Caregiver and Provider Experiences of Home Healthcare for Children with Medical Complexity

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A thesis
submitted in partial fulfillment of the
requirements for the degree of

Master of Science

University of Washington

2017

Committee:

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Program Authorized to Offer Degree:

Health Services (Public Health)

University of Washington

Abstract

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Background

Children with medical complexity (CMC) are a small but growing population that uses home healthcare (HHC). The objective of this study was to characterize the quality of HHC experienced by caregivers and healthcare providers of CMC.

Methods

In-depth key informant interviews of primary caregivers (n=20) and providers (n=20) of CMC were conducted in Washington State. A semi-structured interview guide was used to elicit experiences of quality of HHC. Transcribed interviews were coded and analyzed to identify factors affecting HHC quality using the Institute of Medicine's quality framework (effective, safe, patient-centered, timely, equitable, and efficient).

Results

System complexity, insurance denials, and workforce shortages affected CMC’s ability to establish and maintain access to HHC leading to hospital discharge delays and negative family impacts. When HHC was accessible, respondents experienced HHC as effective in improving patient and family daily life and minimizing use of emergency and hospital services. Care was perceived as safer if HHC providers were present, but respondents identified a need for more pediatric-specific HHC training. Caregivers valued developmentally appropriate patient-centered HHC. HHC was not perceived as timely or equitable due to access barriers. Respondents experienced inefficiencies in communicating the care plan.

Conclusion

This study identified areas for improvement to mitigate perceived quality gaps in establishing and maintaining high-quality HHC for CMC in Washington State. This study also provides a conceptual framework to explaining the relationship between quality of HHC and outcomes for CMC for future quality improvement, research, and policy initiatives.

Introduction

Children with medical complexity (CMC) are a small but growing population that require intensive health service utilization and/or technology assistance to achieve optimal health outcomes.[1] In recent decades, family advocates and providers have supported shifting daily care of CMC away from the institutional setting to home healthcare (HHC) to provide comprehensive care within a nurturing environment while maximizing a child's capabilities.[2,3] Examples of HHC services include "private duty nursing" (PDN), which delivers hourly clinical services, and "personal care", which provides assistance with activities of daily living. HHC also includes equipment and housing modifications necessary for a child to live at home.[4]

Guidelines by the American Academy of Pediatrics (AAP) and the American Thoracic Society promote care of CMC at home and suggest competencies for HHC providers.[3-6] However, caregivers of CMC report physical, emotional, and financial challenges when caring for their child at home, particularly for children with technology dependence.[7-9] While HHC may be more cost-effective than caring for technology-dependent children in institutional settings, this may be due to shifting the financial and labor costs to families.[10,11]

Recent studies have shown that one in twenty children are discharged after hospitalization to some level of HHC, and even a brief period of HHC services may have lower readmission than peers without HHC.[12,13] However, the existing research on pediatric HHC is insufficient to develop measures to assess the quality of HHC for CMC. Therefore, the objective of this study was to characterize the quality of HHC experienced by caregivers and providers of CMC. This was then used to develop a conceptual framework examining the relationship between quality of HHC and outcomes for CMC to be used for quality improvement, research, and policy initiatives.

Methods

Study Design

This was a qualitative study using in-depth key-informant interviews.[14] Interviews were performed by phone or in-person at a regional freestanding academic children's hospital from April 2016 to October 2016 with institutional review board approval.

Study Population

Caregiver Recruitment

CMC 0-17 years of age who presented to the Seattle Children's Hospital neurodevelopment clinic, affiliated general pediatric clinic, or inpatient service were identified by chart review. Patients were considered CMC if they had a complex chronic disease.[15] The patient must also have received at least three outpatient ancillary care visits of any type (e.g. PDN, rehabilitative/habilitative therapies) within the past year. Caregivers of eligible patients were then approached and consented for participation in the study. Caregivers with limited English proficiency (LEP) and/or foster children were excluded. Caregivers were purposively sampled to increase diversity in race/ethnicity, geography, and insurance type.[16]

Provider Recruitment

Providers were eligible if they: a) directly provided HHC (e.g. home health nurse); b) managed HHC (e.g. agency director); c) facilitated HHC access (e.g. physician, social worker); or d) participated in statewide HHC programing (e.g. Developmental Disabilities

Administration). Providers were recruited by email invitation and purposively sampled across a range of job titles and practice settings.

Interview Guide Development and Procedure

Semi-structured interview guides were developed after literature review and revised for understandability and topic relevance by five non-participating providers and a CMC caregiver (**Appendix 1**). The Institute of Medicine's (IOM) six quality domains (effective, safe, patient-centered, timely, equitable, and efficient) informed the quality-related questions.[17]

The principal investigator (CF) conducted in-depth one-on-one interviews. All respondents were given definitions of HHC and responded to questions regarding care experiences. Questions were followed by prompts asking about barriers to achieving higher HHC quality. Providers with direct care responsibilities were asked about providing HHC whereas support providers and public health personnel were asked about their experiences facilitating access to HHC and their perceptions of HHC quality.

Analysis

All interviews were transcribed, anonymized, and then coded with qualitative software (Dedoose, V7.5.9, © 2016) using applied thematic analysis, which uses a rigorous inductive approach to represent study participants experiences by identifying themes from textual data.[18] Directed content analysis was also used to organize thematic concepts within the *a priori* IOM quality framework.[19] Analysis was performed by a multidisciplinary team with expertise in general pediatrics (CF), pediatric rehabilitation medicine (MF), neurodevelopment social work

(LW), and medical anthropology (EJF). Early intervention/outpatient therapy services were reviewed in a separate analysis.

Coding

Initial open coding was performed to identify factors facilitating quality; barriers to higher quality; characteristics of HHC by IOM quality domains; and impact of HHC on patient and family outcomes.[20] Four caregiver and four provider transcripts were coded using the initial codebook (CF, MF, EJF). Analysis team members then revised the codebook over seven iterations until complete agreement of coding definitions was reached. Two coders (CF, MF) then independently coded all of the remaining transcripts with the finalized codebook.

Thematic Analysis

While interviews were conducted, the analysis team met over ten sessions to compare coded excerpts and iteratively summarize the key factors affecting the quality of HHC and how they relate to patient and family outcomes. Coded excerpts were reviewed until identified themes captured the majority of the data.[21] Characteristics of high-quality pediatric HHC and barriers to achieving higher quality also were organized by IOM domain. A **conceptual framework** explaining the relationship between quality of HHC and outcomes for CMC was created.

Results

Respondent Demographics

A total of 18 caregiver interviews and 20 provider interviews were conducted prior to achieving agreement among the analysis team that no new concepts had emerged.[14] Two additional caregiver interviews were conducted to increase the number of non-white caregiver participants, for a final sample of 20 caregivers (**Tables 1 and 2**).

Conceptual framework

A conceptual framework explaining the relationship between quality of HHC and outcomes for CMC is shown in **Figure 1**. We found interplay between how patient/family, insurance, and workforce factors affect the quality of the HHC received. For example, patient/family factors, such as income, education level, and language, impact equitable access to adequate insurance coverage for HHC services and supplies. Insurance coverage and reimbursement levels then drive workforce factors such as HHC provider availability (equitable access) and training (effectiveness of services), both key aspects of HHC quality. Subsequent availability and receipt of high-quality HHC then influences CMC health and family wellbeing as well as CMC emergency and hospital use. Details of how these factors interplayed to affect HHC are as follows.

Factors Affecting Quality of Pediatric Home Healthcare

Patient/Family Factors

The patient's level of medical complexity, particularly need for a tracheostomy and/or mechanical ventilation, and family income affected access to adequate HCC insurance coverage. Social determinants of health including state of residence, rural/urban location, language, and education level then were thought to impact how caregivers accessed HHC and other elements of quality received. Generally, the inability to understand the complexity of or obtain advocate support to receive state-based waivers and/or negotiate insurance denials was a key barrier to accessing HHC. Caregivers typically relied on hospital-based care coordinators or outpatient palliative care nurses with specialized knowledge of HHC to navigate barriers. Developmental Disabilities Administration caseworkers were variably helpful due to worker turnover and competing priorities. Interviewed providers had concerns regarding equity of access to HHC especially for low income, lower educated, and LEP families.

> *"It was really hard to figure out how to even apply for a waiver program and what was available for someone like [my daughter]...I'm a well-educated person, and if it was really challenging for me, someone who might be less [educated] may struggle and never get the resources they need."* - Mother 1

Insurance Coverage

While patient/family factors were perceived to drive insurance access, insurance plans did not consistently cover HHC compared to hospital-based services. Public insurance (i.e. Medicaid) was perceived to provide more comprehensive coverage than private insurance, however, because Medicaid reimbursed at lower rates, HHC agencies were thought to preferentially enroll privately insured patients.

> *"… It's well understood that [home health agencies] prefer private insurance cases over Medicaid cases [because of the hourly rate]. If the Medicaid family has open nursing shifts and a private insurance case has open shifts, probably the private insurance case is going to get the nurses…"* – Care coordinator

Challenges with timeliness of supplies and establishing PDN or personal care services were consistently reported. Insurance denials for HHC supplies, including durable medical equipment (DME) ranging from diapers to electric lifts, were routine. Some caregivers also reported challenges securing Medicaid contracts for home modifications. Regulations restricting state-based waivers to Medicaid-contracted providers and contractors limited options for purchasing pediatric-specific DME and conducting home modifications, especially in rural areas. Caregivers and HHC agencies reported using their own funds to "fill the gap" for basic supplies that were not covered (e.g. gloves).

> *"I mean it took almost a year [for my son] to get his first wheelchair and by that time he had had a pressure ulcer on his back, and he had to be in the hospital for months and months…He's gotten the supplies eventually but having to jump through all the hoops was really hard. It's takes weeks and so I have to figure out how to get the supplies in the meantime."* – Mother 17

Respondents perceived that allocation of PDN or personal care hours by caseworkers could be inconsistent year-to-year but not necessarily in response to a child's changing needs. Caregivers with CMC who had moved to Washington noted state-to-state variability in HHC coverage, especially PDN hours. Some interviewed caregivers and providers noticed referring providers sometimes held off on referrals because of the perception that a child's needs were not great enough to receive PDN services or, in the setting of a worker shortage, that the child wouldn't be able to get the services anyway.

> *"I think (clinical) providers tend to have sort of a public health viewpoint of resources; meaning, "We have this limited pool or resources we need to allocate efficiently so that we help the people who need the help the most."…I think lawyers can bring a slightly different perspective to that and help doctors think about (legal) entitlement (to services)…"* – Attorney

Workforce Factors

Lower insurance reimbursement for HHC service hours compared to hospital-based care was perceived to drive an absolute shortage of HHC providers and low workforce retention. Respondents working in HHC felt that this may be due to the perception that other nursing opportunities have higher prestige, more variety, and fewer night/weekend hours. Other identified barriers were: wariness of working amongst "difficult" family dynamics, working in a perceived "unsafe" locale, and commuting to either rural or heavily urban areas.

> *"Right now we're low with nurses. There're a lot of hospitals around that are offering jobs to even new students…And, even once [a family] gets a nurse its not guaranteed (the nurse will stay). I guess that's the biggest issue. You bring [the nurse] in and make sure they're trained and then it could work for two weeks, and the nurse may come back to us and say, "Oh, I can't do that because I feel too alone." – Home nurse manager*

As a result, families with insurance-approved service hours reported gaps in HHC, particularly at night, and hospitalized patients experienced delays in discharge. High provider turnover led families to work with multiple HHC agencies and/or frequently re-train providers leading to extensive care coordination needs.

> *"We went home [from the hospital] with pretty much full nursing, and within a couple weeks, it went down to one nurse a couple days a week, so we've managed. But I mean even now, I only have days covered, there's no sign of any night nurses currently, so it's always been a challenge."* - Mother 11

On the job training of PDN by caregivers was routine. Interviewed providers had safety concerns regarding the level of PDN training, especially for CMC with tracheostomies and/or mechanical ventilation, and noted the need to balance a safe hospital discharge with adequate HHC coverage. Concerns regarding the quality of community airway safety training led to a multidisciplinary hospital initiative to provide education outreach.

> *"I think the basic nursing skills are medications, basic care, moving patients, repositioning, feeding pumps, [is done well], but when you get down to [pediatric airway] emergencies that is where the nurses lack."*- Care coordinator

Due to these many workforce challenges, respondents often characterized the workforce as "mission-driven" by providers who were intrinsically driven towards home-based work. Some caregivers reported cycling through providers until finding a long-term relationship with specific providers who created a "team" and became "part of the family" for extended periods of time.

> *"In the beginning of my career, I wouldn't have chosen to do home health if I got paid half (as much as other jobs). Are you kidding me? Unless it was truly a calling."*- Nurse

> *"[Our nurse] become more than just a nurse…she's "*Grandma*"…She's been with our family so long."* – Mother 8

Characteristics of High-Quality Pediatric Home Healthcare

Characteristics of high-quality pediatric HHC and barriers to achieving higher quality are organized by IOM domain and shown in **Table 3**. Respondents experienced HHC as effective in preventing or minimizing acute illnesses through execution of a patient's plan of care and early identification and treatment of acute illness. HHC providers also ideally facilitated care coordination with primary care physicians or specialists. Care was perceived as safer when a HHC was sufficiently staffed to avoid caregiver exhaustion and HHC providers had received emergency training. Caregivers strongly emphasized that they valued providers who could provide individualized, reliable, developmentally-appropriate care and respected family privacy. Timely receipt of home healthcare services and equipment was wanted. Respondents identified the need for equitable HHC for CMC regardless of family characteristics (e.g. educational level, race/ethnicity, language). Lastly, efficient communication of changes in the plan of care during and after hospitalizations or specialty visits was needed.

Patient and Family Outcomes

CMC Health

Caregivers reported that HHC enhanced their child's daily life through increasing participation in home and school activities. PDN, in particular, was perceived to improve CMC health through daily symptom evaluation and management.

> *“Having the equipment in place and people who know how to use them has kept [child’s name] out of the hospital because we catch things earlier, and they know how to treat her… I don't think that without it she'd be able to stay this healthy. I think she'd wind up in the hospital more frequently because I don't have the energy to maintain that kind of regimen or focus the nurses provide and bring to the day*s.” - Mother 1

Family Wellbeing

HHC afforded caregivers time for self-care and to attend to their other children and household responsibilities. Caregivers reported that inadequate access to HHC led to caregiver physical and emotional exhaustion, financial insecurity, and social isolation; sibling wellbeing also was impacted.

> *“I think [our goal] is to provide care to allow the family to have their loved one at home with the least amount of stress.”* – Home nurse

Lack of alternative appropriate childcare for CMC meant that a caregiver, usually the mother, would limit or stop workforce participation. Protective factors included patients who were dually insured or had family members able to fill care gaps. HHC did negatively impact some caregivers due to feelings of lack of privacy and guilt.

CMC Emergency and Hospital Use

In addition to improving patient health through symptoms evaluation and management as noted above, higher quality of home healthcare, especially reliable daily access, was perceived to minimize emergency and hospital use by supporting caregiver wellbeing. Lack of formal respite care combined with inconsistent PDN was believed to increase CMC hospital use.

> *“I see a lot that [caregivers] just may need respite care because there’s no nurse at night, and they might have to be up for three or four nights in a row with no one to take care of their child if the nurse calls in sick or something happens and the nurse can’t come in.”*– Primary care physician (rural)

Measurement of Pediatric HHC Quality

Respondents reported inconsistent or incomplete measurement of HHC quality. Home health agency managers noted that internal metrics typically were driven by voluntary accreditation and were not pediatric-specific. Some agencies conducted periodic home visits and administered non-validated satisfaction surveys. Caregivers occasionally recalled being surveyed, but most perceived that concerns were reactive to caregiver request or complaint rather than proactively addressed. When done, measurement of quality was focused on the timeliness.

> *"I don't think [keeping track of quality] is being done at all and I think the metric has been more quantity than quality [such as]…how fast assessments are done and how fast we move eligible applications..."* – Developmental Disabilities Administration interviewee

Discussion

Our study found that high-quality HHC is perceived to improve a child's health and daily life, minimize CMC acute medical crises, and support family daily life. Patient/family, insurance, and workforce factors impacted the quality of HHC received. Furthermore, our findings suggest that high-quality HHC is perceived to be inadequate to meet the current need for CMC in Washington State.

Our study is concordant with a body of literature describing how patient and family factors such as social determinants of health impact access to high-quality care.[22-24] Specifically, barriers to adequate insurance coverage may lead to a "squeaky wheel" phenomenon where caregivers and providers who advocate more receive more HHC, likely exacerbating disparities for disadvantaged groups.

The insurance coverage issues identified in this study are also consistent with the recently renewed AAP Policy Statement on the Financing of Pediatric HHC that describes how inadequate insurance reimbursement and workforce shortages impact HHC availability.[25] Not only is HHC insurance coverage mandated by the Early and Periodic Screening, Diagnostic, and Treatment law, but limiting coverage for HHC may be short-sighted for payers if a simple lack of HHC providers and supplies leads to more costly health services use (e.g. PDN availability may prevent use of the hospital for respite; gloves to care for a technology-dependent child may prevent infection).[26] The current insurance model also undervalues healthcare that improves patient life at home (e.g. lifts, home modifications).

Our results also highlight the need for improved training opportunities for HHC providers to enhance their pediatric clinical skills and integrating HHC providers better into the "medical neighborhood".[27] This finding is consistent with a recent study in North Carolina that found variation and deficits in the skill of PDN care for CMC.[28] Tertiary care centers with expertise in advanced nursing and respiratory care as well as HHC coordination may provide a critical role in improving the quality of the HHC workforce and communication inefficiencies through innovative outreach education and case management unavailable in the community.

Previous work describing the normalization of extraordinary effort by family members to enable their child to live at home is also echoed in our study.[7-9,28-30] Lack of high-quality HHC for CMC may contribute to negative family impacts (e.g. poorer caregiver health and under-employment).[31] Opportunities raised by this study include the need to better understand and measure caregiver and sibling mental health service need, identify specific barriers to respite care, and find ways to improve caregiver workforce participation. Interventions that target caregiver wellbeing may in fact provide an opportunity to mitigate utilization in their children, a goal which remains challenging in the CMC population.[32]

Lastly, we found that the quality of pediatric home healthcare is often not measured in a standardized, validated, or pediatric-specific manner. We provide a framework of the characteristics of high-quality pediatric HHC organized by IOM domain that may be used to facilitate future work to address this measurement gap.

Limitations

This was a single institution study occurring in a state with a PDN shortage, which may have overshadowed subtler factors related to access. The generalizability of our results is limited by volunteer bias, however this allowed for reporting of in-depth experiences. Future research should include families with limited English-proficient and more non-white respondents, as emergent themes from their perspectives may be different.

Conclusions

This study provides evidence for the value of high-quality HHC to improve CMC health and family daily life and potentially prevent emergency department and hospital use. However, significant gaps in availability of pediatric-trained HHC providers and timely affordable HHC supplies raise concerns about maintaining effective and safe care for CMC at home with subsequent negative impact on CMC health and their families' wellbeing. This study also provides a conceptual framework to evaluate high-quality HCC and related outcomes. Such future work should focus on understanding how HHC quality varies across states as well as how HHC quality impacts hospitalization and previously unmeasured family costs. Future studies should also explore how the HHC model may differ between CMC sub-groups (e.g. CMC with or without mechanical ventilation).

Acknowledgements

We would like to acknowledge Seattle Children's Research Institute's Center for Child Health, Behavior and Development Hearst Foundation Fellowship Award for funding this project.

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Tables

Table 1: Primary Caregiver Respondent and Patient Demographic Characteristics

Caregiver Demographic Characteristics (n=20)	N (%)
Age in years [mean (SD), range]	43 (14), 22-77
Gender	
Male	3 (15%)
Female	17 (85%)
Race/ethnicity	
White, non-Hispanic	16 (80%)
Non-white, Hispanic, or mixed	4 (20%)
Highest level of educational attainment	
High-school degree or equivalent	4 (20%)
Some college (non-degree)	8 (40%)
Completed college degree	3 (15%)
Masters or graduate degree	5 (25%)
Relationship to patient	
Mother	16 (80%)
Father	2 (10%)
Grandparent	2 (10%)
Marital status	
Married	14 (70%)
Non-married	6 (30%)
Employment outside of home	
Employed outside of home	5 (25%)
Not employed outside of home	15 (75%)
Household size in persons [mean (SD), range]	4.4 (1.7), 1-8
Family home location	
Urban core	12 (60%)
Non-urban core (total)	8 (40%)
Suburban	5 (25%)
Large rural town	2 (10%)
Small town/isolated rural	1 (5%)
Patient Demographic Characteristics (n=20)	**N (%)**
Age in years [mean (SD), range]	8.1 (5.5), 10 mo. – 17 yr.
Gender	
Male	10 (50%)
Female	10 (50%)
Race/ethnicity	
White, non-Hispanic	12 (60%)
Non-white, Hispanic, or mixed	8 (40%)
Insurance coverage	

Dual public/private	5 (25%)
Public only	8 (40%)
Private only	7 (35%)
Primary diagnosis	
Cerebral palsy or other non-progressive neurologic disease	7 (35%)
Genetic syndrome (e.g. trisomy)	8 (40%)
Myelomeningocele (i.e. spina bifida)	5 (25%)
Medical technology	
Feeding tube (e.g. gastrostomy, nasogastric)	17 (85%)
Ventriculoperitoneal shunt	13 (65%)
Tracheostomy with/without mechanical ventilation	5 (25%)
Baclofen pump	5 (25%)
Central line	1 (5%)
Current private duty nursing or personal care services	
Currently receiving private duty nursing or personal care support	12 (65%)
Private duty nursing support	11 (55%)
Personal care support	2 (10%)
Not currently receiving any private duty nursing or personal care	7 (35%)
Tried or actively trying to establish services	5 (25%)
Re-seeking discontinued services	1 (5%)
Family member providing care, not seeking services	1 (5%)
Hospitalizations in past year [mean (SD), range]	2.5 (2.0), 0-6
Emergency department visits in past year [mean (SD), range]	3.2 (2.8), 0-10
School enrollment	
Non-school aged	6 (30%)
Enrolled, school-aged	11 (55%)
Non-enrolled, school-aged	3 (15%)

TABLE 2: Participating Providers Demographics, Job Titles, and Practice Settings

Demographic Characteristics (n=20)	N %	
Age in years [mean (SD), range]	49 (12), 35-65	
Gender		
Male	7 (35%)	
Female	13 (65%)	
Race/ethnicity		
White, non-Hispanic	18 (90%)	
Non-white, Hispanic, or mixed	2 (10%)	
Current job duration		
1-5 years	7 (35%)	
6-10 years	7 (35%)	
>10 years	6 (6%)	
Job title and practice setting	**Direct Care Providers** [10 (50%)]	
	Nurses (n=4)	3 urban, 1 large rural town
	Primary Care Pediatrician	Large rural town
	Primary Care Pediatrician	Urban
	Neurodevelopmental Physician	Urban tertiary care hospital
	Rehabilitation Physician	Urban tertiary care hospital
	Pulmonology Physician	Urban tertiary care hospital
	Respiratory Therapist	Urban tertiary care hospital
	Managers [4 (20%)]	
	Home Supply Company Manager	Urban
	Home Healthcare Agency Manager (2)	1 urban, 1 large rural town
	School District Nursing Manager	Urban
	Support Providers [4 (20%)]	
	Social Worker	Urban tertiary care hospital
	Care Coordinator	Urban tertiary care hospital
	Community Outreach Organization	Statewide
	Attorney	Urban
	Public Healthcare Providers [2 (10%)]	
	Developmental Disabilities Administration	Statewide
	Department of Health	Statewide

Table 3: Characteristics of High-Quality Pediatric Home Healthcare for Patients with Medical Complexity

Table shows thematic summary of high-quality pediatric home healthcare organized by the Institute of Medicine's (IOM) quality domains. Barriers to achieving higher quality for each theme and perceived outcomes are noted and illustrative quotes shown.

IOM Quality Domain	Theme of High-Quality Pediatric Home Healthcare	Barriers to Higher Quality and Perceived Outcomes	Illustrative Quotes
Effective	• Execution of a patient's plan of care, early identification and treatment of acute illness, and care coordination with primary care physicians and specialists facilitates the patient's participation in daily activities and minimizes emergency and hospitalization use	• Lower access to consistent nursing or personal care services is perceived to lead to higher emergency and hospitalization use • High cost of and inadequate financial reimbursement for equipment and home modification can decrease patient mobility and lead to family social isolation	• **Mother 7:** "[The nurse] has been a really good watchdog, [when she says], "I'm noticing that [your son] is looking a lot more gunky in his breathing…" She's also really great at pulling the specialists at [hospital name] together with [the PCP]…and getting them all connected, which is one of the hardest things for me to do as a parent." • **Grandmother:** "I have five stairs to come into the house and so we have to carry him in, because he has this wheelchair. But, I can no longer pull him and the wheelchair up the stairs, so we [we need help] putting in a ramp so we can just wheel him into the house and out to the car."
Safe	• Sufficient staffing with fully rested home healthcare providers • Comprehensive and regular caregiver and home health provider emergency training • Medical equipment and supplies sufficient in number and appropriate for pediatric age group and patient's individual needs	• Insufficient numbers of home healthcare providers due to state-wide shortage leads to caregiver exhaustion resulting in less safe care • No or minimal standard training for pediatric emergencies (e.g. artificial airway management) • Limited insurance coverage and availability of specialized pediatric equipment (e.g. ventilator type)	• **Mother 9**: "I'm a human being. I cannot be up 24/7. The fact that I have to try to sleep intermittently in between [my daughter's] needs does not give her as good a care if there was a nurse sitting there watching her throughout the night. I'm not as alert. I'm not as quick to respond…We don't want her back in the hospital and we want her to be safe, healthy, and able to spend time at home." • **Home Healthcare Agency Manager (Rural)**: "[The state insurance] went to everybody only gets two boxes of gloves a month [covered].' That's it. [*Laughs*]. I was ready to write a letter to the CDC because I kept going, "This isn't safe. We're not just changing briefs. We're suctioning tracheostomies. We're trying to keep [the

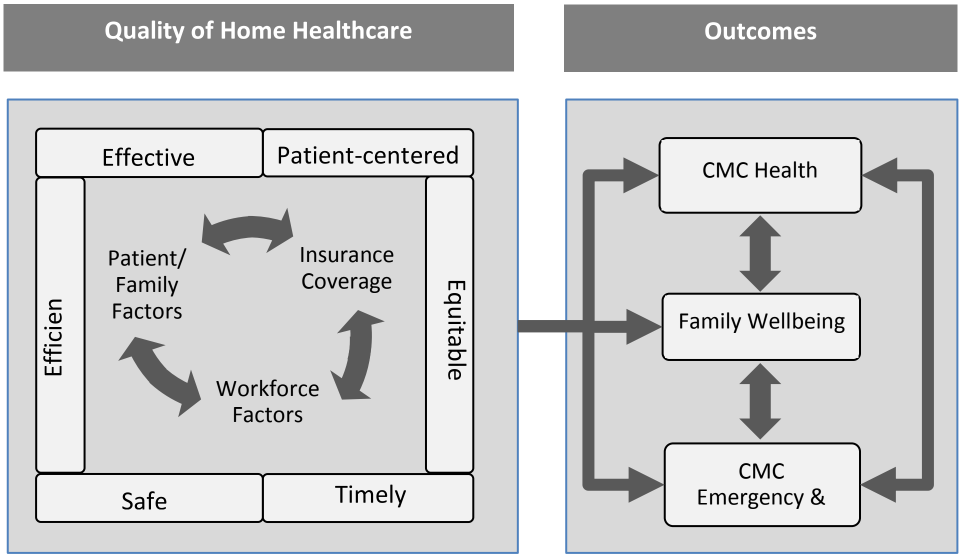
			patients] out of the hospital."
Patient-centered	• Reliable, developmentally-appropriate care individualized to the child's unique medical needs • Home healthcare providers respect family privacy and relationship dynamics	• Some providers lack experience engaging with children, especially children with cognitive differences • Mismatch between caregiver and home healthcare provider approach to care and/or running of the home can lead to challenging interpersonal interactions	• **Mother 11**: "What's really important to me is someone who's going to [be kind to my son], talk to him, try to engage with him, no matter what his disability is and just make sure that his medications and feeds are on schedule and just kind of being personable with [him] and having a good bedside manner…The nurses they don't end up being strangers, they end up being a part of the family." • **Home Healthcare Agency Manager (Urban)**: "We try to find out from the family what's important [regarding the families' values, cultures and/or traditions] and then let the nurses know. Sometimes that means we're doing a real good job in honoring and other times I know we are walking over things that are important to families that the nurses aren't paying good attention to."
Timely	• Timely receipt of home healthcare services and equipment.	• Delay in insurance approval and requirement to use contracted suppliers leads to delays in hospital discharge or access to supplies	• **Grandfather:** "We're trying to get an electric Hoyer for [my granddaughter] because she's over 70 pounds now and the nurses can't lift anything over 50 pounds so between my grandson and I do the lifting…she's also outgrown her wheelchair and so they've fitted her for a special wheelchair and we're waiting on [both for almost a year]."
Equitable	• HHC is available to eligible patients and their families regardless of income, race/ethnicity, geographic location, language, and health literacy	• Differences in public and private insurance coverage lead to variability in access • Complexity of the system and limited available resources exacerbates access disparities, especially for limited English proficient families	• **Neurodevelopmental Physician:** "I think it's a significantly increased challenge to provide good care with diverse ethnicities… Systems like Medicaid, DDA, [transportation service], and anything else that [families] might need to access to… are not easy to navigate." • **Primary care provider (urban):** "…English-speaking families and non-impoverished families tend to not have the same barriers in front of them, and it doesn't seem like it's just because they're not better at advocating for themselves."

Efficient	- Efficient communication of changes in the plan of care between home healthcare providers, suppliers, and agencies can facilitate access to HHC service and adequate supplies during and after hospitalizations or specialty visits	- Lack of standards in agency plan of care forms and paper-based systems leads to redundancy and delays in plan of care updates as well as unused supplies during periods of hospitalization - System complexity, inefficient communication, and worker turnover leads to extensive care coordination for caregivers and support providers (e.g. social worker)	- **Primary Care Physician (Rural)**: "At least every month I get a fax and it's usually about a seven-or-eight-page [plan of care] and I'm supposed to sign it and verify that all of those orders are correct from last month. But usually there's no indication of what has been changed … I feel like I'm not able to do the justice that I need because I can't find the information, and I can't spend an hour combing through those every month." - **Mother 17** "To get the services or even know how to get the services…sometimes it takes me all day, and I have to use every single moment of my day to do phone calls when I can I'm at work, and that's really hard…"

Figures

Figure 1: Conceptual Framework to Assess Quality and Outcomes of Home Health Care for Children with Medical Complexity

Patient/family factors (e.g. income) affect insurance access, which variably covers home healthcare. Insurance reimbursement level then drives workforce factors (e.g. wage) affecting workforce availability and training. Higher quality of home health care impacts CMC health and family daily life, which affects emergency and hospital use.



Appendix 1: Caregiver and Provider Key Informant Interview Structure and Sample Questions

Caregivers were asked to list the type of HHC their child currently used. The interviewer then asked service/supply specific questions with each service or supply listed. General questions were asked once per caregiver. For physicians, support, and public providers, questions were adjusted with phrasing of how they might experience the quality of HHC services/supplies. All questions were followed by prompts asking about barriers to achieving higher quality.

Caregiver Guide

Service Specific Questions

1. What is your understanding of why your child receives this service or supply?
2. What is it like to find and keep providers for this service? To schedule the service?
3. What choice did you have in choosing which provider and/or agency cares for your child?
4. What would be the ideal timing to receive the service (e.g. day of the week or time of day)?
5. How is the service paid for?
6. Is there anything else you would like us to know about how hard or easy it is for you to get the service for your child?
7. How/why do you think this service helps your child's health and/or help his/her achieve her health goals? How does it affect your family?
8. What makes this service "good quality"? What makes the provider of this service (home healthcare worker) "good" at his/her job?
9. How satisfied are you with the overall quality of the service provided? How satisfied are you specifically with the safety of the service?
10. How well do the providers of the service communicate with you about changes to the service? What documentation do you receive?
11. If you have questions, how are these questions answered? Did you find the answers helpful?
12. How well does the provider(s) of the service communicating with:…with each other? …your primary care provider? …your specialty providers (e.g. cardiologist)? …your child's school?

General Questions

13. Has your child ever had services or supplies recommended to you that have not been covered by your insurance? If so, what were they?
14. Are there services your child receives that you think she/he doesn't need? If yes, which and why?
15. Are there services your child doesn't receive that you think she/he needs? If yes, which and why?
16. Have services ever not been available because of where you lived?
17. Do you have anyone help you get services or supplies for your child? (e.g. case manager or care coordinator)

Family Impact/Support

18. What are the ways in which these services have affected: …your family's daily routine? …affected your family's finances?

19. How do providers' respect your family's values/culture/traditions?
20. Do you have access to respite, personal care, private duty nursing, or other formal caregiving support? (if not already discussed)
21. What other support systems help your family? (e.g. religious, community, etc.)
22. If you could get more help to care for your child at home, what would this help look like for you and your family?

Overview

23. Overall, if you could change anything about your and your child's experiences receiving these services, what would it be (if anything)?
24. Is there anything else we should know about your and your child's experiences receiving these services?

Providers Guide

Service Provision

1. What types of home services or supplies does your organization/group/department provide to this patient population?
2. How do you determine which services or supplies to offer? For clinicians, how is it decided whether a patient needs a service or supply?
3. What government agency or regulatory body provides oversight to the services or supplies you provide?
4. What are your different payers (sources of revenue) and how do you receive payment?
5. What are the eligibility requirements that determine which patient/caregiver can use your services? (e.g. income, insurance, etc.).
6. What are the mechanisms by which you receive referrals for your services?
7. What sorts of options do patients/caregivers have in choosing your /an agency/organization in their community?
8. What is it like for a patient/caregiver to establish services? Maintain ongoing provision of services?

Quality Measurement

9. How do you measure/assess: …your ability to schedule the services in a timely manner? …the quality of the services you provide?…the safety of the services you provide? …patient/family satisfaction with the services you provide? Etc.

Communication/Documentation

10. What sort of documentation is created when services are provided?
11. How do you communicate with and receive communication from patients' other providers and school?
12. How do you accommodate patients/caregivers with limited English proficiency (LEP)?...patient/caregiver values/culture/traditions?

Overview

13. Overall, what do you think your group/organization/department does well in providing care for this patient population?
14. Overall, if you could prioritize changing anything about providing home healthcare to this patient population what would that be and why?