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BMJ Open Postdischarge health information tools and information needs for mothers of vulnerable newborns in low- and middle-income countries: a scoping review

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ABSTRACT

reference checking.

Objectives The postdischarge period is crucial for vulnerable newborns at risk of morbidity, readmission and mortality in low- and middle-income countries (LMICs). Addressing gaps in care during this period could improve outcomes. This review consolidates evidence on caregiver information needs and relevant information tools used in postdischarge care for vulnerable newborns in LMICs. **Design** Scoping review using the methodological framework developed by Arksey and O'Malley. Data sources We searched six databases for relevant articles published in English between 2001 and 2021. Additional articles were identified through citation and

Eligibility criteria Articles on postdischarge care for newborns in LMICs, excluding economic and technical development studies, discharge to other healthcare facilities (rather than to home) and maternal-focused

Data extraction and synthesis Data extraction followed Arksey and O'Malley's data charting method. Using a descriptive synthesis approach, heterogeneous data were collated in narrative format.

Results From 5190 articles, 22 were included. Only a small number of articles discussed caregiver challenges, like receiving insufficient information at discharge which led to uncertainty in caring for vulnerable newborns. Caregivers had a number of needs in relation to maternal and newborn care, including in terms of coordination of follow-up care. Although a number of tools have been used to support relevant needs (for postnatal care in general rather than specifically for postdischarge care of vulnerable newborns), these have shown mixed effectiveness due to challenges with completeness, lack of training and support, supply chain issues and cultural barriers to adoption, such as preference for alternative providers.

Conclusion Our understanding of postdischarge information needs for those looking after vulnerable newborns in LMICs remains limited. More effective use of information tools could help address some of these needs and contribute towards reducing neonatal mortality rates.

STRENGTHS AND LIMITATIONS OF THE STUDY

- ⇒ Comprehensive scoping review: we conducted a comprehensive search for relevant articles followed by an in-depth analysis to understand the different ways in which caregiver needs and associated support tools have been discussed (or not) in the
- ⇒ Systematic and transparent methodology: the review followed a clearly defined and structured process for selecting and analysing studies, which enhances the reliability and reproducibility of our findings.
- ⇒ Time restriction in literature review: our review focused on articles published within the last two decades, potentially excluding older literature, which means there may be perspectives that we missed.

INTRODUCTION

Background and rationale

Globally, 98%-99% of neonatal deaths occur in low- and middle-income countries (LMICs)¹⁻³ with root causes including preterm birth, severe infection, asphyxia and low birth weight. Suboptimal neonatal care often means poor child health, development and well-being, making neonatal, infant and child health significant concerns and key sustainable development goal targets.^{5 6} Evidence shows that most newborn deaths are preventable and treatable, 2 3 7 8 but healthcare interventions are needed spanning from conception through postpartum and beyond.910

As newborn deaths decrease, the importance of postnatal and postdischarge care for maternal and newborn health grows. 11-13 A 2013 systematic review indicated that postdischarge neonatal mortality in LMICs was as high as or higher than in-hospital mortality.¹⁴



The WHO's standards, previous research and a proposed model for scaling up care in LMICs all emphasise the need to improve postdischarge care. ^{15–17} Yet, despite its importance, postdischarge care remains under-researched, with the literature placing more emphasis on in-hospital care. ¹⁴ ¹⁸ ¹⁹

Recent literature highlights obstacles to improving postdischarge care (eg, at home or in follow-up consultations at the hospital or in community settings) for newborns in LMICs, including caregiver non-compliance with medical instructions²⁰ ²¹ and lack of coordination among healthcare providers without a standard follow-up schedule. ¹⁸ ²² ²³ Clinical documentation often includes inaccuracies, and there is insufficient monitoring of the quality and completeness of discharge summaries. ²⁴ Caregivers also require extra support to be able to look after their sick newborns after discharge, ²⁵ with effective communication between caregivers, healthcare teams and community workers becoming key. ²² ²³ ²⁶ Lack of support and ineffective communication can lead to caregivers feeling isolated, thus hindering home care provision. ²² ²³

Information sharing and tools

Health information is necessary at every level of the healthcare system for a wide range of purposes, such as informing decisions and monitoring services. ²⁷ According to WHO, the provision of accurate and timely health information is fundamental in well-functioning healthcare systems, contributing significantly to the quality of care. ¹⁵ ²⁷ In postdischarge care for newborns, information sharing varies based on the clinical condition and the type of follow-up care required. Typically, to provide adequate follow-up care for newborns, clinicians need access to information including measures of growth and development (eg, height, weight), the primary diagnosis, length of hospitalisation, prescribed medication and supplements. ²¹ ²⁸

A number of information and record-keeping tools have been introduced in LMICs to support postnatal care, including paper tools (eg, the Maternal and Child Health (MCH) passport), electronic systems (eg, Electronic Health Records (EHRs)) and hybrid approaches (use of electronic and paper sources). These tools usually contain crucial maternal, newborn and child health information, including immunisations, visit history, laboratory findings, prescriptions and management of illnesses and chronic conditions. Per 30 Record-keeping tools have the potential to improve care, enhance patient–provider communication, empower caregivers and increase vaccination rates among children. Per 31 care patient provider communication, empower caregivers and increase vaccination rates among children.

In this review, we focus primarily on information needs and tools relevant to the care of 'vulnerable' newborns. We use the term 'vulnerable' to refer to high-risk populations, recognising that it remains challenging to define vulnerability in this context. For example, the term 'vulnerable children' has been used to refer to children more susceptible to exposure to risk and poor life outcomes compared with their peers. ³² Tickell *et al*

emphasise clinical risk factors (eg, undernourishment, acute or chronic illnesses), defining vulnerable children as those small and sick in need of hospitalisation.³³ We will refer to 'vulnerable' newborns as small and sick newborns admitted to the hospital following birth and then discharged.

Our review takes a sociocultural perspective to explore how caregivers engage with, resist and reframe healthrelated information, going beyond traditional conceptions of information as a tangible artefact (eg, written information). 34 This perspective allows us to examine the dynamics of information within healthcare systems, focusing on the interactions, experiences and practices of caregivers and mothers seeking health-related information for themselves and their dependents.³⁴ By integrating an understanding of sociocultural dimensions, we aim to provide an in-depth view of how vulnerability emerges in the context of restricted information flows, underpinned by the complexity of health conditions but also broader social determinants such as poverty, access to care and cultural practices. This approach enriches our understanding of information flows and their significance for health outcomes. 34 35

Review objectives

To synthesise existing evidence on caregivers' information needs and on information tools used in the context of postdischarge care for vulnerable newborns. This will deepen our understanding of information flows and gaps within LMIC healthcare systems, ultimately informing strategies to enhance postdischarge care delivery and improve health outcomes.

Review questions

- 1. What are the key information needs of caregivers of vulnerable newborns after hospital discharge in LMICs as described in previous literature?
- 2. What tools are used by caregivers and healthcare workers to share information during post-discharge care, including for vulnerable newborns, in LMICs?
- 3. To what extent do existing tools fulfil caregivers and healthcare workers information needs, and what are the challenges to their implementation and sustained use?

METHODS Review type

We conducted a scoping review to be able to account for the heterogeneity of the literature related to post-discharge care for vulnerable newborns. The considerable approach of the literature approach, starting with an exploratory review to map key concepts. The accommendations were used, in terms of progressive focusing (eg, on health information booklets) and consultation with experts. The exploratory review of existing literature and consultation with experts also supported the iterative refinement of the review questions.



Table 1 Eligibility criteria for included studies			
Criteria	Inclusion	Exclusion	
Study design	All types (quantitative, qualitative, mixed methods, etc)	 Economic-focused studies (eg, cash transfer app, cost-effectiveness research) Information technology focus research (eg, availability, accessibility, feasibility, describes the design and architecture of the electronic tool) 	
Focus	Primarily postdischarge (to home) care for vulnerable newborns, including those with clinical vulnerabilities (eg, preterm birth, low birth weight) and social vulnerabilities (eg, poverty, lack of access to care). Broader literature on the postnatal period that includes useful learning on the care of vulnerable newborns after discharge was also included.	 Discharge to other healthcare facilities Maternal focus (eg, measuring maternal impacts and diseases) 	
Study location	Low- and middle-income countries (LMICs) based on the filters from World Bank Classification ⁴⁰ (see online supplemental appendix 2)	Other countries	
Type of publication	Peer-reviewed journal articles, book chapters, reports	Conference abstracts, posters, protocols and opinion articles/commentaries	
Language	English	All other languages	
Year of publication	Between 2001 and 2021	Publications before 2001	

Search strategy

We searched six databases (MEDLINE, Embase, Global Health, Web of Science, Scopus and Cochrane Library) for articles in English published between 2001 and 2021 to reflect recent developments in postdischarge care. Search keywords were refined based on seminal publications and were developed with the assistance of a medical librarian (online supplemental appendix 1). To define LMICs, we drew on a classification produced by the World Bank. Additional articles were identified through citations and reference lists. Our search was conducted in August 2021.

Study screening

After removing duplicates, we conducted title and abstract screening using the Rayyan website and EndNote software. This was followed by full-text screening based on the eligibility criteria in table 1. In both screening rounds, a 10% sample was independently screened for consistency, a practice widely used in other reviews. Discrepancies were resolved through discussion between the two reviewers (AR and GG) without the need to involve other coauthors.

Data extraction and analysis

Data extraction followed Arksey and O'Malley's data charting approach. ³⁶ ⁴⁶ ⁴⁷ The lead author extracted key descriptive data into an MS Excel spreadsheet and used a separate spreadsheet to extract data related to the research questions. We piloted and edited spreadsheets through preliminary analysis to ensure relevance. To improve extraction consistency, a second reviewer (GG) validated data extraction for a 10% sample of articles reviewed. ⁴⁸ Using a descriptive synthesis approach, ³⁶ ⁴⁸ ⁴⁹ we collated heterogeneous data in narrative format to account for

different study designs and engage the studies in dialogue with each other. This involved using standardised forms to capture study design, population, setting, interventions and outcomes, allowing us to map and synthesise the literature comprehensively. Analysis was partially informed by the Non-adoption, Abandonment, Scale-up, Spread and Sustainability (NASSS) framework to extend an understanding of complexity in postdischarge care practices. Specifically, we applied the NASSS framework to categorise findings into domains such as information tools, organisational factors for implementation and sustained use and caregivers' needs, ensuring a structured and systematic analysis.

Patient and public involvement

None.

RESULTS

A total of 5190 articles were retrieved by searching the included databases. After removing duplicates and performing two rounds of screening against eligibility criteria, 22 articles were included in the review (see the Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart in figure 1 for more details).

Article characteristics

Among the articles in the review, 16 employed quantitative study designs (12 cross-sectional surveys and five randomised controlled trials), four used qualitative interview approaches and two employed mixed methods. Studies were conducted in 12 countries: South Africa (n=4), Kenya (n=4), Uganda (n=2), Indonesia (n=3), Pakistan (n=2) and one each in Afghanistan, Bangladesh, Iraq, India, China, Mongolia and Iran. An overview of the

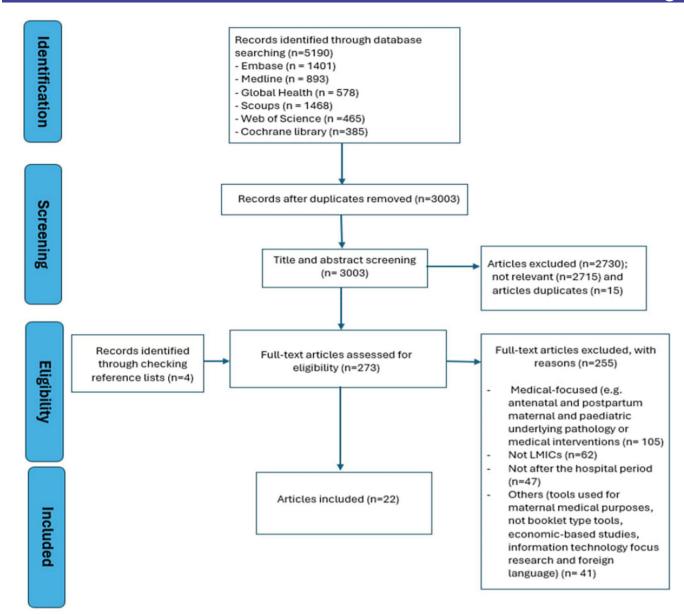


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart. This flowchart outlines the study selection process for the scoping review. It shows the number of records identified through database searching, the number of additional records identified through other sources, the number of records after duplicates were removed, the number of records screened, the number of full-text articles assessed for eligibility and the number of studies included in the final review. LMICs, low- and middle-income countries.

key characteristics of the included articles is provided in the online supplemental appendix 3.

When categorised by thematic areas, only five articles focused on caregivers' and healthcare workers' information needs (published between 2017 and 2019)^{51–55} and 17 explored information tools (published between 2006 and 2022).^{56–72} Few articles specifically addressed post-discharge care; most examined the broader postnatal period. Only two studies concentrated on the Neonatal Intensive Care Unit (NICU) discharge onwards.^{52–55} Five articles covered the period after childbirth using terms such as postpartum/postnatal,⁵¹ puerperium⁵⁴ and 'period after delivery'.^{53–56–58} The remaining 15 articles focused on after-birth routine services, including

MCH care, ⁵⁷ ^{60–62} ⁶⁵ ⁶⁸ ⁶⁹ routine immunisation, ⁶³ ⁶⁴ ⁶⁶ ^{70–72} paediatric care services ⁵⁹ and growth and development management. ⁵⁶ We reviewed articles related to the postnatal period more generally to draw transferable learning on postnatal care for vulnerable newborns after their discharge, especially in relation to information tools used without discriminating based on risk factors.

Findings

Information needs of caregivers

Few articles focused on caregivers' information needs (n=5). Of these, only two examined information needs post-NICU discharge for premature newborns.^{52 55} The first explored challenges caregivers faced due to the lack



of information at/after NICU discharge in Iran,⁵² and the second identified information needs of caregivers of premature newborns to inform the development of a guidance booklet in South Africa.⁵⁵ In both studies, caregivers were interviewed in health facilities either at the point of discharge or during visits after discharge, thus only covering a postdischarge period of a few weeks. Findings included a perceived lack of information at the point of NICU discharge, which affected parents' selfconfidence and prevented them from looking after their premature infant effectively. 52 55 Even mothers in South Africa who had previous experience with motherhood still required more information when caring for premature newborns.⁵⁵ Both articles highlighted the significant role NICU nurses play in providing information during hospitalisation and discharge, with Sengane et al recommending that they verify mothers' understanding by asking them to repeat the information given. 52 55

The rest of the articles on caregivers' information needs focused more broadly on the postnatal period, also covering unmet information needs concerning healthy newborns. Standard Rotich and Wolvaardt interviewed Kenyan mothers at three points during the first 6 weeks

post partum, concluding that health information needs remained consistent.⁵¹ Ge *et al* investigated the anticipated information needs of 206 Chinese fathers immediately after the delivery.⁵⁴ Nabugoomu *et al* focused on healthcare needs and barriers of Ugandan pregnant adolescent and teen mothers.⁵³

Overall across the five articles, caregiver information needs fell into three main categories (see table 2): (a) maternal needs after delivery (eg, information on managing discomfort after labour to ensure mothers could physically care for their newborns⁵¹), (b) maternal self-care needs as related to newborn care (eg, diet to increase milk production for breastfeeding ⁵¹ ⁵² ⁵⁴) and (c) newborn care needs (eg, taking care of the umbilical cord stump, feeding, but also medication administration and advanced care for vulnerable newborns ⁵² ⁵⁴).

Information tools

Of the 17 articles on information tools, 15 examined tools integrated into healthcare systems, while two were pilot projects.^{57 68} The majority of articles (n=16) focused on paper-based tools like booklets, cards or home-based records (HBRs) (see online supplemental appendix 4).

<u> </u>	ation needs	
Caregivers' key information needs	Summary	Quotes
Category 1: materna	I care	
Recovery after giving birth	The experience of giving birth was new to some mothers, who required information on postpartum recovery, including managing physical symptoms (eg, pain, fatigue) and addressing emotional challenges to ensure they could effectively care for their newborns.	"After how long will I be allowed to leave the house? You see I have examinations next week and I don't know whether I can go and do them. Will I be still weak?" — page 5
Category 2: materna	l-newborn care	
Maternal self-care	Information needs on maternal self-care were linked to the care required for their newborns.	"I want to know if there's any injection that somebody can be given for the milk?" 51—page 5
Maternal-infant bonding	Mothers expressed the need for information on how to establish a strong bond and promote attachment with their newborns.	"Now see baby is crying I don't understand why he is crying" ⁵¹ – page 4
Category 3: newborr	n care	
Routine care for newborns	Bathing (body hygiene), feeding, sleeping, positioning, etc.	"What do you do with a baby who does not want to be breastfed?" 51—page 4
Newborn danger signs	Recognise, manage and avoid illness. Differentiate between normal and abnormal signs.	"Would like to be told how to know that the baby is sick and I would like to know diseases babies suffer from" 51—page 5
Advanced care for newborns	Medication administration, growth monitoring and development.	"You know, sometimes you want to know everything about a premature baby, how to take care, how to feed and how to take control. They must just give us guidelines" page 241
Follow-up and immunisation	Immunisation schedule, side effects, etc.	"Why my baby should be immunised and when?" 55—page 241
Newborn information resources and guidance	Counselling, advice, understanding health booklets	"Now that booklet says the first bath is after 24 hours. Does it mean we shall wait for 24 hours before we bath(e)the babynow I delivered at five in the morning will I wait until five in the morning?" page 6



Only one article referred to a digital tool.⁵⁷ Notably, the literature reviewed did not explore hybrid approaches (eg, combining paper and electronic tools) in LMIC settings.

MCH booklets were described in several studies as enhancing infant cognitive development in resourceconstrained environments like Mongolia and Kenya. 56 60 61 They also proved effective in studies conducted in rural Bangladesh and Indonesia, improving maternal and child care. 68 69 Child Health Booklets (CHBs) and Child Health Cards (CHCs) have shown effectiveness for immunisation and nutrition support in Uganda and Iraq. $^{62\,63}$ When Roadto-Health Books (RtHB) and Cards (RtHC) were used in South Africa to monitor health services and child growth, gaps were identified that required improved recordkeeping methods. 58 59 67 Innovative approaches, such as updated vaccination cards combined with maternal education, increased adherence to immunisations and reduced dropout rates in Pakistan. 70 71 HBRs have also been used to raise immunisation rates and improve child health outcomes in Kenya, 64 Indonesia 66 72 and Afghanistan. 65 Furthermore, a pilot study in India demonstrated how a mobile app-based EHR system contributed to improved healthcare access.⁵⁷ Yet, several articles also highlighted the tension between intentional wider-system benefits and perceived effectiveness for users, including caregivers and healthcare workers. 58 63 68 71

Content and technical features

A small number of articles provided descriptions of the tools' content and technical features (mainly size, pages and language). 60-62 66 70-72 For example, the Kenyan MCH booklet (A5, 34 pages, English) prioritised portability but risked excluding non-English speakers. 60 61 In contrast, the Afghan version used Dari/Pashto languages to align with local needs. 65 Some articles only provided high-level information about relevant tools (eg, RtHB as 'simple' and 'readily available tool'58) while others offered more critical assessment (eg, Iraq's CHB as a 'surveillance instrument'62). Only two articles included visual examples of information tools. 59 63

The overall level of information provided by the tools differed based on the sections included. MCH booklets, for example, generally provided comprehensive obstetric and child health information as they had antenatal, delivery, postnatal and child health sections, plus health messages directed to caregivers. ⁵⁶ 60 61 64 66 68 69 72

Other articles described how tools had been developed in simpler formats to begin with but were subsequently improved. For instance, in South Africa, the RtHC had been in use since 1973, containing only the immunisation and growth chart section. ⁵⁸ In 2010, a more advanced version of the RtHC called RtHB was introduced. RtHB provided more comprehensive details on a child's health information, including HIV-related information, detailed growth monitoring (such as length-for-age, head circumference and mid-upper arm circumference), doctor's notes and health promotion messages. ^{58 59 67 73}

However, RtHB and RtHC did not incorporate medical history and health information for vulnerable newborns, indicating a gap in documentation for this population in South Africa. ⁵⁹ Also, studies on these tools did not involve user input, meaning that some of the reasons behind changes to documentation completeness remained inadequately explained.

Distribution of tools and user training

Tool distribution and utilisation varied across articles. Generally, MCH booklets were provided to expectant mothers after their initial antenatal appointment, with the anticipation that they would carry these booklets during subsequent healthcare facility visits. ⁵³ ⁵⁸ ⁶¹ ⁶⁴ On the other hand, RtHB, RtHC and CHB were typically handed to caregivers following childbirth and before departure from the maternity ward, ⁵¹ ⁵² ⁵⁴ ⁵⁹ whereas CHC was presented during the first childcare visit. ⁵⁵ Supply shortages of paper-based information tools hindered tool accessibility in Africa and Bangladesh. ⁶⁴ ⁶⁷⁻⁶⁹

Users varied among identified tools. ⁵¹⁵²⁶⁴ Although caregivers retained these tools, healthcare workers, including nursing staff, midwives and community/primary health workers, were responsible for reviewing and updating the information included in the tools during each interaction, ensuring accuracy and reflecting the most recent information. ^{51–5658–72} Yet, training approaches for healthcare workers differed. Some focused on tool usage/distribution, ⁵⁶ ⁶¹ ⁶³ while others emphasised caregiver education. ⁶⁵ ⁶⁶ Studies stressed the need for ongoing training updates ⁵⁹ and technical support for digital tools. ⁵⁷

Challenges to implementation and sustained use

Tool utilisation and implementation varied with articles reporting non-adoption, lack of retention and incomplete tool usage. ⁵⁸ ⁵⁹ ⁶²-⁶⁴ Poor RtHB completeness was found in two studies in Africa, suggesting difficulties with record-keeping accuracy and consistency. ⁵⁸ ⁵⁹ One study showed that not all sections of the RtHB and RtHC were completed regularly by healthcare workers, which could impact care quality. ⁵⁹ Three articles stated challenges with maintaining data quality and retention of the tools in the longer term, describing how paper-based tools were susceptible to damage, incompleteness and loss. ⁶⁶ ⁶⁹ ⁷²

Challenges were also reported at the hospital level, related to the availability of resources and support. Four of the articles stated challenges with healthcare staff acceptance and knowledge of used tools. ⁵⁷ 62 63 67 One article reported that Kenyan healthcare workers had an increased workload due to MCH booklet usage in their healthcare facilities. ⁶¹

Ownership of MCH booklets in Kenya was associated with higher maternal education and family wealth, indicating possible social inequalities in access to tools. Two studies showed that cultural beliefs and behaviours, such as receiving treatment from traditional non-medical



herbalists, can influence the use of information tools in Kenya and Afghanistan. $^{64\,65}$

Digital tools faced infrastructure hurdles (poor connectivity, limited support) in India/Indonesia. ⁵⁷ ⁶⁸ Hybrid approaches (eg, MCH booklets with mobile alerts in Bangladesh ⁶⁸) showed promise but lacked long-term outcome data due to short follow-ups (4weeks postdelivery), making it harder to detect outcomes related to newborn care.

DISCUSSION

This review aimed to (1) synthesise the information needs of caregivers of vulnerable newborns postdischarge in LMICs, (2) identify tools used to share information during postdischarge care and (3) evaluate the extent to which existing tools fulfil these needs. Several articles demonstrated the positive role of tools like paper-based booklets and cards, including infant cognitive development, ⁵⁷ ⁶¹ ⁶² maternal and child care, ⁶⁹ ⁷⁰ immunisation rates ^{63–67} ⁷³ and child health outcomes. ⁵⁹ ⁶⁰ ⁶⁸ However, the literature inadequately addressed how tools meet caregivers' information needs, particularly for vulnerable newborns at high risk of mortality. The dominance of quantitative methods meant 'how' and 'why' questions remained underexplored, highlighting the need for more in-depth research in line with WHO recommendations. ¹⁵ ¹⁶ ²⁹

Information needs

Articles indicated that caregivers seek information on maternal care (also related to supporting the baby such as lactation) and newborn-specific care (such as routine care, danger signs, medication administration, etc), across different sociocultural contexts. ⁵¹ ⁵² ⁵⁴ Socioeconomic factors, including cultural values, socioeconomic status and healthcare access, significantly influenced these needs. ⁵¹ ⁵³ ⁵⁴ Insufficient information hindered care quality and caregiver confidence, ⁵² ⁵⁵ echoing prior research on the need for targeted postdischarge interventions. ^{74–76} This is particularly important when it comes to looking after premature (or otherwise vulnerable) newborns, as the information needs of their caregivers exceed basic requirements. ⁷⁷ ⁷⁸

Information tools

Most tools focused on immunisation, maternal health and HIV-related child health, with limited alignment to caregivers' expressed needs. Reliance on paper-based records persisted. ⁵⁶⁵⁷ 60 61 65–72</sup> None of the articles assessed whether existing tools met the expressed (as in the section above) information needs, with articles evaluating tools chronologically published before the articles assessing information needs. It was also suggested that the development and implementation of these tools occurred without caregiver and healthcare worker input. ³⁰ In addition, none of the tools described in these studies specifically addressed the needs of vulnerable newborns, highlighting a critical

gap. This was also noted in previous research, which similarly identified a lack of official follow-up records beyond the MCH booklet in Kenva. ⁷⁹

A 2018 systematic review found that home-held booklets effectively improved the knowledge of pregnant women and caregivers, highlighting the potential for such tools to support caregivers. Yet, our review revealed challenges hindering the effective use of information tools, such as inadequate training, lack of acceptance among healthcare workers, for 62 63 67 poor record-keeping accuracy and limited usage, consistent with previous literature. Previous research has also noted deficiencies in postnatal care resources regarding content and features. There has been insufficient focus on clinical information sharing for vulnerable newborns post-discharge. Lack of follow-up tools and official documentation underscores gaps in information-sharing practices, as also discussed in previous studies on recording-keeping and postdischarge care.

Implications for practice and future research

Our review highlights critical gaps in understanding postdischarge information needs and developing responsive tools. The reviewed articles had limitations like small sample sizes and short follow-up periods, indicating a need for better-quality research. Addressing implementation challenges is also essential to improve the effectiveness and sustainability of tools.⁸³ Tailored interventions must address socioeconomic and cultural disparities. Our review underscores the need for additional exploration into caregiver and healthcare worker perspectives to identify gaps and improve information-sharing practices. Empirical studies focused on parents' and healthcare workers' experiences after NICU discharge can extend our understanding, particularly in African contexts at significant need. Qualitative research can capture contextual factors and the role of healthcare workers in facilitating effective information sharing.

Limitations and strengths

We conducted a systematic search across six databases as well as used additional searching techniques. This was followed by comprehensive analysis and synthesis processes, including drawing partially on the NASSS framework. However, our review focused on articles published within the last two decades, potentially excluding older literature. This restriction is justified based on previous studies indicating a low risk of missing significant articles in the MCH field.⁸⁵

Conclusion

Follow-up care of vulnerable newborns in LMICs presents significant challenges but remains poorly understood, as there is limited data on caregivers' (and healthcare workers') information needs and how these can be better supported by postdischarge information tools. Caregivers have a number of needs in relation to maternal and newborn care, including in terms of coordination of



follow-up care for their newborns. Although a number of tools have been used to support relevant needs, these have shown mixed effectiveness, due to challenges with record completeness, lack of training for healthcare workers, supply chain issues and cultural barriers, such as the preference for treatment from traditional non-medical herbalists. It remains imperative to extend our understanding of how caregivers' (and healthcare workers') information needs for effective follow-up care can be met, particularly by an in-depth examination of their experiences during the postdischarge period.

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REFERENCES

- 1 Garces AL, McClure EM, Pérez W, et al. The Global Network Neonatal Cause of Death algorithm for low-resource settings. Acta Paediatr 2017;106:904–11.
- 2 Belizán JM, McClure EM, Goudar SS, et al. Neonatal death in low- to middle-income countries: a global network study. Am J Perinatol 2012;29:649–56.
- 3 WHO. Newborns: improving survival and well-being, 2022. Available: https://www.who.int/news-room/fact-sheets/detail/newborns-reducing-mortality
- 4 Desalew A, Sintayehu Y, Teferi N, et al. Cause and predictors of neonatal mortality among neonates admitted to neonatal intensive care units of public hospitals in eastern Ethiopia: a facility-based prospective follow-up study. *BMC Pediatr* 2020:20:160.
- prospective follow-up study. *BMC Pediatr* 2020;20:160.
 Tekelab T, Chojenta C, Smith R, *et al*. The impact of antenatal care on neonatal mortality in sub-Saharan Africa: A systematic review and meta-analysis. *PLoS One* 2019;14:e0222566.
- 6 UNICEF. Child survival and the SDGs, 2021. Available: https://data. unicef.org/topic/child-survival/child-survival-sdgs
- 7 Irimu G, Aluvaala J, Malla L, et al. Neonatal mortality in Kenyan hospitals: a multisite, retrospective, cohort study. BMJ Glob Health 2021:6:e004475.
- 8 Chou D, Daelmans B, Jolivet RR, et al. Ending preventable maternal and newborn mortality and stillbirths. BMJ 2015;351:h4255.
- 9 Kinney MV, Cocoman O, Dickson KE, et al. Implementation of the Every Newborn Action Plan: Progress and lessons learned. Semin Perinatol 2015;39:326–37.
- 10 Gülmezoglu AM, et al. Interventions to reduce maternal and newborn morbidity and mortality. In: Reproductive, maternal, newborn, and child health. 2016: 115–36.
- 11 WHO. Newborns: improving survival and well-being, 2020. Available: https://www.who.int/news-room/fact-sheets/detail/newborns-reducing-mortality
- 12 Konje ET, Hatfield J, Sauve R, et al. Late initiation and low utilization of postnatal care services among women in the rural setting in Northwest Tanzania: a community-based study using a mixed method approach. BMC Health Serv Res 2021;21:635.
- 13 World Health Organization. WHO technical consultation on postpartum and postnatal care. World Health Organization, 2010.
- 14 Wiens MO, Pawluk S, Kissoon N, et al. Pediatric post-discharge mortality in resource poor countries: a systematic review. PLoS One 2013;8:e66698.
- 15 Expert W-U. A comprehensive model for scaling up care for small and/or sick newborns at district level-based on country experiences presented at a WHO-UNICEF expert consultation. J Glob Health 2023:13:13.
- 16 World Health Organization. Standards for improving the quality of care for small and sick newborns in health facilities. 2020.
- 17 Bhutta ZA, Das JK, Bahl R, et al. Can available interventions end preventable deaths in mothers, newborn babies, and stillbirths, and at what cost? *The Lancet* 2014;384:347–70.
- 18 Prendergast AJ, Walson JL. Seeking interventions to reduce postdischarge mortality among children in sub-Saharan Africa. *Lancet Glob Health* 2019;7:e1306–7.
- 19 Chisti MJ, Graham SM, Duke T, et al. Post-discharge mortality in children with severe malnutrition and pneumonia in Bangladesh. PLoS One 2014;9:e107663.
- 20 Lyne H, Burgoine K, Ogara C, et al. "They said, let's teach you how you are going to care for the child at home...": caregivers' and healthcare worker's perceptions and experiences of post-discharge preterm care in eastern Uganda. BMC Health Serv Res 2022;22:1521.



- 21 Kang SR, Cho H. Research Trends of Follow-Up Care after Neonatal Intensive Care Unit Graduation for Children Born Preterm: A Scoping Review. Int J Environ Res Public Health 2021;18:3268.
- 22 Nemetchek B, Khowaja A, Kavuma A, et al. Exploring healthcare providers' perspectives of the paediatric discharge process in Uganda: a qualitative exploratory study. BMJ Open 2019;9:e029526.
- 23 Purdy IB, Craig JW, Zeanah P. NICU discharge planning and beyond: recommendations for parent psychosocial support. *J Perinatol* 2015;35 Suppl 1:S24–8.
- 24 Anbu Chakkarapani A, Chicoine L, Soni R, et al. G86 Improving discharge summary quality in a greenfield single room quaternary neonatal intensive care unit. Royal College of Paediatrics and Child Health, Abstracts of the RCPCH Conference–Online, 25 September 2020–13 November 2020. 2020.
- 25 Tibil PE, Ganle JK. What Support Systems do Women Caring for Preterm Infants at Home Require in Urban Ghana? A Qualitative Study. Matern Child Health J 2022;26:1239–45.
- 26 Paul S, Tickell KD, Ojee E, et al. Knowledge, attitudes, and perceptions of Kenyan healthcare workers regarding pediatric discharge from hospital. PLoS One 2021;16:e0249569.
- 27 World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. World Health Organization, 2010.
- 28 Loureiro CV, Fonteles MM, Mascarenhas MB, et al. Medication follow-up in newborns with extremely low birth-weight. *Pharm Pract* (*Granada*) 2019:17:1584.
- 29 World Health Organization. WHO recommendations on homebased records for maternal, newborn and child health. World Health Organization, 2018.
- 30 Carandang RR, Sakamoto JL, Kunieda MK, et al. Roles of the Maternal and Child Health Handbook and Other Home-Based Records on Newborn and Child Health: A Systematic Review. Int J Environ Res Public Health 2021;18:7463.
- 31 Magwood O, Kpadé V, Thavorn K, et al. Effectiveness of home-based records on maternal, newborn and child health outcomes: A systematic review and meta-analysis. PLoS One 2019;14:e0209278.
- 32 Public Health England. No child left behind: a public health informed approach to improving outcomes for vulnerable children. 2020.
- 33 Tickell KD, Mangale DI, Tornberg-Belanger SN, et al. A mixed method multi-country assessment of barriers to implementing pediatric inpatient care guidelines. PLoS One 2019;14:e0212395.
- 34 Hicks A. The missing link: Towards an integrated health and information literacy research agenda. Soc Sci Med 2022;292:114592.
- 35 Isah EE, Byström K. The mediating role of documents: information sharing through medical records in healthcare. JD 2020;76:1171–91.
- 36 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005;8:19–32.
- 37 Sargeant JM, O'Connor AM. Scoping Reviews, Systematic Reviews, and Meta-Analysis: Applications in Veterinary Medicine. Front Vet Sci 2020;7:11.
- 38 Peters MD, Godfrey CM, Mcinerney P, et al. Chapter 11: scoping reviews (2020 version). In: JBI Manual for Evidence Synthesis, JBI. 2020.
- 39 Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69.
- 40 World Bank. World Bank list, 2021. Available: https://datahelpdesk. worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups
- 41 Mourad Ouzzani HH, Fedorowicz Z, Elmagarmid A. Rayyan a web and mobile app for systematic reviews, 2016. Available: http://rayyan.gcri.org
- 42 The EndNote Team. EndNote. Philadelphia, PA: Clarivate, 2013.
- 43 Papoutsi C, Mattick K, Pearson M, et al. Interventions to improve antimicrobial prescribing of doctors in training (IMPACT): a realist review. 2021.
- 44 Papoutsi C, Mattick K, Pearson M, et al. Social and professional influences on antimicrobial prescribing for doctors-in-training: a realist review. J Antimicrob Chemother 2017;72:2418–30.
- 45 Carrieri D, Briscoe S, Jackson M, et al. "Care Under Pressure": a realist review of interventions to tackle doctors' mental ill-health and its impacts on the clinical workforce and patient care. BMJ Open 2018;8:e021273.
- 46 Kitila SB, Feyissa GT, Olika AK, et al. Maternal Healthcare in Lowand Middle-Income Countries: A Scoping Review. Health Serv Insights 2022;15:11786329221100310.
- 47 World Health Organization. Scoping review of interventions to maintain essential services for maternal, newborn, child and adolescent health and older people during disruptive events: web annex: summary of interventions and evaluations by type of event. Scoping review of interventions to maintain essential services for maternal, newborn, child and adolescent health and older people

- during disruptive events: web annex: summary of interventions and evaluations by type of event. 2021.
- 48 Sondaal SFV, Browne JL, Amoakoh-Coleman M, et al. Assessing the Effect of mHealth Interventions in Improving Maternal and Neonatal Care in Low- and Middle-Income Countries: A Systematic Review. PLoS One 2016;11:e0154664.
- 49 Godfrey CM, Harrison MB, Graham ID, et al. Utilisation of theoretical models and frameworks in the process of evidence synthesis. JBI Libr Syst Rev 2010;8:730–51.
- 50 Greenhalgh T, Wherton J, Papoutsi C, et al. Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies. J Med Internet Res 2017;19:e367.
- 51 Rotich E, Wolvaardt L. A descriptive study of the health information needs of Kenyan women in the first 6 weeks postpartum. BMC Pregnancy Childbirth 2017;17:385:385:.
- 52 Hemati Z, Namnabati M, Taleghani F, et al. Mothers' challenges after infants' discharge from neonatal intensive care unit: A qualitative study. Iranian J Neonatol 2017;8:31–6.
- 53 Nabugoomu J, Seruwagi GK, Corbett K, et al. Needs and Barriers of Teen Mothers in Rural Eastern Uganda: Stakeholders' Perceptions Regarding Maternal/Child Nutrition and Health. Int J Environ Res Public Health 2018;15:2776.
- 54 Ge B, Wan S-X, Li H-L, et al. Studying perceived needs for information on maternal and infant health care in the puerperium period among fathers of newborns in China. *Midwifery* 2019;78:32–41.
- 55 Sengane MLM, Maree C, Niekerk LR van. Information needs for Inclusion in a Post-Discharge Guideline Booklet for Mothers with Prematurely born Babies in a Low-Resource Setting in South Africa. TONURSJ 2021;15:236–43.
- 56 Dagvadorj A, Nakayama T, Inoue E, et al. Cluster randomised controlled trial showed that maternal and child health handbook was effective for child cognitive development in Mongolia. Acta Paediatr 2017;106:1360–1.
- 57 Shilpa DM, Naik PR, Shewade HD, et al. Assessing the implementation of a mobile App-based electronic health record: A mixed-method study from South India. J Educ Health Promot 2020;9:102.
- 58 Ramraj T, Goga AE, Larsen A, et al. Completeness of patient-held records: observations of the Road-to-Health Booklet from two national facility-based surveys at 6 weeks postpartum, South Africa. J Glob Health 2018;8:020901.
- 59 Naidoo H, Avenant T, Goga A. Completeness of the Road-to-Health Booklet and Road-to-Health Card: Results of cross-sectional surveillance at a provincial tertiary hospital. South Afr J HIV Med 2018;19:765.
- 60 Kawakatsu Y, Sugishita T, Oruenjo K, et al. Effectiveness of and factors related to possession of a mother and child health handbook: an analysis using propensity score matching. Health Educ Res 2015;30:935–46.
- 61 Mudany MA, Sirengo M, Rutherford GW, et al. Enhancing Maternal and Child Health using a Combined Mother & Child Health Booklet in Kenya. J Trop Pediatr 2015;61:442–7.
- 62 Abdulrahman MA, Habeeb QS, Teeli RH. Evaluation of child health booklet usage in primary healthcare centres in Duhok Province, Iraq. Public Health (Fairfax) 2020;185:375–80.
- 63 Mukanga DO, Kiguli S. Factors affecting the retention and use of child health cards in a slum community in Kampala, Uganda, 2005. Matern Child Health J 2006;10:545–52.
- 64 Brown DW, Tabu C, Sergon K, et al. Home-based record (HBR) ownership and use of HBR recording fields in selected Kenyan communities: Results from the Kenya Missed Opportunities for Vaccination Assessment. PLoS One 2018;13:e0201538.
- 65 Saeedzai SA, Sadaat I, Anwari Z, et al. Home-based records for poor mothers and children in Afghanistan, a cross sectional population based study. BMC Public Health 2019;19:766.
- 66 Osaki K, Hattori T, Kosen S, et al. Investment in home-based maternal, newborn and child health records improves immunization coverage in Indonesia. Trans R Soc Trop Med Hyg 2009;103:846–8.
- 67 Cloete I, Daniels L BSc, MPH R, Jordaan J BSc RD(SA), et al. Knowledge and perceptions of nursing staff on the new Road to Health Booklet growth charts in primary healthcare clinics in the Tygerberg subdistrict of the Cape Town metropole district. South African J Clin Nut 2013;26:141–6.
- 68 Gai Tobe R, Haque SE, Mubassara S, et al. Maternal and child health handbook to improve continuum of maternal and child care in rural Bangladesh: Findings of a cluster randomized controlled trial. PLoS One 2022;17:e0266074.



- 69 Osaki K, Hattori T, Toda A, et al. Maternal and Child Health Handbook use for maternal and child care: a cluster randomized controlled study in rural Java, Indonesia. J Public Health (Bangkok) 2019;41:170–82.
- 70 Usman HR, Rahbar MH, Kristensen S, et al. Randomized controlled trial to improve childhood immunization adherence in rural Pakistan: redesigned immunization card and maternal education. *Tropical Med Int Health* 2011;16:334–42.
- 71 Usman HR, Akhtar S, Habib F, et al. Redesigned immunization card and center-based education to reduce childhood immunization dropouts in urban Pakistan: A randomized controlled trial. Vaccine (Auckl) 2009;27:467–72.
- 72 Osaki K, Hattori T, Kosen S. The role of home-based records in the establishment of a continuum of care for mothers, newborns, and children in Indonesia. *Glob Health Action* 2013;6:1–12.
- 73 Wiles JI, Swingler G. Descriptive study evaluating the use of the Road to Health card by doctors in a tertiary Paediatric hospital setting. S Afr J CH 2018;12:63.
- 74 Rao SPN, Minckas N, Medvedev MM, et al. Small and sick newborn care during the COVID-19 pandemic: global survey and thematic analysis of healthcare providers' voices and experiences. BMJ Glob Health 2021;6:e004347.
- 75 Griffith T, Singh A, Naber M, et al. Scoping review of interventions to support families with preterm infants post-NICU discharge. J Pediatr Nurs 2022:67:e135–49.
- 76 Deierl A, Platonos K, Aloysius A, et al. Evaluation of parental experience post-discharge and development of a parent focus group. J Neonatal Nurs 2018;24:21–8.
- 77 Nyaloko MJ, Lubbe W, Moloko-Phiri SS, et al. Parental experiences of caring for preterm infants in the neonatal intensive care unit, Limpopo Province: a descriptive qualitative study exploring the cultural determinants. BMC Health Serv Res 2024;24:669.

- 78 Van Schalkwyk EA, Gerber B. Vulnerable mothers' experience of feeding their preterm infant in neonatal care. S Afr J Commun Disord 2021;68:e1–9.
- 79 Silveira RC, Mendes EW, Fuentefria RN, et al. Early intervention program for very low birth weight preterm infants and their parents: a study protocol. BMC Pediatr 2018;18:268.
- 80 Magwood O, Kpadé V, Afza R, et al. Understanding women's, caregivers', and providers' experiences with home-based records: A systematic review of qualitative studies. PLoS One 2018;13:e0204966.
- 81 Joseph L, Lavis A, Greenfield S, et al. A systematic review of home-based records in maternal and child health for improving informational continuity, health outcomes, and perceived usefulness in low and middle-income countries. PLoS One 2022;17:e0267192.
- 82 Carandang RR, Sakamoto JL, Kunieda MK, et al. Effects of the maternal and child health handbook and other home-based records on mothers' non-health outcomes: a systematic review. BMJ Open 2022;12:e058155.
- 83 Nakamura Y. The role of maternal and child health (MCH) handbook in the era of sustainable development goals (SDGs). J Glob Health Sci 2019:1.
- 84 Turner KE, Fuller S. Patient-Held Maternal and/or Child Health Records: Meeting the Information Needs of Patients and Healthcare Providers in Developing Countries? *Online J Public Health Inform* 2011;3:ojphi.v3i2.3631.
- 85 Dol J, Campbell-Yeo M, Tomblin Murphy G, et al. Parent-targeted postnatal educational interventions in low and middle-income countries: A scoping review and critical analysis. Int J Nurs Stud 2019:94:60–73.