

HHS Public Access

Author manuscript *Pediatrics.* Author manuscript; available in PMC 2023 February 01.

Published in final edited form as:

Pediatrics. 2022 February 01; 149(2): . doi:10.1542/peds.2021-050534.

Home Health Care Utilization in Children With Medicaid

Sarah A. Sobotka, MD, MSCP^a, David E. Hall, MD^b, Cary Thurm, PhD^c, James Gay, MD, MMHC^b, Jay G. Berry, MD, MPH^d

^aDepartment of Pediatrics, Section of Developmental and Behavioral Pediatrics, University of Chicago, Chicago, Illinois

^bMonroe Carell Jr, Children's Hospital at Vanderbilt, Department of Pediatrics, Vanderbilt University School of Medicine, Nashville, Tennessee

°Children's Hospital Association, Lenexa, Kansas

^dDepartment of Pediatrics, Division of General Pediatrics, Complex Care Service, Boston Children's Hospital, Department of Pediatrics, Harvard Medical School, Boston, Massachusetts

Abstract

BACKGROUND: Although many children with medical complexity (CMC) use home health care (HHC), little is known about all pediatric (HHC), utilizers. Our objective was to assess characteristics of pediatric HHC recipients, providers, and payments.

METHODS: We conducted a retrospective analysis of 5 209 525 children age 0-to-17 years enrolled Medicaid in the 2016 IBM Watson MarketScan Medicaid Database. HHC utilizers had \$1HHC claim. Healthcare Common Procedure Coding System (HCPCS) and Current Procedural Terminology (CPT) codes were reviewed to codify provider types when possible: registered nurse (RN), licensed practical nurse (LPN), home health aide (HHA), certified nursing assistant (CNA), or companion/personal attendant. Enrollee clinical characteristics, HHC provider type, and payments were assessed. Chronic conditions were evaluated with Agency for Healthcare Research and Quality's Chronic Condition Indicators and Feudtner's Complex Chronic Conditions.

RESULTS: Of the 0.8% of children who used HHC, 43.8% were age <1 year, 25% had no chronic condition, 38.6% had a noncomplex chronic condition, 21.5% had a complex chronic condition without technology assistance, and 15.5% had technology assistance (eg, tracheostomy). HHC for children with technology assistance accounted for 72.6% of all HHC spending. Forty-five percent of HHC utilizers received RN/LPN-level care, 7.9% companion/personal

Address correspondence to Sarah A. Sobotka, MD, MSCP, Department of Pediatrics, Section of Developmental and Behavioral Pediatrics University of Chicago, Chicago 950 E. 61st St Suite 207 Chicago, IL 60637. ssobotka@peds.bsd.uchicago.edu. Dr Sobotka participated in the study concept and design, interpretation of results, and drafting of the manuscript, and orchestrated the critical revision of the manuscript by all coauthors; Dr Hall participated in the study concept and design, data analysis and interpretation, and the writing and critical revision of the manuscript; Dr Thurm had full access to all data in the study and is responsible for the integrity of the data and the accuracy of the data analysis. He participated in the study concept and design, data analysis and interpretation, and the drafting and critical revision of the manuscript; Dr Gay participated in the study concept and design, data analysis and interpretation, and the writing and critical revision of the manuscript; Dr Berry participated in the study concept and design, data analysis and interpretation, and the writing and critical revision of the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

CONFLICT OF INTEREST DISCLOSURES: The authors have indicated they have no conflicts of interest relevant to this article to disclose

attendant care, 5.9% HHA/CNA-level care, and 36% received care from an unspecified provider. For children with technology assistance, the majority (77.2%) received RN/LPN care, 17.5% companion/personal assistant care, and 13.8% HHA/CNA care.

CONCLUSIONS: Children using HHC are a heterogeneous population who receive it from a variety of providers. Future investigations should explore the role of nonnurse caregivers, particularly with CMC.

Pediatric home health care (HHC) is an essential but understudied health service sector for children with medical complexity (CMC) living in the community.¹ HHC has been shown to optimize the health and well-being of children and families who rely on it through direct health care delivery, support of parent caregivers, and coordination of care.² Without adequate HHC many children with complexity would otherwise experience more health care utilization errors, be hospitalized for longer periods of time, be readmitted to the hospital, or would be forced to enter institutional care.^{3–6} CMC receiving HHC have less inpatient costs and are less likely to be readmitted than children without HHC.^{7,8} However, ubiquitous shortages in HHC may exist because the supply of HHC providers does not match patient demand, which may be increasing over time.⁹ Consequently, the responsibility for nursing care for children falls squarely on family caregivers, to the detriment of their employment, health, and overall well-being.^{10–19} These HHC shortages differ regionally. Staffing availability combined with heterogeneity in scope of practice and changing labor market conditions likely contribute to wide variability observed in home HHC use.^{20–22}

HHC encompasses a wide range of activities, including, but not limited to, assistance with activities of daily living, measurement of weight and vital signs, administration of medications, and physical examination. HHC can be delivered in a variety of ways, including brief intermittent nursing visits to the home (eg, one visit for a weight check of a newborn) and long-term, repeated visits to the home (eg, 24-hour daily comprehensive care giving for a child with a tracheostomy and home mechanical ventilation). HHC is provided by a variety of health care professionals and persons, including registered nurse (RN), licensed practical nurse (LPN), home health aide (HHA), certified nursing assistant (CNA), and nonnursing trained caregivers often referred to as companions or personal attendants. We acknowledge that important inhome services are also provided by therapists, such as physical or occupational therapists. We did not include therapists in this analysis of HHC.

Despite its critical nature, HHC remains severely understudied in children. Most studies on HHC have been limited to CMC.^{11,23,24} Further, many studies are limited to skilled nursing or presumed skilled nursing (RN and LPN). Contributions of nonnurse caregivers in HHC are less well known, although existing reports suggest benefit in reducing overall other health care payments²⁵ and international cohorts suggest the potential for critical support for complex children.^{26,27}

To address the gaps in our understanding of HHC, we sought to describe the landscape of HHC utilization, with attention to both recipient and provider characteristics. Our objectives were to describe the characteristics of HHC recipients, providers, and payments.

METHODS

Study Design, Setting, and Population

This was a retrospective analysis of the 2016 IBM Watson *MarketScan Medicaid Database* (Truven Healthcare Analytics, Ann Arbor, MI), a proprietary database of a large sample of paid medical and prescription drug claims from dispersed, undisclosed, and indistinguishable Medicaid state contributors. Data from 2016 was the most current year available to the study team. This database is constructed from raw data with data element names and values standardized to enable analysis. An advantage of this database is that it provides data on Medicaid payments for services rather than billing or charge information. This database has been used previously in analyses of health services.^{28,29} This study of deidentified health administrative data were not considered human subjects research in accordance with the policies of the University of Chicago institutional review board.

Patient Demographic and Clinical Characteristics

Enrollee age, sex, and race and ethnicity were assessed. Type of chronic condition was also assessed by using the array of ICD-10 diagnosis codes from health care claims across the care continuum: (1) none, (2) noncomplex chronic conditions (non-CCC), (3) complex chronic condition (CCC) without technology assistance, and (4) technology assistance.

CCCs were first classified with Feudtner and colleagues system (v2) and defined as a significant chronic disease expected to last over 12 months and involve either several organ systems or 1 organ system severely enough to require specialty care and hospitalization.³⁰ CCCs allow one to focus on organ systems involved with chronic conditions and also those requiring medical technology such as gastrostomy tube or tracheostomy.^{31,32} Technology assistance was defined as the use of indwelling medical devices, including gastrostomy, tracheostomy, cerebrospinal fluid ventricular shunts, pacemaker, etc, as established by the Feudtner system.³⁰

Second, non-CCC conditions were distinguished from nonchronic conditions using the Agency for Healthcare Research and Quality (AHRQ) Chronic Condition Indicator system.^{33–37} The AHRQ Chronic Condition Indicator system and Feudtner's CCC system have been used together extensively to profile chronic conditions of pediatric populations.^{33,38}

Chronic conditions were defined in the AHRQ System as a condition lasting 12 months or longer with either (1) limitations on self-care, social interactions, or independent living; or (2) resulting in a need for ongoing intervention with medical products, services, or equipment. Those without a chronic condition were categorized as children without chronic conditions in our cohort.

To our knowledge, there is no standard method for identifying home health claims from a Medicaid database. Therefore, descriptions of Healthcare Common Procedure Coding System (HCPCS) and Current Procedural Terminology (CPT) codes were reviewed by study investigators to codify nurse and provider types when possible. Four categories were generated based on common groupings in code descriptions: (1) RN and LPN; (2)

home health aide (HHA) or certified nursing assistant (CNA); (3) companion and personal attendant; (4) not specified. We included all children age <18 years old enrolled in Medicaid with at least 1 HHC claim in 2016 from the HCPCS or CPT coding system indicating (1) nursing care was delivered in the home setting or (2) the provider of the service was a home health agency, if home setting was not articulated in the claim description (Appendix 1 and 2). None of the CPT codes specified a provider type, so claims using CPT codes were categorized as "not specified."

Home Health Care Utilization

HHC utilization and Medicaid payments occurring during 2016 were described by the proportion of enrollees using HHC categories. Medicaid payments were measured in total across all health services and for inpatient and outpatient health services. Outpatient payments were further categorized HHC versus non-HHC. All payments are reported in unadjusted 2016 dollars.

Statistical Analysis

Categorical variables were summarized by using frequencies and proportions. χ^2 tests were used for differences in proportions of HHC utilization between patient populations of variable complexity. SAS 9.4 (SAS Institute, Inc., Cary, NC) was used for all analyses.

RESULTS

Home Health Utilizers

Of the 5 209 525 children (<18 years) enrolled in Medicaid in 2016, 41 434 children (0.8%) used HHC. HHC utilizers were 43.8% infants (age <1 year), 9.6% toddlers (age 1 to 2 years), 17.9% young children (age 2 to 9 years), and 28.6% preadolescent and adolescent (age 10 to 17 years). Most children using HHC were non-Hispanic White race and ethnicity (38.5%), followed by non-Hispanic Black (28.8%). Overall, 54% of HHC utilizers were male. One-fourth (24.5%) of HHC recipients had no chronic condition, 38.6% had a noncomplex chronic condition, 21.5% had a complex chronic condition but no technology assistance, and 15.5% had technology assistance (Table 1). Overall children had median (IQR) 2 (1–4) chronic conditions, and this increased with increasing complexity: 1 (1–2) for children without CCCs, 3 (2–4) for children with CCCs, and 5 (4–7) for children with technology assistance. In 2016, 15.7% of children in this HHC cohort were hospitalized.

Rates varied by medical complexity: 1.8% for children without chronic disease, 8.5% for children with noncomplex chronic disease, 19.5% for children with CCCs, and 48.1% for children with technology assistance.

Among HHC utilizers with a chronic condition with any degree of complexity, the most common condition types were neurodevelopmental/or psychiatric (42.4%), digestive (24.9%), respiratory (21%), and neurologic (20.7%). Children with chronic (noncomplex) conditions most commonly had neurodevelopmental or psychiatric (55.9%), digestive (18.4%), respiratory (16.5%), and skin conditions (15%). Children with complex chronic conditions without technology most commonly had neurodevelopmental or psychiatric

(47.9%), neurologic (37.4%), cardiac (30.2%), and respiratory conditions (25.7%). Children with complex chronic conditions with technology assistance most commonly had digestive (82%), neurologic (68.2%), neurodevelopmental and psychiatric (68.1%), and respiratory conditions (58.9%) (Supplemental Table 6).

Home Health Care Providers

Nearly half of HHC utilizers received RN- and LPN-level care (45.3%), 5.9% received home health aide or certified nursing assistant care, 7.9% received companion or personal attendant care, and 36% had HHC claims which did not specify the provider type. Children without chronic conditions most often had HHC claims (76.7%) that did not specify provider type. However, as medical complexity increased, so too did the proportion of patients who had services by specified providers. For example, 50.5% of children with CCC without technology had RN or LPN services, 10.3% had HHA and CNA services, and 17.3% had companion or personal attendant services. For children with technology assistance, 77.2% had RN and LPN services, 13.8% had HHA or CNA services, and 17.5% received companion or personal attendant care. (Table 3)

Health Care Spending

Of the \$1.02 billion (US dollars) of Medicaid spending in 2016 on children receiving HHC, 24.8% was attributed to HHC itself. Of the HHC spending, 67.3% was for RN or LPN care, 15.6% for HHA or CNA, and 13.6% for companion or personal assistant care. The proportion of total spending attributable to HHC increased across the spectrum from children with no chronic condition to children with technology assistance (5.6% vs 28.1%, P < .001) (Table 3). Within HHC spending, children without chronic conditions contributed 0.6% of HHC spending, 8.7% for children with non-CCC conditions, 18.2% for children with CCC without technology, and 72.6% for children with technology assistance. Children with technology assistance had a greater number of months with HHC median (IQR) 8 (3-12) compared to 1 (1-1) month for children with noncomplex chronic disease or no chronic disease and 2 (1-2) for children with CCC. Further, total annual HHC spending per Medicaid enrollee increased across complexity groups. Overall, children contributed a median (IQR) of \$60 (\$59-\$390), children without chronic disease contributed \$60 (\$60-\$60), children with noncomplex chronic diseases contributed \$60 (\$11-\$94), children with CCCs contributed \$120 (\$60-\$1792), and children with technology assistance contributed \$10 585 (\$547-\$43 150).

DISCUSSION

In this analysis of children (<18 years) enrolled in Medicaid, one-fourth of HHC utilizers were children without any chronic condition, whereas three-fourths of HHC spending was for children with chronic conditions who required medical technology assistance. The bulk of home health nursing spending was for RN- and LPN-level care; however, interestingly, other nonnurse carers also played a substantial role in care delivered, including for patients with the greatest medical complexity.

Our findings demonstrate that HHC is provided to a heterogenous pediatric population, from infants without chronic disease to children with complex chronic conditions and technology assistance. Although complex pediatric populations use the greatest intensity of services, as evidenced by the increased duration and expense of HHC compared to children without chronic conditions, the broader population utilizing HHC warrants further study.

We found that as medical complexity increased, so did the proportion of HHC utilizers who were non-Hispanic White. However, the current study was not positioned to assess differences in use of health services by the children's race and ethnicity. This trend in this limited analysis may demonstrate the disadvantage for patients of racial-ethnic minorities in accessing health care services. Additionally, perhaps at higher versus lower levels of medical complexity, non-Hispanic white children were more prevalent because they had qualified for Medicaid because of disability status instead of low income. Further assessments are essential to interpret the race and ethnicity findings from the current study.

The cohort of HHC utilizers without chronic disease were majority infants (85.8%) and only represented 0.6% of HHC payments. This group of infants without chronic conditions likely overall received less intense home health care: more brief, intermittent nurse visits, for example, rather than primarily shift-based skilled nursing care. It is also likely that some percentage of these infants without chronic disease have or will have chronic disease yet unidentified by data available in this single-year claims database. It has been shown that home nurse visiting programs for high-risk neonates improve maternal and child outcomes.³⁹ In contrast to children without complex chronic disease, children in our analysis with technology assistance only represented 15.5% of the total HHC population yet were responsible for 72.6% of the total spending on HHC in this cohort. This finding is consistent with other studies which demonstrate high costs in children with technology assistance.⁴⁰ These patients likely had high volumes of private duty nursing shifts from skilled nurses. Many previous studies on HHC have focused on CMC, yet our analysis demonstrates that children without complexity are significant utilizers of HHC. In future studies, these distinct patterns of HHC utilization ought to be further explored to understand the supply and demand of pediatric home health care to understand where the most critical discrepancies exist.

HHC is also delivered by heterogenous providers. Care from RN and LPN providers was delivered to 77% of children with technology assistance, although HHA or CNA providers cared for 13.8% of this population, and companion and personal assistants cared for 17.5%. The role of these paid nonnursing home care providers ought to be further studied as a potential opportunity to address service gaps in home health. In our analysis, using our system of CPT and HCPCS descriptions of provider types, we acknowledge that providers for children without chronic diseases were often unable to be determined (Supplemental Tables 4 and 5). To our knowledge, it is not known whether children without a chronic condition currently receive HHC from more or less skilled nursing providers, or if this care is typically delivered by the same agencies, organizations, or independent providers that care for CMC. Clarifying the types of skills and specific care needed for the subpopulations receiving HHC is essential for understanding this heterogenous health care sector and designing systems for efficient health care delivery. We were not able to determine how

payers and home health care provider companies determined the appropriate level of nursing support for each type of patient, and in what capacity such support was provided. However, we suspect that sometimes the choice of provider may be affected by local availability and state-specific regulations. Although HHC shortages have been described for CMC,^{10,24} it is not known whether they impact children with more transient HHC needs or children with chronic HHC needs. Future studies are needed to investigate the supply and demand of HHC for children that need it. Perhaps there are opportunities to improve delegation of HHC among the populations that require it to improve access for all.

This study should be interpreted in the context of important limitations. First, there is no gold standard for identifying HHC from claims data. Our categorization based on descriptions in HCPCS and CPT codes was limited to clarification provided in coding descriptions, including a third of HHC utilizers who received at least some care from a provider who could not be specified. Further, these codes may not align accurately with how the codes are used in practice. For example, a number of codes did not distinguish between home health and hospice provision, which did not allow a separate consideration of children receiving hospice care. Future studies would benefit from a standardized method for identifying the HHC population from health care claims developed by key informants throughout the health care sector: physician prescribers, home health agencies, and direct care providers. Also, perhaps analyses directly using service data from home health agencies would help to understand different intensities of delivered HHC. Second, we used diagnostic codes to categorize children into complexity categories. Ideally, clinical data from medical records and/or self-reported diagnoses would be combined with utilization data to accurately categorize patients. Third, we acknowledge the substantial state-to-state variability in home health services. The data set used in the current study, while representing a large cohort of Medicaid beneficiaries, may not be representative of the full US Medicaid population and did not enable comparisons among included states. Further, many children covered by Medicaid have primary private insurance and qualify for wrap-around Medicaid services through Katie Beckett or related waivers. Therefore, our analysis of Medicaid-only payments may inflate the percentage of health care spending attributable to HHC for those children. Our data also do not capture information on unpaid or out-of-pocket costs for HHC, which are understudied.⁴¹ This limitation is unlikely to be significant since most families are unable to afford HHC services. Although overall our estimated outpatient to inpatient spending proportions were consistent with previous literature,²⁸ we continue to be limited by the lack of combined Medicaid and private payer databases for health services research.

The largest limitation to our analysis is that the only available data were on billed and received services, yet a large proportion of children with HHC needs have unmet nursing needs in the home because of HHC shortages.^{10,42,43} These unbilled services are not represented in our analysis of paid claims for received services. It is important to note that home health care coverage is often essential; many of these patients would otherwise require hospital admission^{3,4,44} and even intensive care without HHC at a much higher cost. In the long-term, families who do not have the support of quality, consistent HHC may need to consider out-of-home placement for their children, which is not the preferred environment for most families.⁴⁵ Research looking at home- and community-based program

spending across states has found that expanding home care is associated with a reduction in institutionalized care and long-term costs.⁴⁶

Overall, our study raises several important questions which warrant future investigation. The HHC sector of pediatric health care includes heterogenous patient recipients with various home health needs. However, the exact roles and skills of home health providers, regardless of level of nursing degree or certification, are not fully characterized. What are the roles and skills needed for specific patient subpopulations? Which patient populations are more likely to be cared for by nonnursing HHC providers? Further, the level of nursing degree or certification, which was the only HHC characteristic we could infer from these data, does not capture skillset or completed training. Literature suggests that training and skill gaps exist for HHC,⁴⁷ yet standardizing training including simulation and inhome opportunities has the potential to improve nurse preparedness for home care.⁴⁸ Can targeted training mitigate home health care workforce shortages? Perhaps considering programs to provide targeted training for nonnurse providers may provide essential back-up support for family caregivers to children with home nursing needs. Further, it is not known to what extent clinical populations who use HHC differ from those who do not. Future investigations, for example, with large cohorts of children with technology assistance, should describe differences between HHC users and nonusers to evaluate the impact of HHC on hospitalizations, overall health care spending, and long-term health outcomes. Ideally, such investigations should also assess HHC use and impact in infants compared to older children. With access to longitudinal databases, investigations should examine HHC use over time.

Part of the variability in HHC may be driven by state-specific guidelines for home health. Some national standards exist which unify health delivery. For example, the home health care plan must be established and maintained over time by a physician and cannot be determined by other licensed providers (physician assistants, nurse practitioners). National guidelines also stipulate that on-site supervisory visits must occur at least every 60 days for patients receiving home health aide services only.⁴⁹ Home health agencies across the country are numerous, estimated to be 12 200 in 2016, which likely adds complexity to standardization and regulation of training and care.⁵⁰

CONCLUSIONS

HHC is a diverse and essential sector of pediatric home health care for Medicaid-insured patients in the United States. Efforts to improve patient access to these critical services and standardize quality care must include collaboration between the home health agencies, state waiver and care coordination programs, national and local health care regulatory bodies, hospital centers, and providers who provide diagnostic and inpatient services as well as determinations of home health need, and family recipients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

FUNDING:

This project was funded by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS) under UA6MC31101 Children and Youth with Special Health Care Needs Research Network. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication. Dr Sobotka receives support from The Eunice Kennedy Shriver National Institute of Child Health and Human Development (grant NICHD, K23 HD097276) and the T73 Leadership Education in Neurodevelopmental and Related Disorders Training Program (grant LEND, T73MC11047). Funded by the National Institutes of Health (NIH).

ABBREVIATIONS

AHRQ	Agency for Healthcare Research and Quality
СМС	children with medical complexity
CCC	chronic complex condition
ННС	home health care
RN	registered nurse
LPN	licensed practical nurse
HHA	home health aide
CNA	certified nursing assistant
HCPCS	Healthcare Common Procedure Coding System
СРТ	Current Procedural Terminology

REFERENCES

- 1. Elias ER, Murphy NA; Council on Children with Disabilities. Home care of children and youth with complex health care needs and technology dependencies. Pediatrics. 2012;129(5):996–1005 [PubMed: 22547780]
- 2. Edelstein H, Schippke J, Sheffe S, Kingsnorth S. Children with medical complexity: a scoping review of interventions to support caregiver stress. Child Care Health Dev. 2017;43(3):323–333 [PubMed: 27896838]
- 3. Maynard R, Christensen E, Cady R, et al. Home health care availability and discharge delays in children With medical complexity. Pediatrics. 2019;143(1):e20181951 [PubMed: 30509929]
- 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 [PubMed: 31153586]
- Simpser E, Hudak ML; Section on Home Care, Committee on Child Health Financing. Financing of pediatric home health care. Pediatrics. 2017;139(3):e20164202 [PubMed: 28242864]
- 6. Patel R, Nudelman M, Olarewaju A, et al. Home care and healthcare utilization errors post-neonatal intensive care unit discharge. Adv Neonatal Care. 2017;17(4):258–264 [PubMed: 28252522]
- Gay JC, Thurm CW, Hall M, et al. Home health nursing care and hospital use for medically complex children. Pediatrics. 2016;138(5):e20160530 [PubMed: 27940764]

- 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 [PubMed: 32212321]
- Muesing C, Schimelpfenig B, Hustvet D, Maynard R, Christensen EW. Longitudinal prevalence of tracheostomized children in Minnesota. Hosp Pediatr. 2020;10(8):663–669 [PubMed: 32718915]
- Foster CC, Agrawal RK, Davis MM. Home health care for children with medical complexity: workforce gaps, policy, and future directions. Health Aff (Millwood). 2019;38(6):987–993 [PubMed: 31158008]
- Boss RD, Raisanen JC, Detwiler K, et al. Lived experience of pediatric home health care among families of children with medical complexity. Clin Pediatr (Phila). 2020;59(2):178–187 [PubMed: 31849237]
- 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 [PubMed: 25933227]
- Miles MS, Holditch-Davis D, Burchinal P, Nelson D. Distress and growth outcomes in mothers of medically fragile infants. Nurs Res. 1999;48(3):129–140 [PubMed: 10337844]
- Kirk S, Glendinning C, Callery P. Parent or nurse? The experience of being the parent of a technology-dependent child. J Adv Nurs. 2005;51 (5):456–464 [PubMed: 16098162]
- Murphy NA, Christian B, Caplin DA, Young PC. The health of caregivers for children with disabilities: caregiver perspectives. Child Care Health Dev. 2007;33(2):180–187 [PubMed: 17291322]
- 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 [PubMed: 29152895]
- 17. Dybwik K, Tollåli T, Nielsen EW, Brinchmann BS. "Fighting the system": families caring for ventilator-dependent children and adults with complex health care needs at home. BMC Health Serv Res. 2011;11:156 [PubMed: 21726441]
- Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. Arch Pediatr Adolesc Med. 2011;165(11):1020–1026 [PubMed: 22065182]
- 19. Thomson J, Shah SS, Simmons JM, et al. Financial and social hardships in families of children with medical complexity. J Pediatr. 2016;172:187–193.e1 [PubMed: 26897040]
- Rasooly IR, Shults J, Guevara JP, Feudtner C. State variation in posthospital home nursing for commercially insured medically complex children. Pediatrics. 2020;146(2):e20192465 [PubMed: 32641356]
- 21. 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 [PubMed: 26902773]
- 22. Christensen EW, Maynard RC. Do changing labor market conditions affect the length of stay for chronic respiratory failure hospitalizations? Home Health Care Manage Pract. 2017;29(4):235–241
- Nageswaran S, Golden SL. Improving the quality of home health care for children with medical complexity. Acad Pediatr. 2017;17(6):665–671 [PubMed: 28450083]
- 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 Hosp Palliat Nurs. 2018;20(3):260–265 [PubMed: 29910692]
- Miller TR, Elliott TR, McMaughan DM, et al. Personal care services provided to children with special health care needs (CSHCN) and their subsequent use of physician services. Disabil Health J. 2013;6(4):317–324 [PubMed: 24060254]
- Maddox C, Pontin D. Paid carers' experiences of caring for mechanically ventilated children at home: implications for services and training. J Child Health Care. 2013;17(2):153–163 [PubMed: 23711491]
- 27. Israelsson-Skogsberg Å, Lindahl B. Personal care assistants' experiences of caring for people on home mechanical ventilation. Scand J Caring Sci. 2017;31(1):27–36 [PubMed: 27126367]
- Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. Health Aff (Millwood). 2014;33(12):2199–2206 [PubMed: 25489039]

- 29. Agrawal R, Hall M, Cohen E, et al. Trends in health care spending for children in medicaid with high resource use. Pediatrics. 2016;138(4):e20160682 [PubMed: 27633920]
- Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. BMC Pediatr. 2014;14:199 [PubMed: 25102958]
- Berry JG, Graham DA, Graham RJ, et al. Predictors of clinical outcomes and hospital resource use of children after tracheotomy. Pediatrics. 2009;124(2):563–572 [PubMed: 19596736]
- Shah SS, Hall M, Berry JG, Slonim AD, Hornig GW, Sharma V. A multicenter study of factors influencing cerebrospinal fluid shunt survival in infants and children. Neurosurgery. 2009;64(6):E1206
- Berry JG, Rodean J, Hall M, et al. Impact of chronic conditions on emergency department visits of children using medicaid. J Pediatr. 2017;182:267–274 [PubMed: 27979584]
- 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;207:169–175.e2 [PubMed: 30612815]
- 35. Berry JG, Glader L, Stevenson RD, et al. Associations of coexisting conditions with healthcare spending for children with cerebral palsy. J Pediatr. 2018;200:111–117.e1 [PubMed: 29752173]
- 36. Berry JG, Ash AS, Cohen E, Hasan F, Feudtner C, Hall M. Contributions of children with multiple chronic conditions to pediatric hospitalizations in the United States: a retrospective cohort analysis. Hosp Pediatr 2017;7(7):365–372 [PubMed: 28634168]
- Agency for Healthcare Research and Quality. Chronic Condition Indicator (CCI) for ICD-10-CM. 2020. Available at: https://hcup-us.ahrq.gov/toolssoftware/chronic_icd10/chronic_icd10.jsp. Accessed December 24, 2021
- Leahy I, Berry JG, Johnson CJ, Crofton C, Staffa SJ, Ferrari L. Does the current American Society of Anesthesiologists physical status classification represent the chronic disease burden in children undergoing general anesthesia? Anesth Analg. 2019;129(4):1175–1180 [PubMed: 30489312]
- Olds DL, Kitzman H, Hanks C, et al. Effects of nurse home visiting on maternal and child functioning: age-9 follow-up of a randomized trial. Pediatrics. 2007;120(4):e832–e845 [PubMed: 17908740]
- 40. 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–e1470 [PubMed: 23184117]
- 41. Newquist DD, DeLiema M, Wilber KH. Beware of data gaps in home care research: the streetlight effect and its implications for policy making on long-term services and supports. Med Care Res Rev. 2015;72(5):622–640 [PubMed: 26062611]
- 42. 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 [PubMed: 23987826]
- Feudtner C The precarious imperative of home nursing for technology-dependent children. J Pediatr. 2019;212:10–12 [PubMed: 31277899]
- 44. 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 [PubMed: 1905479]
- Friedman SL, Kalichman MA; Council on Children with Disabilities; Council on Children with Disabilities. Out-of-home placement for children and adolescents with disabilities. Pediatrics. 2014;134(4):836–846 [PubMed: 25266436]
- 46. Kaye HS, LaPlante MP, Harrington C. Do noninstitutional long-term care services reduce Medicaid spending? Health Aff (Millwood). 2009;28(1):262–272 [PubMed: 19124878]
- 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 [PubMed: 24706404]
- Estrem B, Wall J, Paitich L, Maynard R. The Ventilator-Dependent Child: Best Practices for Educating Home Care Nurses. Home Healthc Now. 2020;38(2): 75–79 [PubMed: 32134814]
- 49. Director Q. Safety & Oversight Group Centers for Medicare & Medicaid Services. Home Health Agencies State Operations Manual Appendix B Interpretive Guidance Frequently Asked Questions (FAQ). Available at: https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/

SurveyCertificationGenInfo/Administrative-Information-Memos-to-the-States-and-Regions-Items/ Admin-Info-Letter-19-07. Published 2019. Updated January 23, 2019. Accessed January 15, 2021

50. Centers for Disease Control and Prevention. Prevention CfDCa. Home Health Care. 2016. Available at: https://www.cdc.gov/nchs/fastats/home-health-care.htm. Accessed January 15, 2021

WHAT'S KNOWN ON THIS SUBJECT:

Although many children with medical complexity depend on home health nursing care, ubiquitous home nursing shortages impact all children and their families. Little information exists on patient characteristics, home nurse qualifications, and health care spending for home health nursing care.

WHAT THIS STUDY ADDS:

One-in-four children receiving home health nursing care did not have a chronic condition. Nearly three-quarters of spending was for children with technology assistance. RNs/LPNs delivered most home health care; however, nonnursing providers cared for one-in-three children with technology assistance.

~
-
-
_
0
$\mathbf{\nabla}$
~
0)
~
2
5
S
Õ
~ ~ ~
Ξ.
0
_

TABLE 1

Demographic Characteristics and Chronic Condition Cohorts of Children Receiving Home Health Care Who are Enrolled in Medicaid (N = 41 434)

Sobotka et al.

	Total HHC Population n = 41 434	Children With No Chronic Conditions <i>n</i> = 10 138 (24.5%)	Children with Noncomplex Chronic Conditions $n = 16\ 000$ (38.6%)	Children With Complex Chronic Conditions Without Technology $n = 8888 (21.5\%)$	Children with Technology Assistance $n = 6408 (15.5\%)$
Age, y					
<1	18 143 (43.8)	8699 (85.8)	5689 (35.6)	3118 (35.1)	637 (9.9)
1–2	3988 (9.6)	677 (6.7)	848 (5.3)	1173 (13.2)	1290 (20.1)
3-5	2646 (6.4)	76 (0.7)	1006(6.3)	473 (5.3)	1091 (17)
69	4784 (11.5)	107 (1.1)	2427 (15.2)	955 (10.7)	1295 (20.2)
10–14	6938 (16.7)	257 (2.5)	3609 (22.6)	1749 (19.7)	1323 (20.6)
15-17	4935 (11.9)	322 (3.2)	2421 (15.1)	1420 (16)	772 (12)
Sex					
Male	22 574 (54.5)	4885 (48.2)	9306 (58.2)	4955 (55.7)	3428 (53.5)
Female	18 860 (45.5)	5253 (51.8)	6694 (41.8)	3933 (44.3)	2980 (46.5)
Race and ethnicity					
Non-Hispanic White	15 958 (38.5)	2615 (25.8)	6772 (42.3)	3482 (39.2)	3089 (48.2)
Non-Hispanic Black	11 921 (28.8)	3208 (31.6)	5018 (31.4)	2420 (27.2)	1275 (19.9)
Hispanic	4130 (10)	1717 (16.9)	1425 (8.9)	675 (7.6)	313 (4.9)
Other	1231 (3)	399 (3.9)	428 (2.7)	245 (2.8)	159 (2.5)
Unknown	8194 (19.8)	2199 (21.7)	2357 (14.7)	2066 (23.2)	1572 (24.5)
Number of chronic conditions ^a	a si				
None	10 505 (25.4)		Ι	358 (4)	9 (0.1)
1	11 913 (28.8)	I	10 175 (63.6)	1623 (18.3)	115 (1.8)
2	6342 (15.3)	I	4007 (25)	2021 (22.7)	314 (4.9)
3 or more	12 674 (30.6)		1818 (11.4)	4886 (55)	5970 (93.2)

Pediatrics. Author manuscript; available in PMC 2023 February 01.

^aThe number of chronic conditions was measured with the AHRQ Chronic Condition Indicator system.

~
<u> </u>
+
~
U.
<u> </u>
<
\leq
\leq
≤a
Mar
Man
Manu
Manu
Ĕ
SDL
SDI
SDL
SDI
SDI
NUSCL
NUSCL

TABLE 2

Types of Home Health Nursing Care Providers for Children Enrolled in Medicaid

Home Health Provider	Total HHC Population N = 41 434	Children with No Chronic Conditions <i>n</i> = 10 138 (24.5%)	Children With Noncomplex Chronic Conditions <i>n</i> = 16 000 (38.6%)	Children With Complex Chronic Conditions Without Technology n = 8888 (21.5%)	Children With Technology Assistance $n = 6408$ (15.5%)	d
RN or LPN	18 784 (45.3)	2055 (20.3)	7289 (45.6)	4492 (50.5)	4948 (77.2)	<.001
Home health aide or CNA	2460 (5.9)	12 (0.1)	650 (4.1)	912 (10.3)	886 (13.8)	<.001
Companion/personal attendant	3257 (7.9)	62 (0.6)	529 (3.3)	1542 (17.3)	1124 (17.5)	<.001
Not specified	14 927 (36)	7777 (76.7)	4967 (31)	1780 (20)	403 (6.3)	<.001
Data are presented as $n(\%)$.						

Author
Manuscrip
ot

TABLE 3

Author Manuscript

Author Manuscript

Health Care Spending for a Sample of 2016 Medicaid Beneficiaries with Home Health Care Utilization

	All Children			Spending by Ty	Spending by Type of Chronic Condition, \$ (%)	
Health Care Spending	Total HHC Population, \$	% of Total Medicaid Spending	None	Noncomplex Chronic	Complex Chronic, Without Technology Assistance	Technology Assistance
Total Medicaid spending	1 020 046 545	100	28 038 854 (100)	128 780 998 (100)	209 942 946 (100)	653 283 747 (100)
Total outpatient spending	577 720 284	56.6	9 677 643 (34.5)	95 209 846 (73.9)	115 162 911 (54.9)	357 669 885 (54.7)
Total home health nursing spending	252 883 537	24.8	1 565 287 (5.6)	21 879 969 (17.0)	45 945 891 (21.9)	183 492 390 (28.1)
RN or LPN	170 257 624	16.7	430 256 (4.4)	430 256 (4.0)	11 060 380 (9.6)	155 002 803 (43.3)
Home health aide or CNA	39 552 563	3.9	150 545 (1.6)	13 145 772 (13.8)	17 186 888 (14.9)	9 069 359 (2.5)
Companion or personal attendant	34 337 537	3.4	466 892 (4.8)	2 168 761 (2.3)	14730 725 (12.8)	16 971 159 (4.7)
Not specified	2 569 331	0.3	495 054 (5.1)	365 700 (0.4)	248 082 (0.2)	1 460 494 (0.4)
Total inpatient spending	442 326 261	43.4	18 361 212 (65.5)	33 571 153 (26.1)	94 780 035 (45.1)	295 613 862 (45.3)