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BMJ Open Quality of care metrics contributing to the development, implementation, and evaluation processes of telehealth solutions in home-care settings for paediatric palliative care: protocol for a systematic literature review

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ABSTRACT

Paediatric palliative care (PPC) aims to improve the quality of life of children with life-limiting and life-threatening conditions. PPC addresses the needs of both the child and family and preferably starts immediately after a palliative diagnosis. It includes effective symptom management, psychosocial, spiritual and emotional support. Receiving PPC is often challenging due to the varied and complex nature of conditions and the difficulties in reaching all children who require palliative care. Telehealth offers a promising solution by enabling virtual access to interdisciplinary teams, facilitating real-time consultations, extending care into the home, educating professionals across regions and fostering consistent, collaborative, patient- and family-centred PPC. As this requires a seamless integration into the daily routines of all relevant stakeholders, telehealth may raise complexity in terms of privacy, data protection and regulatory compliance. Nevertheless, studies indicate that parents and children are open to using telehealth applications.

Since the COVID-19 pandemic, telehealth development in paediatrics showed a rapid and substantial scale-up. Evaluating the quality of these new technical solutions remains important. One of the main outcome measures used in telehealth evaluation studies is quality of care. Currently, the literature has no consensus on which quality of care metrics can be used to assess the development, implementation and evaluation of telehealth solutions in home-care PPC. In addition, a timely update on the fast-growing field of telehealth solutions in PPC is required. Therefore, this study aims to update and examine quality of care metrics in telehealth solutions for PPC, contributing to the conceptual foundation for the development, implementation and evaluation of home-based PPC telehealth services. Findings from our review will contribute to a deeper understanding of how children and families can receive timely and accessible palliative care regardless of their location, ultimately informing future telehealth models and research projects.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A key strength of this work is its focus on quality of care metrics related to the development, implementation and evaluation of home-based telehealth solutions in paediatric palliative care (PPC), which remains under-represented in the existing literature.
- ⇒ This study adopts a holistic perspective by integrating multiple dimensions of telehealth in PPC.
- ⇒ By identifying and synthesising emerging developments in telehealth, this work strengthens the evidence base on its potential role in PPC.
- ⇒ Our study might be limited by the rapid pace of telehealth development with the consequence that relevant and recent evidence may not have been captured.

Methods and analysis Our systematic review will evaluate studies that describe telehealth solutions in PPC home-care settings, using the Cochrane handbook, and the reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. We will include peer-reviewed articles without language or geographical restrictions. The search will be conducted by an information specialist and data synthesis will be documented via a data extraction table in MS Excel. Along with a Mixed-Method-Appraisal-Tool (MMAT) quality appraisal, data extraction will be managed by Covidence. Two reviewers will screen and extract data independently, with a third reviewer resolving discrepancies. We will present a narrative synthesis, using clear language, defining key terms and following open-access standards to ensure accessibility for non-expert audiences.

Ethics and dissemination No primary or clinical data will be collected. Therefore, ethical approval is not relevant. Review findings will be shared via peer-reviewed journal publications, conferences, stakeholder meetings and online presentations.

PROSPERO registration number CRD420251035350.



INTRODUCTION

Promise of telehealth to transform PPC

According to the WHO, paediatric palliative care (PPC) is 'the approach to prevent and relief suffering of pediatric patients and their families facing the problems associated with life-threatening illness. These problems include the physical, psychosocial, social, and spiritual suffering of child patients and their family members'.¹⁻⁴ The exact number of children in need of PPC is currently unknown. Estimates vary considerably across countries, with the highest rates reported in low-resource settings. Connor *et al* assessed that worldwide more than 21 million children are in need of palliative care delivered by their primary healthcare providers and that more than 8 million children require some form of specialised PPC, provided by a PPC team.⁵

The required spectrum of care is influenced by the child's diagnosis and disease progression,⁶ developmental stage, psychosocial, spiritual and cultural needs,⁷ health literacy, the interaction between the individual and the healthcare system,⁸ and access to adequate resources.

The care journey of children with life-limiting diseases begins with early identification of PPC needs and timely integration of palliative care into their general paediatric care. As the child's condition evolves, early referral to specialised palliative care teams is crucial when complex needs emerge.⁹ PPC teams are multidisciplinary groups that provide comprehensive, specialised care, coordinate services and offer support centred on the needs of both children and their families. The continuity of care they provide, preferentially delivered in a home-based environment, is of utmost importance. As the family of seriously ill children faces greater psychological distress, poorer mental health and worse physical well-being compared with their peers,^{10 11} the need to rely on information, advice and support from specialised paediatric care clinicians is even more important.¹² In practice, PPC requires a delicate balancing between clinical decision-making and the values, preferences and best interests of the child and their family as a unit.

Unfortunately, the clinical care journey is still characterised by diverse challenges, including patient and population diversity, prognostic uncertainty, a preference for home-based care, difficult clinical decision-making, logistical challenges¹³ and limited paediatric palliative resources alongside significant geographical distances.

Considering these challenges, it is essential to explore how the PPC journey can be enriched to better meet the needs of patients and families.

Telehealth has the potential to enhance communication and shared decision-making between healthcare professionals and home-based patients, while improving access to care. Telehealth, defined by the WHO as the 'delivery of health-care services, where patients and providers are separated by distance',^{14 15} can be seen as an umbrella definition encompassing various health technologies, for example, electronic information records, medical devices and sensors.^{16 17} Telehealth may be delivered

synchronously through real-time clinician-patient interactions or asynchronously via data transmission, messaging or remote patient monitoring,¹⁸ enabling and enhancing clinical encounters through information exchange.

Telehealth possesses the potential to provide continuity of care¹⁹ without the need for families and patients to travel to the hospital, search for parking, and endure long waiting times. Reflecting on the holistic approach of PPC, studies also demonstrate the ability of digital technologies to deliver support, extending the medical care of these patients to their homes, while including emotional support for patients and families.²⁰ Telehealth can offer seamless integration into families' daily routines, with simple, user-friendly tools. By minimising complexity, telehealth technologies can also enable easy access to care, which could be of extra value in the context of immediate deterioration, fostering greater engagement and continuous communication with care teams. In addition, another significant gap which telehealth could fill is the restricted availability of specialised PPC teams. Families now often have to turn to local paediatric services, which may not be adequately equipped to meet the specialised palliative needs of the children. Telehealth addresses this gap by facilitating access to expertise in real-time, allowing families and local care teams to connect with PPC professionals regardless of geographical barriers.¹³

Limitations of telehealth in PPC

Telehealth solutions are confronted with a variety of challenges, including the perception of intrusions in home environments and reluctance among healthcare professionals,²¹ accessibility barriers in the enrolment of telehealth research,²² technical difficulties and connectivity issues,²³ socioeconomic differences and limitations in capturing the subjective reality of the patient in clinical encounter.²⁴ Furthermore, establishing trust due to remote interactions can be more difficult compared with in-person encounters.²⁵ This is supported by Nagel *et al* who outlined contradictory aspects of technology, which can, on the one side bridge a service delivery gap, while on the other side create a physical distance to the patient and a perception of losing human presence.²⁶

In general, participants of telehealth services expressed little concern over privacy, comfortably sharing sensitive data digitally, unlike the privacy anxieties often seen in adult palliative care settings with telehealth tools.²⁷ However, there is a remaining concern that telehealth may weaken essential human connections between healthcare professionals and families.^{28 29} Given this concern, evaluating telehealth's impact on context-specific, patient-centred quality of care measures is critical to its implementation.

Importance of quality of care measures in PPC

Despite the potential benefits of telehealth in paediatric care,³⁰ the literature describing its use in PPC remained limited^{12 22} until recently. Steindal *et al* systematically mapped the different health technologies and associated

infrastructures used in home-based PPC.³¹ Other studies examined feasibility, acceptability and ethical, legal, and social challenges of implementation.³²

While evaluation approaches^{33–35} signal that quality of care metrics are a necessary part of the development, implementation and evaluation process of telehealth solutions, consensus is missing on what exact metrics are most relevant.

Only a few studies used broad constructs such as satisfaction, general well-being, anxiety or quality of life. However, quality of life, although frequently considered a core patient-centred outcome in palliative care, is influenced by multiple disease-level, family-level, social-level, and system-level factors and is therefore not sufficiently specific or sensitive to capture the distinct contribution of telehealth interventions for the patient and family experience.¹²

As a result, identifying relevant quality of care metrics remains urgently necessary for the development, implementation, and evaluation of telehealth in PPC. This is also consistent with the WHO's position that telehealth requires critically important and appropriate audit and quality assurance.³⁶

Aims of the study

The primary objective of our study is to identify quality of care metrics, contributing to the development, implementation, and evaluation processes of telehealth solutions in PPC home-care settings. The secondary aim is to give an updated and comprehensive overview of current knowledge on the potential role of telehealth solutions in home-care settings of PPC.

Foundational concepts and definitions

Paediatric palliative care

According to the WHO, 'palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources, and it can be successfully implemented even if resources are limited'.³⁷

Telehealth

In addition, the WHO defines telehealth as the 'delivery of health care services, where patients and providers are separated by distance'.³⁸ For consistency reasons, we have used the term telehealth instead of digital health solutions.

Quality of care

Analysing PPC and telehealth through the lens of quality of care reveals a lack of consensus on its definition and the establishment of metrics. To ensure a comprehensive description of articles addressing quality of care, we will incorporate the measurement framework of Hommes *et al* identifying quality measures recognised by key stakeholders in PPC home-based care. Their framework encompasses seven domains, (1) alleviation of distressing

symptoms, (2) structures and processes of care, (3) health-care utilisation, (4) location of death and bereavement care, (5) patient and family experiences, (6) psychological and spiritual care and (7) cultural, ethical and legal considerations.³⁹

Objectives

In this systematic review, we aim to synthesise and critically evaluate the growing body of literature based on the following research questions (RQs). We hereby focus on qualitative and quantitative data. The first two RQs can be considered primary objectives, while the remaining RQs are secondary objectives.

RQ1: What quality of care metrics contribute to the development, implementation, and evaluation processes of telehealth solutions in home-care settings?

RQ2: Which type of telehealth solutions are described in home-care settings?

RQ3: Who are the stakeholders involved in the home-care pathway?

RQ4: What are the patient, family, and caregiver characteristics of the PPC population?

RQ5: What are the types of clinical issues managed through the telehealth solution?

RQ6: What are the process steps performed throughout the key interaction touchpoints between the healthcare professionals, patients, and families?

RQ7: Which key functionalities and features exist in home-based telehealth solutions?

RQ8: What are the implementation factors of telehealth solutions in PPC home-care environments?

RQ9: What theories, models, practical guidelines, and frameworks are used?

METHODS AND ANALYSIS

This systematic review will evaluate studies that describe telehealth solutions in PPC home-care settings, using the Cochrane handbook,¹ and the reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.² To execute on this, an exhaustive search strategy was developed by an information specialist (CN) in cooperation with the lead author (CA). Two reviewers (CvC and CA) will independently first screen titles and abstracts in Covidence and in the second stage full text. The review will take place between Q1 and Q3 2026. Any discrepancies will be resolved by discussion with a third reviewer. The paper was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on 7 August 2025 under the registration number CRD420251035350.

Inclusion criteria

Table 1 outlines the inclusion criteria.

Exclusion criteria

Table 2 outlines the exclusion criteria.

**Table 1** Inclusion criteria

Priority	Inclusion criteria	Description	Example
1	Document type	<ul style="list-style-type: none"> ▶ Empirical studies ▶ Unindexed material ▶ Quality control studies ▶ Single case studies ▶ Multiple-site studies about telehealth according to the WHO definition ▶ Book chapters 	n.a.
1	Languages	▶ Inclusion of all languages	n.a.
2	Telehealth	<ul style="list-style-type: none"> ▶ Any concept related to the notion of telehealth. ▶ Typically, telehealth solutions cover the notion of geographical separation between patient and provider. ▶ Articles will be included if telehealth solutions include the notion of medical or educational services. ▶ Articles will be included in case telehealth solutions are performed in a home-care setting. 	eHealth, telemedicine, eHealth, mHealth and uHealth, etc.
2	Adoption and implementation factors	Articles will be included if they address the notion of adoption, implementation, initiation, diffusion or scale-up.	Adoption of telehealth solutions.
2	Patient population	We will include articles in which patients are between 0 and 18 years old.	Patients between the ages of 0 and 18 years old.
2	Quality of care metrics	Articles will be included if the definition of quality of care is met.	Process or structural measures of quality of care.

etc., Et cetera; n.a., Not applicable.

Search strategy and information sources

To answer the RQs, our search strategy encompasses key concepts of (1) telehealth, (2) palliative care, and (3) children. We excluded the concept of quality of care in the search string, making sure to avoid any exclusion of relevant search results. To capture evidence from all relevant fields, we will incorporate snowball sampling, incorporating both forward and backward directions to ensure a comprehensive exploration of relevant sources.

The search strategy was developed in collaboration with an information scientist, and we will search the following databases: MEDLINE ALL, Embase, Web of Science Core Collection, Cochrane Central Register of Controlled Trials and Google Scholar. The full list of databases and search terms can be found in the online supplemental file 1. Terms were combined with Boolean operators AND and OR, and proximity operators were used to combine terms into phrases. No study registries

Table 2 Exclusion criteria

Priority	Exclusion criteria	Description	Example
1	Non-eligible document types	<ul style="list-style-type: none"> ▶ Review ▶ Policy documents and guidelines, eg, WHO framework concepts ▶ Commentary ▶ Editorial working papers ▶ Posters ▶ Pre-prints: documents that have not been reviewed yet by a scientific audience. ▶ Conference papers, where only the abstract is available. ▶ Letters ▶ Written forms of communications among editors ▶ Entire books 	n.a.
1	Unavailable full text	If no full text is available, documents will be excluded from review.	n.a.
2	Subject incompatibility for PPC	If none of the definition criteria for PPC is met, the study will be excluded. If partial criteria for PPC are met, the article will be included.	Study solely focuses on the adult population.
2	Telehealth	Should the paper describe an in-hospital setting, articles will be excluded.	In-hospital care.

eg, Exempli gratia; PPC, paediatric palliative care.

were searched, but Cochrane CENTRAL retrieves the contents of ClinicalTrials.gov and WHO's International Clinical Trials Registry Platform. The reference lists of retrieved non-included relevant review articles and of the included references, as well as articles citing these papers, have been scanned for relevant references missed by the search. No authors or subject experts were contacted, and no extra unindexed journals in the field were browsed. References were imported into EndNote and duplicates were removed by an information specialist (CN) using the method as described by Bramer *et al.*³⁸

The search strategies for MEDLINE and Embase used relevant thesaurus terms from Medical Subject Headings and Emtree, respectively. In all databases, terms were searched in titles, abstracts and author keywords. The full search strategies of all databases are available in the online supplemental file 1.

Screening and synthesis process

All decisions regarding study inclusion in the review will be based on the eligibility (inclusion and exclusion) criteria. We will manage all screening records, full-text review, risk of bias assessment, and conflict resolution using Covidence. The study selection process will involve the following stages: (1) initial screening of titles and abstracts, (2) full-text review for eligibility and (3) final inclusion decision. At each stage, two reviewers will independently screen records and assess eligibility, disagreements will be resolved by consensus. In line with the study selection process, data will be extracted from all records eligible for final inclusion by two independent reviewers. Reviewer disagreements will be resolved through discussion, with consensus documented in the final data extraction table. Two authors will screen 10% of articles for consistency, then proceed to screen all remaining articles. Full-text screening will be conducted by reviewers, with bi-weekly meetings and consensus meetings.

Results will be presented in a narrative way and will be aligned with the RQs to ensure a clear connection between the synthesis and the overarching goals of the review.

Data items and review outcomes

Given the outlined research questions, we will aim to extract the following qualitative and quantitative data items. Table 3 outlines the data items to extract.

Roles and responsibilities

Table 4 outlines the expertise and roles of all authors.

Risk of bias in studies

We will assess the methodological quality of the included studies using the Mixed-Method-Appraisal-Tool (MMAT).³ This tool is designed to assess the methodological quality of empirical studies, incorporating various study designs. The selection of the MMAT will be based on the study design of each included study. Quality assessments will be conducted independently by the reviewers. Discrepancies will be resolved via consultation.

Table 3 Data items to extract

Relevant RQs	Data items
What quality of care metrics contribute to the development, implementation, and evaluation processes of telehealth solutions in home-care settings?	We aim to identify data items that relate to our outlined definition of quality of care by Hommes <i>et al</i> , referring to the stages of development, implementation, and evaluation of telehealth solutions in PPC.
Which type of telehealth solutions are described in PPC home-care settings?	<ul style="list-style-type: none"> ▶ Description of the telehealth solution. ▶ Description of medical use cases.
Who are the stakeholders involved in the care pathway?	Demarcation of stakeholders involved based on their activities throughout the PPC care process.
What are the patient, family, and caregiver characteristics of the PPC population?	<ul style="list-style-type: none"> ▶ Patient diagnosis. ▶ Patient and family demographics, eg, age, household income, education. ▶ Technological expertise of patients, family members, and caregivers.
What are the types of clinical issues managed through the telehealth solution?	Clinical, psychosocial, administrative, and logistical challenges as part of the PPC care pathway.
What are the process steps performed throughout the home care?	Cognitive actions and conditions performed in the PPC care process.
Which key functionalities and features exist in home-based telehealth solutions?	<ul style="list-style-type: none"> ▶ Telehealth features ▶ Telehealth functionalities
What are the implementation factors of telehealth solutions in PPC home-care environments?	Barriers and facilitators to technical, operational, social, legal, and regulatory implementation factors.
What theories, models, practical guidelines and frameworks are used?	Involves adoption and implementation framework types and gaps on a conceptual or empirical basis.
eg, Exempli gratia; PPC, paediatric palliative care.	

DISCUSSION

This review provides a foundation for the development of telehealth solutions in PPC by identifying quality of care metrics based on empirical findings, aligned with the heterogeneous palliative care pathways of paediatric patients. By expanding and updating the current literature on telehealth in PPC, this work aims to extend the reach of evidence-based approaches and to inspire broader implementation among healthcare providers. Underlying patterns could reveal quality of care metrics

**Table 4** Expertise and roles of authors

Author	Role	Expertise
CA	Lead author and guarantor of review.	PhD researcher focusing on adoption, implementation, and scale-up of digital health solutions, in specific telemedicine.
CN	Coauthor, search string compilation and database extraction.	Information specialist specialised in composing search strings used in various medical databases.
CvC	Coauthor and domain expert in PPC.	Postdoc researcher and general paediatrician specialised in the field of paediatric chest diseases and coordinator of the paediatric palliative care team.

PPC, paediatric palliative care.

that are relevant for the future development, implementation, and assessment of telehealth solutions in PPC.

Limitations

Our review will encompass qualitative and quantitative studies to ensure a comprehensive evidence base. Given the interdisciplinary nature of the topic, we anticipate a high level of heterogeneity. We acknowledge the wide range of eHealth-related, telemedicine-related, and telehealth-related terminology, hence we incorporated relevant synonyms in our search string. However, by excluding grey literature, some relevant studies may have been missed. In addition, our focus on empirical research may have excluded conceptual work shaping quality of care metrics. Finally, given the rapid pace of telehealth development, relevant recent evidence may not have been captured.

Collaborators The following coauthors and collaborators are included on behalf of Delft University of Technology and Medical Library, Erasmus University Medical Center Rotterdam, The Netherlands.

Contributors CA: lead author and guarantor of review. CN: coauthor, search string compilation and database extraction. CC: coauthor and domain expert in PPC.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

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