The Pediatric Home Health Care Process: Perspectives of Prescribers, Providers, and Recipients

Karen Fratantoni, MD, MPH,[a] Jessica C. Raisanen, MSPH,[b] Renee D. Boss, MD, MHS,[b,c] Jennifer Miller, MD,[c] Kathryn Detwiler, BS,[a] Susan M. Huff, RN, MSN,[d] Kathryn Neubauer, MD,[c] Pamela K. Donohue, ScD[c,e]

abstract

BACKGROUND AND OBJECTIVES: Children with medical complexity (CMC) often require pediatric home health care (PHHC) to meet their daily intensive care needs. Pediatricians are central to planning, implementing, and maintaining quality PHHC for CMC, yet a comprehensive road map for this process is lacking. With this national study, we aim to fill that gap.

METHODS: Semistructured interviews were conducted with parents and professionals from the 10 US Health Resources and Services Administration regions. Parents were recruited via advocacy groups for families of CMC; professionals with experience with PHHC for CMC were identified by using purposive and snowball sampling. Interview transcripts were qualitatively analyzed for themes.

RESULTS: A comprehensive process of prescribing, providing, and maintaining PHHC requires 5 steps: identifying needs, investigating options, developing plans of care, initiating services, and navigating evolving needs. The success of the PHHC process is built on knowledge, anticipation, and early identification of needs; communication; care-coordination infrastructure; skilled home health providers; and the parent-provider relationship.

CONCLUSIONS: Many CMC require PHHC to live safely outside of the hospital. Although the PHHC process involves multiple steps and participants, pediatricians' understanding of the process is the foundation of PHHC success. Fostering interagency relationships, increasing longitudinal care coordination, and investing in the PHHC infrastructure may reduce the burden placed on families and CMC as they navigate the complex process of PHHC.

[a]*Division of General and Community Pediatrics, Children's National Health System, Washington, District of Columbia;* [b]*Berman Institute of Bioethics, Baltimore, Maryland;* [c]*Department of Pediatrics, Johns Hopkins University School of Medicine and* [e]*Department of Population, Family, and Reproductive Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland; and* [d]*Johns Hopkins Home Health Group, Baltimore, Maryland*

Drs Fratantoni, Boss, and Donohue conceptualized and designed the study, designed the data collection instruments, conducted the initial analyses, conceptualized the manuscript, drafted the initial manuscript, and revised the manuscript; Ms Raisanen participated in the design of the study, collected data and conducted interviews, performed qualitative analyses, and conceptualized, drafted, and revised the manuscript; Ms Huff conceptualized and designed the study, participated in designing the data collection instrument, recruited participants, and revised the manuscript; Dr Miller performed the qualitative data analysis and drafted and revised the manuscript; Ms Detwiler and Dr Neubauer participated in the design of the study and of the data collection instruments and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: https://doi.org/10.1542/peds.2019-0897

Accepted for publication Jun 17, 2019

WHAT'S KNOWN ON THIS SUBJECT: Pediatricians must ensure that children with medical complexity have access to home health care services to avoid unnecessary hospitalization and remain at home. However, the process by which pediatric home health care is initiated and maintained has not been described.

WHAT THIS STUDY ADDS: National stakeholders who receive, prescribe, and provide pediatric home health care services describe the process and factors that facilitate these necessary services.

To cite: Fratantoni K, Raisanen JC, Boss RD, et al. The Pediatric Home Health Care Process: Perspectives of Prescribers, Providers, and Recipients. *Pediatrics.* 2019; 144(3):e20190897

Children with medical complexity (CMC) are children with special health care needs who have intensive service needs, chronic conditions, limitations in function, and increased health care use.[1] Because of their medical fragility and technology dependence, CMC may require pediatric home health care (PHHC)[2] for an extended period of time. PHHC is defined as services provided by professionals and paraprofessionals in the home,[3] including nursing visits; extended private-duty nursing; physical, occupational, or speech therapy; and provision of durable medical equipment and services. PHHC provides comprehensive, cost-effective care to optimize a child's health at home, limiting hospitalizations and medical complications,[4] relieving caregiver burden,[5] and reducing health care cost.[6] Without adequate PHHC to help families support their children at home, these children are vulnerable to spending excess days in the hospital.[7,8]

Current guidelines suggest that the pediatrician is a fundamental member of the PHHC team, facilitating a coordinated plan of home care.[4,9] Although outpatient pediatrician knowledge of PHHC has not been described in the literature, data suggest that inpatient clinicians may not fully understand the resources needed for CMC at home.[10] Parents of CMC report substantial unmet needs in the primary care setting, particularly related to care coordination and engagement of community services.[11] In fact, less than one-third of community pediatricians report being comfortable helping families access community resources such as home health supplies and equipment,[12] citing lack of residency training in this area. Finally, a comprehensive road map of the PHHC process is lacking, creating further barriers for pediatricians who wish to improve care for CMC and their families.

In 2018, we recruited parents and professionals with experience with PHHC for CMC to identify barriers and facilitators of home health care services. Using data from the parent study, our goal for this article is to strengthen pediatrician understanding of the PHHC process, highlighting key points in which pediatricians can facilitate services for patients. Better understanding of PHHC will help pediatricians ensure that CMC have access to quality care to meet their medical needs at home.

METHODS

We interviewed professionals who routinely prescribe and deliver PHHC and families who have experience with these services. Using purposive and snowball sampling,[13] we identified eligible professionals within each of the 10 US Health Resources and Services Administration (HRSA) regions to gain an understanding of regional practices, resources, and problems.[14] Eligible professionals included the following: (1) inpatient prescribers, (2) outpatient prescribers, (3) PHHC agency administrators, (4) home care providers, and (5) others with valuable knowledge of PHHC. Professional recruitment continued until there was representation of participants with a diversity of roles across all 10 HRSA regions.

Eligible parent participants were recruited via 2 parent advocacy groups whose members have CMC. One group has a national membership, and parents were recruited via their listserv and newsletter. Because this approach yielded no parent participants from 1 HRSA region, we collaborated with a state-based parent advocacy group to recruit via their listserv. Eligible parents spoke English and had a CMC who received PHHC.

Participants completed an audiotaped, 30- to 60-minute semistructured interview; questions targeted the process of prescribing, providing, and receiving PHHC and barriers and facilitators to care. We defined PHHC broadly, instructing participants to discuss their experiences with skilled nursing, therapies, durable medical equipment, and other services used to care for children at home. Questions were tailored to participant role. Participants were compensated with a gift card and were invited to review their interview transcript for accuracy.

We performed a conventional content analysis[15] on transcribed interviews. Authors systematically coded participant responses individually and then as a group to classify codes into common themes. Thematic saturation was achieved for both professional and parent interviews. Representative quotations were selected to illustrate key themes.

Institutional review board approval was obtained; participants provided oral consent because the research was deemed minimal risk.

RESULTS

Of 60 eligible professionals, 45 were interviewed (37 women; 8 men). Of 51 eligible parents, 48 were interviewed (39 women; 9 men). Five parents were bereaved. In Table 1, we describe participant characteristics. In Table 2, we describe the services that families reported.

The Process of Prescribing, Providing, and Receiving PHHC

As "experts" in prescribing, providing, and receiving PHHC, all participants were asked, "Given what you know, what do you think is the process that occurs from when a clinician or parent identifies a home health need to when the child actually receives those services?" In Fig 1, we describe the road map of translating a child's needs into services. Because many CMC have frequent and prolonged hospitalizations, important steps

TABLE 1 Participant Characteristics

HRSA Region[a]	Parents (N = 48)	Professionals (N = 45)					Total by HRSA Region (N = 93), n
		Inpatient Prescribers (n = 12)[b]	Outpatient Prescribers (n = 10)[c]	Home Care Administrators (n = 10)[d]	In-Home Providers (n = 10)[e]	Other (n = 3)[f]	
CT, MA, ME, NH, RI, VT	4	1	1	1	2	0	9
NJ, NY	3	1	1	1	1	0	7
DC, DE, MD, PA, VA, WV	5	1	1	1	1	0	9
AL, FL, GA, KY, MS, NC, SC, TN	7	2	0	1	1	1	12
IL, IN, MI, MN, OH, WI	7	1	1	1	1	1	12
AR, LA, NM, OK, TX	5	1	2	1	0	0	9
KA, LA, MO, NE	4	1	1	1	1	0	8
CO, MT, ND, SD, UT, WY	5	1	1	1	2	1	11
AZ, CA, HI	6	1	1	1	0	0	9
AK, ID, OR, WA	2	2	1	1	1	0	7

AK, Alaska; AL, Alabama; AR, Arkansas; AZ, Arizona; CA, California; CO, Colorado; CT, Connecticut; DC, Washington, District of Columbia; DE, Delaware; FL, Florida; GA, Georgia; HI, Hawaii; ID, Idaho; IL, Illinois; IN, Indiana; KA, Kansas; KY, Kentucky; LA, Louisiana; MD, Maryland; ME, Maine; MI, Michigan; MN, Minnesota; MO, Missouri; MS, Mississippi; MT, Montana; NC, North Carolina; ND, North Dakota; NE, Nebraska; NH, New Hampshire; NM, New Mexico; OH, Ohio; OK; Oklahoma; OR, Oregon; PA, Pennsylvania; RI, Rhode Island; SC, South Carolina; SD, South Dakota; TN, Tennessee; TX, Texas; UT, Utah; VA, Virginia; VT, Vermont; WA, Washington; WI; Wisconsin; WV, West Virginia; WY, Wyoming.

[a] HRSA region where participant currently lives or practices.

[b] Professionals with experience in prescribing PHHC in the inpatient setting (ie, NICU physicians, PICU physicians, pulmonologist, hospitalist, palliative care, and case managers).

[c] Professionals with experience in prescribing PHHC in the outpatient setting (ie, general pediatricians, pediatricians and nurse practitioners in complex care programs, and case managers in complex care and primary care clinics).

[d] Administrators at home health agencies (ie, chief executive officers, directors).

[e] Various providers of PHHC who are involved in delivering care in the home (ie, nurses, therapists, clinical supervisors, and social workers).

[f] Other professionals who do not fall into other categories but have particular expertise in pediatric home health services (ie, family advocates and Medicaid specialist).

related to PHHC occur in both the inpatient and outpatient setting (participant quotations are in Table 3).

Participants' understanding of the PHHC process was variable, reflective of their personal roles in the process. Inpatient prescribers, who most often initiated PHHC services, were least likely to understand the entire process. They often relied on case managers, nursing staff, and other inpatient team members to identify needs, investigate options, and assist with plans of care; many described their role as limited to signing orders written by case managers. Outpatient prescribers often maintained and revised PHHC orders based on evolving needs and had more direct contact with PHHC providers and, therefore, greater awareness of the PHHC process; our data suggest that they may lack meaningful connections with the inpatient prescribers who initiated PHHC services. Families had a detailed understanding of the process of investigating options and ordering PHHC but spoke less about how PHHC orders were processed and actualized by agencies.

Despite variable understanding and involvement, parents and professionals identified specific steps in ordering, delivering, and modifying PHHC.

Identifying Needs

A PHHC need may be identified by a parent, clinician, or care-coordination team in the inpatient or outpatient setting. Identification may be of a previously unacknowledged need, a change in the child's medical status, or a change in service eligibility.

Investigating Options

When a PHHC need is identified in the inpatient setting, care coordinators (often case managers) work with parents and the clinical team to determine appropriate services and investigate options on the basis of insurance status, agency availability, geography, and family preference. If a need is identified in the outpatient setting, parents work with the outpatient clinician and available care coordinators, including the clinic or practice or insurance case managers or social workers. Families receive a list of possible agencies they may interview before making a choice. Sometimes care coordinators assist families in applying for Medicaid or a state waiver program to obtain PHHC benefits. Many families mentioned that when their child was younger or first eligible, they were likely to accept initial PHHC recommendations but became more discriminating over time.

Developing the Plan of Care

Clinicians and care coordinators work together to write orders to meet the child's needs. Orders are sent to the home health agency, or to the agency and insurance company, to obtain insurance authorization. The agency identifies staffing and begins training designated PHHC providers.

TABLE 2 Scope of PHHC Services Reported by 47 Families

Service Type	No. Families
Home nursing	40
Shift nursing (by an aide, RN, or LPN)[a]	16
Skilled nursing visits[b]	12
Patients receiving both services	12
Durable medical equipment	38
1 company	27
Multiple companies	11
Infusion company	7
Early intervention services[c]	20
PT	31
OT	28
ST	14
Feeding therapy	9
Vision therapy	4
Developmental therapy	3
Behavior therapy	3
Hearing therapy	1
Play therapy	1
Respiratory therapy	2
Music therapy	4
Art therapy	1
Massage therapy	1
Counseling services	2
Mental health services	1
Respite care	6
Palliative care	5
Hospice	4

There were 48 parents; 2 parents were from 1 family. LPN, licensed practical nurse; OT, occupational therapy; PT, physical therapy; RN, registered nurse; ST, speech therapy.

[a] The hours approved per week ranged from 22 to 168 h.

[b] The frequency of skilled nursing visits ranged from multiple visits per week to 1 visit per month and included such tasks as central-line dressing changes, wt checks, blood draws, or administering vaccines or infusions.

[c] Some therapies (eg, PT, OT, and ST) reported were part of the early intervention services a family received.

When services are approved, the home health agency meets the family to develop the plan of care. The finalized plan of care is sent to a prescriber for review and signature. Even when the PHHC referral is generated by inpatient clinicians, the plan of care must often be reviewed and signed by the outpatient clinician, usually the primary care pediatrician.

The family receives training from hospital staff, and sometimes PHHC providers, while inpatient and from PHHC providers after discharge regarding new medical technology, medication administration, and specific cares. For highly complex equipment, such as ventilators and tracheostomies, the PHHC provider may also provide predischarge simulation training at home or at other locations.

Initiating and Providing Services

The agency may require a verbal start-of-care order from the prescriber to begin services while the final plan of care is drafted, a requirement that often causes confusion and a delay in care. Once the child is discharged and PHHC staffing is secured, home services are initiated. Parents often fill gaps in communication and coordination to ensure service delivery and advocate for new or continued PHHC to meet their child's evolving needs. Parents learn more about potential additional PHHC services through other families and community resources. Outpatient clinicians must reapprove existing PHHC at mandated intervals, make adjustments to orders, initiate new orders, and troubleshoot PHHC problems.

Navigating Evolving Needs and Challenges

Many CMC have recurrent hospitalizations, with additional PHHC needs identified. With each inpatient stay, home health services stop and must be renewed or re-initiated at discharge. When new PHHC orders are written, insurance is again navigated, services are staffed, and staff is trained. This iterative process (often initiated by different case managers, discharge coordinators, or clinicians with different insurance and home health care personnel or agencies) places excessive burden on families and providers alike.

Over time, a child may lose services if they are no longer considered medically necessary, and therapies may evolve from being home based to being school based.

Facilitating the PHHC Process

With so many steps in the PHHC process that involve multiple individuals from unconnected agencies or sectors, it is important to leverage common facilitators to augment the PHHC process (Table 4).

Knowledge of the Process

Prescribers should understand available PHHC services and how to access them. This is particularly important for families without previous experience of home health care. Some families reported going without available services because their clinicians were unaware of existing programs, prompting unmet medical needs and family exhaustion. Knowing how to navigate insurance authorization for PHHC was mentioned repeatedly as a specific skill needed by prescribers and support staff.

Anticipation and Early Identification of Needs

Professionals advocated for planning for PHHC well before hospital discharge. Early notification of

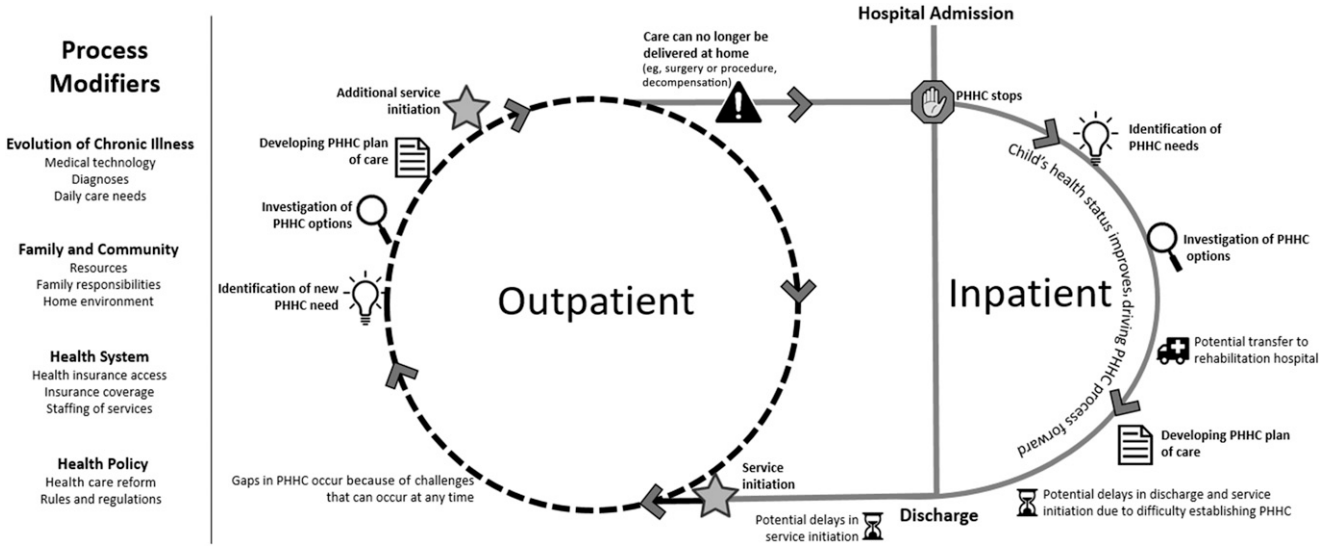

FIGURE 1
The Process of PHHC.

impending discharge allows PHHC agencies to secure staffing, educate parents, and address parent anxiety and expectations. Because services are commonly limited in rural areas, alternate plans for discharge, such as transfer to a rehabilitation hospital, may be necessary. Late notification of the need for PHHC or last-minute changes to the plan of care can delay hospital discharge.

Participants emphasized the need to confirm that a family's home has adequate equipment and supplies before PHHC begins. Early and comprehensive parent education is essential because PHHC is rarely 24/7 and families fill the gaps in home care.

Effective Communication and Interagency Relationships

Participants noted that consistent communication between prescribers, providers, and parents minimizes delays and errors in PHHC. Clear, concise orders and timely order modification prevent unnecessary rehospitalization. Leveraging existing relationships and lines of communication (eg, integrated electronic medical records) helps as care needs of CMC and family social situations evolve. Parents specifically appreciate effective communication between stakeholders and proactive reauthorization of services and supplies.

With experience, and after learning from other parents of CMC, families became more active partners with PHHC prescribers and providers. Harnessing the expertise of medically savvy families can smooth the PHHC process.

Care-Coordination Infrastructure and Support Staff

Participants highlighted the relevance of support staff to ongoing PHHC management. Care coordinators for individual CMC may be employed by a variety of organizations and may have different scopes of work and different titles, including case managers, social workers, discharge coordinators, and home health liaisons. In the inpatient setting, case managers and social workers are often the interface between physicians, families, home health agencies, and insurance companies. Case managers map patient needs to potential PHHC services, investigate PHHC options, and prepare orders for physician signature. They monitor the child's inpatient progress and anticipate how clinical changes might influence PHHC needs. They facilitate family training before discharge.

In the outpatient setting, fewer support staff were available and were often tied to a specific clinic, insurance company, or home health agency. Gaps in care coordination can interrupt PHHC services. When prescribers lack care-coordination support or experience, families become case managers by default, responsible for identifying home health needs and investigating options. Families rarely receive preparation for assuming this role, yet quality of care is consistently enhanced when parents are engaged, knowledgeable, and able to advocate for their child.

Skilled and Consistent Home Health Providers

Participants agreed that quality PHHC depends on providers with strong pediatric skills; these providers are in short supply, which can delay hospital discharge or initiation of PHHC services. PHHC providers unfamiliar with pediatric chronic illness may miss warning signs of decompensation, may lack the ability

TABLE 3 The Process of PHHC

	Quotes
Participant understanding and roles	
Physicians may lack understanding	"[The process] can be a little bit confusing and, actually, that can be another bit of a barrier too because it isn't transparent." (Outpatient prescriber)
Case managers often drive prescribing process	"The nurses in the hospital who were trained for my daughter also worked with the social worker determining exactly what her needs would be even more so than the doctor. The doctor signed off on it, but the nurses do all the dirty work. They have the deeper understanding of exactly what a nurse in our home would need to be doing." (Parent)
	"We're lucky our case managers do the paperwork, do the forms, prepare everything. We discuss it, I sign it." (Inpatient prescriber)
Relationships between inpatient, outpatient, and home providers lacking	"It's important for the inpatient staff to be able to work with the outpatient medical staff for the patient. That we're all on the same page, and that we're all doing the same thing, and doing the right thing for them. There's definitely a coordination between inpatient and outpatient care." (Inpatient prescriber)
	"The familiarity of the provider or clinician ordering those services, the relationships that that individual has with both the process and the people that are actually providing those services [facilitates PHHC]." (Parent)
Importance of family involvement	"I found out a lot of other families with children that were much less involved than mine did have nursing, and I then initiated the process.… So I kinda had to do everything on my own." (Parent)
	"Sitting down and going through with the family what their perception of their needs are, I think, is the first thing that I do, aside from what everybody else is telling me [laughs] a family may need." (Inpatient prescriber)
Steps	
Identifying needs	"We review charts every day, the case managers do, and meet with families and providers. During their hospital stay we anticipate what their home health needs are going to be." (Inpatient prescriber)
	"The combination of the doctors and the parent in my case [who identify PHHC needs], I [am] usually on top of their disease, so I would push for it or ask for it. But it's a combination when it comes to my daughter's disease. It's a combination of both the doctor and us, the parents." (Parent)
Investigating options	"That typically includes having the families meet with our case manager, who gets all the information from them about what their insurance is, where they live, and does some research to figure out how much home services are going to be approved for and what their options are in terms of who's going to provide those home services." (Inpatient prescriber)
	"At that point, as an agency, you'd look to see whether you'd feel like you can accept that patient and that you have a staff in place that you can staff it with. The biggest thing that you don't want to do is accept a patient with the idea that you're going to try to be able to staff it and then not staff it." (In-home provider)
Developing the plan of care	"[T]he registered nurse to the case, she develops a plan with the family and the physician. She'll go to the home. If there's discharge paperwork, that's a little bit easier to read in terms of what the doctor has ordered, but that registered nurse will also call the doctor when she's there to just make sure that everything is being written correctly." (Home health administrator)
	"The way it worked with us is that the doctor put in all the orders. It went to a few different agencies. They got in touch with us a few days to a week or two later…a week of some phone interviews to understand our situation, make sure they understood what his needs were. In one case, they sent somebody out to do an assessment. From there, we started receiving the services." (Parent)
Initiating and providing services	"We get what's called a verbal start [of] care, which states that this primary care physician is aware that we're going to start providing services in the home and he's aware that he'll be signing off on a plan of care." (In-home provider)
	"They had to set up with the company that would provide the devices. They have those delivered. Once that was all set up, the people showed up at our home. They showed us how to use the devices and how to conduct the night feeds with those devices." (Parent)
Navigating evolving needs and challenges	"…my daughter has surgery every six months or so after she's discharged from surgery, we have to go through this process all over again." (Parent)
	"The other problem is if he's stable, if nothing has changed in the three months, they [the insurance company] come back and deny it [home nursing] because there was not a catastrophic event." (Parent)

to troubleshoot pediatric equipment, or may make medication errors. Ongoing education, oversight, and continuity of PHHC providers is viewed as critical to quality care for the child and to relieving burden for the family.

Working Relationship Between Parents and PHHC Providers

PHHC professionals provide in-home care, making communication and respect important to successful working relationships with families. The nature of the parent-PHHC provider relationship varied; some parents reported that PHHC providers became members of the family, whereas others noted the relationship to be more professional. Regardless of the level of interpersonal involvement between

TABLE 4 Facilitators of PHHC

	Quotes
Knowledge of the process	"An experienced pediatrician, experience in not only knowing the medical needs but knowing how to navigate the insurance process and knowing the right DME depot." (Inpatient prescriber) "The familiarity of the provider or clinician ordering those services, the relationships that that individual has with both the process and the people that are actually providing those services." (Parent)
Anticipation and early identification of needs	"Planning early.… When you find out the day before, someone's going to go home, and they have complex needs, it's very difficult to do everything that you need to do to get them home in a short period of time." (Home care administrator) "…thankfully I tried to do things proactively and to get things started well before we brought our son home." (Parent) "When you start communicating early so that you know what your coverages are going to be and are able to plan in advance for that." (Parent)
Communication and interagency relationships	"I think the more we talked about it before they go home, the better facilitated it is; with the home health care agencies and also with the outpatient providers. I think when we're able to achieve that, when we're willing to bring all those people to the table, those are the most successful transitions that we have." (Inpatient prescriber) "I want the doctors, nurses, and myself, my husband, and my kids to all be part of [my daughter's] team. We work together. That's really huge, for the doctors to work with home care and the home care to work with the families." (Parent)
Skilled and consistent home health providers	"Probably the nurse in field that was trained well enough to accommodate their needs and teach the family… If the nurse doesn't have the skill set or even the clinical knowledge to accommodate the family and teach them properly, it's not going to be successful. If you can't teach the family because you don't know, the family is going to fail." (Home care administrator) "Continuity of care. It's so important. Staffing being available, being consistent, following the physician's orders.… When you have continuity of care you're going to catch the little things that aren't right." (In-home private-duty nurse) "I would say having those primary nurses, not a ton of nurses floating through, a different nurse every day. Trying to find nurses that are looking for three, four, five days, and have them as primaries, and then they work as a team because the nurses get to know each other from shift report. It's just a better outcome for the patient." (In-home provider)
Parent-PHHC relationship	"One of the biggest factors was just the personality and flexibility of the person [PHHC provider] and their respect of our knowledge and our family." (Parent) "If we can't communicate well, don't get along [parent and PHHC provider], it may get a little rough." (Parent) "Once they [PHHC provider] have a relationship with the family and the patient, they're invested into that family. They want to make sure that they're on time, and they're not calling out because they know what that means to that family and not having coverage." (In-home provider)

DME, durable medical equipment.

parents and providers, all agreed on the importance of clearly defined roles and consistent boundaries. Well-defined expectations and mutually respectful relationships diminished late arrivals and missed shifts by PHHC providers, circumstances that created havoc for families.

DISCUSSION

PHHC has expanded over the past 2 decades to address the needs of a growing pediatric population with medical complexity. For CMC dependent on multiple medications, medical technologies, and therapies, survival outside of an inpatient setting requires PHHC for prolonged periods, sometimes indefinitely. Pediatricians caring for these patients may need to interact with multiple PHHC agencies (some private or hospital-affiliated) caring for children or for children and adults. The pediatrician's role within the PHHC process, although important, has not been well described, leaving potential gaps in care. In this qualitative study, we clarify the PHHC process and highlight key areas in which pediatricians can potentially facilitate care. Although targeted recommendations are offered, the utility of these recommendations will need to be tested with a nationally representative sample.

Our data suggest that pediatricians, especially inpatient pediatricians, are the foundation for PHHC initiation. Inpatient prescribers and their care teams must articulate a child's home care needs, map available PHHC services onto those needs, write clear and timely prescriptions to initiate insurance authorization and PHHC-agency activation, and confirm that parent education, home evaluation, and equipment delivery occur. They are also responsible for handing off PHHC monitoring and maintenance to the outpatient pediatrician. For this transition to happen safely and successfully, the outpatient clinician needs a comprehensive discharge summary and a warm handoff from the inpatient team. We found that inpatient clinicians generally have little understanding of PHHC. Clear opportunities exist for the education of inpatient clinicians about local PHHC resources, how to optimize PHHC prescriptions, and how to promote continuity of PHHC management beyond the inpatient setting.

Clear role delineation among outpatient pediatricians and subspecialists helps increase efficiency, preventing gaps in care and duplication of work. Outpatient pediatricians in our study felt ill

equipped to sign a plan of care for services initiated by inpatient prescribers, a situation that could be obviated by a warm handoff. They relied heavily on care-coordination staff to ensure that services were delivered. However, office-based care-coordination support is not universally available to primary care pediatricians; without those services, pediatricians are challenged to provide a medical home for patients with medical complexity.[16] Care coordination allows pediatricians to anticipate needs rather than react to acute problems,[17] which may avoid hospital readmission. Pediatricians without practice-based care coordinators may be able to collaborate with care coordinators assigned through the patient's insurance, early intervention program, or PHHC agency.

Participants communicated the importance of involving the family, initiating the PHHC process early, and proactively investigating which services may be possible for individual patients. Qualifying diagnoses and needs vary among private and public insurance plans, yet PHHC is a mandated service under Medicaid's Early Periodic Screening, Diagnostic, and Treatment program when a condition needing treatment is discovered during screening.[3,18] Prescribers can also increase a child's access to PHHC by learning how best to write letters of medical necessity, how to facilitate insurance authorization, and how to respond to denials. Online resources exist to guide prescribers.[19] Many pediatric training programs now offer complex-care clinical rotations to develop the skills future pediatricians will need to care for CMC.

Parents and professionals in this study identified the lack of a robust, well-trained, available PHHC workforce as a barrier to safe home care. Our findings support those of colleagues who noted that these deficiencies in PHHC quality and availability contributed to caregiver burden[20] and excess hospital days.[7,8] Pediatricians or care coordinators should ask how likely the designated PHHC agency is to staff the approved hours. They should also inquire about staffing continuity to help families anticipate filling in gaps or inquire about training new staff. Pediatricians should advocate for models of home health care that stress safety, build pediatric-centered skills, and continuously evaluate the competency of home health providers to care for children, as recommended for adults by the Institute for Healthcare Improvement.[21]

Pediatricians can help families understand the realities of PHHC. First, they should prepare families to become care coordinators and advocates for PHHC services for their child indefinitely. Second, connecting parents with other families with PHHC can provide peer mentoring about interviewing, hiring, and working with PHHC agencies. Grassroots organizations, such as Family Voices[22] and the Parent's Place of Maryland,[23] can facilitate connecting families. Third, pediatricians can provide parents with local resources for respite care to help avert burnout from inevitable gaps in PHHC.

Our study has limitations. The sample is not nationally representative. Some inpatient physicians of patients who were CMC receiving PHHC declined to participate, citing a lack of knowledge about PHHC. Although we successfully recruited families from all 10 HRSA regions, rural areas were underrepresented. Although CMC may receive primary care from a family practice physician, none were represented in this sample. All participants spoke English. We likely interviewed parents who were skilled at advocating for their children; we may have overestimated how successful parents were in filling in the care-coordination gaps that occurred.

CONCLUSIONS

In this article, we provide a description of the process and identify barriers and facilitators of PHHC from the perspective of those who receive, provide, and prescribe these services. Targeting interventions to address the barriers and bolster the facilitators have the potential of improving the quality of PHHC.

ACKNOWLEDGMENTS

We thank Rebecca Seltzer, MD, and the members of the Chronically Critically Ill (CCI) Working Group for their contributions to this work.

ABBREVIATIONS

CMC: child/children with medical complexity
HRSA: Health Resources and Services Administration
PHHC: pediatric home health care

Address correspondence to Pamela K. Donohue, ScD, Charlotte R. Bloomberg Children's Center, 1800 Orleans St, Room 8527, Baltimore, MD 21287. E-mail: pdonohu2@jhmi.edu

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: Funded by a Johns Hopkins Children's Center innovation grant.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

REFERENCES

1. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011; 127(3):529–538
2. 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
3. Simpser E, Hudak ML; Section on Home Care, Committee on Child Health Financing. Financing of pediatric home health care. *Pediatrics*. 2017;139(3): e20164202
4. American Academy of Pediatrics Committee on Children with Disabilities. Guidelines for home care of infants, children, and adolescents with chronic disease. *Pediatrics*. 1995;96(1, pt 1): 161–164
5. 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
6. Gay JC, Thurm CW, Hall M, et al. Home health nursing care and hospital use for medically complex children. *Pediatrics*. 2016;138(5):e20160530
7. 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
8. Boss RD, Williams EP, Henderson CM, et al. Pediatric chronic critical illness: reducing excess hospitalizations. *Hosp Pediatr*. 2017;7(8):460–470doi:10.1542/hpeds.2016-0185
9. 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
10. Nageswaran S, Radulovic A, Anania A. Transitions to and from the acute inpatient care setting for children with life-threatening illness. *Pediatr Clin North Am*. 2014;61(4):761–783
11. Kuo DZ, Berry JG, Glader L, et al. Health services and health care needs fulfilled by structured clinical programs for children with medical complexity. *J Pediatr*. 2016;169: 291–296.e1
12. Hobbs JE, Hussey-Gardner BT, Donohue PK. Pediatrician perspectives: caring for NICU graduates in the community. *Contemp Pediatr*. 2015;32(12):18–23
13. Goodman LA. Snowball sampling. *Annals of Mathematical Statistics*. 1961; 32(1):148–170
14. Health Resources and Services Administration. Office of regional operations. Available at: https://www.hrsa.gov/about/organization/bureaus/oro/index.html. Accessed January 3, 2019
15. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9): 1277–1288
16. Okumura MJ, Knauer HA, Calvin KE, Takayama JI. Pediatricians' comfort level in caring for children with special health care needs. *Acad Pediatr*. 2017; 17(6):678–686
17. Van Cleave J, Boudreau AA, McAllister J, et al. Care coordination over time in medical homes for children with special health care needs. *Pediatrics*. 2015;135(6): 1018–1026
18. Centers for Medicare and Medicaid Services. Early and periodic screening, diagnostic, and treatment. Available at: https://www.medicaid.gov/medicaid/benefits/epsdt/index.html. Accessed January 18, 2019
19. Medical Home Portal. Writing letters of medical necessity. Available at: https://www.medicalhomeportal.org/issue/writing-letters-of-medical-necessity. Accessed February 22, 2019
20. Nageswaran S, Golden SL. Improving the quality of home health care for children with medical complexity. *Acad Pediatr*. 2017;17(6):665–671
21. Institute for Healthcare Improvement. No place like home: advancing the safety of care in the home. 2018. Available at: www.ihi.org/resources/Pages/Publications/No-Place-Like-Home-Advancing-Safety-of-Care-in-the-Home.aspx. Accessed July 21, 2019
22. Family Voices. Available at: http://familyvoices.org/. Accessed June 2, 2019
23. The Parents' Place of Maryland. About us. Available at: https://www.ppmd.org/about-us/#our-story. Accessed March 15, 2019

The Pediatric Home Health Care Process: Perspectives of Prescribers, Providers, and Recipients

Karen Fratantoni, Jessica C. Raisanen, Renee D. Boss, Jennifer Miller, Kathryn Detwiler, Susan M. Huff, Kathryn Neubauer and Pamela K. Donohue

Pediatrics 2019;144;
DOI: 10.1542/peds.2019-0897 originally published online August 29, 2019;

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

The Pediatric Home Health Care Process: Perspectives of Prescribers, Providers, and Recipients

Karen Fratantoni, Jessica C. Raisanen, Renee D. Boss, Jennifer Miller, Kathryn Detwiler, Susan M. Huff, Kathryn Neubauer and Pamela K. Donohue

Pediatrics 2019;144;
DOI: 10.1542/peds.2019-0897 originally published online August 29, 2019;