IMPRESS EVIDENCE BRIEF 3

Experience of care for small and sick newborns

Understanding the perspective of caregivers in Malawi

NOVEMBER 2025

Improving the quality of hospital care for small and sick newborns requires attention not only to clinical outcomes but also to the experience of care. Respect, dignity, and clear communication are vital for building trust and supporting caregivers through difficult circumstances.

In Malawi, where most births now take place in health facilities, little is known about caregivers' experiences when their small and sick babies are admitted to neonatal units. Existing evidence has focused mainly on women's experiences during childbirth, leaving a gap in understanding caregivers' experiences of newborn care.

This evidence brief draws on findings from an Experience of Care Survey, conducted in 30 secondary care hospitals across Malawi. The survey captured the responses of 442 caregivers, including in-depth views from a subset of 34 participants, and provides important insights into areas of good practice and priorities for improvement.

KEY FINDINGS

- A novel Experience of Care Survey assessed newborn care across seven domains of care to better understand caregivers' experiences of care in neonatal units.
- Caregivers described many positive experiences, particularly in relation to newborn comfort, access to services, and continuity of advice after discharge.
- The survey highlighted several areas for improvement, including caregiver participation in decisions, the provision of emotional support, and clear communication.
- Although uncommon, harmful practices such as shouting, threats, or discrimination were reported, underlining the importance of ensuring respectful and compassionate care.
- Strengthening feedback systems, improving communication and emotional support, and redesigning neonatal units to include fathers can all help enhance caregiver experiences and build trust in hospital care.

Background

Efforts to understand quality of care in health systems have traditionally focused on clinical measures such as health outcomes and adherence to guidelines. In recent years, there has been a concerted movement to place people at the centre of health systems and better understand their experiences of care. How people experience care determines whether they return for treatment and follow medical advice. It is also important in its own right: patients should be treated with respect and dignity, involved in decisions about their care, and able to trust their providers.

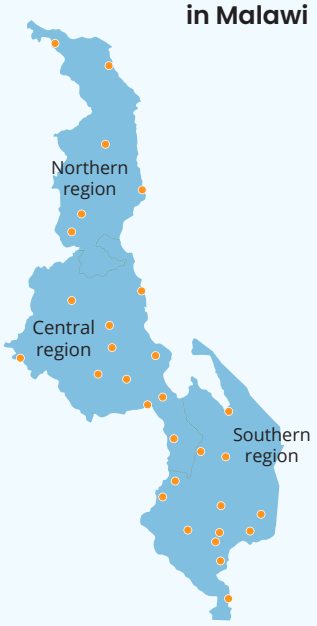
The World Health Organization (WHO) recognises experience of care as a core component of improving the quality of maternal and newborn care. It has proposed eight standards, three of which relate directly to experience of care: communication and participation; rights and dignity; and emotional support. Evidence has focused mainly on women's experiences of care during childbirth, while very little is known about newborns. Measuring newborns' experience is especially challenging, as babies cannot communicate verbally.

IMPRESS is a five-year research project investigating how to strengthen management practices to improve the quality of small and sick newborn care in Malawi. As part of the project, the research team conducted a multi-methods survey to capture the voices of caregivers whose babies were admitted to neonatal units across the country. This survey was not part of the original research plan but was inspired by community engagement with mothers of small and sick babies. The mothers shared striking accounts of their experiences and feelings when their babies were receiving care in the neonatal unit. Their stories prompted the survey, the findings of which are reported in this Evidence Brief.

Experience of Care Survey

The Experience of Care Survey was carried out by the IMPRESS research team in 30 secondary care hospitals across Malawi between 23 September and 13 November 2024 (Figure 1). As a mixed-methods study, both quantitative and qualitative data were collected to better understand caregivers' experiences of neonatal care. There is no single standardised approach for assessing experience of care. A major contribution of this work was the development of a novel tool specific to newborns admitted to hospital neonatal units in low-resource settings.

Figure 1: Map of 30 participating hospitals in Malawi



Domains of experience of care

The survey questionnaire was organised around seven domains considered most relevant to newborns in Malawi (Figure 2). These domains were informed by WHO's standards for improving the quality of maternal and newborn care in health facilities, England's NHS patient experience framework, and community engagement activities with mothers. The study team developed individual questions within each domain, drawing on systematic reviews of tools to measure the experience of newborn care and piloted them in several hospitals. The final tool contained 36 items across seven domains (Figure 4).

Figure 2: Domains of Experiences of Care

Participants

The study participants were caregivers – mostly mothers or guardians – of babies admitted to the neonatal units in the study hospitals. Trained fieldworkers conducted face-to-face interviews at the time of discharge. Caregivers under 18 years of age were excluded from the study, as were caregivers of babies who died in the hospital.

Fieldwork teams spent at least three days in each hospital, with the aim of interviewing at least 15 caregivers per site. Some hospitals fell short of this target due to low admission numbers.

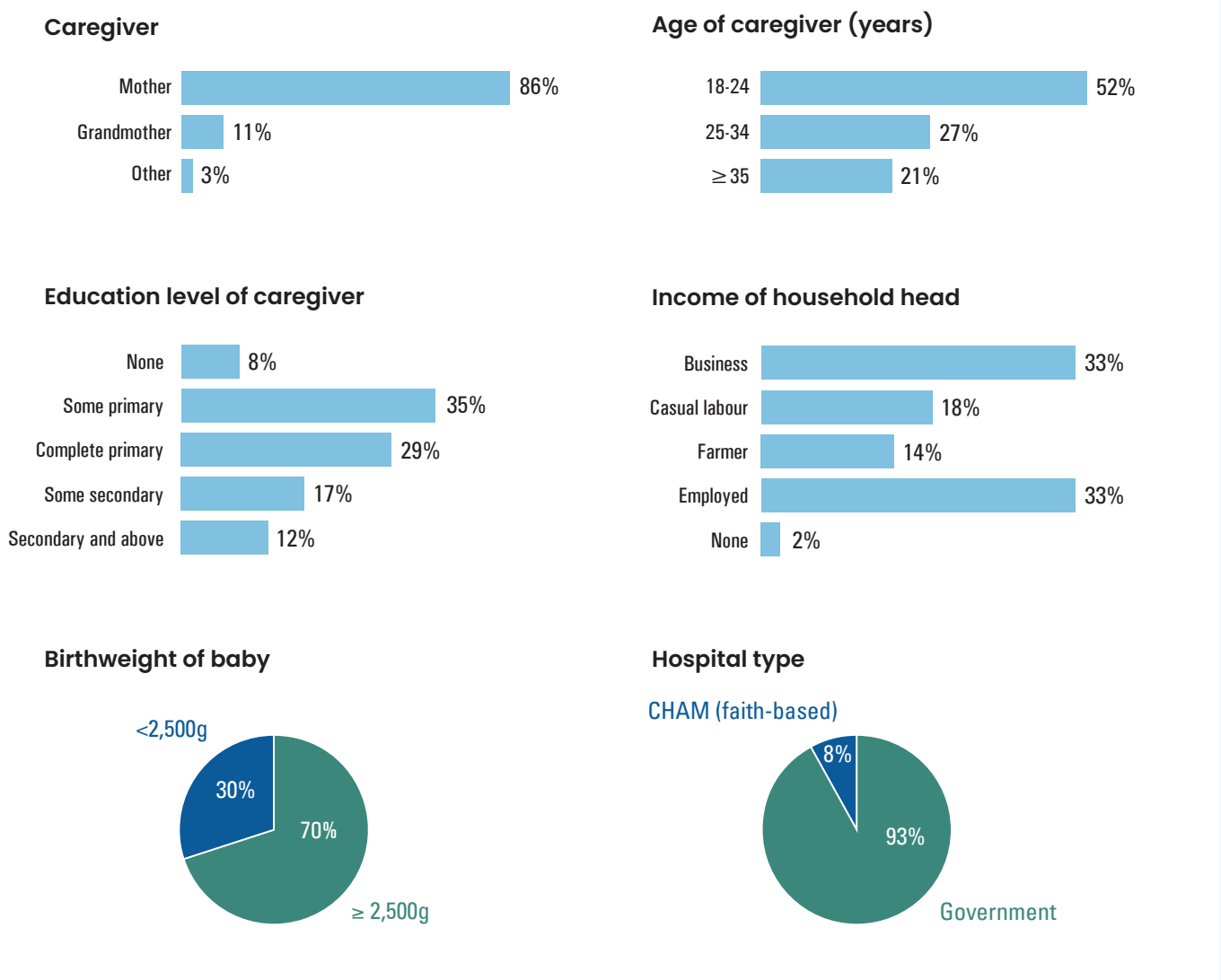
Characteristics of the participants

A total of 442 caregivers completed the survey across 30 study hospitals (ranging from 2 to 36 per hospital). Of these, 34 provided qualitative accounts of their experiences. Caregiver characteristics are shown in Figure 3.

Mixed-methods approach

The survey used both closed-ended and open-ended questions within each domain. The closed-ended questions required either a simple yes or no response (e.g. Did staff at any time mistreat your baby?) or a frequency response option (e.g. Were staff in the neonatal unit always kind to you?). For the analysis, frequency response options "always" and "most of the time" were coded as equivalent to yes, while "only occasionally" and "never" were coded as equivalent to no. To gain more in-depth insights, randomly selected caregivers were invited to share their experiences in each domain using their own words. These narratives were recorded, transcribed, and analysed thematically.

Figure 3: Characteristics of participants



Findings

The findings are organised to help healthcare providers and policymakers understand where practices are working well and where there is a need for improvement. Figure 4 (page 6) presents the complete set of indicators by domain.

Positive experiences of care

Caregivers reported positive experiences across all indicators of newborn comfort. The highest rated indicator was ensuring babies were clean and dry (98%), while the lowest was minimising pain or discomfort (92%). Access to care also received high ratings across all four indicators, ranging from 88% for adequate visiting hours to 99% for not requiring informal payments. Continuity of care indicators were similarly positive, with scores ranging from 80% for advice on danger signs when at home to 94% for advice on exclusive breastfeeding.

The qualitative findings confirmed these views. Caregivers appreciated the comfort and environment in the neonatal units, noting that this was achieved through shared roles and responsibilities with staff.

> "I was very satisfied because hygiene was always maintained. They ensured that the area was thoroughly cleaned every morning before we placed our babies there."

Most caregivers appreciated being attended to immediately on arrival and reported good staff availability. They also felt that the guidance from healthcare staff on exclusive breastfeeding and post-discharge care – such as keeping the baby warm and recognising danger signs – was empowering.

> "I was filled with joy because I knew that once I get home, if I continue providing care in the way I have been taught, then my baby will be taken care of appropriately."

Practices in need of improvement

The findings raise some concerns that indicate room for improvement across several domains. In participation and involvement, only 59% of caregivers reported having opportunities to ask questions, 19% said fathers were involved in care, 58% said staff requested consent, and 29% were aware of how to make a complaint. In the domain of emotional support, just 41% of caregivers were able to discuss feelings or concerns. Communication was also inconsistent, with only 64% reporting that staff explained their baby's prognosis.

Qualitative findings also revealed mixed experiences across these domains. For participation and involvement, some caregivers did not know how to raise complaints, others had inconsistent opportunities to ask questions, and approaches to consent-seeking before procedures varied widely. Communication experiences also varied, with some caregivers noting unclear explanations from staff due to language barriers or the complete absence of communication about their babies' conditions and treatment plans. Some caregivers lacked the courage to ask questions, believing that the staff "knew everything" and were doing their job so they should not be questioned.

> "I didn't know what was wrong with the baby because, although I noticed the baby had a fever when I went to check, the hospital staff did not explain the results of the tests they conducted or tell me what the baby was suffering from."

> "I would have appreciated it if they had informed us about the treatment they intended to give the baby, explaining how it would help the baby feel better, and then asked for our consent before proceeding. Instead, they would simply tell us to place the baby there and carry out the treatment without explaining what they were going to do."

The in-depth responses also revealed gaps in the physical environment that compromised newborn comfort. These included a lack of mosquito nets, inadequate bedding, frequent power outages that disrupted warming equipment, and high noise levels in the units.

Rare but harmful practices

Caregivers reported some rare but harmful practices that should never happen. The majority occurred in the domain of respect and dignity. These included being shouted at (8.8%), hit or slapped (0.5%), threatened with withdrawal of their newborn's care (1.6%), and discriminated against (2.5%).

While most caregivers reported no discrimination against their babies, stating that they were treated according to their conditions, one caregiver found it discriminatory when staff identified her baby by the disease rather than by name.

Most caregivers reported being treated with respect, though a small number were shouted at, particularly during feeding times in the neonatal unit. While the majority reported no threats, some caregivers were threatened with withdrawal of care for their babies. There was one report of staff arriving at the hospital intoxicated, during which they shouted and showed disrespect towards caregivers.

> On the days they came drunk, you could tell by the way they were speaking. When we complained to them on days when they were sober, they would provide a clear response on what to do. However, on the days they came drunk or after smoking, it was obvious that, given their state, nothing productive would come from the interaction. When we raised complaints, they would insult and shout at us, showing no regard for our age or respect.

> When I returned, the doctor asked, "Is this the baby without eyebrows?" I didn't respond because the issue wasn't that the baby didn't have eyebrows, but that the baby couldn't see. I'm not sure what the doctor meant, but the words were very painful to me, especially because I did not expect them to say such at that particular moment.... The words were hurtful, and I'm not sure what the doctor was thinking, but it left me feeling upset.

Reasons for poor experience

Poor experiences in neonatal care stemmed from challenges across multiple areas. Participants described language barriers when staff used English instead of local languages and medical jargon caregivers could not understand. Resource constraints also compromised experience of care, with participants reporting frequent power outages that disrupted warming equipment, the absence of basic comfort items, staff shortages, and overcrowding that affected visiting times. Staff behaviour was generally positive, but there were rare occasions when poor attitudes led to caregivers being disrespected.

Structural issues included restrictive visiting policies, physical separation of caregivers from babies without adequate explanation, limited father involvement due to ward restrictions, and unclear complaint mechanisms. Socioeconomic and educational disparities created additional barriers, with less educated caregivers feeling intimidated and unable to question authority figures.

> For people like us coming from the villages, we do not believe in going against what the health care service providers have told us. Whatever they tell us, it is what we are supposed to follow when doing things.

> It pained me, but mostly we, as the uneducated, feel like we have nowhere to report such issues and just accept it as normal. We live in difficult times, and selfishness is prevalent, so this is not surprising.... Even if there had been a place to lodge a complaint, we wouldn't have spoken up unless asked, like you have. I could have gone home with a heavy heart, wondering why anyone would think a mother would deliberately fail to feed her babies.

It is worth noting that caregivers often had low expectations of care quality or believed that staff knew everything, lacking the confidence to question their care. Participants sometimes reported satisfaction with experiences that would normally be considered inadequate.

Figure 4: Results of the Experience of Care survey by domain

Continuity of care

- 86% Staff advised you how to keep baby warm
- 94% Staff advised you on exclusive breastfeeding
- 84% Staff advised you on how to care for baby at home
- 80% Staff advised you on danger signs when at home
- 85% Staff advised you where to seek care if more problems

Emotional support

- 91% Staff were kind to you
- 73% Staff offered reassurance and encouragement
- 70% Staff helped you cope with baby separation
- 41% Staff gave opportunity for you to talk about feelings or concerns

Participation and involvement

- 90% Staff encouraged you to participate in daily care routine
- 60% Staff involved you in decisions on treatment
- 19% Staff tried to involve father in decisions
- 59% Staff encouraged you to ask questions
- 84% Staff attended to you when you asked for help
- 29% Aware of how to make a complaint
- 58% Staff requested consent before treatment

Example of practice in need of improvement

Getting consent from caregivers for tests and procedures is a WHO standard for improving quality of maternal and newborn care. Yet, fewer than 6 in 10 caregivers said staff sought consent. It is imperative that more is done to ensure caregivers are given information to make informed choices about treatment for their newborn.

Access to care

- 99% Did not have to pay informal payment
- 93% Baby seen by health worker immediately on arrival
- 88% Adequate visiting hours of baby
- 91% Staff always available when needed

Respect and dignity

- 12% Any abusive or discriminatory staff behaviour
- 2.5% Staff treated you in a discriminatory or unfair way
- 1.6% Staff threatened to withhold treatment from your baby
- 0.5% Staff hit or slapped you
- 2.3% Staff mistreated your baby
- 8.8% Staff shouted at you

Example of rare but harmful practice

Shouting at caregivers is highlighted by WHO as a form of mistreatment of women in its compendium on respectful maternal and newborn care. Almost 1 in 10 caregivers reported being shouted at. Ending all instances of mistreatment must be the goal.

Newborn comfort

- 93% Staff ensured baby's environment was calm
- 95% Temperature of your baby's environment always right
- 92% Staff tried to minimise any pain your baby felt
- 96% Baby was positioned comfortably
- 98% Staff helped to ensure your baby was clean and dry

Example of practice going well

Newborn comfort while in hospital is important to caregivers. Almost all caregivers reported that staff were doing what they could to ensure their baby was clean and dry. These positive experiences were repeated for other areas of newborn comfort.

Effective communication

- 96% Staff explained illness of baby
- 64% Staff explained prognosis
- 80% Staff explained treatment plan
- 73% Staff gave daily update
- 86% Staff easy to understand

Recommendations

Based on the findings, we recommend the following to improve caregiver experiences in Malawi's neonatal units:

1. **Embrace a family centered approach to small and sick newborn care:** Take steps to reshape care with the family as central to the baby's health and wellbeing.

2. **Strengthen caregiver empowerment and feedback systems:** Raise awareness of patient rights and improve visibility of feedback mechanisms, such as suggestions boxes and hospital ombudsman offices, to make it easier for caregivers to report concerns.

3. **Communication training for staff:** Include training on respectful care, empathy and emotional support in pre-service training, and explore strategies to address communication barriers arising from NNUs being a restricted space.

4. **Neonatal units redesign:** Adapt neonatal units to better include fathers in newborn care without compromising on the infection prevention and control mechanisms.

Conclusion

The Experience of Care Survey offers valuable insights into how caregivers experience small and sick newborn care given to babies in hospitals across Malawi. It gives voice to the caregivers of those who actually received care and, in doing so, sheds light on an aspect of quality of care that is too often overlooked. Findings point to areas of strength: caregivers reported consistently positive experiences around newborn comfort, access to care, and advice on post-discharge care.

They also highlight clear priorities for improvement: limited opportunities for participation (including consent and complaint awareness), low father involvement, gaps in emotional support, and inconsistent communication about babies' conditions. While uncommon, reports of disrespect and other harmful practices underscore the need for continued attention to respectful care. Addressing these issues, alongside basic environmental constraints, is crucial for enhancing the quality of newborn care.

About this brief

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About IMPRESS

IMPRESS (Innovative Management PRactices to Enhance hoSpital quality and Save lives in Malawi) is a five-year research project led by the Kamuzu University of Health Sciences and the London School of Hygiene & Tropical Medicine in collaboration with Malawi's Ministry of Health, participating hospitals, and stakeholders in Malawi. The project is investigating how to strengthen management practices to improve the quality of care for small and sick newborns. www.lshtm.ac.uk/research/centres-projects-groups/impress

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