

Home health care providers' readiness to care for children and youth with complex medical conditions: A scoping review protocol

Joanne Tay, Margaret Saari, Adam Mulcaster, Edward Cruz

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Joanne Tay^{1*} PhD, MPH; Margaret Saari^{2*} PhD; Adam Mulcaster^{1*} MLiS; Edward Cruz^{1*} MSc, PhD

¹ University of Windsor Windsor CA

² Saint Elizabeth Research Centre Toronto CA

*these authors contributed equally

Corresponding Author:

Joanne Tay PhD, MPH

University of Windsor
401 Sunset Ave
Windsor
CA

Abstract

Background: The advancement of pediatric medicine has improved the life expectancy of CYMCS, many of whom receive care at home. However, recent literature has highlighted that many CYMCs experience prolonged hospital discharges and/or high hospital readmission rates, suggesting possible gaps in the delivery of home care for children.

Objective: This scoping review aims to examine the perspectives of health care providers on their readiness to care for children and youths with medical complexities (CYMCs) at home.

Methods: This scoping review follows the updated JBI Scoping Review Methodology. Articles will focus on 1) children and youth between ages 0 and 18 years of age receiving home care, 2) studies that examine paid home care providers, and 3) children and youth with at least one chronic medical condition. The following academic databases will be searched: MEDLINE, CINAHL, Scopus, ProQuest Nursing & Allied Health, PsycINFO, Cochrane Central Register of Controlled Trials, and Cochrane Database of Systematic Reviews. The search strategy will also include a grey literature search on Google Scholar and ProQuest database (Conference & Proceedings, Dissertations & Theses). Articles will follow a two-stage screening process through Covidence: 1) title and abstract screening and 2) full-text review. Two reviewers will be involved in each stage of the screening process. Data will be extracted using charting categories developed by the research team. Finally, data will be analyzed using qualitative and quantitative analysis approaches. Ethics approval will not be obtained because data will be sourced from published evidence.

Results: The review will identify key factors influencing provider readiness to care for CYMCs at home, including training needs, system-level supports, and role-specific challenges. Gaps in pediatric-specific competencies and workforce preparation may also emerge.

Conclusions: Findings will inform strategies to strengthen home care delivery for CYMCs by highlighting provider needs, guiding workforce development, and supporting policy and system improvements. Clinical Trial: <https://osf.io/n4faj>

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Home health care providers' readiness to care for children and youth with complex medical conditions: A scoping review protocol

Joanne Tay PhD MPH RN ¹

Margaret Saari RN PhD ^{2,3}

Adam Mulcaster MLIS ^{4,5}

Edward Cruz PhD, RN, CCNE, FCAN ^{1,5}

¹ Faculty of Nursing, University of Windsor, Windsor, Ontario, Canada

² SE Research Centre, SE Health, Markham, Ontario, Canada

³ Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada

⁴ Leddy Library, University of Windsor, Windsor, Ontario, Canada

⁵ Queen's Collaboration for Health Care Quality: A Joanna Briggs Institute Centre of Excellence

Corresponding author's name and email address

Joanne Tay

Faculty of Nursing, University of Windsor

Room 317, Toldo Health Education Centre

401

Sunset

Avenue

Windsor, ON N9B 3P4

Phone: (519) 253-3000 ext. 6118

Email: jtay@uwindsor.ca

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Declarations

This proposed protocol was and will be retrieved from publicly available sources. Therefore, ethics approval will not be required for this project.

Author contributions

All authors made substantive intellectual contributions to the development of this protocol. JT conceptualized the protocol in consultation with AM and MS. JT developed the search strategy, wrote the initial protocol, and was involved in subsequent revisions. AM contributed to refining the search strategy and provided recommendations on the types of databases to be accessed. MS provided suggestions on home and community care and search strategies for this protocol. EC will take part as a reviewer after this protocol has been published. All authors critically reviewed and revised the final version before the submission.

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Abstract

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Results (Expected Outcomes): The review will identify key factors influencing provider readiness to care for CYMCs at home, including training needs, system-level supports, and role-specific challenges. Gaps in pediatric-specific competencies and workforce preparation may also emerge.

Conclusion: Findings will inform strategies to strengthen home care delivery for CYMCs by highlighting provider needs, guiding workforce development, and supporting policy and system improvements.

Review registration: Open Science Framework (<https://osf.io/n4faj>).

Keywords: Children; home care; practice readiness; protocol; scoping review.

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Background

Children and youth with medical complexities (CYMCs) are a diverse group of individuals who share the following characteristics: 1) have chronic and severe conditions, 2) have functional limitations, 3) have extensive family-identified needs, and 4) require substantial use of health care services.^{1,2} Diagnosis common to CYMCs are numerous and include preterm birth, as well as congenital genetic, metabolic, and neurological conditions that require constant and close monitoring of their physical, emotional, behavioral, and developmental well-being.³ While many CYMCs are at risk of premature mortality, advances in medical care and technology have extended life expectancy for others.^{4,5} The provision of care for CYMCs was previously delivered almost exclusively in acute care settings by specialized health care providers such as pediatricians and pediatric nurses. However, shifts in family preferences to receive care closer to home and rising health care costs have moved much of this care to home and community care settings.⁶⁻⁸

In regions such as Ontario, Canada, home care services are funded and organized through the provincial government, specifically Ontario Health atHome.⁹ Home care services frequently accessed by CYMCs include but are not limited to nursing, physiotherapy, occupational therapy, dietetics, speech therapy, social work, and personal support worker care. These services support

primary caregivers at home by relieving their caregiving hours and ensuring the continuity of safe care prescribed to CYMCs. However, families continue to spend 15.7 million hours per year caring for children with acute, chronic, and complex health issues.¹⁰ The hours spent caring for a child depend on their medical conditions; for example, it takes approximately 130 hours to care for a child with attention deficit issues and 629 hours to care for a child with complex medical conditions.¹⁰ The more medical needs CYMCs require, the more caregiving hours. While many parents are willing to take on the responsibilities of providing their child's care, they reported that caregiving tasks take away their time for self-care, couple time with their partners, and parenting time and opportunity with their other children.¹¹ Prolonged caregiving for CYMCs without timely home care support puts parents at risk of burnout and other mental health conditions such as anxiety and depression.^{12,13}

The existing home health care services for pediatrics in Ontario are notably fragmented and complicated to navigate.^{14,15} A recent Canadian Institute of Health Information (CIHI) report identified 97,561 CYMCs across Canada in 2020; only 43% of this population received home care.¹⁶ Parents reported that navigating the health care system takes a substantial amount of time, compounded by the fact that they have to continuously 'fight' to obtain supplies or services for their children.^{11,17,18} Maynard and colleagues found that seven in ten children experienced an additional 53.9 hospitalization days due to the lack of home care nursing services.⁸ Parents report that home care services are not always guaranteed, necessitating private nursing care while waiting for publicly funded home care services.¹⁹ Studies have revealed that the lack of available home health care nursing and poor home health care support resulted in high hospital readmissions and extended hospital stays among the CYMC population.^{8,20}

Pediatric home health care is unique in that it requires providers to be familiar with the pediatric population and the child's specific health conditions and care needs.^{21,22} The needs of CYMCs can be intensive and complex when they require the use of at least one medical device in their care, are on multiple medications, and require other supports at home and in school due to their functional limitation.¹⁶ Given the complexity of care, McCann reported that parents "do not trust respite care providers in providing a suitable standard of care for their child."^{18 (p.1)} Research has highlighted that many home health care providers feel unprepared to provide specialized pediatric care due to a lack of specialized training opportunities to gain the necessary experience and skills, a lack of professional practice support from home care organizations, and limited guidance from

supervisors.⁶ This leaves children with substantially unmet needs that parents/caregivers often have to meet independently.²³ While studies show that caring for CYMCs at home is the ideal site for long-term care, the lack of preparedness reported by home health care providers creates a serious safety concern for these children and youth and affects parents'/caregivers' confidence and decision to entrust their CYMCs to home health care professionals.^{3,24,25} The lack of timely and adequate home health care continues to put parents and/or caregivers at risk of experiencing burnout, emotional and psychological distress, financial demands, and social isolation.¹² Therefore, the overarching objective of this scoping review is to examine the extent and nature of the published literature on home and community care health care providers' readiness to care for CYCMs.

Review question(s)

The research team consisting of two nursing faculty members (XX), one nursing librarian (XX), and one clinical scientist (XX) developed the overarching review question 'What is known about home health care providers' readiness to care for CYMCs at home?'. The specific questions are:

1. What are the characteristics of children receiving home health care?
2. How do home health care nurses, including registered nurses and practical nurses, perceive their readiness to provide home health care to CYMCs?
3. What are the perspectives reported by other home care providers on their readiness to provide care for CYMCs at home?
4. What factors influence nurses and other home health care providers' readiness to provide home care to CYMCs?
5. What are recommendations or strategies to enhance home health care providers' readiness to deliver home care to CYMCs?

Inclusion criteria

Participants

Home care providers (Registered Nurses, Registered/Licensed Practical Nurses, physicians, therapists) working in home care settings who provide care and support to families and children and youth ages 0 to 18 years old with at least one complex medical condition (e.g., epilepsy, global developmental delay, cardiopulmonary disease, neurological impairment, genetic and metabolic conditions, etc.). Articles that discuss non-home care settings such as acute care, children's emergency rooms, children's treatment centers, schools, and respite care facilities will not be considered unless results on home care are specifically examined and discussed.

Concept

The readiness of healthcare providers to care for children and youth living with complex medical conditions is defined as having a mix of clinical knowledge, technical skills, critical thinking, communication, professionalism, and management of responsibilities.^{26,27} Complex medical conditions are defined as individuals who 1) have chronic conditions that limit their functional ability, 2) require round-the-clock care, and 3) require substantial use of health care services.

Context

Globally, home care services are delivered by various health care providers and are tailored to the needs of children and youth.²⁷ Some of these services range from supporting CYMCs in their daily living activities to specialized services such as the administration of chemotherapy or antibiotics at home. Articles that examine paid home health care providers and report on the level of readiness of home health care providers will be included.

Types of sources

This scoping review will consider experimental and quasi-experimental study designs, including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies, including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies, will be considered for inclusion. This review will also consider descriptive observational study designs, including case series, individual case reports and descriptive cross-sectional studies for inclusion. Qualitative studies focusing on qualitative data, including but not limited to phenomenology, grounded theory, ethnography, qualitative description, action research, and feminist research, will be considered. In addition, any kind of systematic reviews that meet the inclusion criteria will also be considered. Grey literature such as dissertations and theses, opinion papers, and conference presentations will also be considered for inclusion in this scoping review. However, sources such as theoretical or conceptual papers, books, or book chapters will not be included.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews, and in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).^{28,29} This protocol has been registered in [<https://osf.io/m58zj/>]. As per Joanna Briggs Institute's (JBI) recommendation, a critical appraisal

will not be assessed because the purpose of a scoping review is to describe the extent of available evidence in the field.²⁸

Search strategy

The search strategy will aim to locate both published and unpublished studies. An initial limited search of MEDLINE (Ovid) and CINAHL (EBSCO) was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles and the index items used to describe the articles were used to develop a full search strategy for MEDLINE via Ovid. See Appendix 1. The search strategy, including all identified keywords and index terms, will be adapted for each included database and/or information source. The reference list of all included sources of evidence will be screened for additional studies. The databases to be searched include MEDLINE, CINAHL, Scopus, ProQuest Nursing & Allied Health, PsycINFO, Cochrane Central Register of Controlled Trials, and Cochrane Database of Systematic Reviews. Grey literature search will include dissertations and theses, opinion papers, and conference presentations. The same search strategy will be applied to ProQuest Dissertations & Theses. Papers published in any language will be included. Although the team primarily uses English as its working language, DeepL translator (DeepL, Cologne, Germany) will be utilized for papers published in other languages.

The search strategy for this protocol was developed by XX in consultation with a nursing librarian from the XX to scope out relevant studies from both published and grey literature. Keywords and search terms relating to pediatric home care and care providers were developed and adapted from published search terms. No date restriction will be imposed on the searches as the literature on home care for children is limited.

Study selection

Following the search, all identified citations will be collated and uploaded into Zotero v.6.0.36 (Corporation for Digital Scholarship and Roy Rosenweig Center for History and New Media, VA, USA), and duplicates will be removed. Potentially relevant sources will be retrieved in full, and their citation details will be imported into Covidence (Veritas Health Innovation, Melbourne, Australia). A two-stage review is conducted to screen the articles. In the first stage, two independent reviewers will screen articles for relevance based on title and abstract. In the second stage, two reviewers will perform independent full-text reviews of articles. Any disagreements among the reviewers at each stage of the selection process will be resolved with an additional reviewer(s). Reasons for excluding sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. The screening process results will be presented in a Preferred Reporting Items

for Systematic Reviews and Meta-analyses (PRISMA 2020) flow diagram.³⁰

Data extraction

Data will be extracted from papers included in this scoping review. A pilot test will be undertaken by two or more members of the review team on at least four articles using a data extraction tool developed by the reviewers to ensure reliability and accuracy in capturing data. After this initial review, articles will be reviewed by two or more independent reviewers. Any disagreements among reviewers will be resolved with additional reviewer(s). The extraction tool will provide an overview of knowledge and practice gaps to inform education, training and service delivery in home and community care.

The extracted data will include specific study details, such as sample characteristics, data collection and analysis, results, and other findings. See Appendix II. The draft data extraction tool will be refined as necessary during the data extraction process. Any refinement will be detailed in the scoping review. Findings will then be organized in spreadsheet format.

Data analysis and presentation

The PRISMA extension for Scoping Review (PRISMA-ScR) checklist will guide the reporting of the results in this scoping review. To answer review question 1, the characteristics (e.g., age, sex, types of diagnosis, time since diagnosis, types of medical devices, etc.) will be described, and frequency counts, percentages, mean, and standard deviations will be reported. Similarly, for review question 4, frequency counts and percentages will describe all reported factors identified quantitatively. A qualitative approach will be used to answer review questions 2 and 3, and perspectives of pediatric home care from home care providers will be grouped to identify key themes across studies. Finally, we will use different knowledge translation strategies to share results, including but not limited to open-access publication in a peer-reviewed journal, presentation at home and community care conferences, and infographics to share our findings via social media such as X and Instagram.

References

1. Canadian Association of Paediatric Health Centres (CAPHC), Complex Care Community of Practice. CAPHC guideline for the management of medically complex children & youth through the continuum of care [internet]. 2018 [cited 2024 Dec 4]. Available from: https://www.childrenshealthcarecanada.ca/en/networks-and-hubs/Complex-Care/CAPHC-National-Complex-Care-Guideline-2018_final.pdf
2. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, et al. Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529–38.
3. Elias ER, Murphy NA, the COUNCIL ON CHILDREN WITH DISABILITIES, Liptak GS, Adams RC, Burke R, et al. Home care of children and youth with complex health care needs and technology dependencies. *Pediatrics*. 2012;129(5):996–1005.
4. Feudtner C, Hays RM, Haynes G, Geyer JR, Neff JM, Koepsell TD. Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services. *Pediatrics*. 2001;107(6):e99–e99.
5. Feudtner C, Christakis DA, Zimmerman FJ, Muldoon JH, Neff JM, Koepsell TD. Characteristics of deaths occurring in children's hospitals: Implications for supportive care services. *Pediatrics*. 2002;109(5):887–93.
6. Foster CC, Morales L, Fawcett AJ, Coleman CL. Access and quality of pediatric home healthcare: A systematic review. *Home Health Care Manag Pract*. 2023;35(4):287–98.
7. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. Patterns and costs of health care use of children with medical complexity. *Pediatrics*. 2012;130(6):e1463–70.
8. Maynard R, Christensen E, Cady R, Jacob A, Ouellette Y, Podgorski H, et al. Home health care availability and discharge delays in children with medical complexity. *Pediatrics*. 2019;143(1):e20181951.
9. Ontario Health atHome. About us [internet]. 2024 [cited 2024 Dec 4]. Available from: <https://ontariohealthathome.ca/about-us/>
10. CBC/Radio Canada. Inadequate home care for Ottawa-area families with sick children, study finds [internet]. 2017 [cited 2024 Apr 21]. Available from: <https://www.cbc.ca/news/canada/ottawa/ottawa-champlain-lhin-study-1.4216143>.
11. McCann D, Bull R, Winzenberg T. The daily patterns of time use for parents of children with complex needs: A systematic review. *J Child Health Care*. 2012;16(1):26–52.
12. Anclair M. Fears, stress and burnout in parents of children with chronic conditions: Treatment

- with cognitive behavioural therapy and mindfulness [dissertation on the Internet]. Karlstad University; 2017 [cited 2024 Dec 4]. Available from: <https://www.diva-portal.org/smash/get/diva2:1092596/FULLTEXT02.pdf>
13. Pitch N, Shahil A, Mekhuri S, Ambreen M, Chu S, Keilty K, et al. Caring for children with new medical technology at home: Parental perspectives. *BMJ Paediatr Open*. 2023;7(1):e002062.
14. CHEO. THRIVE: The future of integrated health service planning for children and youth in the Champlain region [internet]. 2017 [cited 2024 Dec 4]. Available from: <https://www.cheo.on.ca/en/news/resources/THRIVE-Report-2017.pdf>
15. Peter E, Spalding K, Kenny N, Conrad P, McKeever P, Macfarlane A. Neither seen nor heard: Children and homecare policy in Canada. *Soc Sci Med*. 2007;64(8):1624–35.
16. Canadian Institute for Health Information. Children and youth with medical complexity in Canada [internet]. 2020 [cited 2024 Dec 4]. Available from: <https://www.cihi.ca/en/children-and-youth-with-medical-complexity-in-canada>
17. Whiting M. Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life-limiting/life-threatening illness or technology dependence. *J Child Health Care*. 2013;17(1):92–108.
18. McCann D. Parenting children with complex needs. *J Child Health Care*. 2021;25(2):179–81.
19. Nageswaran S, Golden SL. Factors associated with stability of health nursing services for children with medical complexity. *Home Healthc Now*. 2017;35(8):434–444.
20. Sobotka SA, Lynch E, Peek ME, Graham RJ. Readmission drivers for children with medical complexity: Home nursing shortages cause health crises. *Pediatr Pulmonol*. 2020;55(6):1474–80.
21. Feudtner C, Nye R, Hill DL, Hall M, Hinds P, Johnston EE, et al. Polysymptomatology in pediatric patients receiving palliative care based on parent-reported data. *JAMA Netw Open*. 2021;4(8):e2119730.
22. Prentice TM, Gillam L, Davis PG, Janvier A. Always a burden? Healthcare providers' perspectives on moral distress. *Arch Dis Child Fetal Neonatal Ed*. 2018;103(5):F441-F445.
23. Amar-Dolan LG, Horn MH, O'Connell B, Parsons SK, Roussin CJ, Weinstock PH, et al. "This is how hard it is". Family experience of hospital-to-home transition with a tracheostomy. *Ann Am Thorac Soc*. 2020;17(7):860–8.
24. Thode S. Better pediatric policies are needed. *Home Healthc Now*. 2021;39(4):185.
25. Libby RC, Imaizumi SO. Chapter 6: family-centered home health care. *Guidelines for pediatric home health care*, 2nd ed. American Academy of Pediatrics; 2009.
26. Wolsky K. Establishment of a standard definition of practice readiness: academia's vs practices'

registered nurses perceptions related to new graduate nurse competencies within Alberta, Canada [dissertation on the Internet]. Capella University; 2014 [cited 2024 Dec 5]. Available from: <https://www.proquest.com/docview/1566193685?pq-origsite=primo&sourcetype=Dissertations%20&%20Theses>

27. Berkow S, Virkstis K, Stewart J, Conway L. Assessing new graduate nurse performance. *Nurse Educat.* 2009;34(1):17–22.

28. Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. *JB Evid Synth.* 2020;18(10):2119–26.

29. PRISMA-P Group, Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev.* 2015;4(1):1.

30. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ.* 2021;n71.