



Parent-performed invasive procedures in children with complex care needs: scoping review protocol

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ARTICLE INFO

Received 21 May 2026

Accepted 29 July 2026

Keywords:

caregivers
children with complex care needs
invasive procedures
parents
pediatric nursing
transitional care

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DOI: 10.62741/ahrj.v3iSuppl.229

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ABSTRACT

Introduction: Advances in pediatric medicine and life-support technologies have increased survival among children with complex care needs, while healthcare reorganization has shifted complex care from hospital to home. As a result, parents are increasingly performing invasive or high-risk clinical procedures traditionally delivered by healthcare professionals. However, the literature remains fragmented regarding which procedures are undertaken by parents and how these practices are organized across care contexts.

Objectives: To map the invasive or high-risk clinical procedures performed by parents or family caregivers of children with complex care needs across care contexts; and to analyze how parental execution, autonomy, training, competency validation, supervision, organizational support, and accountability are described across the four predefined procedural domains and care contexts.

Methodology: This scoping review will be conducted in accordance with the JBI methodology and reported following the PRISMA-ScR guidelines. A three-step search strategy will be implemented across MEDLINE (via EBSCO), CINAHL Ultimate (via EBSCO), Scopus, and Web of Science Core Collection, as well as relevant grey literature sources. Study selection and data extraction will be conducted independently by two reviewers. Findings will be presented in descriptive and tabular formats.

Results: Findings will be presented descriptively, supported by charts and figures, and synthesized narratively to characterize the procedures performed by parents and how accountability, training, competency validation, and support are described across care contexts.

Conclusion: This review will clarify how parent-performed invasive or high-risk clinical procedures are described and supported across care contexts, identifying gaps in training, supervision, and accountability that may inform safer and more consistent approaches to complex care in the home setting.

Contributions: Conceptualization: CT, MF and MS; Data curation: CT and VS; Formal Analysis: CT and VS; Funding acquisition: MF and MS; Investigation: CT and VS; Methodology: CT, MF and MS; Project administration: CT, MF and MS; Resources: MF and MS; Software: CT and VS; Supervision: MF and MS; Validation: CT, VS, MF and MS; Visualization: CT and VS; Writing - original draft: CT, VS, AN, MF and MS; Writing - review & editing: CT, VS, AN, MF and MS. All authors have read and agreed to the published version of the manuscript.

Please cite this article as: Torres CPMB, Soares VLS, Noreña-Peña AL, Figueiredo MCB, Soler MLM. Parent-performed invasive procedures in children with complex care needs: scoping review protocol. *Athena Health & Research Journal*. 2026; 3(Suppl.). doi: 10.62741/ahrj.v3iSuppl.229

INFORMAÇÃO DO ARTIGO

Recebido 21 maio 2026

Aceite 29 julho 2026

Palavras-chave:

cuidadores
crianças com necessidades complexas de saúde
pais
procedimentos invasivos
enfermagem pediátrica
cuidados de transição

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DOI: 10.62741/ahrj.v3iSuppl.229

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RESUMO

Introdução: Os avanços na medicina pediátrica e nas tecnologias de suporte de vida aumentaram a sobrevivência de crianças com necessidades complexas de saúde, enquanto a reorganização dos sistemas de saúde tem promovido a transferência de cuidados complexos do hospital para o domicílio. Como resultado, os pais têm vindo a assumir a realização de procedimentos clínicos invasivos ou de alto risco tradicionalmente assegurados por profissionais de saúde. No entanto, a literatura permanece fragmentada quanto aos tipos de procedimentos realizados pelos pais e à forma como estas práticas são organizadas nos diferentes contextos de cuidados.

Objetivos: Mapear os procedimentos clínicos invasivos ou de alto risco realizados por pais ou cuidadores familiares de crianças com necessidades complexas de cuidado nos diferentes contextos de cuidados; e analisar como a execução parental, a autonomia, a formação, a validação de competências, a supervisão, o apoio organizacional e a atribuição de responsabilidade são descritos nos quatro domínios procedimentais predefinidos e nos diferentes contextos de cuidados.

Metodologia: Esta revisão de escopo será conduzida de acordo com a metodologia JBI e reportada segundo as orientações PRISMA-ScR. Será implementada uma estratégia de pesquisa em três etapas nas bases de dados MEDLINE (via EBSCO), CINAHL *Ultimate* (via EBSCO), *Scopus* e *Web of Science Core Collection*, bem como em fontes relevantes de literatura cinzenta. A seleção dos estudos e a extração de dados serão realizadas de forma independente por dois revisores. Os resultados serão apresentados em formato descritivo e em quadros.

Resultados: Os resultados serão apresentados de forma descritiva, com recurso a tabelas e figuras, sendo acompanhados por uma síntese narrativa que caracterizará os procedimentos realizados pelos pais e a forma como a responsabilidade, a formação, a validação de competências e o suporte são descritos nos diferentes contextos de cuidados.

Conclusões: Esta revisão pretende clarificar a forma como os procedimentos clínicos invasivos ou de alto risco realizados por pais são descritos e apoiados nos diferentes contextos de cuidados, identificando lacunas na formação, supervisão e atribuição de responsabilidade, com potencial para informar práticas mais seguras e consistentes na prestação de cuidados complexos em contexto domiciliário.

Introduction

Advances in pediatric medicine and life-support technologies have contributed to increased survival among children with complex chronic conditions and technological dependence. This group, often referred to as children with complex care needs, is characterized by chronic medical conditions, clinical fragility, and the need for ongoing specialized care.^{1,2} Simultaneously, healthcare system reorganization has promoted deinstitutionalization and strengthened home-based care, resulting in the transfer of interventions previously performed exclusively in hospital settings to the home environment. Among the forms of care progressively integrated into the home setting are invasive and high-risk clinical procedures, such as tracheostomy management, home mechanical ventilation, intravenous therapy administration via central venous catheters, and parenteral nutrition. Pediatric home mechanical ventilation requires family caregivers to acquire technical competencies related to ventilator operation, respiratory monitoring, and emergency management.³ Similarly, home parenteral nutrition involves manipulation of central venous access devices and strict adherence to aseptic techniques to prevent severe infectious complications.⁴

These care models enable children to remain within their family environment and are associated with psychosocial and organizational benefits. However, they entail a significant redistribution of technical responsibilities to parents

and family caregivers. The literature has described the impact of such care on family life, including training demands, emotional burden, and the need for ongoing support.⁵ This shift may reflect not only family-centered care and improved quality of life, but also a redistribution of clinical labor, technical accountability, and risk from healthcare services to families.^{5,6} In pediatric complex care, parental involvement should also be understood through partnership in care, which recognizes parental experiential expertise and involves negotiated roles, shared decision-making, and continuing collaboration with healthcare professionals.^{7,8} Partnership does not remove professional or organizational responsibility for structured education, competency validation, supervision, and continuing support.⁹ This transition requires families to adapt to complex care demands within the home environment, often integrating technical care into everyday routines.^{10,11}

Despite the existence of dispersed studies on home ventilation, parenteral nutrition, and intravenous therapy in paediatrics, there is limited systematisation of the types of procedures effectively performed by parents, the training and competency validation models implemented, and the organisational and professional frameworks structuring this practice. No comprehensive synthesis has been identified that comparatively maps the different domains of invasive clinical procedures performed by parents of children with complex care needs.

Beyond mapping procedures, this review seeks to examine how clinical responsibilities are delegated, negotiated,

and operationalized across care contexts. In this review, the term “invasive or high-risk clinical procedures” is an operational term and does not represent a formal classification of risk. It refers to technical clinical activities within four prospectively defined domains: airway management and home ventilation; intravenous therapy and central vascular access; parenteral nutrition; and complex gastrostomy or technology-assisted enteral feeding care. Non-invasive but safety-critical activities, including monitoring, alarm response, secretion clearance, assisted cough, or emergency management, will be eligible only when directly related to one of these domains and when incorrect performance or delayed response may result in significant clinical harm. Broader parental responsibilities, including learning, skill development, care management, and detection of clinical changes, will be examined only in relation to the preparation, performance, support, and accountability associated with these procedures.

Primary objective: To map the invasive or high-risk clinical procedures performed by parents or family caregivers of children with complex care needs across care contexts.

Secondary objective: To analyze how parental execution, autonomy, training, competency validation, supervision, organizational support, and accountability are described and operationalized across the four predefined procedural domains and care contexts.

Methodology

This scoping review will be conducted in accordance with the current JBI Manual for Evidence Synthesis and the JBI guidance for scoping reviews.^{12,13} The review will be reported following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist.¹⁴ The study-selection flow diagram will use the PRISMA 2020 template for new reviews that identify records through databases and other sources.¹⁵ This scoping review protocol is registered on the Open Science Framework (OSF): <https://osf.io/6htv5/>

Review question

How are invasive or high-risk clinical procedures performed by parents or family caregivers of children with complex care needs described and organized across discharge preparation, hospital-to-home transition, home care, and community care contexts?

To address the complexity of the phenomenon under investigation, the main review question is supported by a set of sub-questions focusing on key analytical dimensions, including types of procedures, parental execution and autonomy, training and competency validation, supervision and organizational support, and the allocation of accountability between parents and healthcare professionals.

Sub-questions:

1. Which invasive or high-risk clinical procedures are described as being performed by parents or family caregivers?

2. How is parental execution described, including explicit or implicit performance and levels of autonomy?
3. How are training processes, competency validation, and preparation for parental performance described?
4. What forms of supervision, follow-up, and organizational support are reported?
5. How is accountability for these procedures described, structured, delegated, or shared between parents and healthcare professionals?

Inclusion criteria

Participants

Parents or family caregivers of children and adolescents (0-18 years) with complex care needs, including technological dependence and/or the need for ongoing specialized care. For the purposes of this review, “complex care needs” is used as an umbrella term and will be operationalized through database subject headings and free-text terms capturing chronic complexity and technological dependence.

Studies including mixed adult and pediatric populations will be included only when pediatric data are reported separately or can be clearly identified.

Concept

This review will consider studies addressing the performance by parents or family caregivers of invasive or high-risk clinical procedures traditionally integrated within professional healthcare practice and falling within the four prospectively defined procedural domains.

For the purposes of this review, invasive or high-risk clinical procedures are defined as clinical activities within the four predefined domains that are performed by parents or family caregivers and involve either: (a) the management of invasive medical devices or access to internal body systems; or (b) care requiring technical skill, clinical judgement, protocol adherence, monitoring, or immediate response capacity, where incorrect performance or delayed action may result in significant clinical deterioration, complications, or harm.

A procedure will be considered eligible if it meets at least one of the following criteria:

- Involves an invasive device or access to an internal body system;
- Requires specialized technical skill or manipulation of clinical equipment;
- Requires adherence to safety-critical protocols, including aseptic technique;
- Involves monitoring, decision-making, or emergency response where incorrect action may result in clinical harm.

Eligibility is restricted to four prospectively defined procedural domains: (1) airway management, tracheostomy care, and home ventilation; (2) intravenous therapy and central venous catheter care; (3) parenteral nutrition; and (4) complex gastrostomy or technology-assisted enteral feeding care. Within these domains, eligible activities may include tracheal, nasopharyngeal, or oropharyngeal

secretion aspiration; invasive or non-invasive ventilation management; assisted cough techniques; response to ventilator alarms; central venous catheter care; intravenous therapy administration; parenteral nutrition administration; enteral feeding-pump management; and management of device-related complications. Peritoneal dialysis and diabetes management are outside the scope of this review because they constitute distinct clinical domains that were not included in the prospectively defined and registered protocol.

Routine oral medication administration, basic hygiene, general caregiving, emotional support, routine feeding without technical complexity, and general parental involvement in care will not be included unless linked to clearly described invasive or high-risk clinical procedures.

Context

Eligible contexts include hospital discharge preparation, hospital-to-home transition, home care, community care, continuing care, and other settings where parents are trained, prepared, supported, or expected to perform invasive or high-risk clinical procedures.

Eligibility criteria are structured according to the PCC framework (Chart 1).

Chart 1. Eligibility criteria according to the PCC framework.

Component	Description
Participants (P)	Parents or family caregivers of children and adolescents (0-18 years) with complex care needs, including technological dependence and/or need for ongoing specialised care.
Concept (C)	Parental performance of invasive or high-risk clinical procedures restricted to four prospectively defined domains: airway management and home ventilation; intravenous therapy and central venous catheter care; parenteral nutrition; and complex gastrostomy or technology-assisted enteral feeding care. Related monitoring, emergency response, training, competency validation, supervision, organisational frameworks, and accountability allocation will be included when directly associated with one of these domains.
Context (C)	Discharge programmes, home care, continuing care, and hospital-to-home transition contexts.

Abbreviation: PCC, Population-Concept-Context.

Types of sources

Qualitative, quantitative, and mixed-methods studies; observational studies; implementation studies, and relevant guidelines will be considered. Editorials, opinion papers, narrative commentaries, and single-patient case reports will be excluded unless they contain original empirical data relevant to the review objectives. Conference abstracts, dissertations, theses, and documents without sufficient methodological or operational detail will be excluded.

Studies published from 2000 onwards will be included to reflect contemporary models of pediatric care. This period corresponds to the expansion of home-based care and hospital-to-home transitions, alongside advances in life-sustaining technologies enabling complex care to be delivered in domestic settings.^{3,4,5} These developments have occurred in parallel with increased survival among children with complex chronic conditions.^{2, 7}

Sources that only address general caregiving, parental experience, emotional burden, or discharge planning without reference to parent-performed invasive or high-risk clinical procedures will be excluded.

In accordance with JBI recommendations for scoping reviews, methodological quality appraisal will not be conducted.

Search strategy

The search strategy will follow the three-step approach recommended by JBI.

Step 1: Initial search

An initial scoping search was conducted in MEDLINE®, CINAHL® and SciELO, as well as in grey literature sources, including the Scientific Open Access Repository of Portugal and OpenGrey. This preliminary search aimed to identify relevant studies and refine search terms. Studies published between 2000 and 2026 were considered, in line with JBI methodological guidance and reported according to PRISMA-ScR recommendations.

Step 2: Comprehensive database search

A comprehensive search strategy was developed and adapted for each database, including MEDLINE® (via EBSCO), CINAHL® Ultimate (via EBSCO), Scopus, and Web of Science Core Collection. Controlled vocabulary (MeSH and CINAHL Headings) and free-text terms were combined using Boolean operators (AND, OR), truncation, and proximity operators (N5, W/5, NEAR/5), according to the specifications of each database.

Step 3: Additional searching

The reference lists of all included studies will be screened to identify additional relevant studies. Full search strategies for each database are presented in Appendix II. The main search concepts, along with examples of controlled vocabulary and keywords, are detailed in Chart 2.

Chart 2. Structure of search terms (controlled vocabulary and keywords).

Concept	Controlled Vocabulary	Free-text Keywords
Parents / Caregivers	Parents; Caregivers	parent*; caregiver*; family; mother*; father*; informal caregiver*
Children with complexity	Child; Infant; Adolescent; Children with Special Health Care Needs	pediatric*; paediatric*; medically fragile; medical complexity; complex care needs; chronic condition*; long-term condition*
Invasive procedures	Tracheostomy; Respiration, Artificial; Catheterization, Central Venous; Infusions, Intravenous; Parenteral Nutrition; Gastrostomy; Enteral Nutrition	tracheostom*; home mechanical ventilation; ventilation; intravenous; central line; PICC; parenteral nutrition; TPN; gastrostom*; PEG; enteral feeding; feeding tube; gastrostomy tube; G-tube; invasive procedure*; high-risk procedure*; complex care procedure*

Home / Transition context	Home Care Services; Patient Discharge; Transitional Care	home care; home health care; hospital discharge; transition to home; community care
Parental roles, training, and support	Health Education; Patient Education as Topic; Caregivers / education; Family / education	role*; accountability*; training; education; competence; skill*; supervision; support; care coordination

Abbreviations: CINAHL, Cumulative Index to Nursing and Allied Health Literature; MeSH, Medical Subject Headings; PEG, percutaneous endoscopic gastrostomy; PICC, peripherally inserted central catheter; TPN, total parenteral nutrition.

Study selection

All identified records will be exported to a reference-management application for deduplication. Automated duplicate detection will be followed by manual verification. The name and version of the application will be recorded in the final review report. Following removal of duplicates, records will proceed to the screening phase. Study selection will be conducted in two stages: (1) title and abstract screening and (2) full-text review. Two reviewers will independently assess records against the predefined eligibility criteria, in accordance with JBI recommendations for scoping reviews.¹⁴

Study-selection and data-extraction decisions will be made manually by the review team. A machine-translation tool may be used solely to support the reading of reports published in languages not fully mastered by the reviewers. Review decisions will be based on the original report; any uncertainty arising from translation will be resolved through discussion and, where necessary, consultation with a proficient reader. The translation tool will not independently determine eligibility, data extraction, analysis, or interpretation. No generative artificial intelligence tool will be used for study selection, data extraction, analysis, interpretation, or synthesis.

Prior to formal screening, a pilot exercise will be undertaken on a sample of records to ensure clarity and consistency in the application of the inclusion criteria. During pilot screening, reviewers will specifically test the operational criteria for invasiveness, high-risk procedures, implicit parental execution, and accountability attribution. Decision rules will be refined before full screening.

Parental execution will be coded as explicit when the study directly states that parents or family caregivers perform the procedure. It will be coded as implicit only when the study describes care activities, routines, or accountability in the home setting that logically require caregiver execution and cannot reasonably be attributed to healthcare professionals within the context described.

Disagreements at either stage will be resolved through discussion and consensus or, if required, by consultation with a third reviewer. Reasons for exclusion at the full-text stage will be recorded and reported.

The study selection process will be presented using the PRISMA-ScR reporting framework and the PRISMA 2020 flow-diagram template for new reviews that identify records through databases and other sources.^{13,15}

Data extraction

Data will be extracted independently by two reviewers using a structured data charting form developed for this review in accordance with JBI guidance (Appendix I). A pilot test will be conducted on 5-10 studies to refine the charting form, ensuring clarity and consistency in interpretation.

Extracted data will include study characteristics (Chart 3), procedural domain and procedural characteristics across domains (Chart 4), the nature of parental execution, training and competency validation, supervision and organizational framework, reported outcomes, and gaps identified by authors. Disagreements will be resolved by consensus or, if necessary, by a third reviewer.

Chart 3. Descriptive characteristics of included studies.

Field	Description
Author(s)	Name(s) of author(s)
Year	Year of publication
Country	Country where the study was conducted
Study design	Qualitative, quantitative, mixed-methods, observational, implementation study, guideline
Study objective	Description of the study aim
Context	Hospital, home care, continuing care, transition
Population	Number and characteristics of participants

Chart 4. Characterisation of parent-performed invasive or high-risk clinical procedures and their organization across care contexts.

	Field	Description
	Care setting	Hospital / Transition / Home / Continuing care
D. Procedural characteristics	Procedural domain	Airway/ventilation; Intravenous/CVC; Parenteral nutrition; Complex gastrostomy/enteral care
	Specific procedure(s)	Free text
	Device/technology	Free text
	Type of parental involvement	Routine management / Therapy administration / Emergency response / Device manipulation
B. Execution and autonomy	Who performs	Mother / Father / Both / Other caregiver / Not specified
	Nature of execution	Explicit / Implicit / Not specified
	Level of autonomy	Supervised / Partially supervised / Independent
	Shared care with professionals	Yes / No / Not specified
C. Training and preparation	Training provided	Yes / No / Not specified
	Training modality	Practical / Simulation / Informal / Not specified
	Competency validation	Yes / No / Not specified
D. Organisation and responsibility	Organisational model	Formal programme / Protocol / Not specified
	Accountability attribution	Professional / Family / Shared / Not specified
	Basis of delegation/ accountability	Formal / Discharge requirement / Informal / Not specified
	Post-discharge support	Yes (type) / No / Not specified

Abbreviation: CVC, central venous catheter.

Data analysis and presentation

Data will be synthesized descriptively in accordance with JBI guidance for scoping reviews.⁹ In addition to descriptive mapping, an analytical framework will be applied to examine how parental execution, autonomy, accountability, training, and support are constructed across procedural domains and care contexts.

Data will first be mapped descriptively by procedural domain and care context. A second analytical layer will examine how parental execution, autonomy, accountability, training, competency validation, and support are constructed and operationalized across studies.

Findings will be organized into four predefined procedural domains: (1) airway management and home ventilation; (2) intravenous therapy and central vascular access; (3) parenteral nutrition; and (4) complex gastrostomy or enteral feeding-related technical care.

Within each domain, the types of procedures performed by parents will be mapped, alongside descriptions of training approaches, competency validation processes, supervision mechanisms, and organizational frameworks.

Attention will be given to how accountability is described and operationalized across studies, using a structured analytical framework encompassing:

- Type of accountability (execution, monitoring, decision-making, emergency response)
- Basis of accountability (formal delegation, informal expectation, discharge requirement)
- Distribution of accountability (professional, family, shared, undefined)

These dimensions will be analysed across procedural domains and care contexts to identify patterns in how clinical accountability and associated risks are transferred to parents.

Results will be presented using structured mapping charts (Charts 3 and 4), accompanied by a narrative synthesis describing the extent, nature, and key patterns in the available evidence.

No attempt will be made to assess the effectiveness of interventions, as the purpose of this review is to map the scope, characteristics, and organization of the evidence.

Any deviations from the registered protocol occurring during the review process will be documented, justified, and reported in the final review manuscript.

Ethical considerations

As this review involves the analysis of published literature, ethical approval is not required. Nevertheless, ethical principles in research will be upheld, including accurate representation of findings, proper citation of sources, and avoidance of plagiarism. The review will be conducted transparently and reported in accordance with established methodological guidelines.

Discussion

Parental involvement in the care of children with complex needs increasingly extends beyond supportive roles to include the performance of clinical procedures traditionally

undertaken by healthcare professionals, particularly in home-based care and hospital-to-home transitions.^{5,6} This shift requires parents to acquire technical skills, adhere to safety-critical protocols, and respond to clinical instability, highlighting the importance of structured training, competency validation, and ongoing professional support.^{3,4,9} Recent evidence also shows that transition and caregiver education should recognize parental expertise and be organized as a partnership rather than as a one-directional transfer of tasks.^{8,9}

However, the literature remains fragmented regarding how these procedures are operationalized, how parents are prepared, and how accountability is structured and distributed between parents and healthcare professionals.^{5,10} This lack of clarity has implications for clinical safety, accountability, and the organization of care, while systemic and organizational barriers may intensify the burden placed on families.¹¹

This review is expected to provide an overview of current practices and identify gaps in training, supervision, and organizational support. The findings may inform clinical practice, discharge processes, and caregiver training approaches, contributing to safer and more consistent delivery of complex care in the home setting.

Conclusion

The review is expected to clarify how invasive or high-risk clinical procedures performed by parents are described, organized, and supported across care contexts. By identifying gaps in training, supervision, and accountability allocation, it may contribute to more consistent and safe approaches to complex care in home settings.

Data availability statement

No datasets were generated or analyzed for this protocol. The planned search strategies and data-charting instrument are provided in the manuscript and its appendices. The protocol registration is available through the Open Science Framework at <https://osf.io/6htv5/>

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