

PediHome: Development of a Family-Reported Measure of Pediatric Home Healthcare Quality

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Dr. Foster received compensation for medical record consultation and/or expert witness testimony.

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Received for publication June 8, 2021; accepted April 8, 2022.

ABSTRACT

OBJECTIVE: No validated tools exist to measure pediatric home healthcare quality. The objective of this work was to develop a family-reported survey (*PediHome*) to measure the quality of home healthcare for children with medical complexity (CMC).

METHODS: A national multidisciplinary expert panel (N = 19) was convened to develop survey content domains. Panelist were joined by 3 additional experts to rank candidate survey items for importance and evaluate relevance and structure. Cognitive interviews were conducted with English-speaking (n = 12) and Spanish-speaking (n = 4) family caregivers of CMC to revise problematic items and clarify response options. A cross-sectional survey was then fielded (6/1/20–10/31/20) to parents whose children receive healthcare at 2 regional academic medical centers.

RESULTS: The final measure included N = 28 total items with 4 items quantifying access, 1 evaluating overall quality rating, and 21 items assessing provider tasks (11 home nursing only,

2 certified nursing assistant/home health aide only, and 1 dual). Out of 312 caregivers of CMC, 142 (46%) responded and one-half (n = 68, 48%) reported a child receiving home nursing. They received a weekly median of 58.4% (IQR \pm 31.2%) of approved nursing hours with 55% reporting a missed nursing shift within the last month. Median overall quality was 75-9 (0–10 scale) and median scores on specific quality items ranged from 31.4 to 43.4 (0–4 scale).

CONCLUSIONS: *PediHome* is a new content-valid family-reported measure of home healthcare quality for CMC that is useful for evaluating healthcare quality across several domains. Future work will involve assessing *PediHome*'s construct and predictive validity.

KEYWORDS: access; children with medical complexity; children with special health care needs; home healthcare; quality

ACADEMIC PEDIATRICS 2022;XXX:1–10

WHAT'S NEW

PediHome is a new content-valid family-reported survey measure of home healthcare quality for children with medical complexity. *PediHome* can identify deficits in timely access to care, overall home health quality, and specific tasks such as confidence in nursing care provided.

CHILDREN WITH MEDICAL complexity (CMC) are a growing group of patients defined by one or more chronic conditions that typically require daily healthcare, such as medication administration and medical device dependence, in order to achieve optimal health outcomes.¹ Since the early 1980s, healthcare delivery for CMC has

shifted away from institutional to home-based care, where CMC are thought to achieve best health outcomes.^{2–4} Home healthcare (HHC) services can be provided by private duty nurses, certified nursing assistants (CNAs), and home health or personal care aides, with their work ranging from clinical treatments and monitoring to assistance with activities of daily living. HHC's goal, per the American Academy of Pediatrics (AAP), is to provide comprehensive care within a nurturing home environment so that the children can be an integrated member of the family, while maximizing a child's capabilities to participate in daily life.^{3,4}

While home is upheld as the ideal site of long-term care for children, the peer-reviewed literature increasingly indicates that families of CMC are experiencing

insufficient access to high-quality HHC,^{2,5–12} especially pediatric-trained private duty nursing.^{8,10–14} A recent claims-based study also has highlighted the variability of pediatric HHC provision between states.¹⁵ Despite these published reports, no current reproducible, valid methods exist to measure what constitutes accessible high-quality HHC for CMC.

As the US healthcare system increasingly connects quality metrics and payment arrangements to promote high-value care, a reliable means of including the patient-family perspective of what constitutes “accessible” and/or “high-quality” care is critical for CMC.^{16,17} While instruments exist to evaluate HHC generally, they either focus on the home healthcare agency (eg, National Home and Hospice Care Survey [NHHCS]) or are designed for adult respondents (eg, Home Health Care Consumer Assessment of Healthcare Providers and Systems [CAHPS] survey) and are not directly relevant for the CMC population. Moreover, the need to better measure what constitutes high-quality care for CMC within the home has been identified as a national priority.^{17,18} We are not aware of any previously published peer-reviewed measures to assess pediatric home health care quality.

The goal of this project was to develop a content-valid family-reported survey instrument (*PediHome*) that can be used to: 1) describe the current state of HHC today; 2) compare the access to and quality of HHC across communities nationally; and 3) evaluate changes to the access and quality of a HHC program(s) over time for intervention evaluation and quality monitoring.

METHODS

The Institutional Review Board of the Ann & Robert H. Lurie Children’s Hospital of Chicago approved all study activities. Consent was obtained from family survey participants.

PEDIHOME INITIAL CONTENT DEVELOPMENT

Survey content development began with a review of the extant literature including the peer reviewed publications in the PubMed/MEDline database referring to home health care, private duty nursing, personal care, home health aide care for children. We additionally reviewed academy-issued HHC guidelines (eg, AAP, American Thoracic Society, etc.) and established HHC surveys (eg, NHHCS, CAHPS, etc.).^{2–4,19,20} Then, semistructured concept elicitation interviews of 20 caregivers and 20 providers (N = 40 total) were conducted to determine what constituted accessible, high-quality home care framed by the National Academy of Medicine’s (NAM) (previously the Institute of Medicine’s) 6 quality domains (effectiveness, safety, patient-centeredness, timeliness, equity, and efficiency) from its seminal publication “Crossing the Quality Chasm.”^{12,21} A conceptual framework characterizing the relationship between HHC quality and outcomes for CMC and mapping content themes to each quality domains were published based on that work.¹² Within that

framework, access to care was considered a quality domain under timeliness and equity.

We then convened a national multidisciplinary expert panel (N = 19) to advise instrument development and content development using the previously published conceptual framework.¹² Panelists had broad national representation from 10 states plus the District of Columbia and included: CMC family caregivers (n = 4), a nursing researcher (n = 1), pediatricians with expertise in care of CMC across different disciplines (n=5), and state-based Title V or Medicaid official (n = 2), HHC agency physician medical directors (n = 2), HHC agency nursing supervisors (n = 2), and HHC agency administrators (n = 3).

The experts met in 2 split groups over 2 sessions (4 sessions total) to review and prioritize the survey content. Experts were divided into groups to accommodate scheduling conflicts and be small enough to facilitate input from all participants, especially for family caregivers. Prior to the sessions, experts were given background materials including the conceptual framework to prompt discussion regarding content generation. Panelists were asked to affirm a working definition of HHC for children, deliberate on the survey’s ideal recall window, and generate a list of content domains that should be covered in the survey measure. Panelists were asked to consider content that would have impact on the patient’s health outcomes and utilization but also consider impact to family as well, given the child exists within a larger familial context. Between sessions the research team summarized and integrated panel recommendations. The last session was used to further refine the generated list of content domains and reconcile any cross-session differences.

PEDIHOME SURVEY ITEM CONTENT REFINEMENT, COMPREHENSIVENESS REVIEW, AND FINALIZATION

Based on initial expert panel input, the research team then created an initial pool of 30 candidate survey items for further review. The goal of the review and ranking process was to select the most important items relevant to HHC, while also narrowing down the number of items to minimize respondent burden. During the review process, the authors identified a need for insights from additional experts, which was supplemented by a pediatric rehabilitation and physical medicine physician with expertise in CMC (n = 1), a clinical nurse with expertise in CMC (n = 1), and a survey methodologist (n = 1) for a total of 21 expert reviewers. Panelists were asked to rank each candidate item for importance (not important/routine importance/very important) based on relevance to pediatric HHC and provide qualitative feedback regarding item content and structure. Research team members reviewed the scores and written qualitative feedback of the expert reviewers to decide which candidate survey items to retain.

Candidate items were further refined using iterative cognitive interviews with English- and Spanish-speaking family caregivers of CMC (n = 12 and n = 4, respectively).^{22,23} Participating caregivers of cognitive

interviews were identified at the study's main site, an independent freestanding children's hospital. Participants were ≥ 18 years old and a legal guardian. Their children were ≤ 21 years old and CMC as defined by Cohen et al.'s framework.¹ Interviewees were given a \$30 gift card and reimbursed for parking or public transportation. A Spanish version was created using a professional translation service. In the cognitive interviews, participants were asked semistructured questions to evaluate interpretation of item content, appropriateness of response options, item relevance to HHC quality, and feedback on the survey flow. Changes to the Spanish version were conducted by a native bilingual research coordinator (LM). Feedback was reviewed iteratively until no new revisions were identified.²³

Finalized survey items measuring quality, hereto referred to as "*PediHome*," were then formatted in an electronic survey platform (Qualtrics, Provo, UT) in preparation for fielding.

SURVEY ADMINISTRATION

Following *PediHome* development, the items were fielded in a cross-sectional sample of family caregivers of CMC recruited from two locations, a Midwest children's hospital (lead site) and an east coast pediatric complex care hospital program. Children were identified from the lead site's care coordination program and clinic for children with home mechanical ventilation. Eligible families were English and Spanish-speaking family caregivers of CMC who were ≥ 18 years old, and a legal guardian. Eligible families were approached by phone, email, and/or letter between 6/1/20 and 10/31/20, consented, and given a \$15 gift card for participation. Respondents who identified their child as having received home nursing or CNA/home health aide care in the past 12 months were prompted to answer the *PediHome* items.

Given that neither hospital's electronic records tracked whether children were receiving home health care services, family caregivers of CMC broadly were asked to participate and the *PediHome* questions were administered only to those who identified that their child was receiving home health care services in the past year. The survey also asked about characteristics of participants' children, themselves, and their household as well as other details about HHC including access to equipment.²⁴ If caregivers had ≥ 1 child, they were instructed to answer based on their child who had the greatest healthcare needs.

Given that the 2020 COVID-19 pandemic outbreak occurred at the time of survey launch with concurrent reports of major disruptions to in-home care, respondents were asked to answer the *PediHome* items based on their experiences in the last month (30 days) that their child received HHC before the pandemic, which for most respondents was March 2020 but could be answered based on their family's circumstances. Respondents were also asked additional questions about how the COVID-19 pandemic affected in-home supports and supplies.

SURVEY ANALYSIS

Descriptive statistics were conducted for CMC and respondent characteristics as well as *PediHome* item responses. Given the limited number of respondents who received only CNA/home health aide care ($n = 2$) and that they were asked a more limited scope of questions, presentation of the analysis was focused on the group of CMC who received any type of home nursing care. Medians were reported with interquartile ranges (IQR). For descriptive purposes, responses to scaled general quality items were dichotomized as "never/seldom/sometimes" versus "usually/always", and task-specific items were dichotomized as "not at all/a little/somewhat confident" versus "very/quite confident."

We additionally evaluated the correlation between the overall quality score, the mean score for the general quality items, and the mean score for the participant-relevant task specific quality items, and conducted pairwise comparisons between overall quality scoring groups (9–10, 7–8, ≤ 6) after correcting *P* values for multiple comparisons.

RESULTS

PANEL CONTENT RECOMMENDATIONS

Using lead government agencies' definitions as guidance, the panelists affirmed a definition of HHC as the range of services and supplies delivered in the home for individuals with disabilities, chronic conditions, and functional impairments to support living outside of health care facilities (ie, community-based settings). Given the range in scope of practice nationally, the panel recommended dividing the evaluation of HHC services based on 2 broad levels of clinical care: 1) private duty nursing (home nursing) care provided by registered nurse (RN) or licensed practical nurse (LPN) who can administer complex medication regimens and manage medical devices and 2) CNA and home health aides/personal care aides which at minimum can perform support for activities of daily living and simple monitoring. Experts also recommended adding an overall rating item modeled off of the Agency for Healthcare Research and Quality's (AHRQ) CAHPS survey Overall Rating measures to allow comparison with other care settings.²⁵ A survey recall of one month was chosen to minimize recall bias but also capture sufficient variability in HHC access.

PEDIHOME SURVEY ITEMS

Table 1 presents the final *PediHome* survey items which assess the quality of home nursing and CNA/home health aide, organized by domain and item response type. The table also indicates which relevant NAM quality domains the items reflect (eg, effectiveness, safety). During the development process, all items relevant to any provider type were kept. Three items were removed, and 3 new items added relevant to home nursing tasks. Three items were removed, and one was added specific to CNA/

Table 1. *PediHome* Survey Items and Relevant National Academy of Medicine Quality Domains for Pediatric Home Healthcare

Item Domain N = 28 total items	Item Stem	Item Response Options	†Relevant National Academy of Medicine Quality Domains
Access to Home Healthcare 4 Items for all provider types	How many total hours per week was your child approved to get [home nursing OR CNA or home health aide], by your child's insurance company and/or government program? (Denominator hours) On average, how many total hours per week did your child actually receive [home nursing OR CNA or home health aide] care? (Numerator hours) How many different [nurses OR CNAs or home health aides] took care of your child in that last month (30 days) your child was supposed to receive nursing care? (Turnover) To the best of your knowledge, what was the reason or reasons why a [nurse OR CNA or home health aide] did not come to care for your child? (Missed shifts)	Number of hours Number of providers Categorical responses	Timeliness, Equity, Patient-Family Centeredness
Overall Quality Rating 1 Item for all provider types	Please tell us your overall rating of your child's [home nursing OR CNA or home health aide]. Using any number from 0 to 10, where 0 is the worst [home nursing] care possible and 10 is the best [home nursing] care possible, what number would you use to rate your child's [home nursing] care?	0, 1, 2, 3, 4, 5, 6, 7, 8, 9, or 10	<i>Not applicable (overall rating)</i>
General Scaled Quality 9 Items for all provider types	<i>How often were you able to . . .</i> Get [a nurse OR care] at times of the day that worked well for your family? Get [a nurse OR care] on days of the week that worked well for your family? Choose which [nurse OR CNA or home health aide] cared for your child? <i>How often did your child's [home nurse(s) OR CNA or home health aide]. . .</i> Treat your child with respect? Treat you with respect? Respect your family's privacy? Interact with your child in an appropriate way, given your child's abilities? Arrive on time for the shift? Focus on caring for your child and was not distracted by other things?	Never (0), Seldom (1), Sometimes (2), Often (3), Always (4)	Timeliness, Patient-Family Centeredness, Efficiency, Effectiveness, Safety
Task-Specific Scaled Quality 11 Items for home nurse only 1 item for all provider types 2 items for CNA/home health aide only	<i>How confident were you that your child's home nurse (s) . . .</i> Knew when to give your child his/her medications? Knew how to give (administer) your child his/her medications? Could feed your child, including knowing how to prepare the feeding and give it? Could follow your child's overall treatment plan? Knew how to use your child's medical equipment? Could move your child around the home safely? Could tell if your child was in pain? Could respond to a medical emergency, until help arrived? Was rested enough to care for your child? Could care for your child alone without you there? Could recognize changes in your child's condition? <i>How confident were you that your child's [home nurse (s) OR CNA or home health aide]. . .</i> Cared about your child's well-being? <i>How confident were you that your child's CNA or home health aide. . .</i> Knew your child's daily routine? Could help your child with activities, such as bathing or toileting, in a safe way?	Not confident at all (0), A little confident (1), Somewhat sometimes (2), Quite confident (3), Very confident (4), Does not apply to my child (not scored)	Effectiveness, Safety, Efficiency, Patient-Family Centeredness

home health aide tasks. Therefore, the final *PediHome* has a total of 28 final survey items.

The first domain, “*Access to Home Healthcare*” (4 items), asks respondents to quantify the number of hours per week their child was *approved* for care followed by how many hours were *actually received* of that care in the past month. From these 2 questions a value could be calculated to determine the percent of hours accessed per week (received/approved). An additional 2 items ask about provider turn-over and missed provider shifts in the past month.

The next item domain is “*Overall Quality Rating*” (1 item), in which respondents are asked to *rate* their child’s overall HHC from 0 to 10 based on provider type (home nursing or CNA/Home health aide), in the past month.

The third domain is “*General Scaled Quality*” (9 items) and asks respondents to answer scaled items from 0 to 4 on *how often* their care was timely, patient-family centered, and efficient in the past month for home nursing and CNA/home health aide-level care. For correlations and cross-domain comparisons, these person-specific mean of these items were analyzed.

The last item domain was “*Task-Specific Scaled Quality*” (14 items) in which respondents were asked to choose *how confident* they were in their child’s HHC provider’s ability to complete different home healthcare tasks efficiently, safely, and in a patient- and family-centered way, again scaled from 0 to 4, in the past month. Eleven items assess for home nursing care (eg, administering medication, preparing and administering feeds, etc.), one item assesses for both home nursing and CNA/home health aide care (caring about the child’s wellbeing), 2 items assess for CNA/home health aide care only (knowing daily routine, helping with activities of daily living). Not all items were relevant to all participants (eg, if it was a task that was not necessary for their provider to complete). For correlations and cross-domain comparisons, these person-specific mean of the person-specific relevant items were analyzed.

CLINICAL SAMPLE SURVEY RESULTS

RESPONDENT AND CMC CHARACTERISTICS

Of 312 family caregivers of CMC invited to complete the survey, 142 participated (46%). Among those respondents, 68 (48%) had a CMC who received home nursing in the past year and so were eligible to answer the *PediHome* questions. Twenty-one (14%) CMC received CNA/home healthcare aide in addition to home nursing and 2 (1%) CMC received CNA/home health aide care only. Among the 68 respondents who received home nursing for their child, 18 (26%) reported receiving no additional caregiving help from family or friends (ie, they were sole family caregivers).

Characteristics of the respondents and CMC receiving home nursing are presented in [Tables 2](#) and [3](#). Most respondents whose children received home nursing were female and were racially and ethnically diverse. Over one-third had less than a college degree.

Table 2. Characteristics of Participating Family Caregivers Whose Children Received Home Shift (Private Duty) Nursing

Characteristics	N = 68 N (%)
Family Caregiver Age (Years)	38.6 (9.0)
Family Caregiver Gender Identity	
Female	61 (90%)
Male	7 (10%)
Family Caregiver Race and Ethnicity, Self-Reported	
White, non-Hispanic	21 (31%)
Hispanic	26 (38%)
Black, non-Hispanic	12 (18%)
Other race, mixed race and/or ethnicity	9 (13%)
Family Caregiver Relationship to Child	
Biological or adoptive parent	63 (93%)
Grandparent	2 (3%)
Other	1 (1%)
Missing/Not Reported	2 (3%)
Family Caregiver Preferred Language	
English	60 (88%)
Spanish	8 (12%)
Family Caregiver Current Employment Status	
Do not work outside of the home	26 (38%)
Full-time or part-time employment outside of the home	20 (30%)
Missing/not reported	13 (19%)
Other (not specified)	9 (13%)
Family Caregiver Highest Educational Attainment	
High school/GED or less	10 (15%)
Vocational/trade or some college	16 (24%)
Associate or bachelor’s degree	12 (18%)
Master’s, doctorate, or professional degree	17 (25%)
Missing/Not Reported	13 (19%)
Family Caregiver Marital Status	
Married or living with partner	41 (60%)
Not married or living with partner	14 (21%)
Missing/Not Reported	13 (19%)

Among the CMC receiving home nursing, about half were female biological sex and almost half of the sample were 3 years or younger. Almost all of the CMC receiving home nursing were publicly insured in whole or part. The CMC had a wide range of medical conditions, most commonly chronic lung disease and a seizure disorder/epilepsy. Most children required medication by tube. A range of medical treatments, medical technology dependence, and disposable supply needs were also described.

PEDIHOME HOME NURSING QUALITY RESULTS

Families reported that their CMC were approved, on average, for about 100 hours per week of home nursing but only received about half in actual filled hours (delivered care). CMC were cared for by an average of about three different nurses within the past month, and half of respondents reported a nonfilled shift within the month; further details regarding the reasons for those missed shifts are listed in [Table 4](#).

When asked to rate the overall quality of home nursing from 0 (worst) to 10 (best), families answered with a median overall score of 7 (IQR 5–9). About one-third of families (37%) chose either 9 or 10 (a “top-box” score),

Table 3. Characteristics of Children Receiving Home (Private Duty) Nursing

Characteristic	N = 68N (%)
Child Age (years) mean (SD)	5.8 (5.2)
Child Age (years) by age group	
Age < 1	2 (3%)
Age 1 – 3	28 (41%)
Age 4 - 12	31 (46%)
Age 13 - 17	2 (3%)
Age 18 – 21	5 (7%)
Child Biologic Sex Assigned at Birth	
Female	32 (47%)
Male	36 (53%)
Child Race and Ethnicity, Reported by Respondent	
Hispanic	27 (40%)
White, Non-Hispanic	16 (24%)
Black, Non-Hispanic	12 (18%)
Other race, mixed race and/or ethnicity	13 (19%)
Child Insurance Payer	
Public only	34 (50%)
Public and private	32 (47%)
Private only	3 (3%)
Other	1 (1%)
Conditions (child may have more than one)	
Chronic lung disease or bronchopulmonary dysplasia	30 (44%)
Seizure disorder or epilepsy	28 (41%)
Genetic disorder (eg, trisomy, named syndrome, etc.)	19 (28%)
Heart condition (congenital heart disease)	16 (24%)
Cerebral Palsy	14 (21%)
Brain injury or head injury	12 (18%)
Skeletal dysplasia, muscular dystrophy, or spinal muscular atrophy	6 (9%)
Chronic kidney disease or failure	5 (7%)
Behavioral/mental health (eg, Autism Spectrum Disorder, depression, etc.)	5 (7%)
Cancer	3 (4%)
Spina bifida or spinal cord injury	3 (4%)
“Short-gut” syndrome (intestinal insufficiency)	2 (3%)
Diabetes	2 (3%)
Other (eg, cystic fibrosis, transplant, etc.)	6 (9%)
Medical treatments delivered in the home (child may need more than one)	
Medication administration	53 (78%)
Monitoring for breathing rate, oxygen level, or other parameter	51 (75%)
Feedings or receiving nutrition through a tube	50 (74%)
Respiratory treatments, such as a cough assistance/vest	45 (66%)
Dressing changes	36 (53%)
Oxygen delivery	32 (47%)
Gastric decompression or venting	28 (41%)
Emergency seizure treatment	16 (24%)
Intermittent bladder catheterization	10 (15%)
Other, not listed	1 (1%)
Route by which child's medication is given (child may use more than one)	
By tube (gastrostomy (G), gastrostomy-jejunostomy (GJ), or nasogastric (NG))	51 (75%)
By breathing/inhalation (such as inhaler, nebulizer)"	31 (46%)
Into the muscle or skin directly	8 (12%)
By mouth	5 (7%)
Intravenous or central line	3 (4%)

(Continued)

Table 3. (Continued)

Characteristic	N = 68N (%)
Child's feeding (nutrition) route (child use more than one)	
Through a gastrostomy, gastrostomy-jejunostomy, or nasogastric tube	51 (75%)
By mouth	15 (22%)
Missing or Not Reported	12 (18%)
Through an intravenous line (TPN)	4 (6%)
Medical technology needed by child in the home (child may need more than one)	
Any of the listed medical technologies	54 (79%)
Gastrostomy or gastrojejunostomy (G-tube or GJ-tube)	49 (72%)
Oxygen monitor (pulse oximeter)	46 (68%)
Tracheostomy (breathing tube)	36 (53%)
Ventilator (invasive breathing machine)	33 (49%)
CPAP or BiPAP machines (noninvasive breathing machine)	8 (12%)
Nasal cannula	8 (12%)
Central line or port	6 (9%)
Glucose monitor	5 (7%)
Shunt for fluid in brain, such as a ventricular peritoneal (VP) shunt	4 (6%)
Seizure monitor	4 (6%)
Nasogastric tube (NG-tube)	3 (4%)
Cardiac defibrillator and/or pacemaker	2 (3%)
Disposable supplies child needed at home	
Gloves	52 (76%)
Diapers	50 (74%)
Tube feeding supplies	47 (69%)
Suction catheters	45 (66%)
Medication administration supplies	36 (53%)
Wound care supplies	33 (49%)
Bed pads/"Chucks"	32 (47%)
Bladder catheters	9 (13%)
Hazard bags or other supplies to dispose waste	7 (10%)
Ileostomy or colostomy bags	5 (7%)
Central line kit	3 (4%)

SD indicates standard deviation.

another one-third (35%) chose 7 or 8 (“middle-box” score), and the remainder (28%) chose a number from 0 to 6.

PediHome quality items scores ranged from a median of 31.4 to 43.4 when scaled from 0 (worst) to 4 (best). The general item results are presented in Figure 1. The highest-rated general quality item was *treating their child with respect* compared to the lowest-rated item of *focusing on caring for their child, and not being distracted by other things*. About one-third (35%) of respondents reported that they “never, seldom, or sometimes” nurse at the “times of day” or “days of the week” that worked well for their family.

Among task-specific quality items presented in Figure 2, the highest-rated item was confidence that the nurse(s) *knew when to give their child's medications*, compared with the lowest-rated item that the nurse(s) *could recognize changes in their child's condition*. Among the nursing task-specific quality items, respondents rated their confidence as only “not at all, a little, or somewhat” between 15% and 34% of the time.

When examining the correlation between quality types, general quality was highly correlated with both overall

Table 4. Family Reported Quality of Home Nursing for Children with Medical Complexity, Access Items

Access to home nursing hours	Median (IQR)
Hours per week of approved by insurance or government program	112 (70, 140) hours
Hours of home nursing per week actually received	50 (21, 90) hours
Percent of hours accessed per week	63 (37, 83) percent
Caregiver continuity	Median (IQR)
Number of different home nurses caring for child over the past month	2 (1–4) nurses
Non-filled shifts	N (%)
Child experience a non-filled nursing shift in the past month (*any reason)	37 (54%)
An agency was not able to identify a nurse to take child's shift	27 (40%)
A nurse was scheduled but then cancelled or did not show up	17 (25%)
A nurse would not work the hours that were needed, such as nights	13 (19%)
A nurse was available, but family did not want that particular nurse to care for child	9 (13%)
A nurse would not come because of where child lives	6 (9%)
Child's nurse was used to staff another patient's care	5 (7%)
Child became sick and was in the hospital	5 (7%)
Other reason	11 (16%)

*Patients may have experienced more than one reason for nonfilled shifts in a given month.

quality ($r = 0.79$) and task quality ($r = 0.66$), but task quality and overall quality were only moderately correlated ($r = 0.49$). Significant group differences emerged on the general and task quality ratings depending on the overall quality categories. Those respondents who selected a 9 or 10 had significantly higher general quality scores than those who chose a 7 or 8, or those who selected a 6 or below (standardized mean difference (SMD) = 1.03 and 2.26, $P = 0.009$ and $P < 0.001$, respectively); further, those who selected a 7 or 8 also had significantly higher general quality scores than those who selected a 6 or below (SMD = 1.23, $P = 0.001$). On the task quality, those who selected a 9 or 10 scored significantly higher than the other two groups (SMD = 0.84 and 1.48, $P = 0.04$ and $P < 0.001$, respectively), though the 2 lower groups did not differ from each other (SMD = 0.63, $P = 0.13$).

COVID-19 EXPERIENCE

Among respondents with home nursing, 37 (54%) reported a change in HHC they received during the pandemic. When asked how that care changed, 20 (29%) reported that providers were unable to come to care for the child at home, 20 (29%) reported that the caregiver did not let any providers come into the home to care for

the child, and 11 (16%) decreased the number of providers who were let into their home to care for their child.

DISCUSSION

PediHome is a new content-valid family-reported measure of HHC quality for CMC that permitted measurement of deficits in quality across several domains in a diverse clinical sample. This work is a first step in filling the critical gap to measure CMC's access to high-quality medical care at home in a validated manner. The ability to reproducibly evaluate the quality, including timely and equitable access, of in-home services for CMC will enable measurement over time and across settings, including benchmarking across states and among home health providers, and enable ongoing measurement of equitable access to HHC.

In our sample, family caregivers of CMC reported accessing only about half of their possible home nursing hours. Additionally, the overall rated quality of home nursing was a median of 7 with only 37% of families choosing the "top-box" score of 9 or 10 and 28% rating the care from 0 to 6. For comparison, in the 2016 pediatric CAHPS national data reporting, 74% of respondents rates the child's personal doctors with a "top box" score and only 7% rated their overall care in the 0 to 6 range.²⁶ Our

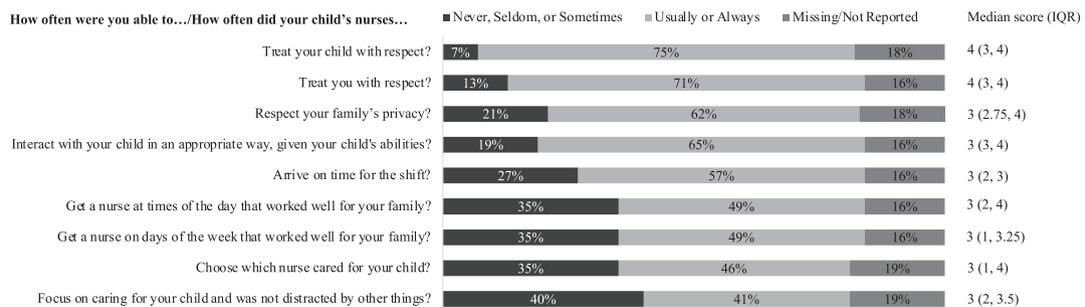


Figure 1. Family-reported general quality of home nursing for children with medical complexity, scaled items. Total N = 68. General scaled items were scored as never (0), seldom (1), sometimes (2), often (3), or always (4). Median quality score with standard deviation which is shown to the right of the bar graph.

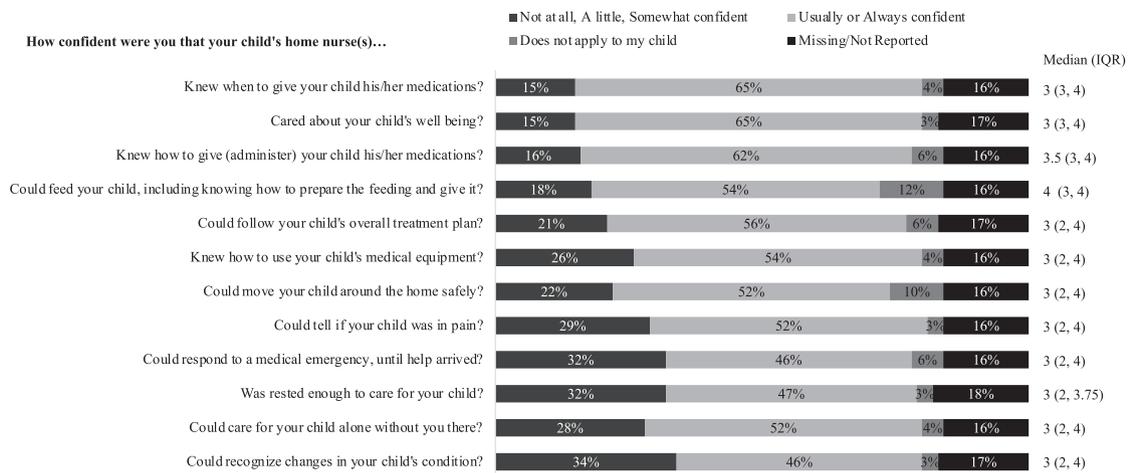


Figure 2. Family-reported task-specific quality of home nursing for children with medical complexity, scaled items. Total N = 68. Task-specific items were scored as not confident at all (0), a little confident (1), somewhat confident (3), very confident (4) or does not apply to my child (not scored). Median quality score with standard deviation which is shown to the right of the bar graph.

correlation findings suggest that the general quality items that covered constructs such as trust, respect, privacy, and timeliness seemed to drive the overall quality rating more than parents' perceptions of nurse performance on task-specific such as medication administration, pain assessment, and emergency preparedness. Lower quality ranking on task-specific scores seemed to primarily affect whether the overall rating dropped off the top box score. This suggests that addressing areas of improvement to fundamental elements of patient-family centered care could substantially improve the quality of home care experiences from the family perspective.

Still, family members reported deficits in task-specific domains reflecting effectiveness, efficiency, and safety of nursing care. While parent report is not a direct measure of nursing activity or skill, previous research has shown that patient-report is closely aligned to health outcomes, patient functional status, and identification of safety events in other areas of care.^{16,27,28} These family reported deficits in care are also consistent with the qualitative reports found in the literature across a range of pediatric chronic conditions.^{2,5–12,29}

As a result, the *PediHome* instrument may allow for future tracking of pediatric home healthcare quality that can be utilized to improve the quality of care for children with a range of chronic complex diagnoses. This is particularly relevant given the recent request for information by the Centers for Medicare and Medicaid Services to solicit public feedback on its efforts to track Medicaid-funded home and community-based services;³⁰ to the best of our understanding there is no pediatric in-home care specific measure currently. Additionally, an effort to comprehensively expand access to home and community-based services for both adults and children, the Home and Community-Based Services Access Act (HAA),³¹ has been announced. The ability to adequately report on the current and future access and quality of home healthcare for children will be necessary for these regulatory and legislative efforts' to achieve successful implementation. *PediHome* could be used to compare access to and quality

of HHC across states to understand policy-level differences or within states to understand more community-level differences to wages or training requirements that may impact access or quality of services. The tool could be used to evaluate the parents' perceptions in improvements to their children's care after quality improvement projects to enhance access to better quality care (eg, enhanced opportunities for pediatric home nurse training, wage increases, etc.). Lastly, the tool can also be used longitudinally by payors for quality monitoring in value-based contracts with home health agencies.

In addition to the *PediHome* quality survey itself, we identified in this work a concern for worsened access to HHC during the COVID-19 pandemic and an ongoing concern. Respondents reported loss of their usual supports in caring for CMC at almost twice the rate measured in the general population.³² Isolation experienced by families of CMC reflect understandable fears posed by the risk of COVID-19 for themselves and their children, given that CMC require specialized caregiving (3) and are disproportionately hospitalized with COVID-19.³³ Notably, although telemedicine was expanded during the pandemic, virtual provider visits do not address access to HHC services suggesting a need to work with families of CMC within healthcare systems to strategize ways to (re-) engage them in their in-home care. Having *PediHome* as an available tool to measure patient access to nursing over time may prove helpful to gauge the changing access to home healthcare as the pandemic response and healthcare impacts continue to evolve.

LIMITATIONS AND FUTURE WORK

As with any research relying on expert opinion, the item subject matter and prioritization reflects the stakeholder group's experiences, and ideally all panelists would have participated in all portions of the panel activities and would have been involved in final item selection. However, bias was minimized by engaging a nationally representative multidisciplinary group of stakeholders,

including family members. By developing the survey with both English- and Spanish-speaking families, we were also able to validate the content for a broader family group earlier than is typical in most survey work.

As with any cross-sectional survey, we cannot draw causal inferences between analyzed items and this initial sample size was insufficient to conduct factor analysis for construct validity. Recall bias may have impacted perceptions of quality, particularly given the pandemic's impact. While we recruited from 2 sites, these results are not fully generalizable. Response bias and missing items can also impact findings with unknown magnitude and direction, especially for those with missing items in entire sections. Administration of the survey through complex care programs likely decreased the number of respondents with only CNA/home health aide level care (ie, those with lower medical complexity and primarily ADL needs). Additionally, if complex care program care coordination was successful at assisting families with maximizing their access to home care, it may have overrepresented participants who had children with higher level access and better perceptions of care.³⁴ However, we note access remained relatively poor.

Therefore, future work in a larger sample of CMC receiving home healthcare and one that includes a larger population of children with CNA and home health aide care will allow evaluation of PediHome's construct validity. Further work will ideally also evaluate the relationship between perceptions in HHC quality and acute healthcare such as hospitalization and other quality metrics (ie, predictive validity).

While asking family caregivers to complete this survey may add to the already large amount of administrative care burden they experience, it does provide an opportunity for them to have a voice in their children's care. Future work should include identifying other clinical measure of HHC quality and safety such as rates of infection or death at home to compliment this family reported measure.

CONCLUSION

PediHome is a new content-valid family-reported measure of HHC quality for CMC that permitted measurement of deficits in quality across several domains. Families reported receiving about half of their potential home nursing hours. Further development of this measure will allow not only measurement of quality in the present but also a means to measure future improvement to that care over time.

ACKNOWLEDGMENTS

This study was funded by the Lucile Packard Foundation for Children's Health, Palo Alto, California (Grant No. 2017-00219).

We thank the following experts for their participant in our survey development (in alphabetical order): Rishi Agrawal, MD, MPH; David A. Bergman, MD; Courtney K. Blackwell, PhD; Catherine L. Curtis RN, BSN; Kathryn M. Detwiler, BS; Robert Ebel; Chani Feldman; Deborah Gaebler-Spira, MD; Mary Jo George, RN, DON; Lindsey Hird-McCorry, BSN, RN, CPN; Molly Hofmann, APRN, PCNS-BC; Roy C. Maynard MD; Douglas McNeal, MD; Steven Merahn, MD; Jill Morrow-

Gorton MD MBA; Nancy A. Murphy MD; Garey H. Noritz, MD; Heather L. Tubbs Cooley, PhD, RN; Jennifer Ward.

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