

Access and Quality of Pediatric Home Healthcare: A Systematic Review

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Abstract

Despite the rising prevalence of children with medical complexity who need extensive medical care at home, the literature evaluating pediatric home healthcare has not been well summarized. Our objective was to systematically review the evidence-base of pediatric home healthcare to understand what is currently known about access and quality of home healthcare for children. PubMed, Ovid Medline, Embase, CINAHL, Cochrane Library, Proquest Dissertations and Theses Global were searched for studies in the United States, United Kingdom, Canada, and Australia English publications (1980–2020) regarding children (≤ 18 years) using shift-based home healthcare services. Blinded independent review was conducted followed by extraction of study characteristics including how each study examined access and/or quality, which was categorized using the National Academy of Medicine quality dimensions. Of 9533 abstracts, 101 were included. Most were US (82%) and regional (72%) studies. Half (54%) focused on home nursing followed by home services generally (43%). The majority (77%) evaluated access and patient-family centeredness (62%); their results identified consistent limitations in access and quality resulting in negative impacts on patients and families. Less than 20% of publications addressed safety, effectiveness or equity. Bias scoring found that quantitative studies were universally weak, but qualitative studies were mostly moderate or strong. Results are limited by design heterogeneity and exclusion of training research. While research in pediatric home healthcare has increased, studies remain observational and rarely evaluate quality in reproducible ways. More rigorous measures and interventional research are needed to improve this healthcare sector for children.

Keywords

home healthcare, children with medical complexity, children and youth with special healthcare needs, chronic illness; disability, private duty nurse, personal care aide, home health aide, home and community-based services, long-term care services and supports, paid family caregiving

Introduction

A wellspring of healthcare advancement over the past several decades has improved the life expectancy of children with complex chronic conditions and disabilities. Along with these medical improvements have come legislative and policy watersheds, including passages of the Medicare and Medicaid Act, Americans with Disabilities Act, and Tax Equity and Fiscal Responsibility Act (i.e., Katie Beckett Act) which provide legal infrastructure to secure medical services and community integration for persons with chronic conditions and disability.^{1,2} Long-term care has since moved toward home and community-based living to align with these standards.

Consequently, children with medical complexity (CMC) are routinely discharged home with multifaceted medical regimens that may require continuous nursing care and support with activities of daily living (ADLs).³ While the American Academy of Pediatrics (AAP) guidelines identify

home as the ideal site of long-term care, there remains minimal documentation holistically summarizing the quality of the research about pediatric home healthcare.^{4,5} A national research agenda has highlighted the need for improved research in care at home,^{6,7} but to our knowledge there is no recent assessment devoted to the field of pediatric home healthcare research itself. Moreover, lay press have

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increasingly been reporting current gaps in the access and quality of home care for children which raises a question as to what the medical literature has documented to date on this topic.

Since home healthcare is essential for children and families, a better understanding of whether home care is currently accessible and of high-quality for children is needed. Our objectives in this review were to understand how research to date has measured what it means for children to “access” home healthcare, how it has measured the “quality” of home healthcare, and with what levels of methodologic rigor. Our overarching goal was to inform current research gaps and inform prioritization of which future studies that may be needed to improve this fundamental healthcare sector for children and their families.

Methods

This study followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 updated guidance.⁸ The protocol was registered on PROSPERO (CRD42020199105) and is available in full on the National Institute for Health Research website (<https://www.crd.york.ac.uk/prospéro/>).

Eligibility Criteria

Inclusion criteria. This review focused on research evaluating longitudinal shift-based nursing and personal care home healthcare for children and youth (≤ 18 years old) who received care for 1 or more complex medical conditions and/or disabilities.⁵ Longitudinal shift-based nursing can be referred to differently in different states but may include “private duty nursing” or “home nursing” in which a nurse comes for shifts of typically 8 to 12 hours at a time for long-term care. Shift-based nursing is distinguished from visiting nursing which is limited to discrete visits for more acute needs. Publications were selected from 1980 onward to understand the pediatric home healthcare literature since the inception of home and community-based care. We chose English-language manuscripts from the United States (US), United Kingdom (UK), Canada, and Australia for insights across a selection of English-speaking healthcare systems. Peer-reviewed manuscripts, accepted conference abstracts, and dissertation/theses were included.

Exclusion criteria. We excluded non-English work and publications that included home healthcare for healthy newborn/postnatal care, telemedicine, community assessments, intermittent visiting nursing, or other intermittent home healthcare. Home-based psychiatric, palliative, or in-home (re)habilitative services were deemed out of scope. Literature reviews and gray literature, such as commentaries or editorials, without their own empirical data were excluded.

Information Sources and Search Strategies

The search strategy included medical, nursing, social work, and rehabilitation databases: Pubmed (Medline), Ovid Medline, Embase (Elsevier), CINAHL with Full Text (EBSCO), Cochrane Library (Wiley), and Proquest Dissertations & Theses Global. Search queries were executed in December 2020 various terms related to home nursing and personal care (Appendix A). Search records were exported and de-duplicated using Endnote (Clarivate Analytics, PA, USA).

Study Selection and Data Collection

After the medical librarian (AF) executed the search, the titles and publications pdfs were uploaded to Covidence (V2.0, Veritas Health Innovation, Melbourne, Australia), to facilitate blind review.⁹ The project co-leads (CF, CC) independently reviewed all abstracts for inclusion then met to review conflicts until consensus was reached. This process was repeated with full-text review. Data extraction was then conducted by a co-lead (CF) and research coordinator (LM) using the software’s extraction tool. A data extraction template was trialed with 20 publications for comprehensiveness and reproducibility. The tool was revised and reapplied to the initial and remaining publications. The team members conducted independent data extraction then reviewed results together, resolving discrepancies that occurred during extraction.

Data Items and Effect Measures

Study details and population. Identifying data was extracted for each study publication. Key details about the study purpose and design were identified, including whether it evaluated access to home healthcare services broadly, nursing-level care, or personal care/home aide care. We identified whether a study reported on participant race or ethnicity and limited English proficiency (LEP) to ascertain the representativeness of diverse patient-family experiences.

Study home healthcare access and quality measurement. Given that this body of literature does not have standardized outcomes, we systematically categorized how studies measured access and quality. First, we extracted each publication’s key results related to home healthcare. Then, each publication was categorized by how it examined the access and quality of home healthcare. Publications were categorized as addressing *overall access* when they addressed the degree to which patients received home healthcare services, with access defined as whether a patient was able to use a given service or not, such as hours or shifts filled.¹⁰ Then we detailed how they described access, such as whether in hours received or shifts filled. Additionally we categorized whether the publication examined different quality dimensions, as

categorized by the National Academy of Medicine (NAM): effective, safe, patient-centered, timely, equitable, and efficient.^{11,12} We extended the patient-centered construct to patient- and family-centeredness given pediatric home healthcare occurs within the family context.¹³ Studies assessed the differential cost of in-home versus in-hospital care were categorized under efficiency. Any remaining non-specific appraisals of quality were categorized as *overall quality*.

Risk of Bias Within and Across Studies

The risk of bias of individual studies was conducted using a previously published method that assesses both quantitative and qualitative studies.^{14,15} This risk of bias approach uses the Quality Assessment Tool for Quantitative Studies which grades studies on 6 categories: selection bias, study design, confounders, data collection, analysis using the grades of strong, moderate, or weak.^{16,17} An overall score is then applied: strong (0 weak categories), moderate (1 weak category), and weak (≥ 2 weak categories). The National Institute for Health and Care Excellence's methodology checklist was used to grade qualitative studies on 12 categories in 6 domains: theoretical approach, study design, data collection, validity, analysis, and ethics.¹⁸ An overall score was then applied using the strong (++), moderate (+), weak (-) modified rubric.¹⁴ Mixed methods studies were evaluated using both tools.

Due to the variability in study design type in our review, the GRADE system was used to assess risk of bias across studies.¹⁹ The strength of the literature regarding access and quality was assessed using high, moderate, low, or very low evidence based on GRADE's system of assessing risk of bias, inconsistency, indirectness, imprecision, and publication bias.^{24,25}

Synthesis of Results

The team qualitatively synthesized the data by summarizing the type and breadth of studies that have been published on the topic and other extracted characteristics to describe the literature available on pediatric home healthcare. These characteristics as well as access, quality, bias assessments were summarized using univariate frequency statistics.

Results

Study Selection

Over 9000 studies were identified in the initial search of which about a third were duplicates (n=3283) (Figure 1 PRISMA diagram).⁸ Of 6250 abstracts screened, the majority (85%, n=5434) were excluded primarily based on the wrong topic. Of these, 693 were assessed for eligibility using full text review, the largest group was excluded for a wrong publication type leading to a total of 101 publications.

Study Characteristics

Study location and type. The published literature increased over time with 7% (n=7) of studies published in 1980 to 1989 and 54% (n=54) in 2010 to 2020. Most of the publications were from the US (82%, n=85) followed by the UK (9%, n=9), Canada (6%, n=6), and Australia (2%, n=2). Most publications were assessed population of children receiving care at a regional site (72%, n=73). Study design varied but was primarily cross-sectional (65%, n=66) collected by primary data sources (63%, n=64). A third of studies were qualitative (33%, n=34), some using mixed methods (8%, n=8), with the remaining (56%, n=57) conducting a quantitative approach. Three publications were either policy analyses or quality improvement reports.

Unit of analysis-level characteristics. Thirty-one percent (n=31) of the publications were concentrated on children reliant on home mechanical ventilation (HMV) and another 20% (n=20) concentrated on CMC with medical technology dependence (excluded CMC without technology). Another 27% (n=27) of publication included all CMC (with/without medical technology dependence) followed by children with special healthcare needs or children with disability (23%, n=23). Only 31 total publications collected language information and among those only 15 included patient-families with LEP. Race and ethnicity were reported in about two-thirds of publications with individual level data (63%, n=62).

Risk of Bias Within Studies and Across Studies

The ratings of the risk of bias across publications with quantitative and qualitative methods are summarized in Figures 2 and 3. The overall scores for quantitative publications (N=64) were universally weak primarily because of a lack of interventional studies with randomization. The strongest domain was data collection methods with a third of publications receiving a strong rating. The overall scores for the qualitative publications (N=42) were stronger with 10% (n=4) of publications receiving a strong score and 57% (n=24) receiving a moderate score. The qualitative publications tended to be strongest in theoretical approach, richness of analysis, and obtaining ethics approval. The overall quality of the evidence of children's access to home healthcare was graded as low for both quality and access to care.

Results Overview

Outcome scope. Half of the studies (54%, n=55) assessed outcomes related specifically to shift nursing followed by general home healthcare services (43%, n=44); only 3% (n=3) of studies focused solely on personal/home aide care. The body of literature measured outcomes not just of the pediatric patients themselves (84%, n=85) but also of their families (55%, n=56), providers (31%, n=31), and home healthcare agencies (6%, n=6).

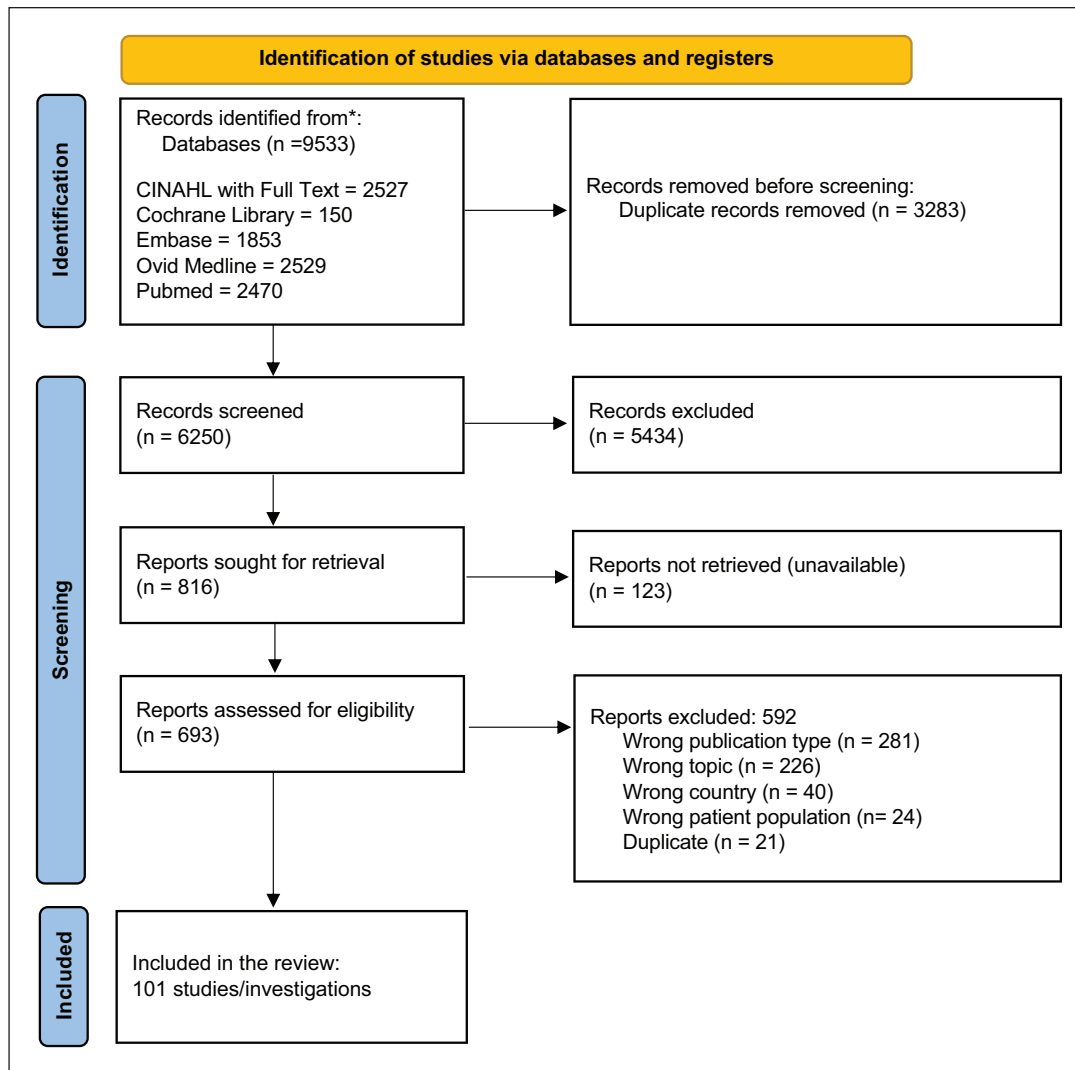


Figure 1. PRISMA flow diagram of study review.

Home healthcare access and quality domain examination. Specific domains addressed by each publication are shown in detail in Appendix B. Overall, the 2 most examined domains were *overall access* and *patient-family centeredness* in 73% (n=74) and 72% (n=73) of studies respectively (Figure 4). Only 17% (n=17) addressed *effectiveness* and 19% (n=19) evaluated *safety* or *timeliness* respectively. When home healthcare *equity* was addressed (11%, n= 11) it was primarily regarding focused on comparing care for English versus LEP patient-families.

Results Synthesis

Overall access and timeliness of home healthcare. Essentially all publications that attempted to assess home healthcare access found insufficient access to home healthcare to execute a child's plan of care.²⁰⁻³⁵ However, problems with access were evaluated in several different ways ranging from

insufficient hours received^{20,36} to also excessive provider turnover or no-showing for shifts.³⁷⁻⁴⁰ Most of the literature simply described the number of home healthcare hours delivered to patients.^{26,41-49} A few studies compared the hours patients actually received versus the hours allotted, as a means to analyze intended versus received care. In 1 in-depth cross-sectional survey of 38 family caregivers of children receiving in-home care, the gap in the average number of home nursing hours allotted versus received was 40 hours/week/family.⁵⁰ Also, the study assessed correlation between patient characteristics and gaps in home nursing access.

A few studies that the hours allocated to children requiring personal care and evaluated the variance among the population's allocated hours, finding that patient's health did not necessarily drive hour allocation.^{45,51,52} Specifically, patient needs and characteristics explained only 27% and 20% of the variance in personal care hours authorized in 2 Texas Medicaid studies; both finding that variability in the case

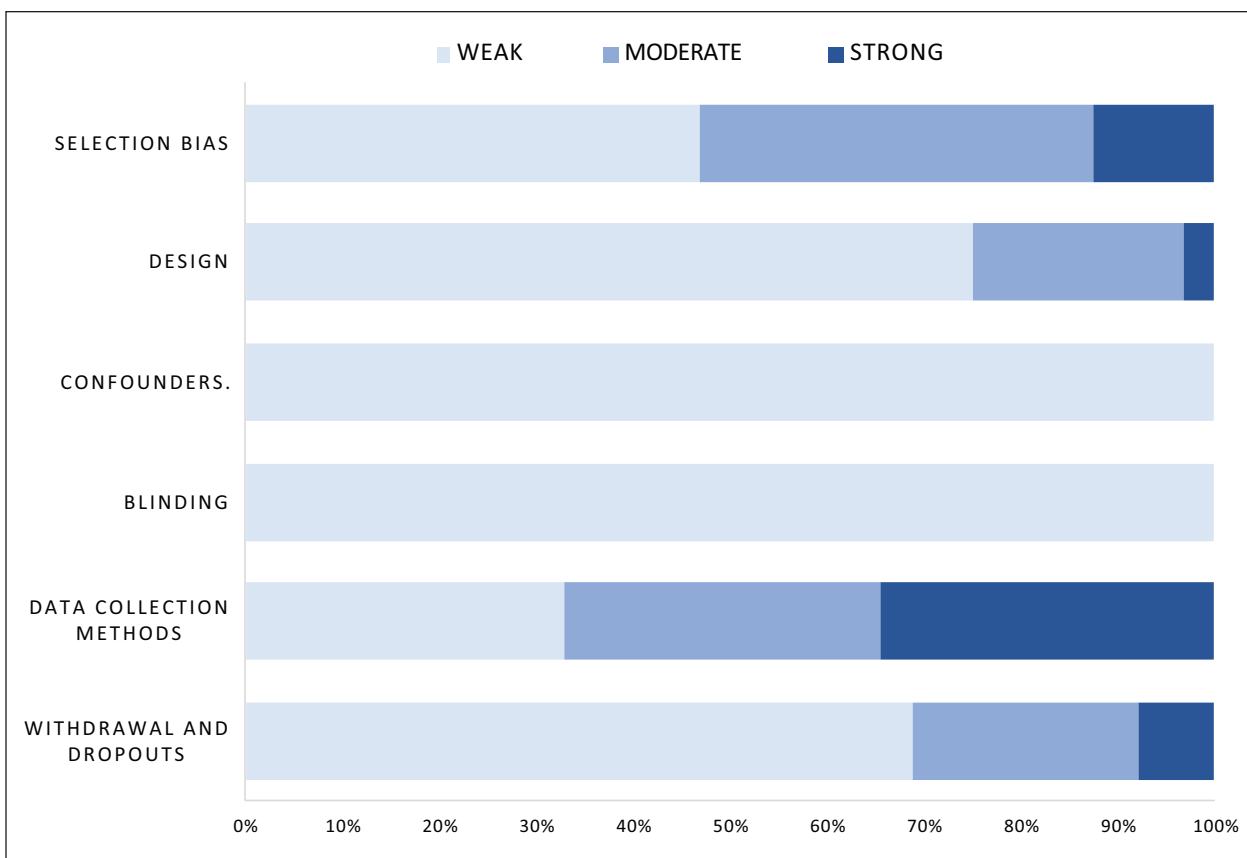


Figure 2. Quality assessment rating for quantitative studies in pediatric home healthcare.

Note. Bar graph shows proportion of studies (Total, N=64) with quantitative methods that received a weak, moderate or strong rating using the Quality Assessment Tool for Quantitative Studies, by category.

manager completing the assessment played a comparable role in hour determination.^{45,52}

Some studies assessed variation in home healthcare utilization as a measure of access. A retrospective cohort review of 2,423,031 pediatric discharges in the Kids' Inpatient Database showed that after case-mix adjustment, there was significant variation across states in home healthcare use (range, 0.4%-24.5%).⁴⁸ Another retrospective cohort evaluation of 88,139 commercially insured children, found that the adjusted probability of receiving post-hospitalization home nursing within 30 days varied substantially across states (3.4%-19.2%).⁵³

Studies also evaluated home healthcare access through the lens of hospital discharge delays.^{23,25,27,34,38,47,50,54-57} The most methodologically rigorous study was a multi-site prospective cohort study of 185 patients found that inadequate home healthcare nursing accounted for an average excess stay in the hospital of 53.9 days (range: 4-204) and 35.7 days (3-6) for new and existing patients, respectively.⁵⁷

Lastly, qualitative analyses and survey-based assessments were used to demonstrate that inconsistent and or complete lack of home healthcare access were associated with a negative impact on patient-family physical, mental, and financial well-being.^{21,29,50,58-61}

Efficiency of home healthcare. When efficiency was evaluated, it concentrated primarily on costs from the healthcare system perspective, consistently finding that home healthcare costs were substantially less than in-hospital or institutional care.^{21,55,62-64} A few studies did conduct assessments that considered family cost and found that home healthcare cost "savings" were often partly due to cost-shifting to families who were covering some or all of the medical labor costs^{20,21,62,65} and out-of-pocket expenses.^{22,32,44,58,66-68} Other studies quantified home healthcare proportionally within the patient's healthcare utilization.^{69,70} A few studies found that CMC with greater disability and medical technology dependence, especially those with neurologic impairment and respiratory equipment use, had the greatest utilization and cost.^{44,46,69,71,72}

Overall quality and effectiveness of home healthcare. Several publications used interviews and surveys to reported that home healthcare was essential to fully execute a child's health care plan,^{40,67,73-76} and that home healthcare was helpful for children's health, functioning, quality-of-life, and survival.^{11,59,67,77} Additionally, qualitative work identified that the lack of home nursing was a driver of readmissions in children with HMV.⁷⁸ Several qualitative studies raised

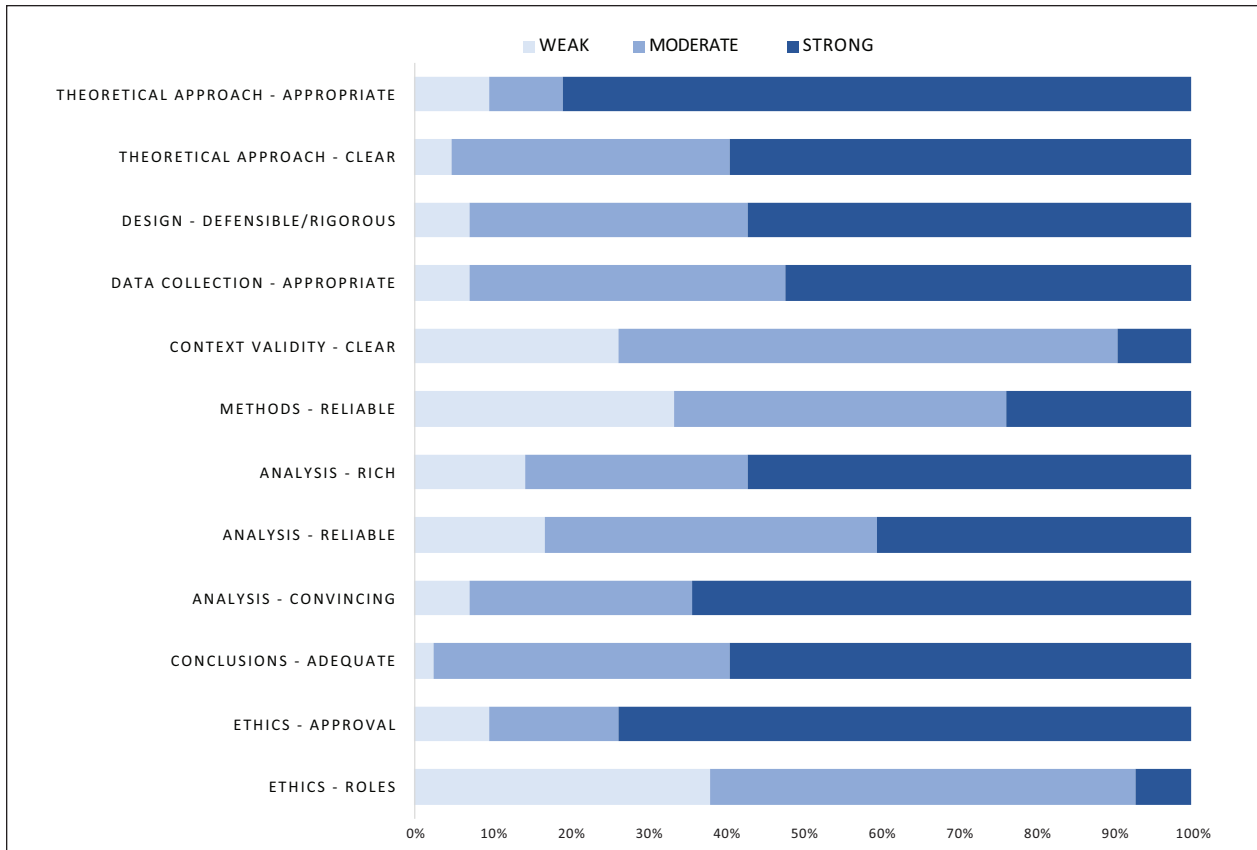


Figure 3. Quality assessment rating for qualitative studies in pediatric home healthcare. Note. Bar graph shows proportion of studies (Total, N=42) with qualitative methods that received a weak (-), moderate (+), or strong (++) rating using the National Institute for Health and Care Excellence’s methodology checklist, by domain and category.

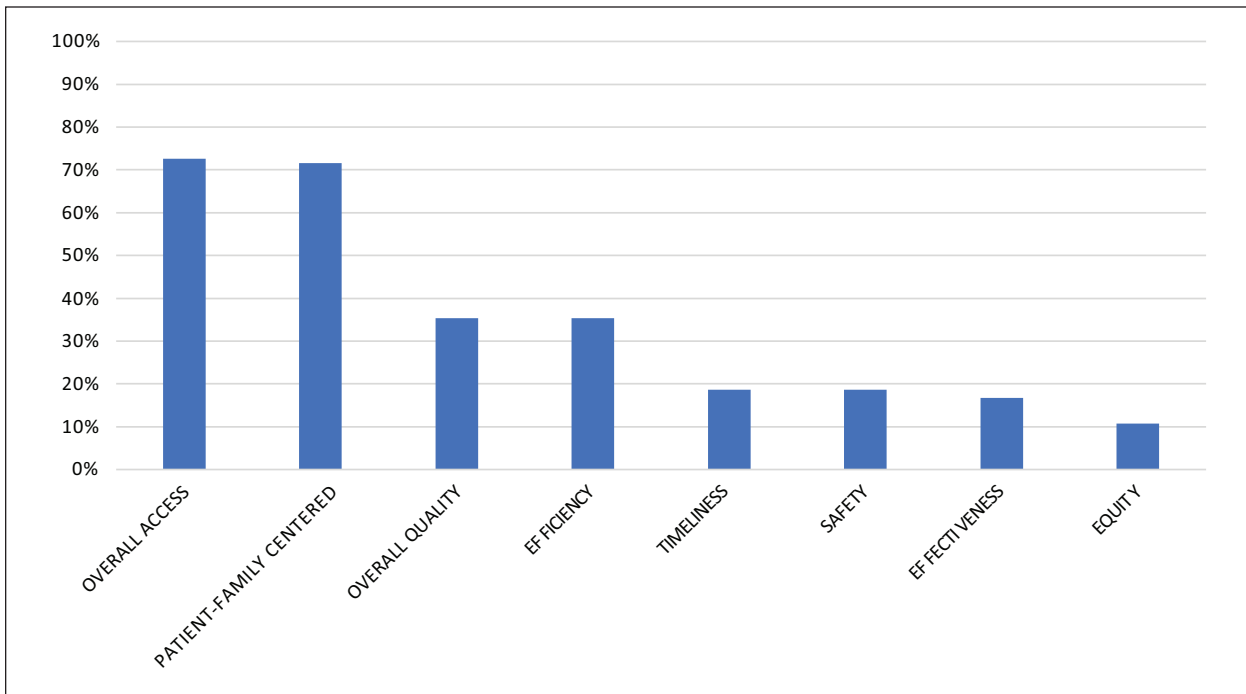


Figure 4. Proportion of publications addressing access and quality dimensions in pediatric home healthcare. Note. Bar graph shows proportion of studies (n = 101) that addressed overall access, overall quality, and any of the National Academy of Medicine quality dimensions (effectiveness, safety, patient-family centeredness, timeliness, equity, and efficiency).

concerned about overall quality of care in general terms.^{11,24,29,33,79-81} In these reports, skill in pediatric home healthcare was described as poor, specifically with regard to provider aptitude with different forms of medical technology^{11,21,27,47,79,80,82-84} but also with basic skills like hygiene and documentation.^{82,85} Some reporting described direct health consequences resulting from those documented skill gaps to include hospitalizations, emergency room visits, and need for medical procedures.^{11,38,79}

Only a few studies assessed quality in using a matched control group or with skill testing. A retrospective case-matched cohort study found that 30-day readmission rates were lower in 2783 home healthcare patients compared to 7631 match controls (18.3% vs 21.5%, $P=.001$) despite higher healthcare needs in those receiving home healthcare. A scenario-based test of home healthcare nurses' knowledge of how to respond to ventilation emergency scenarios, found that half of the 79 home nurses incorrectly answered all 4 of the scenarios and another quarter received low total scores.⁸⁶

Safety of home healthcare. A few studies enumerated mortality for children receiving care at home and showed no difference in deaths between patients cared for at home.^{63,74} Safety concerns were raised regarding poor communication between the home healthcare sector and the rest of the pediatric healthcare system, leading to concerns for medical error and delays in care.⁸⁷⁻⁸⁹ At least 1 study scrutinized overseeing agencies' lack of responsiveness and accountability for ensuring nurse expertise.⁴⁰ But, none of the studies performed surveillance and assessment of safety, and if safety was addressed, it was typically opinion-based and not quantitatively measured or addressing specific safety metrics.⁸⁷⁻⁹⁰

Patient-family centeredness of home healthcare. Patient-family centeredness was primarily assessed through qualitative interviews or focus groups. These studies documented relational challenges between home healthcare providers and family caregivers were identified regularly including conflicts related to privacy, communication, parenting-style, and medical management.^{28,33,36,40,43,66,76,83,91-97} However, some studies identified families as happy with their child's home healthcare care, and that home health nurses were a knowledgeable resource, even teachers, for families as they transitioned their child home.^{40,43,92,98} Positive relationships between parents and home nurses were identified as helpful at supporting the family's care experience and even reduced stress for parents and nurses alike.^{97,99} Descriptive findings suggested that home healthcare providers could engender trust, demonstrate respect, support the family and integrate into their routine while setting boundaries, and collaborate to provide effective care when adequately trained.^{93,100-102}

Equity of home healthcare. A few studies identified differences in referral patterns for families with LEP, including a

nationally representative study showed that Hispanic children were less likely to use home healthcare (3.3% vs 5.5%; OR, 0.8 [95% CI, 0.7-0.8]) compared with other children.^{48,103} This was replicated in another nationally represented survey-based study that showed families were more likely to provide their child's own home healthcare if they had children ages 0 to 5 years, were Hispanic, lived below the federal poverty level, and had no parents/guardians who had finished high school.⁶⁵

Discussion

This systematic review examining the research in pediatric home healthcare found that while the number of pediatric home healthcare studies has increased over 40 years, potentially due to an increase in pediatric survival with improved technology and expanded payment mechanisms. However, this literature base remains primarily descriptive, cross-sectional, regional, and often excluding patient-families with diverse perspectives. The existing body of research does raise significant concerns about inconsistent access to high-quality home healthcare at the expense of patient health and family wellbeing without much improvement over time. The reviewed studies, regardless of region, steadily reported that home nursing providers had inadequate skills for the level of care patients required, raising concerns about training and staffing models nationally. However, few studies evaluated fundamental dimensions of quality including effectiveness and safety.

Among the most commonly addressed topics was access and timeliness which consistently found problems with children being able to use home health care starting with determinations of eligibility through actual receipt of hours. However, no consistent metrics were used to allow comparison of hour receipt or timeliness. Efficiency was evaluated primarily in regard to cost but not in regard to other elements of home care such as provider turn-over or supply use. Only a fraction of the publications quantified home healthcare safety or effectiveness in keeping children well and out of the hospital, and virtually none evaluated whether specific elements of home healthcare can improve patient health outcomes, such as mortality or infection rates. The safety of care in the home appears largely unknown within the scholarly literature, despite family caregivers of CMC and their nurses often being discharged home with complex medication regimens,^{104,105} equipment and devices.^{106,107}

A concerted effort, conducted with a diversity of family partners, is needed to develop approaches to better understand where specific gaps in clinical management can be improved at home. Without better understanding of home healthcare effectiveness at preventing costly hospitalizations or how to reduce potential safety events in the home, states may continue to be incentivized to keep home healthcare eligibility thresholds high, despite being legally entitled services, and for healthcare systems to prioritize improvements to in-hospital care over in-home care.

This review highlights the lack of interventional studies designed to improve home healthcare. We urge a shift toward rigorous studies that can address known gaps. More specifically, we must move away from descriptive studies in favor of designing and testing new approaches to meaningfully address access and quality of home healthcare, developed through partnership with patient-families, providers systems, and payer stakeholders. These may include testing of new payment, training, staffing, and/or care delivery models.

Of note, while there was no comparable measure of access across the body of literature, this review raises fundamental questions about how states determine eligibility for home healthcare hours, allocate hours once approved, and then monitor receipt of hours to ensure children are receiving the care they need to achieve optimal health outcomes. Much like recent calls to improve data collection in long-term pediatric facilities,¹⁰⁸ this review highlights the need for systematic monitoring of home healthcare eligibility, receipt, and quality. This ideally includes metrics that can be reproducibly measured across healthcare systems for benchmarking.

Lastly, we would like to highlight that many studies investigated outcomes relevant to family and providers' well-being which are often overlooked in other healthcare sector analyses. The results underscore how failing to provide pediatric home healthcare not only affects children's health, but also that of their families. However, the reviewed studies typically excluded the experiences of diverse patient-families especially those with LEP. Future work investigating home healthcare should be considered incomplete if not representative of the children eligible for and accessing home healthcare; because, all patient-families have a right to high-quality and accessible home healthcare .

Limitations

As with any systematic review, eligible studies that should have been included may have been unintentionally excluded or unavailable. Data extraction is at risk of error or omission and abstract exclusion review was not included. However, using a double blinded review and conducting the search in both medical and nursing databases minimized these possibilities. Given the heterogeneity of study designs within the review's scope, evaluation of effective measures was not conducted. Future comparison in a narrower group of studies may inform measure development and monitoring. We also recognize the potential for additional information regarding home healthcare quality may be present in the training literature that was excluded from this review. Additionally, comparison of literature over the course of 40 years may have resulted in capturing out of date views on home care that are not necessarily relevant to today's systems of care. Future work should consider what is known about how training might improve the quality of pediatric home healthcare. Lastly, by excluding patients from age 19 to 21 years-of-age, we have limited insights into how the access and quality of care may differ during the transitional age.

Conclusions

This systematic review assesses the peer-reviewed literature evaluating access and quality of pediatric home healthcare in the last forty years. The existing evidence base, though weak in rigor, has produced increasingly more studies to suggest pediatric home healthcare access and quality remain highly inadequate in both number of hours served to patients and the provider skill level to care for children with complex medical needs. More rigorous research and accountability for existing policy and legal frameworks, including metric development, are needed to improve this healthcare sector for diverse patient-families.

Author Contribution

C.F. conceptualized the review, established review design, conducted abstract and full text review, performed quality review, and drafted the manuscript. L.M. conducted abstract and full text review, contributed to review design, performed quality review, and contributed to manuscript drafting. A.F. contributed to review design, conducted the literature search, and drafted the manuscript. C.C. conceptualized the review, contributed to review design, conducted abstract review, contributed to full text review, and drafted the manuscript.

Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Dr. Foster has received compensation for medical record consultation and/or expert witness testimony. The remaining authors have nothing to disclose.

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Supplemental Material

Supplemental material for this article is available online.

References

1. Perkins J, Agrawal R. Protecting Rights of children with medical complexity in an era of spending reduction. *Pediatrics*. 2018;141(Supplement_3):S242-s249. doi:10.1542/peds.2017-1284I
2. United States Department of Justice Civil Rights Division. About Olmstead. Accessed May 27, 2022. <https://www.ada.gov/olmstead/>.

3. Adams S, Nicholas D, Mahant S, et al. Care maps for children with medical complexity. *Dev Med Child Neurol*. 2017;59(12):1299-1306. doi:10.1111/dmcn.13576
4. Simpser E, Hudak ML. Financing of Pediatric Home Health Care. *Pediatrics*. 2017;139(3):1-6 doi:10.1542/peds.2016-4202
5. Libby R, Imaizumi S. *Guidelines for Pediatric Home Health Care*, 2nd ed. Academy of Pediatrics Section on Home Care; 2009.
6. Coller RJ, Berry JG, Kuo DZ, et al. Health System Research Priorities for children and Youth with Special Health Care needs. *Pediatrics*. 2020;145:e20190673. doi:10.1542/peds.2019-0673
7. A National Research Agenda for Children and Youth with Special Health Care Needs. Children and Youth with Special Health Care Needs National Research Network. Accessed March 9th, 2023. <https://cyshcnet.org/national-research-agenda/>.
8. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;74:790-799. doi:10.1016/j.rec.2021.07.010
9. *Covidence systematic review software*. Veritas Health Innovation. www.covidence.org
10. Institute of Medicine Committee on Monitoring Access to Personal Health Care Services. (1993). *Access to Health Care in America*. National Academies Press. <https://www.ncbi.nlm.nih.gov/books/NBK235882/>.
11. Foster CC, Fuentes MM, Wadlington LA, et al. Caregiver and provider experiences of home healthcare quality for children with medical complexity. *Home Healthc*. 2020;38:138-146. doi:10.1097/NHH.0000000000000857
12. Institute of Medicine Committee on Quality of Health Care in A. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academies Press (US) Copyright 2001 by the National Academy of Sciences. All rights reserved.
13. Millenson ML, Shapiro E, Greenhouse PK, DiGioia AM III. Patient- and family-centered care: A systematic approach to better ethics and Care. *AMA J Ethics*. 2016;18(1):49-55. doi:10.1001/journalofethics.2017.18.1.stas1-1601
14. Jindal M, Mistry KB, Trent M, McRae A, Thornton RLJ. Police exposures and the health and well-being of Black Youth in the US: a systematic review. *JAMA Pediatr*. 2022;176:78. doi:10.1001/jamapediatrics.2021.2929
15. Stern C, Lizarondo L, Carrier J, et al. Methodological guidance for the conduct of mixed methods systematic reviews. *JBI Evid Implement*. 2021;19(2):120-129. doi:10.1097/xe.0000000000000282
16. Thomas BH, Ciliska D, Dobbins M, Micucci S. A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. *Worldviews Evid Based Nurs*. 2004;1(3):176-184. doi:10.1111/j.1524-475X.2004.04006.x
17. Armijo-Olivo S, Stiles CR, Hagen NA, Biondo PD, Cummings GG. Assessment of study quality for systematic reviews: a comparison of the Cochrane collaboration risk of bias tool and the effective public health practice project quality assessment tool: methodological research. *J Eval Clin Pract*. 2012;18(1):12-18. doi:10.1111/j.1365-2753.2010.01516.x
18. National Institute for Health and Care Excellence (NICE). (2016). *The Social Care Guidance Manual*. National Institute for Health and Care Excellence (NICE). Copyright © 2016 National Institute for Health and Clinical Excellence, unless otherwise stated. All rights reserved.
19. Guyatt G, Oxman AD, Akl EA, et al. GRADE guidelines: 1. Introduction-GRADE evidence profiles and summary of findings tables. *J Clin Epidemiol*. 2011;64(4):383-394. doi:10.1016/j.jclinepi.2010.04.026
20. Splaingard ML, Frates Re Jr, Harrison GM, Carter RE, Jefferson LS. Home positive-pressure ventilation. Twenty years' experience. *Chest*. 1983;84(4):376-382. doi:10.1378/chest.84.4.376
21. Hazlett DE. A study of pediatric home ventilator management: medical, psychosocial, and financial aspects. *J Pediatr Nurs*. 1989;4(4):284-294. doi:citation1989/08/01 00:00Hazlett DE
22. Quint RD, Chesterman E, Crain LS, Winkleby M, Boyce WT. Home care for ventilator-dependent children: psychosocial impact on the family. *Am J Dis Child*. 1990;144(11):1238-1241. doi:10.1001/archpedi.1990.02150350070028
23. Millner BN. Technology-dependent children in New York State. *Bull N Y Acad Med*. 1991;67(2):131-142. doi:citation1991/03/01 00:00Millner BN
24. Hollingsworth J. Service needs of children with disabilities and their families. *J Paediatr Child Health*. 1992;28(4):283-285. doi:10.1111/j.1440-1754.1992.tb02667.x
25. DeWitt PK, Jansen MT, Ward SL, Keens TG. Obstacles to discharge of ventilator-assisted children from the hospital to home. *Chest*. 1993;103(5):1560-1565. doi:10.1378/chest.103.5.1560
26. Nelson VS, Carroll JC, Hurvitz EA, Dean JM. Home mechanical ventilation of children. *Dev Med Child Neurol*. 2008;38(8):704-715. doi:10.1111/j.1469-8749.1996.tb12140.x
27. Jardine E, O'Toole M, Paton JY, Wallis C. Current status of long term ventilation of children in the United Kingdom: questionnaire survey. *BMJ*. 1999;318(7179):295-299. doi:10.1136/bmj.318.7179.295
28. Kirk S, Glendinning C. Developing services to support parents caring for a technology-dependent child at home. *Child Care Health Dev*. 2004;30(3):209-218. doi:10.1111/j.1365-2214.2004.00393.x
29. Neuss J. (2004). Mothers as primary caregivers for their technology-dependent children at home: a qualitative study (Ph.D.):181.
30. Warfield ME, Gulley S. Unmet need and problems accessing specialty medical and related services among children with special health care needs. *Matern Child Health J*. 2006;10(2):201-216. doi:10.1007/s10995-005-0041-3
31. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges of more-complex children with special health care needs. *Arch Pediatr Adolesc Med*. 2011;165(11):1020-1026. doi:10.1001/archpediatrics.2011.172
32. Seear M, Kapur A, Wensley D, Morrison K, Behroozi A. The quality of life of home-ventilated children and their primary caregivers plus the associated social and economic burdens: A prospective study. *Arch Dis Child*. 2016;101(7):620-627. doi:10.1136/archdischild-2015-309796
33. Edwards JD, Morris MC, Nelson JE, Panitch HB, Miller RL. Decisions around long-term ventilation for children.

- Perspectives of directors of pediatric home ventilation programs. *Ann Am Thorac Soc*. 2017;14(10):1539-1547. doi:10.1513/AnnalsATS.201612-1002OC
34. Sobotka SA, Foster C, Lynch E, Hird-McCorry L, Goodman DM. Attributable delay of discharge for children with long-term mechanical ventilation. *J Pediatr*. 2019;212:166-171. doi:10.1016/j.jpeds.2019.04.034
 35. Andrews MM, Nielson DW. Technology dependent children in the home. *Pediatr Nurs*. 1988;14(2):111-151.
 36. Baumgardner DJ, Burtea ED. Quality-of-life in technology-dependent children receiving home care, and their families—a qualitative study. *Wis Med J*. 1998;97(8):51-55. doi:citation1998/09/01 00:00Baumgardner DJ
 37. Nageswaran S, Golden SL. Factors associated with stability of health nursing services for children with medical complexity. *Home Healthc*. 2017;35(8):434-444. doi:10.1097/NHH.0000000000000583
 38. Foster CC, Jacob-Files E, Arthur KC, Hillman SA, Edwards TC, Mangione-Smith R. Provider perspectives of high-quality pediatric hospital-to-home transitions for children and youth with chronic disease. *Hosp Pediatr*. 2017;7(11):649-659. doi:10.1542/hpeds.2017-0031
 39. Toly VB, Blanchette JE, Musil CM. Mothers caring for technology-dependent children at home: What is most helpful and least helpful? *Appl Nurs Res*. 2019;46:24-27. doi:10.1016/j.apnr.2019.02.001
 40. Mai K, Davis RK, Hamilton S, Robertson-James C, Calaman S, Turchi RM. Identifying caregiver needs for children with a tracheostomy living at home. *Clin Pediatr*. 2020;59(13):1169-1181. doi:10.1177/0009922820941209
 41. Clemens CJ, Davis RL, Novack AH, Connell FA. Pediatric home health care in King County, Washington. *Pediatrics*. 1997;99(4):581-584. doi:10.1542/peds.99.4.581
 42. Cramp C, Tripp S, Dale J. Children's home nursing: results of a national survey. *Paediatr Nurs*. 2003;15(8):39-43. doi:10.7748/ paed2003.10.15.8.39.c879
 43. Margolan H, Fraser J, Lenton S. Parental experience of services when their child requires long-term ventilation. Implications for commissioning and providing services. *Child Care Health Dev*. 2004;30(3):257-264. doi:10.1111/j.1365-2214.2004.00414.x
 44. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics*. 2004;114(1):79-85. doi:10.1542/peds.114.1.79
 45. Elliott TR, Phillips CD, Patnaik A, et al. Medicaid personal care services and caregivers' reports of children's health: the dynamics of a relationship. *Health Serv Res*. 2011;46(6pt1):1803-1821. doi:10.1111/j.1475-6773.2011.01284.x
 46. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttman A. Patterns and costs of health care use of children with medical complexity. *Pediatrics*. 2012;130(6):e1463-e1470. doi:10.1542/peds.2012-0175
 47. Amin R, Sayal A, Syed F, et al. How long does it take to initiate a child on long-term invasive ventilation? Results from a Canadian pediatric home ventilation program. *Can Respir J*. 2015;22(2):103-108. doi:10.1155/2015/107914
 48. Berry JG, Hall M, Dumas H, et al. Pediatric hospital discharges to home health and postacute facility care: A national study. *JAMA Pediatr*. 2016;170(4):326-333. doi:10.1001/jamapediatrics.2015.4836
 49. Raisanen JC, Ruth A, Donohue PK, et al. Paying for Pediatric Home Health Care: How Families of children with medical complexity navigate gaps in coverage. *Fam Community Health*. 2021;44:184-193. doi:10.1097/FCH.0000000000000300
 50. Weaver MS, Wichman B, Bace S, et al. Measuring the impact of the home health nursing shortage on family caregivers of children receiving palliative care. *J Hospice Palliat Nurs*. 2018;20(3):260-265. doi:10.1097/NJH.0000000000000436
 51. Adepoju OE, Zhang Y, Phillips CD. Modeling the determinants of Medicaid home care payments for children with special health care needs: A structural equation model approach. *Disabil Health J*. 2014;7(4):426-432. doi:10.1016/j.dhjo.2014.05.003
 52. Patnaik A, Elliott TR, Moudouni DM, et al. Severity of children's intellectual disabilities and medicaid personal care services. *Rehabil Psychol*. 2011;56(4):383-390. doi:10.1037/a0025619
 53. Rasooly IR, Shults J, Guevara JP, Feudtner C. State variation in posthospital home nursing for commercially insured medically complex children. *Pediatrics*. 2020;146(2):1-8. doi:10.1542/peds.2019-2465
 54. Noyes JANE. Barriers that delay children and young people who are dependent on mechanical ventilators from being discharged from hospital. *J Clin Nurs*. 2002;11(1):2-11. doi:10.1046/j.1365-2702.2002.00565.x
 55. Noyes J, Godfrey C, Beecham J. Resource use and service costs for ventilator-dependent children and young people in the UK. *Health Soc Care Community*. 2006;14(6):508-522. doi:10.1111/j.1365-2524.2006.00639.x
 56. Graf JM, Montagnino BA, Hueckel R, McPherson ML. Children with new tracheostomies: planning for family education and common impediments to discharge. *Pediatr Pulmonol*. 2008;43(8):788-794. doi:10.1002/ppul.20867
 57. Maynard R, Christensen E, Cady R, et al. Home health care availability and discharge delays in children with medical complexity. *Pediatrics*. 2019;143(1):1-9. doi:10.1542/peds.2018-1951
 58. Edwards JD, Panitch HB, Constantinescu A, Miller RL, Stone PW. Survey of financial burden of families in the U.S. with children using home mechanical ventilation. *Pediatr Pulmonol*. 2018;53(1):108-116. doi:10.1002/ppul.23917
 59. Caicedo C. Health and functioning of families of children with special health care needs cared for in home care, long-term care, and Medical Day Care Settings. *J Dev Behav Pediatr*. 2015;36(5):352-361. doi:10.1097/dbp.0000000000000167
 60. Hefner JL, Tsai WC. Ventilator-dependent children and the health services system. Unmet needs and coordination of care. *Ann Am Thorac Soc*. 2013;10(5):482-489. doi:10.1513/AnnalsATS.201302-036OC
 61. Meltzer LJ, Boroughs DS, Downes JJ. The relationship between home nursing coverage, sleep, and daytime functioning in parents of ventilator-Assisted Children. *J Pediatr Nurs*. 2010;25(4):250-257. doi:10.1016/j.pedn.2009.01.007
 62. Burr BH, Guyer B, Todres ID, Abrahams B, Chiodo T. Home care for children on respirators. *New Engl J Med*. 1983;309(21):1319-1323. doi:10.1056/NEJM198311243092112
 63. Frates Rc Jr., Splaingard ML, Smith EO, Harrison GM. Outcome of home mechanical ventilation in children. *J Pediatr*. 1985;106(5):850-856. doi:10.1016/s0022-3476(85)80372-3

64. Fields AI, Rosenblatt A, Pollack MM, Kaufman J. Home care cost-effectiveness for respiratory technology-dependent children. *Am J Dis Child.* 1991;145(7):729-733. doi:citation1991/07/01 00:00Fields AI
65. Romley JA, Shah AK, Chung PJ, Elliott MN, Vestal KD, Schuster MA. Family-provided health care for children with Special Health Care needs. *Pediatrics.* 2017;139(1):19-19. doi:10.1542/peds.2016-1287
66. Hock-Long LE. (1997). Pediatric home ventilator care: family caregivers' perspectives (Ph.D.):231.
67. Boss RD, Raisanen JC, Detwiler K, et al. Lived Experience of pediatric home health care among families of children with medical complexity. *Clin Pediatr.* 2020;59(2):178-187. doi:10.1177/0009922819894006
68. Nonoyama M, Katz S, Amin R, et al. Healthcare utilization and costs of pediatric home mechanical ventilation in Canada. *Eur Respir J.* 2019; 9: 54. doi:10.1183/13993003.congress-2019; 9:PA1043
69. Ireys HT, Anderson GF, Shaffer TJ, Neff JM. Expenditures for care of children with chronic illnesses enrolled in the Washington State Medicaid program, fiscal year 1993. *Pediatrics.* 1997;100(2 Pt 1):197-204. doi:10.1542/peds.100.2.197
70. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff.* 2014;33(12):2199-2206. doi:10.1377/hlthaff.2014.0828
71. Berry JG, Goodman DM, Coller RJ, et al. Association of home respiratory equipment and supply use with health care resource utilization in children. *J Pediatr.* 2019;207:169-169. doi:10.1016/j.jpeds.2018.11.046
72. Kim J, Stevens P, Carbone PS, Jones KB. Health Care Use and spending of pediatric patients with an intellectual or developmental disability. *Med Care.* 2020;58(5):468-473. doi:10.1097/MLR.0000000000001293
73. Griffin Agazio J. Family transition through the termination of private duty home care nursing. *J Pediatr Nurs.* 1997;12(2):74-84. doi:10.1016/s0882-5963(97)80027-9
74. Fields AI, Coble DH, Pollack MM, Kaufman J. Outcome of home care for technology-dependent children: success of an independent, community-based case management model. *Pediatr Pulmonol.* 1991;11(4):310-317. doi:10.1002/ppul.1950110407
75. Zollinger TW, Saywell RM Jr, Smith MA, Robinson RL, Knudson NE. Indiana Children's Special Health Care Services program: Impact of administrative changes on health care utilization, access to care, and unmet needs. *Child Health Care.* 1999;28(4):349-364. doi:10.1207/s15326888chc2804_5
76. Wang KW, Barnard A. Caregivers' experiences at home with a ventilator-dependent child. *Qual Health Res.* 2008;18(4):501-508. doi:10.1177/1049732307306185
77. Baldwin-Myers AS, Oppenheimer EA. Quality of life and quality of care data from a 7-year pilot project for home ventilator patients. *J Ambul Care Manag.* 1996;19(1):46-59. doi:10.1097/00004479-199601000-00005
78. 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):1474-1480. doi:10.1002/ppul.24744
79. Nageswaran S, Golden SL. Improving the quality of home health care for children with medical complexity. *Acad Pediatr.* 2017;17(6):665-671. doi:10.1016/j.acap.2017.04.019
80. Roque N, Walls N, Vargas-Friere L, Patel A. A Qi approach to challenges in home care for families of tracheostomy-dependent children. *Am J Respir Crit Care Med.* 2019;199(9):1. doi:10.1164/ajrccm-conference.2019.199.1_meetingabstracts.a3590
81. Amar-Dolan LG, Horn MH, O'Connell B, 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):860-868. doi:10.1513/AnnalsATS.201910-780OC
82. Scharer K, Dixon DM. Managing chronic illness: parents with a ventilator-dependent child. *J Pediatr Nurs.* 1989;4(4):236-247. doi:citation1989/08/01 00:00Scharer K
83. Kirk S, Glendinning C. Supporting 'expert' parents—professional support and families caring for a child with complex health care needs in the community. *Int J Nurs Stud.* 2002;39(6):625-635. doi:10.1016/s0020-7489(01)00069-4
84. Parker G, Spiers G, Cusworth L, Birks Y, Gridley K, Mukherjee S. Care closer to home for children and young people who are ill: developing and testing a model of service delivery and organization. *J Adv Nurs.* 2012;68(9):2034-2046. doi:10.1111/j.1365-2648.2011.05893.x
85. Peacock J, Stanik-Hutt J. Translating best care practices to improve nursing documentation regarding pediatric patients dependent on home mechanical ventilation and tracheostomy tube support: a quality improvement initiative. *Home Healthc Nurse.* 2013;31(1):10-17. doi:10.1097/NHH.0b013e3182778e8b
86. Kun SS, Beas VN, Keens TG, Ward SS, Gold JI. Examining pediatric emergency home ventilation practices in home health nurses: opportunities for improved care. *Pediatr Pulmonol.* 2015;50(7):691-697. doi:10.1002/ppul.23040
87. Berry JG, Goldmann DA, Mandl KD, et al. Health information management and perceptions of the quality of care for children with tracheotomy: a qualitative study. *BMC Health Serv Res.* 2011;11(1):117-117. doi:10.1186/1472-6963-11-117
88. Nageswaran S, Sebesta MR, Golden SL. Transitioning children with medical complexity from hospital to home health care: Implications for hospital-based clinicians. *Hosp Pediatrics.* 2020;10(8):657-662. doi:10.1542/hpeds.2020-0068
89. Nageswaran S, Golden SL. Home Health Nurse collaboration in the medical neighborhood of children with medical complexity. *Home Healthc.* 2016;34(9):507-518. doi:10.1097/NHH.0000000000000463
90. Kanady JA. (1990). Chronically ill children: perceptions of the nurses who provide their care at home and in the hospital (Ph.D.):153.
91. Coffman S. Crossing lines: parents' experiences with pediatric nurses in the home. *Rehab Nurs Res.* 1995;4(4):136-143.
92. Sharkey T. The effects of uncertainty in families with children who are chronically ill. *Home Healthc Nurse.* 1995;13(4):37-42. doi:10.1097/00004045-199507000-00006
93. Coffman S. Home-care nurses as strangers in the family. *West J Nurs Res.* 1997;19(1):82-96. doi:10.1177/019394599701900106
94. (2001). Sarvey SLI. Living with a machine: the experience of the child who is ventilator-dependent (Ph.D.):134.
95. O'Brien ME, Wegner CB. Rearing the child who is technology dependent: perceptions of parents and home care nurses. *J Spec Pediatr Nurs.* 2002;7(1):7-15. doi:10.1111/j.1744-6155.2002.tb00143.x

96. Manhas KP, Mitchell I. (Dis)-Trust in transitioning ventilator-dependent children from hospital to homecare. *Nurs Ethics*. 2015;22(8):913-927. doi:10.1177/0969733014551598
97. Nageswaran S, Golden SL. Establishing relationships and navigating boundaries when caring for children with medical complexity at home. *Home Healthc*. 2018;36(2):93-102. doi:10.1097/NHH.0000000000000636
98. Joffe PD. (1998). African-American, Hispanic, and Caucasian parents' perception and management of chronically ill children in the home (Ph.D.):199.
99. Patterson JM, Jernell J, Leonard BJ, Titus JC. Caring for medically fragile children at home: the parent-professional relationship. *J Pediatr Nurs*. 1994;9(2):98-106. doi:citation1994/04/01 00:00Patterson JM
100. McIntosh J, Runciman P. Exploring the role of partnership in the home care of children with special health needs: qualitative findings from two service evaluations. *Int J Nurs Stud*. 2008;45(5):714-726. doi:10.1016/j.ijnurstu.2006.12.012
101. Mendes M. Pediatric Nurses' views of ideal home nursing care for technology-dependent children. *Home Healthc Nurse*. 2013;31(8):412-418. doi:10.1097/nhh.0b013e3182a1dbee
102. Mendes MA. Parents' descriptions of ideal home nursing care for their technology-dependent children. *Pediatr Nurs*. 2013;39(2):91-96.
103. Levas MN, Cowden JD, Dowd MD. Effects of the limited english proficiency of parents on hospital length of stay and home health care referral for their home health care - Eligible children with infections. *Arch Pediatr Adolesc Med*. 2011;165(9):831-836. doi:10.1001/archpediatrics.2011.61
104. Feinstein JA, Orth LE. Making polypharmacy safer for children with medical complexity. *J Pediatr*. 2023;254:4-10. doi:10.1016/j.jpeds.2022.10.012
105. Feinstein JA, Friedman H, Orth LE, et al. Complexity of medication regimens for children with neurological impairment. *JAMA Netw Open*. 2021;4(8):e2122818. doi:10.1001/jamanetworkopen.2021.22818
106. Barton HJ, Coller RJ, Loganathar S, et al. Medical device workarounds in providing care for children with medical complexity in the Home. *Pediatrics*. 2021;147(5): 1-10. doi:10.1542/peds.2020-019513
107. Barton HJ, Pflaster E, Loganathar S, et al. What makes a home? Designing home personas to represent the homes of families caring for children with medical complexity. *Appl Ergon*. 2023;106:103900. doi:10.1016/j.apergo.2022.103900
108. Alon L, Boss RD, Seltzer R. Long-term Care for children with medical complexity: a call for data. *Pediatrics*. 2022;149:e2021054952. doi:10.1542/peds.2021-054952