

Post-discharge care frameworks, guidelines, and protocols for newborns affected by preterm birth or hypoxic-ischemic encephalopathy: A scoping review

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Abstract

Objective: This scoping review aimed to map and analyze existing post-discharge care frameworks, guidelines, and protocols for newborns affected by preterm birth and/or hypoxic ischemic encephalopathy (HIE).

Introduction: Despite improvements in in-hospital care for preterm and HIE-affected newborns, the post-discharge period presents unique challenges, particularly in resource-limited settings. There is a lack of standardized guidelines tailored to the specific needs of vulnerable infants in sub-Saharan Africa, which potentially compromises their long-term health and development.

Inclusion criteria: The review will include studies published in English within the past decade that examine post-discharge care protocols and guidelines for premature and HIE-affected newborns and young children (up to five years of age) globally. Studies lacking post-discharge protocols, care, guidelines, and frameworks were excluded.

Methods: A comprehensive literature search was conducted using PubMed, SCOPUS, Web of Science, EBSCOhost, Science Direct, and Google Scholar for publications published between 2014 and 2024. Grey literature sources are also examined. Two independent reviewers evaluated the article titles and abstracts. Only articles that passed this initial stage were selected for full-text review to assess their eligibility. Data were extracted using a standardized form and analyzed both quantitatively and qualitatively. The Mixed Method Appraisal Tool (MMAT) version 2018 was used to evaluate the methodological quality of the selected articles.

Introduction

Newborn health remains a critical concern in sub-Saharan Africa, with preterm birth and hypoxic-ischemic encephalopathy (HIE), otherwise commonly referred to as birth asphyxia, being a significant contributor to newborn morbidity and mortality (1). While in-hospital care for these conditions has improved, the post-discharge period presents unique challenges that are often overlooked (2). The transition from hospital to home is a critical phase in the care continuum for neonates affected by preterm birth and HIE and requires specialized attention and follow-up to ensure optimal outcomes. Despite the importance of post-discharge care, there is a lack of standardized guidelines tailored to the specific needs of vulnerable infants in resource-limited settings (3). This gap in care protocols potentially compromises the long-term health and development of affected newborns, highlighting the need for a comprehensive understanding of the existing practices and guidelines. Care of premature infants and those affected by HIE is particularly challenging in sub-Saharan Africa, where resources are often limited. Although interventions such as obstetric care, newborn resuscitation, treatment of HIE-affected infants, and care for preterm births (including corticosteroids and continuous positive air pressure) have been identified as impactful in reducing neonatal mortality (1), their implementation has been hindered by various factors. This includes infrastructure, training, and financial constraints (4). The economic burden on families for hospital-based care is significant, with families spending a considerable portion

of their annual income on acute care for conditions such as perinatal asphyxia and preterm/low birth weight (4). Moreover, psychosocial and emotional stress on mothers, as well as varied knowledge and expectations regarding preterm birth, highlight the complexity of care required for these infants (5). While there are known interventions that can significantly reduce newborn mortality from HIE and preterm births(6-8), their implementation in sub-Saharan Africa is challenged by economic, infrastructural, and educational barriers. Addressing these challenges requires a multifaceted approach that includes improving infrastructure, training healthcare providers, supporting families financially and emotionally, and enhancing the early detection and treatment of neonatal conditions (4, 5, 9). A recent scoping review by Maraschin et al. (3) underscored the critical care needs of infants post-surgery for congenital conditions, highlighting the necessity for monitoring, feeding, and specific care practices. However, it also reveals a significant gap in the literature, with most studies conducted in high-income countries (HICs) leaving a dearth of information applicable to low- and middle-income countries (LMICs), where the burden of congenital anomalies is highest. Kaur et al. (10) and Clair et al. (11) discussed barriers to quality of care and the potential for simple, low-cost interventions in low-resource settings. However, they did not provide concrete guidelines for post-discharge care. Daga (12) critiques the WHO guidelines on newborn health, suggesting that they may not be adequately tailored to low-resource contexts, while Ortiz et al. (13) emphasized the need for syndromic management strategies that are feasible in resource-limited settings.

These insights suggest that, while there is recognition of the need for context-specific guidelines, actual implementation remains a challenge. The literature indicates a clear need for standardized post-discharge care guidelines specifically designed for resource-limited settings. The lack of such guidelines is a significant barrier in providing adequate care to vulnerable infants in these areas.

A scoping review is deemed the most appropriate methodology for addressing this knowledge gap for several reasons.

- Topic scope: The broad nature of post-discharge care for preterm and HIE-affected neonates, encompassing various interventions and practices, is well-suited to the comprehensive exploration afforded by a scoping review.
- Evidence diversity: Given the likely heterogeneity in study designs, interventions, and outcomes within the available literature, a scoping review is better equipped to accommodate this variability than are other review types.
- Research gap identification: Through systematic mapping of the existing literature, a scoping review effectively elucidates areas lacking research, which is particularly crucial given the limited information available for LMICs.
- Future research guidance: The results of this scoping review can serve as a foundation for developing targeted systematic reviews and primary research studies.
- Practical and policy impact: By synthesizing the available evidence, this review contributes to the formulation of context-appropriate guidelines and policies for post-discharge care in resource-

constrained settings. This scoping review aimed to systematically examine the current landscape of post-discharge guidelines for newborns previously admitted for HIE and/or premature birth. Through a thorough literature review, this study sought to identify, analyze, and synthesize existing guidelines, protocols, and best practices in post-hospitalization care for high-risk infants.

For this review, the key terms were defined as follows: preterm birth and birth occurring before 37 weeks of gestation. Birth asphyxia, also known as perinatal asphyxia or hypoxic-ischemic encephalopathy, refers to acute brain injury as evidenced by clinical and laboratory findings. Hypoxic-ischemic encephalopathy may occur due to prenatal, intrapartum, or postnatal hypoxic insults (14).

Post-discharge care: The continuum of care provided to infants after they leave the hospital, including follow-up appointments, home visits, and parental education. Resource-limited settings: Healthcare environments with constrained financial, human, or infrastructural resources, typical of many areas in sub-Saharan Africa. The findings of this review will serve as a foundation for developing standardized context-appropriate protocols for post-discharge care in resource-limited environments. Such a framework, guidelines, and protocols are essential to ensure continuity of care, reduce readmission rates, and improve long-term outcomes in newborns with preterm birth and HIE.

Primary Review Question:

What are the existing post-discharge care frameworks, guidelines, and protocols for newborns with preterm birth and/or hypoxic-ischemic encephalopathy?

Sub-questions:

1. What are the essential components of these post-discharge care frameworks, guidelines and protocols?
2. How are these frameworks, guidelines and protocols adapted for implementation in resource-constrained environments?
3. What are the reported outcomes associated with the implementation of these frameworks, guidelines and protocols?
4. What are the gaps in the current post-discharge care framework, guidelines and protocols for these high-risk newborns globally?

Keyword

Prematurity, hypoxic-ischemic encephalopathy, neonatal asphyxia, post-discharge, aftercare, guidelines, protocol, neonatal, newborn, resource limited

The PCC framework, which illustrates the study's population concept and context, is presented in Table 1.

Table 1: PCC Framework items

Framework item	Framework activity
Population	Newborns affected by preterm birth and/or hypoxic ischemic encephalopathy globally who are under five years of age classified as high-risk, and who required hospitalisation within the first 28 days of life.
Concept	Post-discharge care frameworks, guidelines, and protocols that delineate the post-hospital care for newborns under five years of age who have experienced premature birth or HIE at birth, and who were admitted to hospital within their initial four weeks of life. For the scholarly articles drawn from studies such as randomised control trial, cohort studies, cross-sectional studies and case studies that addresses newborn follow-up care, post-discharge care practices and those which identify post-discharge care gaps.
Context	Global – study conducted in any country or setting

Inclusion criteria

Participants:

Newborn affected by preterm birth and/or hypoxic ischemic encephalopathy

Concept:

Post-discharge care protocols, guidelines, or frameworks; follow-up care practices and their duration; transition of care from hospital to home; continuity of care for high-risk neonates.

Context:

Studies conducted globally; in any country or setting;

Types of sources:

This scoping review will investigate a range of research methodologies, including experimental designs such as randomized controlled trials. It will also include analytical observational studies, including prospective and retrospective cohort, case-control, and analytical cross-sectional studies. Moreover, the review will encompass descriptive observational study designs including case series, individual case

reports, and descriptive cross-sectional studies. The review will also incorporate qualitative research approaches with a focus on qualitative data from designs such as phenomenology, grounded theory, ethnography, qualitative descriptions, action research, and feminist research.

In addition to these scholarly sources, this scoping review will explore other resources, such as international guidelines and framework websites, including WHO guidelines on neonatal care, UNICEF protocols for newborn health, and the United Nations Sustainable Development Goals related to neonatal health.

Furthermore, the review examines national policies and protocol websites, such as country-specific neonatal care guidelines from health ministries and national health service protocols for sub-Saharan African countries. Research institution publication websites, including the London School of Hygiene and Tropical Medicine research papers, Johns Hopkins Bloomberg School of Public Health reports, and Harvard T. H. Chan School of Public Health studies.

Additionally, the review will consider non-governmental organization reports, such as the Save the Children's Neonatal Care Protocols and Médecins Sans Frontières (MSF) field guidelines. Clinical textbooks and manuals, including "Care of the Newborn" by Meharban Singh, "Neonatology: Management, Procedures, On-Call Problems, Diseases, and Drugs" by Tricia Lacy Gomella, and "Manual of Neonatal Care" by John P. Cloherty.

Significance

This scoping review aimed to investigate post-discharge frameworks, guidelines, and protocols for neonates affected by preterm birth and HIE. Furthermore, follow-up care practices and their duration were reviewed to identify the best possible practices. This study is significant because it seeks to identify existing guidelines for the post-hospitalization care of vulnerable newborns, with the ultimate goal of developing standardized frameworks, guidelines, and protocols suitable for implementation in resource-limited settings. The findings from this review will contribute to improving the quality of care for neonates in sub-Saharan Africa, potentially reducing morbidity and mortality rates associated with preterm births and HIE.

Methods

The study design followed a rigorous methodology that combined the JBI scoping review approach (15, 16) with Hong et al.'s methodological enhancement (17). This comprehensive framework consists of five key phases: formulating the research question; identifying relevant studies; selecting appropriate studies; extracting data; and collating, summarizing, and reporting the findings. By adhering to this structured approach, researchers can conduct a systematic and thorough review of the available literature. A pilot test is conducted using the JBI approach. Two independent reviewers screened titles and abstracts to assess the inclusion criteria. Once the articles were deemed eligible, their full text was

gathered and reviewed to confirm their eligibility. Additionally, the study will comply with the Preferred Reporting Items for Systematic reviews and Meta-Analyses for scoping reviews (PRISMA-ScR) guidelines, further enhancing the transparency and reproducibility of the review process. This methodological rigour strengthens the validity and reliability of the study's findings, providing a solid foundation for future research and policy development in neonatal care in resource-limited settings. The title of this review is registered under the Open Science Framework (https://osf.io/hwp95/registrations?view_only=)

Search strategy

In consultation with the librarian, a preliminary search of the following databases will be conducted: MEDLINE (PubMed), CINAHL (EBSCO), government websites, international guidelines and framework websites (WHO and UNICEF), clinical textbooks and manuals, and research institution publication websites. The search employed the following keywords and index terms.

Table 2 presents the initial search strategy and outcomes following the use of PubMed on May 21, 2025.

Table 2: Pilot search query for PubMed database conducted on 21-04-2025

Search strategy	Pilot Search Query which included abstract and full text	Database	Number of Articles
Population	(Neonate* OR Neonates* OR infant, newborn* OR Newborn infant* OR Newborn Infants*) AND (preterm OR premature OR low birth weight OR birth asphyxia OR perinatal asphyxia OR hypoxia-ischemia, brain Or respiratory distress syndrome)	PubMed	61,610 (21-04-2025)
Focus/Intervention	(Post-discharge OR follow-up, OR community-based follow-up* OR aftercare) AND (framework*, OR guideline*, OR protocol*, care plan*, best practice*, transition of care, OR continuity of care	PubMed	151,541 (21-04-2025)
Setting	Globally	PubMed	70,473 (16-04-2025)
Outcome	Neonatal morbidity OR Neonatal mortality OR survival OR neurodevelopment* OR growth OR health outcome*	PubMed	386,816 (21-04-2025)
Combined search strategy	((((Neonate* OR newborn*) AND (preterm OR premature OR low birth weight OR birth asphyxia OR perinatal asphyxia OR hypoxia-ischemia, brain) AND (post-discharge OR follow-up OR aftercare) AND (framework* OR guideline* OR protocol* OR care plan* OR best practice*) AND (Morbidity OR mortality OR survival OR neurodevelopment* OR growth OR health outcome*))) AND ((y_10[Filter] AND (fha[Filter])))) AND ((y_10[Filter]) AND (fha[Filter]))	PubMed	701 21-04-2025

The research methodology will entail adapting the search strategy to various databases including SCOPUS, Web of Science, EBSCOhost (Medline and CINAHL), ScienceDirect, and Google Scholar. Frameworks, guidelines and protocols from government, non-governmental, international institutional websites and clinical textbooks including articles published between 2014 and 2024 will be considered. The selection criteria included materials relevant to the research topic, source credibility, and comprehensiveness of the information provided. A predefined search strategy using relevant keywords and Boolean operators was employed to ensure a thorough and consistent approach across all the sources. Two independent reviewers screened the selected materials using a standardized inclusion/exclusion checklist to ensure objectivity in the selection process.

Additionally, the study will incorporate grey literature from ProQuest and OpenGrey, encompassing reports, conference proceedings, working papers, governmental documents, theses, dissertations, and unpublished data from organizations and institutions. The reference lists of the included studies were examined to identify any additional relevant articles.

To enhance and validate the search strategy, the principal investigator will collaborate with a subject matter expert and information specialist.

Selection of studies

The scoping review will adhere to predefined inclusion and exclusion criteria to ensure accurate identification and selection of relevant articles. Relevant articles were extracted from the health database and imported into ENDNOTE 20, a reference management tool for organizations.

Potentially relevant sources will be retrieved in full, and their citation details imported into the JBI System for the Unified Management, Assessment, and Review of Information (18). The full texts of the selected citations were assessed in detail by two independent reviewers using inclusion criteria. Reasons for excluding sources of evidence in the full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements between reviewers at each stage of the selection process were resolved through discussion or by an additional reviewer. The results of the search and study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (19).

The degree of concordance between reviewers after full-article screening was evaluated using Cohen's kappa statistic. The agreement ratings, 0.01–0.20 indicating slight agreement, 0.21–0.40, fair agreement, 0.41–0.60 representing moderate agreement, 0.61–0.80, substantial agreement, and 0.81–1.00, almost perfect agreement.

Data charting

Data will be extracted from the papers included in the scoping review by two independent reviewers using a data extraction tool developed by the principal investigator. The data extraction form included the following elements: bibliographic information (author, year, title), study characteristics (objective, country, methodology, setting), participant data, and information on preterm births and HIE. This review provides information on the following aspects.

- Geographical coverage: Determine the nations or regions encompassed by each framework or guideline.
- Intended demographics: Elucidate whether the framework is designed for preterm infants, HIE cases, or both cohorts.
- Age scope: Specify the age range of infants covered by each guideline (such as up to one year, two years, or longer).
- Follow-up period: Ascertain the recommended duration of post-discharge monitoring.

- Areas of care: Identify the specific care domains addressed (e.g., neurodevelopmental, nutritional, and respiratory).
- Evaluation instruments: Enumerate recommended screening or assessment tools for monitoring infant progress.
- Check-up regularity: Document advises intervals for follow-up appointments or evaluations.
- Interdisciplinary approach: Delineate the healthcare professionals involved in post-discharge care.
- Family-oriented care components: Identify elements that emphasise family support and education.
- Care transition: Summarise recommendations for transitioning from hospital to home care.
- Evidence foundation: Evaluate the level of evidence supporting each guideline or framework.
- Participant involvement: Identify the stakeholders engaged in developing each guideline.
- Implementation tactics: Detail any recommended methods for implementing guidelines.
- Performance indicators: Enumerate the key outcomes used to assess the effectiveness of post-discharge care.
- Cultural considerations: Highlight any culturally specific elements within the guidelines.
- Resource necessities: Specify the required resources for implementing each framework.
- Revision process: Document the frequency and procedure of guideline updates.
- Shortcomings and constraints: Emphasise any acknowledged gaps or limitations in the existing frameworks.

The draft data extraction tool will be evaluated by two reviewers to assess its suitability and determine whether it adequately captures all relevant information for the study. Modifications, if necessary, will be detailed in the scoping review. Any disagreements between reviewers will be resolved through discussion. If disputes persist during the full article review, a third reviewer will be consulted for mediation. The degree of concordance between reviewers after full-article screening will be evaluated using Cohen's kappa statistic, with the following interpretation criteria: - ≤ 0 : No agreement - 0.01–0.20: Slight agreement - 0.21–0.40: Fair agreement - 0.41–0.60: Moderate agreement - 0.61–0.80: Substantial agreement - 0.81–1.00: Almost perfect agreement

Data Analysis and Presentation of Results

The findings from the scoping review will be subjected to both quantitative and qualitative analysis.

Quantitative Analysis: This will involve conducting a descriptive statistical analysis of the included studies, focusing on: a) number of studies by year of publication, b) distribution of studies by country globally, c) types of study designs represented, d) sample sizes and participant characteristics, and e) frequency of different post-discharge care protocols or guidelines.

Qualitative Analysis: A thematic analysis of the extracted data will be conducted to identify common themes, patterns, and gaps in post-discharge care guidelines for preterm and HIE-affected infants. The findings will be categorized based on the key components of post-discharge care such as follow-up schedules, monitoring practices, parental education, and resource utilization.

Data Presentation: a) PRISMA Flow Diagram: A PRISMA flow diagram was created to illustrate the study selection process, including the number of studies identified, screened, assessed for eligibility, and included in the final review. b) Tables: A comprehensive characteristics table of the included studies will be developed, detailing authors, publication year, country, study design, sample size, and key findings. Additionally, a table summarizing the identified post-discharge care protocols or guidelines was created, highlighting their main components and target populations. c) Figures: A bar chart or pie chart was generated to show the distribution of studies by country. A timeline graph was created to illustrate the evolution of the post-discharge care guidelines during the review period (2014-2024). d) Thematic Maps: A conceptual map was developed to illustrate the key components of the effective post-discharge care frameworks identified across studies. A gap analysis map was created to highlight areas where the evidence was lacking or inconsistent.

Narrative Synthesis: A detailed narrative summary will accompany the visual presentations, addressing a) an overview of the current landscape of post-discharge care guidelines globally, b) common elements of effective post-discharge care protocols, c) challenges and barriers to implementing guidelines in resource-constrained settings, d) innovative approaches or adaptations for low-resource environments, and e) gaps in current research and areas requiring further investigation.

Implications and Recommendations: The findings will be synthesized to propose key elements of an effective post-hospitalization care framework for high-risk neonates in resource-constrained environments. Areas in which further research or policy development is required are highlighted. This comprehensive data analysis and presentation plan will ensure a thorough examination of the existing literature on post-discharge care guidelines for preterm and HIE-affected infants, directly addressing the review objectives and research questions.

Appraisal of quality evidence

The Mixed Method Appraisal Tool (MMAT) version 2018 (17) was used to evaluate the quality of the selected articles. Two independent reviewers will conduct the quality assessments. Reviewers will evaluate each criterion by selecting one of the three options: yes, no, or unsure, and will ultimately offer a descriptive summary of the study.

Ethical Clearance

As this scoping review did not involve human subjects, ethical approval was not required. This review was conducted for academic purposes at the University of Pretoria, Saudi Arabia.

Declarations

The authors of this scoping review protocol acknowledge the importance of equity, diversity, and inclusion. The focus of our study on post-discharge care for preterm and HIE-affected newborns globally addresses the critical health disparities affecting vulnerable populations in resource-limited settings.

Our research team had diverse expertise in this project. Precious L. Hajison, the principal investigator, has extensive experience in pediatric and neonatal care in sub-Saharan Africa. Prof. Debashis Basu contributed expertise in public health and primary care research, with a focus on resource-limited environments. - Dr. Sanele Ngocbo brings clinical knowledge as a specialist in neonatal care. Prof. Ute Feucht offers valuable insights from her work with the WHO Collaborating Center and experience in pediatric research in Africa. Dr. Jacqueline, Dr. Charles, Dr. Fatima, and Dr. Tedbabe have vast experience in childcare from UNICEF; Dr. Ajib is a pediatrician working with the KUHeS; Dr. Takondwa Chimowa is a neurodevelopmental pediatrician serving in the MOH of Malawi with hands-on experience with children; and Mr. Norman is a clinician serving in the MoH with experience in child health-related experience. Additionally, Dr. Loveness, a biostatistician, has extensive experience in data analysis, which shaped this review. We are committed to conducting this review with cultural sensitivity and awareness of the unique challenges faced by health care providers and their families. Our aim was to produce findings that can inform the development of context-appropriate, feasible guidelines for post-discharge care of high-risk neonates in resource-constrained settings.

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Author contributions

P. H. conceptualized and wrote the first draft of the manuscript under the supervision of D.B., U.F., S. N. D.B., and P. H. optimized the search strategy and performed the initial search query. JC, NL, TC, AP, FG, TH, and LD helped design the study, pilot test search, and wrote the manuscript. All authors reviewed and approved the final version of the manuscript.

Conflicts of interest

JC, CN, FG, and TH are employees of UNICEF. However, their participation in this review does not represent UNICEF. The other authors declare no conflicts of interest related to this scoping review.

Data Availability declaration

To access the data for this manuscript, please contact the corresponding author.

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