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Mothers' experiences and caregiving responsibilities in newborn units

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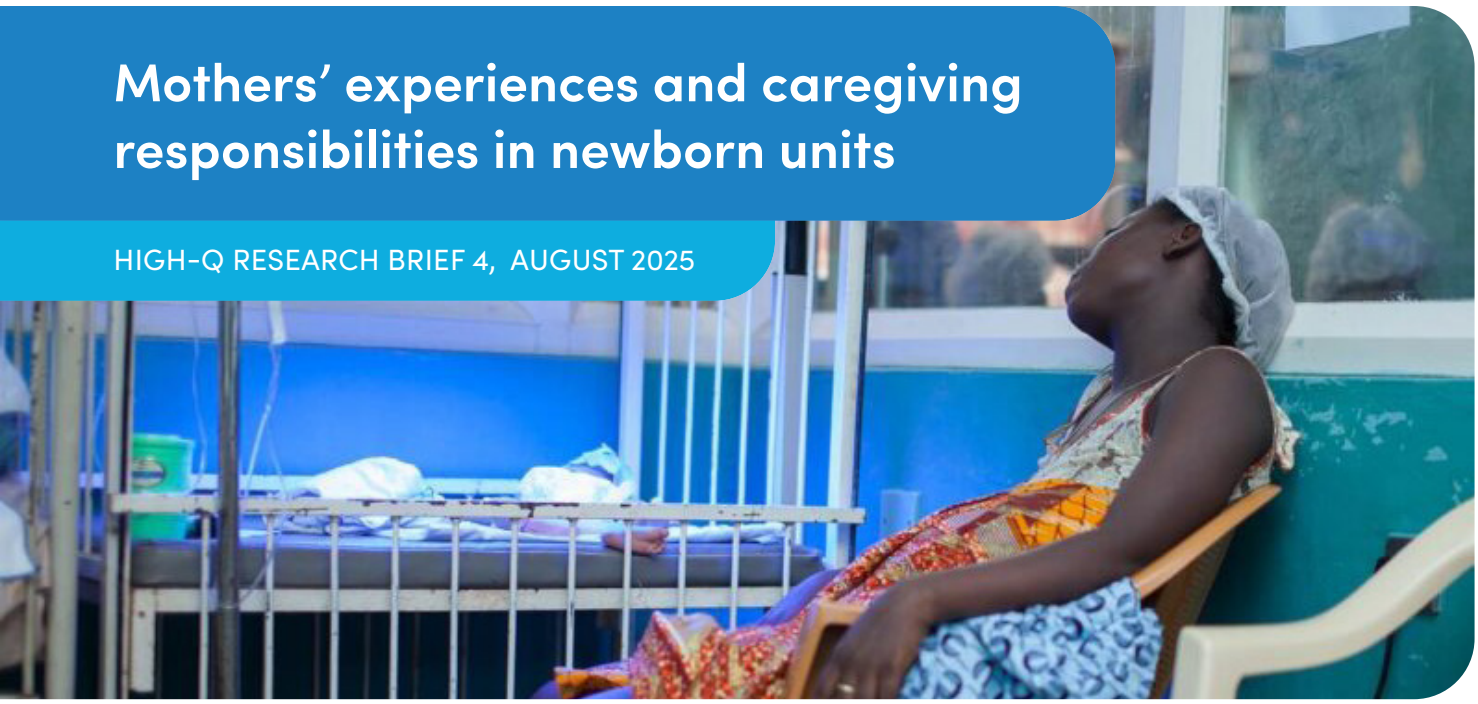


About this brief

This brief is the fourth in a series based on the HIGH-Q (Harnessing Innovation in Global Health for Quality Care) project and related research on neonatal care in Kenyan hospitals. This work was carried out by the KEMRI-Wellcome Trust Research Programme and the Kenya Paediatric Research Consortium (KEPRECON), with support from the University of Oxford.

HIGH-Q is a multi-disciplinary study evaluating how the introduction of new technologies and workforce innovations influences the quality of care in newborn units (NBUs). Ethnographic and observational research has also explored the everyday experiences of nurses, the physical environment of NBUs, and mothers' experiences within these settings. Each brief focuses on a different aspect of this work.

The brief was written by members of the HIGH-Q research team.

Introduction

Newborn Units (NBUs) provide critical, life-saving interventions for small and sick babies. However, in Kenya's under-resourced public hospitals, the experience of having a baby admitted to an NBU is challenging for mothers. Many arrive unprepared for the demands of neonatal care and must quickly navigate an unfamiliar medical environment where they are expected to take on caregiving responsibilities with minimal support.

While parental involvement in newborn care has well-documented benefits, in resource-limited settings with severe nurse shortages, it frequently occurs without adequate orientation, psychosocial support or resources. This lack of guidance increases maternal distress and can pose risks to babies.

To better understand these challenges, KEMRI-Wellcome Trust conducted ethnographic research in Kenyan public hospitals, examining mothers' experiences and caregiving roles, alongside the broader ward routines and norms that shape their experiences in NBUs.

Mothers' experiences in newborn units

Maternal distress and stigma

The admission of a baby to an NBU is emotionally and physically overwhelming for mothers, particularly when they are still recovering from childbirth. Mothers are accommodated in separate postnatal wards, requiring them to make frequent and often exhausting trips to the NBU to visit their baby and provide routine care. Separation from their newborns, combined with the physical and emotional toll of these repeated journeys, further adds to their distress. Once inside the NBU, mothers are confronted with overcrowded, poorly ventilated, and noisy environments that are unfamiliar and difficult to endure.

Beyond the emotional toll, some mothers face stigma linked to having a baby in an NBU. This is especially pronounced when babies are premature and have visible health conditions or require medical interventions like oxygen support or feeding with tubes.

After hospital discharge, stigma often continues within the community. To protect themselves and their babies, mothers may limit or avoid visitors to prevent negative comments regarding their baby's size, growth, and development. They may also face criticism for feeding methods, especially when using cup feeding instead of breastfeeding, which can deepen feelings of inadequacy.

Fear and anxiety

Many mothers in NBUs experience high levels of anxiety, primarily due to concerns about their baby's survival. The unfamiliar and highly medicalised environment of neonatal units – filled with equipment such as incubators, oxygen support and nasogastric (NG) tubes – intensifies these fears.

This emotional toll is particularly heavy for mothers of babies requiring intensive support. Without orientation or adequate explanation from healthcare staff, they frequently struggle to interpret what their baby's condition means or how to provide care without causing harm. Even basic tasks like feeding, repositioning, or top-and-tailing can become a source of anxiety. Feeding, in particular, is a significant area of concern. Cup feeding is often introduced with minimal instruction, and there is little support for breastfeeding, leaving mothers uncertain about whether their baby is receiving enough nutrition.

"They would insist that I express, but it is not that I did not want to express... it's because I knew I had no milk, so I wondered what they expected me to express yet I did not have, I just didn't have!" (Mother)

Severe staffing shortages, especially at night, further exacerbate these fears. During overnight shifts, there can be only one nurse on the ward for up to 40 babies and only a doctor on call. Mothers report feeling vulnerable and worried about the lack of immediate access to healthcare providers.

Challenges to mothers' dignity and wellbeing

Mothers' dignity is often compromised by inadequate living conditions in the postnatal wards, where they are required to share beds and bed linen with other mothers in some units. They also experience challenges related to ill-fitting gowns, lack of privacy, limited seating during feeding, and minimal emotional support. In some NBUs, the absence of designated spaces for expressing milk compels mothers to do so while standing next to their baby's cot. In some hospitals, inadequate facilities contribute to concerns about hygiene and the potential contamination of milk and feeding items.

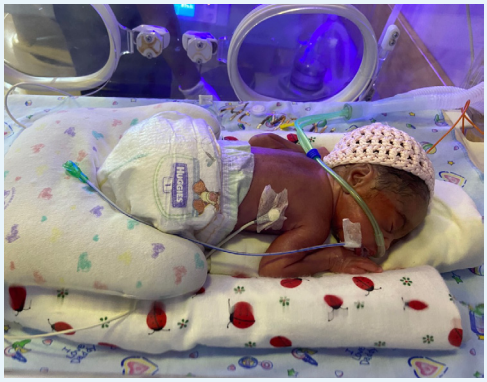
Beyond these physical challenges, interactions with healthcare providers also impact mothers' sense of dignity. Many report feeling dismissed or blamed when they struggle with breastfeeding or caregiving tasks, with some being scolded rather than supported. These experiences discourage mothers from seeking help and deepen their feelings of helplessness.

Fear and anxiety around medical equipment and neonatal technologies

For many mothers, the medical technologies in NBUs, such as Continuous Positive Airway Pressure (CPAP) and phototherapy machines, can be confusing and frightening. CPAP, which supports breathing, is particularly alarming due to the baby's laboured breathing and visible secretions.

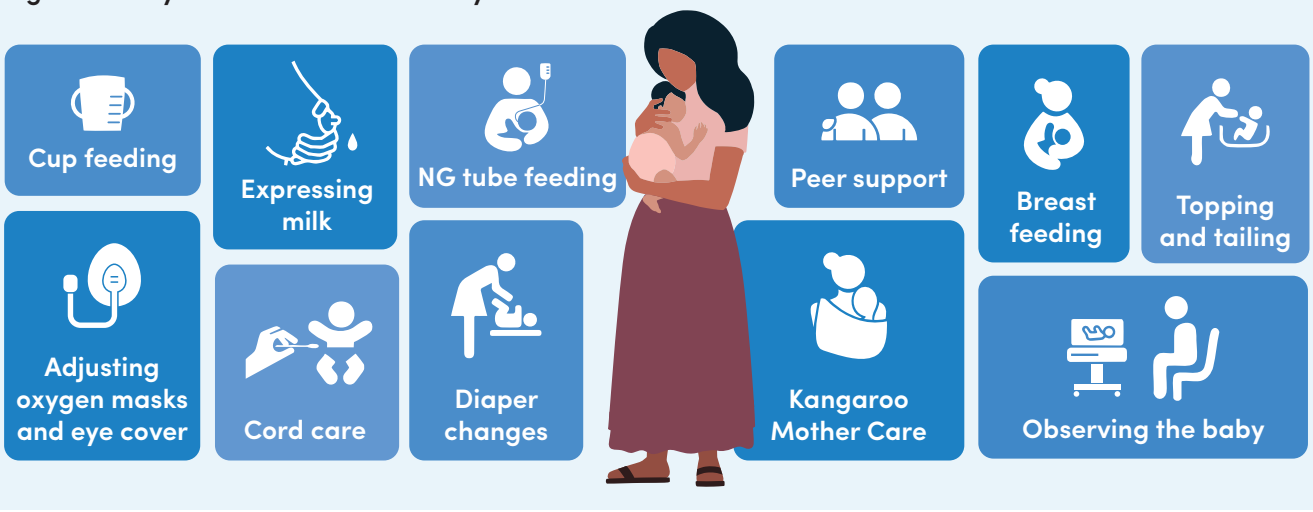
In practice, nurses often prioritise clinical and practical tasks over explaining equipment to mothers. This limited communication makes it hard for mothers to understand or trust the purpose of devices – especially invasive ones such as intravenous (IV) lines, oxygen via nasal prongs, and NG feeding tubes.

Shared incubators also cause anxiety, with concerns about infection risks and babies moving within the space. In an effort to protect their newborns, some mothers try to clean the equipment, despite lacking proper supplies or knowledge of cleaning and disinfection practices.



"All the time the machines beep, if you just hear that sound 'twitwitwi' that baby is gone [passed away]. It gave me a heavy burden in the heart." (Mother)

Figure 1: Daily care tasks carried out by mothers



Mothers as neonatal care providers

Severe nurse shortages in public hospitals mean that mothers are expected to assume caregiving responsibilities almost immediately, regardless of their physical and emotional state. With nurses responsible for up to 40 babies per shift, routine tasks such as feeding, monitoring, and repositioning are informally delegated to mothers (Figure 1).

Some mothers must also handle complex tasks in addition to basic care, such as assisting with NG feeding, adjusting oxygen masks, and ensuring proper eye protection for phototherapy. However, learning is largely unstructured, with mothers relying on observation or peer instruction rather than formal training. The absence of proper training can leave them feeling helpless as they navigate unfamiliar responsibilities. When errors occur, these feelings are often compounded by guilt, as mothers worry that their inexperience may have contributed to their baby's condition.

Communication with healthcare staff

Mothers notice and appreciate explanations and acts of kindness from staff.

> *There were some good ones who handled you well, explained things well, and if the baby had a problem, they would explain it well to you... And even if the baby is in a situation that is not so good, they encourage you and you feel satisfied". (Mother)*

At the same time, their broader experiences highlight ongoing communication challenges.

Limited information and support

Communication between mothers and healthcare staff in NBUs is frequently limited, rushed, and directive, leaving many mothers feeling confused and unsupported. Interactions tend to prioritise instructions over explanation, with few opportunities for mothers to ask questions or seek clarification.

This lack of clear, consistent communication contributes to stress and increases the risk of caregiving errors, creating a cycle of uncertainty and blame. When mistakes occur, mothers are more often reprimanded than supported, reinforcing feelings of anxiety, guilt and helplessness. Dismissive or curt responses from nurses can discourage mothers from seeking further guidance.

> *"I was scared of asking the nurses...there is a time I asked something and I was asked, "How long have you been here?" And I told them one week. "One week and you are not aware of things?" So you see this will make you afraid of approaching them. Maybe they will answer you in a bad way or they ignore you." (Mother)*

Disrespectful communication

These strained interactions are often not a reflection of nurses' personal attitudes but rather a result of their overwhelming workloads and emotional exhaustion. Nurses in under-resourced NBUs experience distress as they struggle to care for critically ill newborns with insufficient staffing and resources. This pressure can lead to nurses emotionally withdrawing, resulting in minimal engagement with mothers and further reinforcing the gap in supportive communication (see Brief 5).

When mothers receive distressing news, such as their baby's deterioration or death, psychosocial support is minimal. While some healthcare workers offer support, its delivery is inconsistent and often depends on the individual healthcare provider and their workload. Sometimes, the setting for these conversations is also inappropriate. This variability further compounds mothers' emotional distress during already difficult moments.

How mothers find support in NBUs

One of the most significant sources of support for mothers in NBUs is other mothers. Peer-to-peer learning is a key mechanism through which mothers acquire caregiving knowledge and reassurance. Many form informal networks, exchanging advice, encouragement, and assistance with tasks such as feeding and diaper changes.

Ward assistants and student nurses also play a role in supporting mothers. In some hospitals, ward assistants help clean and feed babies, and orient mothers to the NBU environment. Mothers frequently turn to them for assistance with routine caregiving tasks. Similarly, student nurses often serve as intermediaries, providing guidance and addressing mothers' questions when senior nurses are unavailable. Despite these forms of support, structured education and counselling for mothers remain significant gaps.

"Let's say, now it's time to wash the baby, there may be a mother who is next to you, and she tells you 'don't do that, do this'. Maybe you went to the nursery and you forgot the diaper or wipes, she will help you with some ... And she can also tell you if she observes you using the surgical spirit wrongly to wipe the baby. She can tell you that you wipe this way or she will even call the nurse to show you." (Mother)

Effects of the HIGH-Q intervention on mothers' experiences

The HIGH-Q intervention aimed to improve neonatal care in Kenyan public hospitals by addressing critical workforce shortages through the addition of three nurses and three ward assistants per NBU (Brief 3).

Limited change in nurse-mother support

An evaluation of the intervention found that despite the additional nursing staff, there were no major changes in communication, nurse-mother relationships, or the level of support offered to mothers. Nurses remained focused on clinical tasks, and while some mothers reported occasional positive interactions, many continued to face unclear feeding instructions, limited guidance on caregiving, and difficulties in seeking help. Though nursing time per baby increased slightly – from 34 to 43 minutes per 12-hour shift – this remained insufficient, and mothers were still expected to take on caregiving responsibilities with little structured support.

Ward assistants as a key source of support for mothers

Ward assistants were introduced to reduce the pressure on nurses by taking over non-clinical tasks, like ward cleaning, organising the care environment and overall hygiene. This allowed nurses to focus more on direct care for sick babies.

Beyond their support to nurses, ward assistants played a helpful role for mothers. They guided new mothers around the unit, helped with tasks like baby cleaning and feeding, and were often more available than nurses to answer questions and give practical help. Mothers described them as approachable and helpful in daily care tasks.

While ward assistants made it easier for mothers to manage daily care routines, their impact on the emotional or overall care experience of mothers was more limited.

Conclusion

Mothers in Kenya's public NBUs face intense emotional, physical, and practical challenges. While their babies receive specialised medical care, mothers often lack the guidance, privacy, and support they need to cope with the demands of neonatal caregiving.

Severe staffing shortages are a key driver of these difficulties. With nurses responsible for large numbers of babies, mothers are expected to take on caregiving responsibilities — often including complex tasks — without formal training. This increases maternal distress and the risk of errors.

Peer support plays a vital role in helping mothers cope. Informal networks among mothers offer emotional reassurance and practical advice, helping them navigate caregiving tasks in the absence of formal guidance.

Improving mothers' experiences in NBUs will require staffing models that recognise the essential role mothers play in newborn care and provide them with structured support. As shown by the HIGH-Q evaluation, ward assistants can ease daily pressures, but they cannot replace trained staff or counselling for mothers.

Addressing workforce shortages is essential — not only to relieve pressure on nurses, but also to ensure mothers receive the guidance, emotional support, and communication they need to care for their babies safely and confidently.

Sources

This brief draws on both published and unpublished research, as well as presentations delivered at conferences and workshops. Key sources include:

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2. Maina M, Odinga N, Kagonya V, Onyango O, Waithera C, Oluoch D, et al. Strengthening Neonatal Care through Ward Assistants: A Kenyan Case Study in Enhancing Infection Prevention and Control Practices. *Draft manuscript.*
3. Oluoch D, Hinton L, English M, et al. Mothers' involvement in providing care for their hospitalised sick newborns in Kenya: A focused ethnographic account. *BMC Pregnancy Childbirth.* 2023;23:389. doi:10.1186/s12884-023-05686-3
4. Oluoch D, Odinga N, Waithira C, Ngaiza G, Maluni J, Mutua E, et al. Examining the experiences of mothers of hospitalised small and sick newborns following the implementation of a staffing intervention in select Kenyan public hospitals. *Draft manuscript.*
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