother interaction, privacy, and space issues, and leveraging the family’s role in supporting mothers.

Introduction

Newborn mortality in Sub-Saharan Africa (SSA) is estimated to be 27 per 1,000 live births, making it the region with the world’s highest burden (1). The ambitious target of reducing mortality to below 12/1,000 live births by 2030 is not likely to be achieved at the current rate of newborn mortality reduction. Most newborn deaths are concentrated around the time of birth (2–4).

Efforts to improve the quality of care for sick newborns have increased in recent years (4). In an attempt to improve facility-based care, the World Health Organization (WHO) has developed key guiding standards (5, 6). These standards emphasize the importance of involving parents or other caregivers in the care of their sick newborns when admitted to the NCU. Indeed, numerous studies have indicated that parental participation in the care of admitted newborns is associated with better clinical outcomes including better weight gain, early discharge (7–9), and fewer complications (7, 8). In addition, improved bonding with the baby (10), an easier transition from hospital to community, and less anxiety among caregivers have been reported (7, 9, 10).

In many low and middle-income countries including Uganda, investments in health are typically biomedically oriented, largely focusing on ensuring the availability of drugs and equipment, addressing human resource capacity deficits, and improving data systems (11). Little consideration is given to social or people-centered aspects, such as how to support and integrate parents in the care of their hospitalized newborns (11, 12). For example, the Ugandan national guidelines do not cover parents’ or caregivers’ involvement in the NCU (13, 14). Despite the lack of official guidance, health workers (HWs) in NCUs ask mothers to participate in the care of their babies by carrying out tasks such as cord care, danger sign recognition, or nasal gastric tube feeding (15).

With a view to informing national guideline development about how to institutionalize participation of parents, specifically mothers in the NCU, we reviewed the literature on caregiver experiences of participating in the care of newborns admitted to NCUs. We found that the vast majority of the research regarding parental participation was from high-income countries, with only a few studies from middle-income settings where family-centered models are in practice (16). There is very little evidence to support parental participation in the care of sick babies in lower-income settings despite these being known to have a larger burden of sick newborns.
In this study, we sought to understand mothers’ experiences of taking care of their babies in resource constrained NCUs in Eastern Uganda in order to inform guidance and policies supporting mothers’ involvement in similar settings.

**Materials And Methods**

**Study setting**

This study was conducted in the NCUs of two high-volume hospitals, one general hospital, and one regional referral hospital. In Uganda, general and regional referral hospitals offer outpatient, inpatient, and emergency care in the fields of medicine, surgery, obstetrics, and pediatrics. A regional referral hospital provides more specialist services than a general hospital because it employs consultant and/or senior consultant pediatricians, surgeons, doctors, and obstetricians. In terms of referral hierarchy, general hospitals refer to regional referral hospitals (17).

These two hospitals were purposively selected as typical high-volume public health NCUs in Uganda. Being government-run, they offer free medical care. Both hospitals manage approximately 550 births per month (17). The NCU’s caseload amounts to 1,000 and 1,200 per year in the general and regional hospital respectively.

The two NCUs offer similar newborn care services including temperature support, newborn resuscitation including oxygen therapy, feeding support (including nasal gastric tube feeding), and provision of essential newborn medications like antibiotics, anti-convulsant, and intravenous fluids. Both NCUs are staffed with two to three nurses working in three 8 hourly shifts. A pediatrician and intern doctor(s) are present during the day and on-call during the night. There are no sleeping arrangements available for mothers or any other caregivers in the NCU.

**Study design**

We chose a qualitative exploratory design using in-depth interviews and observations to understand the experiences of mothers when caring for babies in the NCU.

**Data collection processes:**

No father or other caregiver was selected, because only mothers were present as primary caregivers in the selected NCUs. We only included mothers who had spent at least 48 hours in the NCU as they had gained some experience. We selected a total of 16 mothers who were caring for their babies, nine from the regional referral hospital and seven from the general hospital. In addition to interviews, we conducted non-participatory observations of NCU activities for 12 hours at each of the two hospitals.

Based on existing evidence and our experience, we hypothesized that the experiences of respondents would differ based on social economic status and age (18). We had an initial sample of nine mothers including young and older mothers, and those economically better and not well-off. After a preliminary analysis of these interviews, we selected and interviewed an additional seven mothers including mothers whose babies were severely sick, and those that had been admitted for longer for example those that had stayed for more than 2 weeks at the NCU.

We used an interview guide that was informed by previous research on caregivers’ experiences of caring for sick babies in similar settings (18, 19). Aspects from research evaluating family-centered infant care models inspired our inclusion of probes on emotional attachment during participation and the importance of the physical environment (20). The guide included questions about i) the mothers’ caregiving activities, ii) their motivations, iii) their feelings about participation, and iv) their interactions with HWs. The interviews were conducted in a quiet room outside the NCU. The data was collected by Phillip W (male), with the help of two female research assistants who were social scientists with extensive experience in qualitative research data collection. The interviews were all conducted in the local language (Lusoga) and later translated into English. All interviews were audio recorded with consent from the participants. In addition, descriptive and reflective field notes were taken throughout the study period by PW.

The observations were informed by a guide which included aspects of: General appearance of the NCU; description of the role of individuals in the NCU, highlighting those that stand out, human traffic, personal space, and other human interactions. We had two
research assistants conduct at least six hours of observation of the NCU at each hospital. Field notes of the observations were taken.

**Data analysis:**

The data transcription was performed by the data collectors, each transcribing their own interviews. Thematic analysis was used (21). The process of analysis included reading through the data repeatedly to understand its meaning, coding, identifying key categories, and establishing the relationships between them. At the start, *Phillip W* conducted open coding, which involved coding and presenting emerging themes at a manifest level. *Phillip W* has a clinical background and has worked on newborn clinical quality of care improvement projects for the past four years. Reflecting on initial emerging codes and themes, themes were biased toward clinical quality of care aspects as this is his background. This preliminary coding served to provide an overview of emerging themes at the manifest level.

Following that, the research team had a series of discussions reviewing summarized themes and double checking with the transcripts were necessary. The themes were reviewed to give them meaning and identify underlying patterns (21, 22). This process was guided by HMA, a medical anthropologist. We believe that taking this approach enhanced the richness of the findings. Analysis was done using NVivo software throughout the process.

**Ethical considerations**

Ethical clearance for this study was obtained from the Makerere University School of Public Health Higher Degrees, Research and Ethics committee, (Approval number SPH-2021-126) and Uganda National Council of Sciences and Technology (Approval number: HS2057ES). Following a comprehensive explanation of the study’s objectives and methods, informed consent (signed or witnessed by a thumbprint) was obtained from all eligible participants.

**Results**

**Mothers’ experiences of participating in the care of their babies**

As shown in the conceptual diagram (Fig. 1), mothers’ participation in the care of their newborn baby was driven by an underlying fear of losing their child. This fear also shaped their experiences and was demonstrated in their actions.

Mothers’ experiences are presented under three main thematic areas: Mothers’ perception of care in the NCU, the NCU space, and the family support system. In the following section, we provide a detailed description of the themes and sub-themes.

**Mothers’ perception of care in the NCU**

**Confidence in medical care provided**

Mothers were concerned about the quality of care their babies received, because they needed them to stay alive and were aware that it depended on the care they received. They were generally confident about the care their babies were receiving, mostly because of their observation that both their own and other people’s babies improved after treatment. Mothers whose babies had improved frequently shared the success stories of their babies’ recovery, which provided confidence to those whose babies were still critically ill and/or mothers of newly admitted babies.

*I recall how we arrived here; he was so small that he couldn’t even cry or move. Within a few hours of being cared for, he began moving his hands and crying. And now you can see that he is gaining weight, that he is getting bigger, that the medicine is working.*

(Mother of one, 20-year-old).

Even though most mothers were confident, mothers whose babies deteriorated or did not improve quickly expressed a loss of confidence in the care received. Most mothers had witnessed a baby’s death in the NCU, which heightened their anxiety and lack of confidence. It is important to highlight that the babies who were deteriorating often required more interventions, and mothers frequently questioned the necessity of the numerous procedures and occasionally worried that these interventions might be harming their babies.
Yes, I am concerned. Although the baby has little blood, the HWs are constantly pricking and drawing blood, and the condition remains unchanged. The baby started convulsing the other day after receiving a lot of drugs. The baby has been given so many drugs that it is now weak; they must have given it a lot of medication. I am sceptical of the care provided in this hospital. (Mother of two, 25-year-old).

**Mother’s appreciation of HWs responsiveness**

The mothers’ perception of how responsive HWs were in times of emergencies was another aspect connected to their fear of losing their babies. Whenever a mother believed that their baby was experiencing a life-threatening medical emergency, they would call a HW for assistance. Some of the incidents commonly reported by the mothers were convulsions and babies gasping for air. Most HWs reacted swiftly to the mother’s call for help, which was highly valued. Mothers were very appreciative of the HWs who, despite being quite busy, would occasionally stop what they were doing to answer an urgent call.

*When compared to other wards I have visited, the NCU's HWs are quick to respond. Perhaps this is why my baby is still alive. When I told them (the HWs) that my baby was having a problem, they rushed over to help. When I told them my baby was convulsing, they acted immediately. Even when I informed them that the oxygen was not flowing, they rushed to assist.* (Mother of three, 27-year-old)

However, mothers also interacted with unresponsive HWs. When called upon, these HWs, would either not reply or would promise to come but never actually show up.

*These HWs here! The other time my child convulsed, I ran and told them to come and help; they said they were coming but then went about their business. I was terrified that my baby would die, but God came to my rescue.* (Mother of five, 32-year-old)

We also noticed that some mothers believed that some babies received special treatment from HWs in terms of responsiveness to their needs and time spent with them.

*In this unit, some babies get a lot of attention. Perhaps their mothers bribe the HWs? They (HWs) are constantly checking on the baby, and whenever the mother calls, the HWs rush to see the baby. Meanwhile, they take up to an hour to arrive for me.* (Mother of six, 36-year-old)

**Mothers' dedication and focus on "doing" things that aid their baby's survival**

Mothers felt a duty to make sure that their babies survived, and they therefore actively participated in their care. The activities mothers participated in included those that are routine like breastfeeding, cleaning the baby, and carrying the baby to the nurse for medication. Checking oxygen flow, removing the baby from oxygen when the power goes out because the supply is also cut off, and nasal gastric tube (NG tube) feeding were some of the tasks performed that needed a certain level of skill (As shown in Table 2).
# Table 1
A table showing sociodemographic of mothers who participated in the study

<table>
<thead>
<tr>
<th>Age range</th>
<th>N = 16</th>
</tr>
</thead>
<tbody>
<tr>
<td>19 or less</td>
<td>4</td>
</tr>
<tr>
<td>20–24</td>
<td>4</td>
</tr>
<tr>
<td>25–30</td>
<td>5</td>
</tr>
<tr>
<td>30 or more</td>
<td>3</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Never lived with a spouse</td>
<td>3</td>
</tr>
<tr>
<td>Living with spouse</td>
<td>10</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
</tr>
<tr>
<td>No education</td>
<td>4</td>
</tr>
<tr>
<td>Primary level</td>
<td>4</td>
</tr>
<tr>
<td>Secondary level</td>
<td>5</td>
</tr>
<tr>
<td>Above secondary level</td>
<td>3</td>
</tr>
<tr>
<td><strong>Number of children</strong></td>
<td></td>
</tr>
<tr>
<td>1–2</td>
<td>4</td>
</tr>
<tr>
<td>2–3</td>
<td>5</td>
</tr>
<tr>
<td>3–5</td>
<td>5</td>
</tr>
<tr>
<td>5+</td>
<td>2</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
</tr>
<tr>
<td>Professional with formal employment</td>
<td>4</td>
</tr>
<tr>
<td>Small business owner</td>
<td>4</td>
</tr>
<tr>
<td>Unemployed</td>
<td>8</td>
</tr>
</tbody>
</table>

# Table 2
Activities mothers participated in while in the NCU

<table>
<thead>
<tr>
<th>Routine interventions</th>
<th>More complex interventions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Removing baby off oxygen when the power goes</td>
<td>• Breastfeeding</td>
</tr>
<tr>
<td>• Checking to see if oxygen is flowing in the prongs</td>
<td>• Wiping baby-bathing</td>
</tr>
<tr>
<td>• Notifying HWs when a baby has a danger sign</td>
<td>• Reminding nurses to give their babies medication</td>
</tr>
<tr>
<td>• Feeding in Nasal gastric tube</td>
<td>• Taking babies for medication</td>
</tr>
<tr>
<td>o Expressing milk</td>
<td>• Watching over the baby</td>
</tr>
<tr>
<td>o Using syringes to feed through the NG tube</td>
<td></td>
</tr>
</tbody>
</table>

*Medical interventions: these are typically done by HWs and require a level of medical judgment to be performed satisfactorily

* The non-medical interventions are those that mothers typically do are non-invasive

HW = Health worker

When you conceive and carry a pregnancy for nine months, it is your baby and your responsibility. I need to be involved in his care so that he can survive and live. That is my obligation as a mother and a woman; I cannot delegate it to anyone else, not even HWs. So, I do whatever needs to be done. (Mother of five, 32-year-old).
The fact that there were very few HWs in the NCU further catalyzed the mother's need to take part in their baby's care. The HWs also encouraged mothers to help by taking time to train them on how to perform various tasks.

The health workers are too few and the babies are just so many! They try to take time to empower us to look after our babies in a simple way. The nurses trained me how to express milk and the mills [amount] you are supposed to give the baby. I was also told that before expressing the milk, I need to wash my hands, then wash the cup with hot water, wash the syringe and they dry very well. (Mother of four, 40-year-old mother).

Mothers stated that their main concern was helping the baby stay alive and leave the NCU. They appeared to be trying to avoid developing emotional attachments to their babies. Since the babies were so young, they hoped that they would have time to form a close bond with them later.

Of course, I want my baby to recognize and bond with me as her mother. But that is not possible right now. It is not a priority; the baby needs to stay alive first. I am optimistic, because he is young, and when we get out of the hospital, we will bond, and she will recognize me as his mother. I had the opportunity to love, carry and breastfeed my previous babies, but not this one. She is on oxygen. She feeds through a tube (mother of three, 29-year-old mother).

Mother’s interaction with HWs: Need for empathy

Regarding their interaction with HWs, the desire for empathy emerged as the overarching issue for mothers. We observed that in the NCUs, HWs focused on the babies and paid little attention to the mothers, including those who were visibly ill. Most mothers were aware that the NCU was there for the babies and never raised concerns about their own well-being. This was true even though most mothers looked sick and probably needed medical attention, while others had not rested since giving birth.

Although mothers prioritized their babies and did not object to the NCU HWs’ focus on the babies, they expressed a desire for empathy because they were in what they termed as a “fragile” state. They were healing from giving birth and dealing with the unexpected experience of having a sick baby. The lack of empathy was reflected in the negative response by HWs when mothers, who were asked to carry out some tasks related to the care of their babies, were slow in doing so because of their condition.

The HWs need to stop being angry at us. They should understand our situation. They should talk to us well because we are all human beings. Even if they instruct you to do something and you do not do it, they should understand. We are tired and sick as well! (Mother of two, 25-year-old)

On the contrary, there were various occasions when HWs showed empathy to the mothers by paying attention to them, offering them words of encouragement, and being patient with them when they, for instance, did not bring their children for medication.

I cried a lot. I had lost hope. The HWs comforted me and encouraged me to be strong. I was overwhelmed by thoughts. The HWs strengthened me. You cannot handle this period without someone to encourage you. Of course, for me, it was much better when the encouragement came from HWs as they know better (mother of six, 32-year-old)

There were several times when the mother reported that HWs were rather cruel in the way they treated them. We observed that HWs frequently shouted at mothers for not following NCU practices. Many mothers reported similar events. This happened to a great extent at night when HWs were few and wanted to go to sleep.

I was tired that day and went outside to rest on a mat; by the time I got up, it was after midnight, and the baby had missed his medication. I arrived just as the nurse had finished administering medication to the babies and had gone to sleep. I attempted to awaken her, but she refused. I was outside knocking, but she didn't seem to hear me. She later came out and inquired as to who was knocking. And I came over to explain myself. “Where were you?” she demanded angrily. I told her I had gone to bed because I was tired. She first argued, saying, “Will I always be there waiting for your babies?” (Mother of two, 25-year-old)

The NCU space: feeling unsafe

The NCUs are dormitory-like rooms with around 30 baby cots, three to four beds for Kangaroo Mother Care mothers, and a few chairs for mothers to sit on. Even though the nurses insisted that only mothers should stay in the NCU since they are breastfeeding the babies, additional family members were frequently present. Consequently, NCUs were often congested.
Mothers expressed worry that the environment was not safe. They were concerned that someone might steal their babies in this uncontrolled space. As a result, they were constantly nervous.

I could not sleep because I had to keep an eye on my baby. I have not slept in days as you can see, I am exhausted. I could not go out to wash my clothes or bathe. There are so many people here, you cannot know their intentions. The mothers tell many stories of babies being stolen; it is very frightening (mother of three, 28-year-old mother).

As mentioned in the theme of mothers’ perceptions of care, mothers felt it was their obligation to protect their babies, so they responded to their fear of having their baby stolen by always ensuring that a family member stayed to watch their baby whenever they left the NCU for any reason.

Besides the fear of babies being stolen, examples were given of theft of property in the NCU.

There are no cameras. They steal everything. We are so many of us; you cannot differentiate who is a thief and who is not a thief. For example, they stole my money, and my phone. The man who stole it came and sat on a chair and I assumed he was someone’s husband. When I went out to the pharmacy, upon returning he was not there, and my phone was gone. Imagine some people send you money on the phone; I suffered with eating that whole week (mother of five, 40-year-old)

Support system: Dependency on family

Mothers described the process of caring for the baby in the NICU as financially and physically draining. The common expenses included paying for medicines and laboratory tests that were not available in the hospital, buying food and tea, and sometimes extra baby clothes. Typically, it was the role of the spouse to take care of expenses. The provision of finances seemed to be what mothers primarily expected from them. We observed that some men were involved in other activities like watching over the baby in the NCU or washing clothes, but this was rarely mentioned by the women themselves as the financial role seemed more relevant. It was common that the spouse would not have all the money to cover all costs, so he got support from his family.

My husband buys whatever is needed like diapers. Sometimes he fails to get all the money, his relatives support him. He is a teacher in a government school, and, understandably, he cannot raise all the money we need here. All his brothers and sisters have been very supportive (mother of one, 21-year-old)

We noted from interviews that families that could afford these costs were happy to incur them and it was a source of satisfaction for the mothers, because then they felt that they did what was necessary to save their babies. However, it was challenging for those who couldn’t afford it, who often felt bad about it, and their babies frequently missed treatment.

I feel happy, we (her family) could afford to buy drugs and whatever is needed at NCU. I have made work easy for the HWs but also, I feel glad that I can provide everything needed for my baby to survive. I am lucky God has provided the money. I see other mothers struggling (mother of four, 30-year-old)

Mothers also mentioned that caring for babies was physically exhausting. They did not rest much, and when they needed to rest, there were no beds in the NCU. They often had to go outside the NCU, or they slept on the floor at night. To cope with the demands, mothers depended on their families. Typically, the mother-in-law, sisters, sisters-in-law, and mothers entered the NCU to help with day-to-day care. They stayed at the hospital and supported mothers by watching over the baby, washing clothes, and going out to buy food or any other requirements.

For mothers who had no support from family, HWs would mobilize resources to support them. The HWs encouraged mothers to share resources.

The other day I had spent all my money, I could not afford the medicine I needed to buy, and I had no food. The nurse asked one of the mothers who had an extra dose of medicine to give me, and she did. That nurse also asked all women to give me some food and tea that day. I was so thankful because my hands were tied that day. I was completely stressed out. (27-year-old mother)

Discussion
The study explored mothers’ experiences of participating in the care of their sick newborn babies in the NCUs of two busy public hospitals in rural Uganda. Overall, we found that mothers were willing and committed to participating in their babies’ care. Their participation was largely motivated by their fear of the death of their babies. Their NCU experiences centered around their perceptions of the medical care they received, the NCU environment, and the people in their support network.

Our study proposes that the mother’s primary concern was making sure her newborn baby stayed alive, even at the expense of her own needs. We hypothesise this to be related to the fact that in this society, the duty of reproduction rests on the woman, and giving birth to a living baby is a significant milestone (23, 24). Moreover, many studies in Uganda and Sub-Saharan Africa show that the loss of a baby or failure to have a baby is likely to lead to stigma in the community as well as marital problems (25–27). Mothers whose babies are at risk of dying were particularly anxious about their baby's survival given the multiple negative effects of losing a baby, especially for the mother.

The mothers in the study informed us that they put off creating emotional bonds with their babies because they were prioritizing “doing” things that ensured their baby's survival. Given that newborn death in this setting is common, delaying bonding may be a coping mechanism for parents dealing with the fear of losing their baby and its related grief. There are a number of studies in similar settings that show that individuals deal with the fear of losing a baby by avoiding emotional attachment (25, 26). For instance, some parents wait until their babies are older before naming them. A community study in this setting indicated that the word “a thing,” which refers to a non-living item, is often used to refer to stillbirths and early newborn deaths (26).

Other studies have highlighted that some mothers fail to bond with their newborns because of mental health problems like depression, stress, or anxiety (28, 29). We discovered that mothers experienced a great deal of stress as a result of their babies being admitted to the NCU, due to the fear of the child’s death, fear of the baby being stolen and the financial costs of being in the NCU. It is therefore possible that these mothers’ mental state played a role in their difficulty in bonding with their babies. The delayed bonding may hinder the achievement of some benefits of having a mother in the NCU. For instance, women who do bond with their babies may feel anxious (30).

The role of the NCUs is to care for sick babies and this was the focus of both staff and the mothers themselves. However, the mothers were often sick after birth and dealt with complex emotional needs. We believe that housing these mothers in NCUs with no resting area and not providing them with any care package may be counterproductive, as mothers wellbeing is linked to the baby’s wellbeing. These mothers are still at risk of complications such as postpartum bleeding and mental health issues like postpartum posttraumatic stress (31, 32). In their article, Kinney and colleagues emphasized the importance of integrating baby- and mother care to fully maximize the benefits for the baby (33). Mothers spend a significant amount of time in the NCU caring for their babies; therefore, aspects of their care should be brought to the NCU to facilitate their well-being. This can be done in many ways, for example, HWs from maternity ward could be asked to do a routine check on mothers in the NCU. Synergizing clinical care activities in the NCU with maternal counseling services, as established by HIV/AIDS programs, could be a good innovation (34).

The study illustrates that the physical environment of the NCU is an important determinant of mothers' negative experiences. The NCUs are congested, with many caregivers sharing the same small space. This arrangement increases the risk of property theft, and also makes mothers feel unsafe about their baby's security. Mothers who give birth in high-volume public health facilities in Uganda have long expressed concern about their baby's safety, and it has been identified as one of the reasons some mothers do not give birth in facilities (35). Ensuring the safety of the babies in the NCU has however received little attention.

Many high-income settings have increased the personal safety of the NCU by creating single or double-family NCUs. However, recommending this in Uganda might be unreasonable given that it would require a large amount of space and funding, which are not readily available in Uganda's hospitals. Nonetheless, we believe that increasing the size of the NCU’s floor, which requires comparatively less extension, and clearly designating a specific space for each mother-baby pair could be a good first step.

From The study reveals that there were gaps in essential quality-of-care standards as established by the WHO (36), such as a failure to respond immediately to emergencies, delays in administering medication and other care, and insufficient emotional support for mothers. Although mothers tended to lay the blame on HWs, that lack of quality care can be a product of structural and systemic shortfalls (37, 38). Within the context of high caseloads, understaffing, and inadequate supplies, provision of quality may not be possible. An article by Koblinsky M noted that improving the quality of care requires first addressing the “obvious” structural
problems like understaffing, and lack of supplies (39). Therefore, we contend that without involving or holding accountable those who have the ability to allocate resources, improved quality of care would continue to be a challenging objective to fulfill.

We observed that mothers participated in tasks requiring a certain level of technical expertise, such as providing oxygen therapy and NG tube feeding. Despite their claims that the HWs had trained them, we suspect that their brief instruction may not have been sufficient to prepare them for performing these tasks safely on their own. Therefore, it is crucial to specify which tasks mothers can perform, particularly in environments with insufficient staffing where mothers might feel pressure to perform additional tasks.

The study demonstrates a "whole" family support approach where mothers are supported by many family members doing various tasks. This finding aligns with what Powis found in Senegal and refers to as a family "entourage" (40). As in the Senegal study, the roles of family members in this context were gendered, with females including sisters, mothers, and mothers-in-law supporting with day-to-day hospital chores while males are tasked with finding financial assistance (40). In this study, we found that some men helped out with daily tasks, but mothers hardly ever acknowledged these contributions. In many similar settings, the expected role of male support is to provide financial support as the males are seen as breadwinners (41, 42) and there is no reason to believe that this is not the case here. We believe that while creating male engagement initiatives, it is crucial to take into account these gender norms and expectations.

**Conclusion**

It was found that mothers are willing to actively participate in their newborn's care at the NCU. The underlying drivers for their participation include the fear of losing their baby and also caring being a social role for mothers. We identified a number of challenges related to mothers participating in the care of their sick babies, including taking responsibility for activities that require medical skills. The mothers were also in a risky postpartum period and had complex needs that were frequently left unmet in the NCU. Caring for babies was logistically and financially straining for women and families. Firstly, we recommend that there is clear guidance about precisely which tasks mothers can and cannot perform in the NCU. Secondly, it is necessary to reinforce the mother-baby dyad mindset among HWs even in the NCU where mothers’ needs are often neglected. Lastly, programs should consider leveraging families to support mothers in the NCU, integrating the gendered nature of how families operate in design of any programs.

**Declarations**

**Competing interests**

The authors declare that they have no competing interests.

**Authors' contribution**

All authors (Phillip W, CH, Peter W, AMK, and HMA) were involved in conceptualizing this research project. PW undertook the data collection. Phillip W and HMA analyzed the data. Phillip W, CH, and HMA prepared the manuscript. All authors read and approved the final manuscript (Phillip W, CH, PW, AMK, and HMA).

**Acknowledgment**

We thank Soha El Halabi of the Department of Global Public Health at Karolinska Institutet, Doris Kwesiga of Makerere University, and Mary Kinney of the University of Western Cape for reviewing and providing feedback on the manuscript.

**Funding:**

This work is done under the project titled be alert "Kuwa Macho which is funded by the Swedish Research Council (project ID: 2019-01906_VR). The funder had no role in the study design, data collection, management, or analysis plan of the study

**Availability of data and materials:**

The data sets used in the study are available from the corresponding author on reasonable request.
References


5. WHO. Standards for improving the quality of care for small and sick newborns in health facilities. 2020


Figures

A conceptual framework of mother's experiences caring for babies in the NCU

NCU = Neonatal Care Unit