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BMJ Open Delivery methods and outcomes of eHealth programmes in neonatal transitional care for families of preterm or medically complex infants: a scoping review protocol

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ABSTRACT

Introduction The transition from the neonatal intensive care unit (NICU) to home is a critical period for families with preterm or medically complex infants and is often marked by stress, anxiety and the challenge of managing complex medical regimens. Virtual programmes such as mobile health applications and telehealth interventions have emerged as promising tools to support families during this transition. These programmes aim to provide continuous education and support after discharge. This scoping review will map the existing evidence on virtual interventions supporting families during the NICU-to-home transition and identify their delivery methods and reported outcomes.

Methods and analysis This protocol outlines a scoping review methodology, as described by Arksey and O'Malley and further improved by Levac et al. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Review will be used as a guiding framework for scoping reviews. A comprehensive search will be conducted in six databases: PubMed, Scopus, Web of Science, Embase, CINAHL and PsycINFO. Studies will be included if they (1) focus on virtual programmes supporting families of preterm or medically complex infants, (2) involve transitional care during discharge from the NICU to home and (3) are primary studies. Grey literature, as well as secondary and tertiary literature will be excluded. Data will be charted and analysed to summarise the delivery methods, target populations and outcomes reported.

Ethics and dissemination No ethical approval is required for this study. The findings will be disseminated through publications in peer-reviewed journals and presentations to the relevant stakeholders.

Trial registration number This scoping review protocol is registered in the Open Science Framework (https://doi.org/ 10.17605/OSF.IO/HWVZJ).

INTRODUCTION

The evolution of neonatal medicine, applied technologies and pharmacology over the last decade has significantly improved the survival rates of preterm infants, including those with medical complexities. Advances

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review will systematically map the existing evidence on virtual interventions supporting families with preterm or medically complex infants during the neonatal intensive care unit-to-home transition, focusing on their delivery methods.
- ⇒ The search will be conducted using a structured protocol that consults six electronic databases to ensure comprehensiveness.
- ⇒ The diversity of the included studies may present challenges in comprehensively synthesising the
- ⇒ The findings will be organised and reported based on predefined categories: target populations, delivery methods and outcome types.

in respiratory support, nutritional strategies and infection control have contributed to better outcomes in vulnerable infants.² However, these advancements are responsible for ensuring that infants transition safely from the neonatal intensive care unit (NICU) to home, a process that poses numerous challenges for both infants and their families.³

The transition from NICU to home is a critical period that can be fraught with difficulties.⁴ For many families, this period is characterised by a steep learning curve, as they assume the role of primary caregivers for their medically complex infants.⁵ Parents often experience significant stress, anxiety and depression during this period, stemming from concerns about their infant's health, the need to manage complex medical regimens and fear of potential readmissions. Studies have shown that parents of preterm infants are at a higher risk of developing mental health issues than parents of full-term infants, highlighting the need for comprehensive support systems during the postdischarge period.7-10



Continuity of care, which begins with admission to the NICU and extends beyond discharge, is essential for the well-being of both the infants and their families. Effective discharge planning and transitional care are crucial components of this continuity. Nurses and other healthcare providers play a pivotal role in preparing families for discharge by providing education, resources and emotional support. However, despite these efforts, many families feel unprepared to manage their infants' care at home, indicating a gap in the current discharge and transitional care processes. 14 15

The COVID-19 pandemic has further complicated the transition from the NICU to home. During the initial lockdown, families faced unprecedented challenges, including limited access to in-person healthcare services, increased isolation and heightened anxiety about the virus. ¹⁶ These challenges are particularly pronounced for families with medically complex infants, who require ongoing medical care and monitoring. ¹⁷ The pandemic underscored the need for innovative solutions to support families during the transition from NICU to home. ¹⁸

In response to these challenges, virtual programmes, including mobile health (mHealth) applications and telehealth interventions, have emerged as promising tools for supporting families after NICU discharge. These programmes aim to bridge the gap in transitional care by providing continuous support and education to families in their homes. MHealth applications can offer personalised health information, reminders for medications and appointments and tools for tracking infant growth and development. Helehealth interventions enable real-time communication with healthcare providers, allowing for timely advice and intervention when needed. These virtual programmes have the potential to enhance parental confidence, reduce anxiety and improve the overall health outcomes of infants.

Despite the potential benefits of virtual programmes, their characteristics remain poorly described, owing to the novelty and diversity of these interventions. The heterogeneity of these programmes in terms of content, delivery methods and target outcomes makes it challenging to comprehensively summarise current evidence.

Study objectives

The objective of this scoping review is to map the existing evidence on virtual interventions used to support families with preterm or medically complex infants during the transition from NICU to home, focusing on delivery methods and outcomes, as described in the included studies.

METHODS AND ANALYSIS Protocol design

This protocol outlines a scoping review methodology, as described by Arksey and O'Malley and further improved by Levac *et al.*^{23 24} The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for

Table 1 Keywords and Medical Subject Headings (MeSH terms)

Population	(('neonate' (MeSH) OR 'neonates' (MeSH) OR 'infant, newborn' (MeSH) OR 'neonat*' OR 'child*' OR 'newborn*' OR 'preterm*' OR 'infant, premature' (MeSH) OR 'premature birth' (MeSH) OR 'infant, extremely premature' (MeSH) OR 'infant* newborn' OR 'infant* premature' OR 'premature birth*' OR 'infant* extremely premature') AND ('famil*' OR 'parent*' OR 'caregiver*' OR 'relative*' OR 'father' OR 'mother' OR 'Family' (MeSH)))
Concept	'ehealth' (MeSH) OR 'telemedicine' (MeSH) OR 'telehealth' (MeSH) OR 'medical informatics' (MeSH) OR 'medical informatics' (MeSH) OR 'application' medical informatics'

'telehealth' (MeSH) OR 'telemedicine' (MeSH) OR 'telehealth' (MeSH) OR 'medical informatics' application' (MeSH) OR 'medical informatics' (MeSH) OR 'applications, medical informatics' (MeSH) OR 'mobile health' OR 'ehealth' OR 'e-health' OR 'mhealth' OR 'mhealth' OR 'virtual program*' OR 'telenursing' OR 'medical app*' OR 'digital health' OR 'telehealth' OR 'telemedicine' OR 'medical informatic* application*' OR 'medical informatic*'

'neonatology' (MeSH) OR 'neonatal intensive care' (MeSH) OR 'care, neonatal intensive' (MeSH) OR 'neonatal intensive care units' (MeSH) OR 'neonatal nursing' (MeSH) OR 'care continuity' (MeSH) OR 'discharge plannings' (MeSH) OR 'discharge planning' (MeSH) OR 'home*' OR 'home care' OR 'transitional care' OR 'NICU*' OR 'pediatric*' OR 'paediatric*' OR 'home transition' OR 'continuity of care' OR 'transitional care process' OR 'patient transition' OR 'continuity of patient care' OR 'neonatology' OR 'neonatal intensive care' OR 'neonatal nurs*' OR 'care continuity' OR 'discharge panning*'

Scoping Review will be used as the guiding framework for the scoping review.²⁵ The review will be developed in five phases. This scoping review protocol is registered in the Open Science Framework (https://doi.org/10.17605/OSF.IO/HWVZJ).

Phase 1: identifying the research question

Context

The research question was identified using the PCC method (P=population, C=concept and C=context). The Population (P) focuses on families or caregivers of preterm or medically complex neonates requiring care and support after discharge from the NICU to home. Concept (C) involves virtual support programmes (eg, mHealth applications, virtual platforms and telehealth interventions) designed to assist parents or caregivers of these neonates. Context (C) pertains to the postdischarge period from the NICU to home.

Phase 2: identifying relevant studies

The following databases will be consulted for this scoping review: PubMed, Scopus, Web of Science, Embase, CINAHL and PsycINFO. The keywords and Medical Subject Headings (MeSH) terms are detailed in table 1.



We will search for records published in English up to 1 October 2024, with no restrictions on the publication date. Studies will be included if they (1) focus on transitional care programmes provided to infants and their families or caregivers, (2) involve virtual programmes and (3) mention discharge from the NICUs. The exclusion criteria for this scoping review will be (1) secondary literature (eg, scoping reviews, systematic reviews, meta-analyses or any type of literature review summarising primary research); (2) tertiary literature (eg, textbooks, book chapters, theses or dissertations that synthesise secondary sources); (3) studies with no abstract available and (4) studies that do not focus on virtual programmes supporting families or caregivers during the NICU-to-home transition.

Phase 3: selection of relevant articles

This phase ensures that only the most relevant studies are included, thereby improving the reliability and focus of the review. All articles derived from the search process will be imported into Rayyan, a web and mobile application, to facilitate reviews.²⁷ Initially, the screening phase will be carried out by examining the titles and abstracts of the identified studies to determine if they meet the inclusion criteria. This will be performed independently by two reviewers to minimise selection bias and errors. In case of conflict, a third researcher will be consulted for the final decision. Studies that passed the initial screening were then reviewed in full text to confirm their relevance based on the inclusion and exclusion criteria. In both the first and second phases of the selection process, agreement between the two reviewers will be recorded using Cohen's kappa coefficient as a statistical measure of inter-rater reliability to assess the internal validity of the selection stage. The PRISMA flowchart will be completed during the study selection process.

Phase 4: charting the data

The selected studies will be included in the data extraction table. The following features will be synthesised in the table: (1) study characteristics (eg, author, year, study design and country of origin), (2) population characteristics (eg, caregiver demographics and infant medical conditions), (3) details of the eHealth programme (eg, type of intervention, delivery method and duration) and (4) reported outcomes (eg, neonatal outcomes, caregiver outcomes and satisfaction).

Phase 5: collating, summarising and reporting the results

A narrative synthesis will be conducted to summarise the key characteristics and trends in the evidence, focusing on the delivery methods and outcomes defined by the included studies. The findings will also account for any observed variations in delivery methods or outcomes, as they relate to subgroups within the defined population. The results will be organised and reported based on the target populations, delivery methods and types of outcomes described. In addition, stakeholder

engagement will be incorporated to validate the findings and enhance their practical relevance. Experts and stakeholders, including neonatologists, NICU nurses, eHealth specialists and family representatives, will be consulted through focus groups and semistructured interviews. Their input will help identify any gaps in the review, validate the preliminary results and contextualise the findings for practical applications. Insights gained during this process will be integrated into the final synthesis to ensure that the review reflects both the research evidence and practical realities of neonatal transitional care.

Patient and public involvement

Patients, parents and caregivers will not be involved in writing the protocol.

Limitations

This scoping review will have some limitations related to the search strategy and the topic area. While the review will aim to be comprehensive by searching multiple databases, it will exclude grey literature and non-primary research (eg, conference papers, theses, books and systematic reviews), which may result in the omission of some sources. Additionally, diversity in study designs, populations and intervention reporting may present challenges in comprehensively synthesising findings.

ETHICS AND DISSEMINATION

In light of the study design, no ethical approval is required. The findings of this scoping review will be submitted to pertinent, specialised and indexed peerreviewed journals.

Contributors EB and CEM conceived the idea and wrote the initial draft of the scoping review protocol. SB and LR reviewed and edited in order to obtain the final version of the manuscript. All the authors have read and approved the final manuscript. The guarantor is EB.

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Competing interests None declared.

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