

Discharge and the post-hospital journey for small and sick newborns

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Photo courtesy of KEMRI-Wellcome Trust Research Programme

About this brief

This brief is the sixth 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

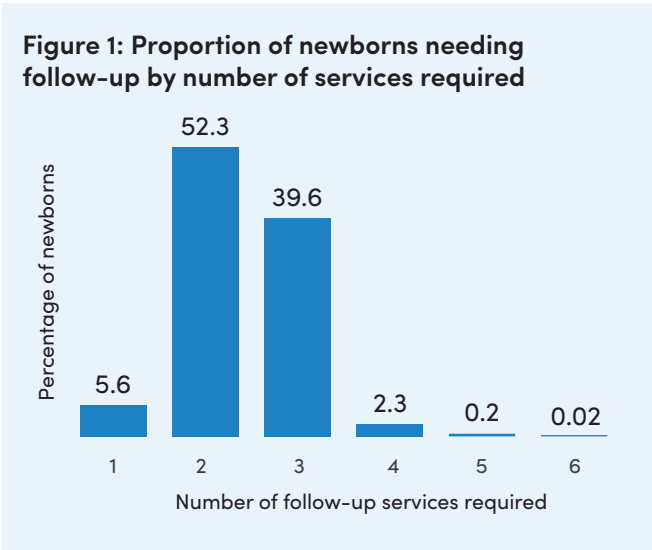
Discharge marks a pivotal moment in the care trajectory of babies born small or sick in Kenya. While more babies are now surviving the neonatal period due to increased facility births and the expansion of newborn units in public hospitals, the transition to home remains a critical and high-risk phase.

Studies show that a large proportion of neonatal deaths occur after discharge, with nearly half of post-discharge deaths happening within the first month, often at home. Premature babies, in particular, face heightened risks due to their medical vulnerability and the extended care they require. Yet this fragile period remains under-addressed in both research and health system planning.

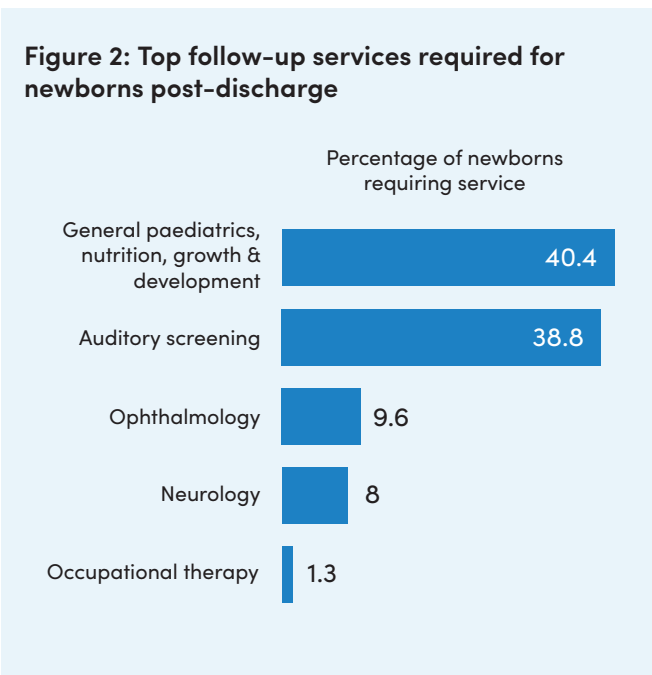
This brief synthesises findings from ethnographic and qualitative research conducted as part of the HIGH-Q project, alongside related research from the KEMRI-Wellcome Trust Research Programme (KEMRI-Wellcome) in Kenya. It highlights the scale and nature of post-discharge care needs and identifies key factors that undermine continuity of care as babies move from hospital to home. It also explores mothers' experiences navigating life at home with premature or vulnerable newborns after discharge, and the support gaps that affect their confidence and capacity to care for their baby safely.

The scale of follow-up needs

Research from KEMRI-Wellcome aimed to quantify the early post-discharge needs of newborns in Kenya, using data from over 136,000 babies discharged from public newborn units between 2018 and 2023.¹ It found that more than 40% of babies required specialist follow-up after discharge, and most of those needed support across multiple areas (Figure 1).



The most common needs included paediatric review for growth and development, followed by auditory screening and ophthalmology screening for retinopathy of prematurity – an eye disease that is a leading cause of childhood visual impairment and blindness in premature babies (Figure 2). These findings reinforce the importance of structured, coordinated follow-up for vulnerable newborns, yet such services remain limited in many facilities, with significant gaps in staffing, planning, and service delivery.



Disruptions to continuity of care

Ethnographic research conducted at several hospitals examined the post-discharge journeys of babies and mothers.² It identified multiple, interrelated factors contributing to breakdowns in continuity of care, affecting both the delivery of post-discharge care and the experiences of mothers at home in caring for their babies. The key challenges are summarised in Figure 3 and are explored further below.

Incomplete or missing documentation

Discharge summaries were often written by junior staff, including interns, with minimal supervision. This sometimes resulted in important clinical information, such as feeding instructions, medication plans, diagnoses, and follow-up needs, being omitted or recorded inconsistently. Documentation practices varied not only across facilities but even within hospitals, where different services (e.g. Occupational Therapy and general paediatric clinics) operated parallel record systems.

“The information that we have in our outpatient clinic may not be directly transferred into their [Paediatric Outpatient Clinic] files, because those are two different setups.” (Paediatrician)

As a result, outpatient staff often struggled to piece together a baby’s prior care. In many cases, they relied on caregivers to fill these gaps, or had to repeat assessments, taking up valuable time and delaying care.

Communication challenges between healthcare workers

Communication around discharge was often fragmented, with limited coordination between different healthcare workers and departments. Interviews with staff revealed uncertainty about who was responsible for key discharge tasks, such as counselling caregivers or preparing follow-up plans.

Team communication was further constrained by heavy workloads, time pressures, and frequent staff rotations. Interns and junior doctors—often responsible for writing discharge summaries—were regularly rotated through departments, which undermined continuity and made it harder to follow through on care plans. In some hospitals, communication between paediatricians and occupational therapists was minimal, resulting in inconsistent or unclear post-discharge guidance.

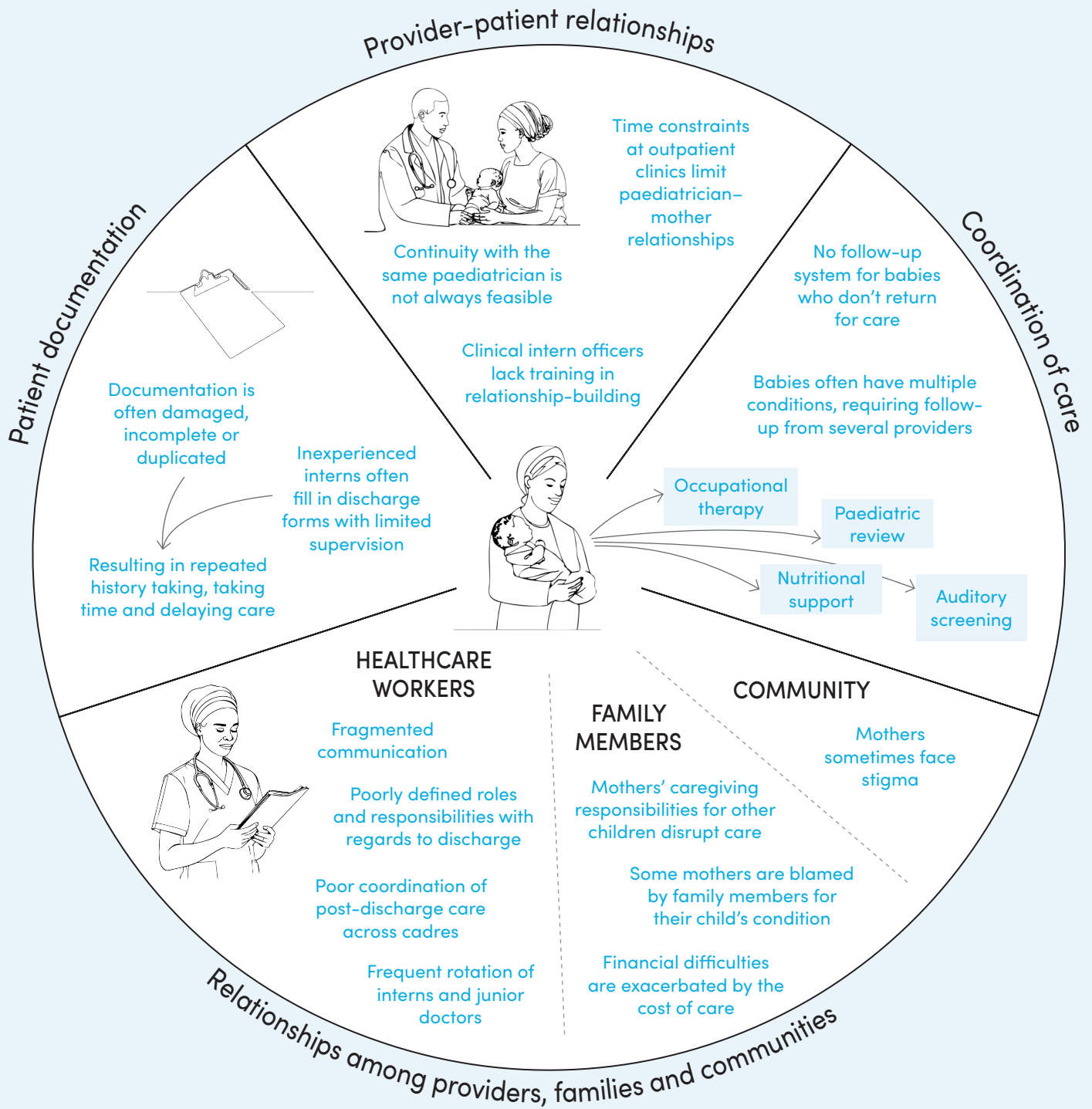
These dynamics contributed to fragmented discharge processes and left families without clear, consistent messages about how to care for their babies at home or what follow-up was needed.

Limited structured follow-up systems and feedback

Hospitals lacked mechanisms to monitor whether families returned for follow-up or to support ongoing care across visits.

Follow-up clinics were under-resourced, and clinicians often had insufficient time to review patient histories or provide guidance. Importantly, staff involved in inpatient care rarely received feedback on post-discharge outcomes, limiting opportunities for reflection, learning, and adaptation of discharge practices.

Figure 3: Key barriers to continuity of care after discharge



Mothers' post-discharge experiences

Continuity of care after discharge cannot be sustained by healthcare systems alone; mothers play a central role in caring for their babies and bridging the gap between hospital and home. Research also explored mothers' post-discharge experiences to better understand the practical and emotional challenges they face, and how these affect the ongoing care of premature and vulnerable newborns.³

Confusion and lack of preparation

For many mothers, discharge marked a moment of relief but also profound anxiety. While excited to return home, they often felt unprepared and uncertain about how to care for their baby, especially if the baby had been born prematurely or required intensive hospital care.

This lack of readiness was shaped by limited involvement in their baby's care during hospitalisation, inadequate counselling on how to manage feeding or respond to complications, and insufficient communication from staff during discharge and at the point of discharge.

"The fact that they didn't tell us the baby had that condition of refluxing, then we go, we don't know how to handle a refluxing baby, you don't even know whether the baby is refluxing in the first place. [.....] Now you are constantly worried, 'Is this child, okay? Is, is this child going to be, okay? Like, did I get a child from hospital to come and have issues at home'" (Mother)

Some experienced mothers expressed self-doubt, highlighting that their anxiety stemmed less from maternal inexperience than from the fragility of their baby's condition and the absence of a structured, supportive discharge process.

Fear, shame, and stigma

Emotional responses to discharge were shaped by fear of complications re-emerging and distress about being alone with a fragile baby. These fears were compounded by experiences of shame and stigma, particularly from community members. Some mothers reported being blamed or judged for their baby's condition or facing negative comments about their baby's appearance or development. This led to emotional distress, social withdrawal, and strained relationships.

As one mother explained:

"[I didn't go out] ... because you used to meet with someone and they ask you, 'did you give birth to that small pregnancy?' And then you know that many questions if you don't want to. I used to lock up myself in the house with my children and because they were very small, I never wanted anyone to see them." (Mother)

Strained family and social support

Many mothers returned home to situations that made consistent care difficult to maintain. Financial difficulties were common, and in some cases intensified by admission costs and new fees for follow-up services such as occupational therapy. Within the household, some mothers experienced reduced support, including abandonment by partners or tension with family members who blamed them for the baby's condition. Mothers also had to juggle care for other children and competing responsibilities, which made sustained attention to the newborn's needs more difficult.

Misinformation and lack of reliable support

In the absence of structured follow-up, many mothers relied on peers or community advice. While sometimes helpful, this also led to conflicting or inaccurate guidance, adding to confusion about how best to care for their baby or when to seek care. Mothers described feeling alone and uncertain, without accessible channels for reliable information or support.

Post-discharge information needs for mothers

Linked to these experiences, a recent scoping review consolidated evidence on caregiver information needs and tools used in post-discharge care for vulnerable newborns in LMICs.⁴ It found that only a small number of studies explored the challenges caregivers faced when they received limited information at discharge. In these studies, a lack of information, particularly at the point of discharge, was reported to undermine caregiver confidence and contribute to uncertainty about how to care for a premature baby at home.

The review highlighted the important role that nurses play in preparing mothers for discharge. Nurses were identified as key providers of information during hospitalisation and at the point of discharge, particularly for premature babies. However, their role in supporting caregivers was often constrained by limited time, staffing pressures, and the absence of standardised guidance.

Conclusion

With more babies surviving the neonatal period, often with longer-term health needs, there is an urgent need to strengthen care after discharge. Recent evidence shows that a substantial proportion of newborns require multiple types of specialist follow-up, yet most facilities lack the systems, staffing, and coordination needed to deliver this care effectively.

The scale and complexity of follow-up needs remain poorly understood, and existing information tools rarely address caregivers' actual concerns. Improving communication within and between facilities can help clarify care pathways. But to support transitions home, the timing and content of discharge information must also be improved. This includes ensuring that caregivers are not just given information, but are helped to understand and use it, and that there are efforts to reach important significant others (including fathers and mothers-in-law).

There remain critical gaps in how post-discharge information needs are addressed. Further research is essential to inform the design of tools and systems that can support caregivers and improve outcomes for vulnerable newborns.

Related research

A growing body of research in Kenya has highlighted the complex risks and challenges faced by mothers, newborns, and young children during the transition from hospital to home, and the need for stronger support systems around discharge and postnatal care.

Research as part of the [CHAIN Network](#) (Childhood Acute Illness and Nutrition) documented care pathways, including discharge, for acutely ill young children in rural and urban Kenya.^{5,6} Findings highlighted the disproportionate caregiving burden on mothers, and the many layers of vulnerability at individual, household and facility levels that mothers have to negotiate. The socioeconomic strain of illness and recovery after discharge, and the varying role of fathers, were underscored.

The **Beyond Survival** study, is exploring how birth complications affect mothers' physical, emotional, and economic wellbeing in the early postpartum period.⁷ Emerging findings suggest that complications are often an unexpected additional shock to mothers and families. There are "multiplier effects" on challenges in facility and post-discharge care, with implications for both maternal recovery and newborn health.

Sources

This brief draws on both published and unpublished research. Key sources include:

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