

“It’s a Different Conversation”: Qualitative Analysis of Pediatric Home-based Hospice/Palliative Care Visits’ Perceived Value

Daniel H. Grossoehme, DMin*†; Jaime Sellers, MD, MPH*; Samuel Accordino, BS†; Steven M. Smith, MD‡; Rachel Jenkins, MA*; Gwendolyn Richner, BA*; Yolanda Moore-Forbes, MD§; Sarah Friebert, MD*

Abstract

Introduction: Home-based hospice and/or palliative care (HBHPC) is an important and increasingly utilized aspect of care for children with serious conditions—those with high mortality risk, which either impacts their quality of life or carries a significant caregiver burden. Provider home visits are a core feature; however, the travel time and human resource allocation are significant challenges. Balancing the appropriateness of this allocation requires further characterization of the value of home visits to families and identification of the value domains of HBHPC for caregivers. For study purposes, we defined a “home visit” as an in-person visit by a physician or advanced practice provider to a child’s residence. **Methods:** The methods include a qualitative study using semistructured interviews and a grounded theory analytic framework enrolled caregivers of children aged 1 month to 26 years receiving HBHPC from either of 2 U.S. pediatric quaternary institutions between 2016 and 2021. **Results:** Twenty-two participants were interviewed; the mean (SD) interview duration was 52.9 (22.6) minutes. The final conceptual model has 6 major themes: communicating effectively, fostering emotional and physical safety, building and maintaining relationships, empowering the family, seeing the bigger picture, and sharing burdens. **Conclusions:** Caregiver-identified themes demonstrated improved communication, empowerment, and support from receiving HBHPC, which can facilitate enhanced family-centered, goal-concordant care. (*Pediatr Qual Saf* 2023;8:e663; doi: 10.1097/pq9.0000000000000663; Published online July 10, 2023.)

Community- or home-based hospice and/or palliative care (HBHPC) is an important and increasingly utilized aspect of care for children with life-limiting and/or life-threatening conditions.¹ This population continues to grow due to many factors, including increased



From the *Department of Pediatrics, Akron Children’s Hospital, Akron, Ohio; †Rebecca D. Considine Research Institute, Akron Children’s Hospital, Akron, Ohio; ‡Department of Pediatrics, Nationwide Children’s Hospital, Columbus, Ohio; and §Department of Pediatrics, Akron Children’s Hospital, Akron, Ohio.

*Corresponding author. Address: Daniel H. Grossoehme, Rebecca D. Considine Research Institute, Akron Children’s Hospital, 215 West Bowery Street, Akron, OH 44308
PH: 330-543-0356
E-mail: dgrossoehme@akronchildrens.org

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survival of premature infants and children with multisystem diseases and improved oncologic, acute intensive, and supportive care.²⁻⁴

Home-based palliative care (PC) was a natural evolution from hospice-based, in-home care. Recent legislative changes, including Accountable Care Organizations, have facilitated increased HBHPC options to reduce hospital utilization for individuals wishing to optimize care at home.⁵⁻⁷

HBHPC provides comprehensive, interdisciplinary team-based care offering many benefits to patients and families. Though team members and services vary by program, they may include home provider visits, skilled nursing visits, pain and symptom management, and care coordination.²

Pediatric HBHPC research, while increasing, remains limited. Studies have shown HBHPC significantly improved patient and family quality of life, decreased caregiver burden, provided effective symptom relief, and facilitated a peaceful death at the end of life.^{8,9} Pediatric HBHPC has also proven beneficial systemically, with significant cost savings and decreased length of inpatient stay.^{10,11} Pediatric patients enrolled in HBHPC spend, on average, 52 fewer inpatient days during their last year of life compared with pediatric PC patients not receiving home-based services.¹² Community-based programs

can also reduce unwanted readmissions and facilitate care delivery at an individual's preferred care location, often at home.¹³

PC provider home visits are a core feature of comprehensive HBHPC; however, several implementation barriers can exist within a pediatric PC program. Many programs cannot offer this service due to staffing needs for inpatient and ambulatory services. Even if staffing is sufficient, there is often an inability to accommodate the travel time required for home visits. It is not unusual for a home visit to require several hours to prepare, travel, and conduct. Researchers must define the benefit of HBHPC to argue for continued investment in this potentially time-consuming treatment modality. While HBHPC outcomes are important in defining value, the value must also consider individual- and family-defined perspectives. Boyden et al¹⁴ gave important insights into parental perspectives on HBHPC using a discrete-choice experiment in which parents ranked HBHPC quality domains. Based on the National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care*, participants ranked physical and psychological aspects of their child's care in addition to care coordination as their highest priorities; addressing spiritual and cultural domains of care was ranked lowest.¹⁵ The present study aimed to identify the domains constituting pediatric HBHPC's value to caregivers, typically parents.

METHODS

Participants

The institutional review boards of the 2 study sites, 467-bed and 551-bed quaternary pediatric Midwest referral hospitals, approved the study. For this study, those receiving home-based PC and hospice were not differentiated as the 2 programs offer similar services and structure to both PC and hospice patients. Studies support this lack of distinction as the difference between children in hospice and home-based PC is often less clear in pediatrics.^{16,17} None of the home visits were related to regulatory requirements (e.g., the "face-to-face" requirement). Inclusion criteria included the following: legal guardian of a child aged 1 month to less than 26 years old who received a home visit by an HBHPC provider between January 1, 2016, and January 31, 2021; and ability to speak English sufficiently to participate in the interview. Exclusion criteria included the following: receiving perinatal PC before HBHPC enrollment; or transferring or receiving care from another PC program other than the participating sites. Individuals seen by the inpatient consultative PC team and enrolled in either home-based PC or hospice were eligible for provider home visits. All children had a diagnosis that limited their life expectancy. The clinical team determined the need for a home visit based on routine follow-up or in response to identified need. Parents of deceased children were interviewed no sooner than 3 months after their

child's death. "Home visit" was defined as an in-person visit to where the child lived by a provider (physician, nurse practitioner, or physician's assistant). Home visit providers were also members of their respective institution's inpatient consultative and ambulatory PC teams.

Procedure

Following Hennink et al,¹¹ the anticipated sample size to maximize achieving meaning saturation was 16–24 persons. Sampling began with a convenience approach, after which sampling was purposive. An electronic medical record query identified eligible persons. Subsequently, study staff mailed recruitment letters introducing the study with "opt-out or opt-in" information. Persons could opt-in or out by calling or emailing study staff. Study staff contacted individuals who did not opt-out approximately 2 weeks later or approached them in person if they had an upcoming appointment. Interested persons received consent documents by mail, email, or fax (at their preference). Study staff reviewed the consent document, answered questions, obtained signed copies, and recorded reasons for nonparticipation to examine for systematic patterns.

A semistructured interview guide was created *de novo* by the study team based on the team's experience interviewing parents of children receiving pediatric HBHPC and incorporating related published data.^{4,8,9,14} Four authors conducted the interviews, comprising 2 female clinical research coordinators, 1 female PC physician fellow, and 1 male undergraduate research intern, all trained by the first author; none had a prior relationship with participants. Interviewers informed participants of the interviewer's role and that the interview's goal was to deeply understand their pediatric HBHPC experience. Interviews with partnered guardians were individual, though they could be interviewed as a dyad if preferred. Participants chose their interview platform: in-person, telephone, or online video. Interviews were recorded, transcribed, verified, and anonymized by study staff. The results were shared with a subset ($n = 7$; 32%) of participants ("member checking") to ensure the results described their perspective.¹⁸ The 32-item Consolidated Criteria for Reporting Qualitative Research (COREQ), developed to guide complete and transparent reporting of interview (or focus group) data, were used to prepare this report.¹⁹

Analysis

Grounded theory provided the analytic framework.²⁰ The coding team comprised 6 females and 3 males; self-described racial make-up included 7 White, 1 Black, and 1 Asian; position titles included PC scientist, clinical research coordinator, PC physician fellow, general pediatrician, and research intern. The coding team coded transcripts together, resolving differences by consensus. Initial coding of individual transcripts was line-by-line, isolating narrative fragments describing or defining aspects of HBHPC value. Participant comments about their experiences with

subspecialists other than hospice or PC were not analyzed. Constant comparative analyses within and across interviews compared data with already-coded data fragments for thematic consistency or unique insights.

Focused coding used the most significant initial codes to develop thematic categories explaining the experience of HBHPC and its value. This approach led to the need to understand some categories more fully, at which point sampling was theoretical.¹⁸ Unlike purposeful sampling, in which the sampling frame is defined prior to data collection, theoretical sampling is the simultaneous collection and use of that data to determine which data remain to be collected and where to find them to develop a theory.²¹ Theoretical sampling began after the sixth interview to deeply understand themes by collecting additional data to capture nuances and insights by seeking greater diversity in participant gender and the child's race and age. The first author defined saturation for both code meaning and frequency.^{11,20,22} Meaning saturation was the consensus among coders that they fully understood the theme and its dimensions.¹¹ Code frequency saturation (the point of no addition of new data) was calculated by determining the point of no added codes in the interview sequence (interview 18 of 22).²³ Data were organized using the NVivo 12.0 software (QSR, Melbourne, Australia).²⁴

RESULTS

Twenty-two caregivers participated (76% enrollment rate; see Table 1). The mean (SD) interview duration was 53 (23) minutes; the median (range) was 45 (24–111) minutes. The final conceptual model is presented in Figure 1, which depicts 6 major themes: communicating effectively, fostering emotional and physical safety, facilitating relationship-building, empowering the family, gaining broader insight, and sharing burdens. The circumferential multicolor band depicts the interrelatedness of the themes. While each theme is a distinct component of providing enhanced family-centered goal-concordant care, the components do not function in isolation. We describe each theme below and present exemplar quotations in Table 2.

Table 1. Demographic Characteristics of Participants and Their Children

Sample	Characteristics	N (%)	
Caregiver (n = 22)	Gender, female	18 (82)	
	Race	White	18 (82)
		Black	2 (9)
		Asian	2 (9)
	Relationship to child	Mother	16 (73)
		Father	3 (14)
Grandmother		2 (9)	
Grandfather		1 (4)	
Child (n = 18)	Gender, female	7 (39)	
	Age, 0–10	5 (28)	
	Age, 11–18	11 (61)	
	Age, 19–26	2 (11)	

Communicating effectively

Communication in the home was qualitatively different than that in the clinic. This difference included speaking more deeply (e.g., “Everyone’s so gut-level honest”) and facilitating shared decision-making and problem-solving, for example, “We made a group decision that we were going to get vaccinated when it was available for COVID.” The increased visit length and provider time allowed for additional and more thoughtful, deeper questions, leaving participants feeling heard and clearly understanding the care plan.

Fostering emotional and physical safety

The impact of home visits on the ability to provide safe care was demonstrated in several dimensions. Themes included a perception of emotional safety in the home environment, resulting in a different level of communication. It also meant safer care for the child. Caregivers identified not missing breathing treatments, nutrition, hydration, or medication doses. Home visits eliminated the risks inherent in traveling to an appointment—both traffic safety and an en-route medical emergency. Participants expressed diverse views, including being equally comfortable in either home or hospital and being able to converse outdoors. Participants also perceived lower infection control risks than in the clinic or hospital setting. Although the pandemic increased many participants’ appreciation for the lower infection risk posed by home visits compared to ambulatory clinic visits, they also stated they had infection risk concerns before the 2020 SARS-Cov-2 pandemic.

Facilitating relationship-building

HBHPC served to build and maintain relationships, beginning with the initial home visit. One participant noted that it set their perception of the whole team beyond the individual providers in the first encounter. Several participants noted the broader focus on how the family was doing during home visits. The informality of the experience fostered this perception. One participant described being less intimidated by PC when the providers sat on their living room floor during the initial visit and the physician talked while petting the family dog. HBHPC also reportedly normalized the child’s life by having outside people enter the home and interact with the child. The external contact further served as a corrective to the isolation experienced by caregivers before and especially during the pandemic.

Empowering the Family

Participants reported HBHPC as empowering. Reasons included being able to speak more freely because of the shift of power from provider/hospital to parent/home. One participant stated, “...in the clinic, it’s almost like there’s a little power difference...you’re in an unfamiliar environment that’s their professional place of work”; another said, “I’m probably more open (at home) because

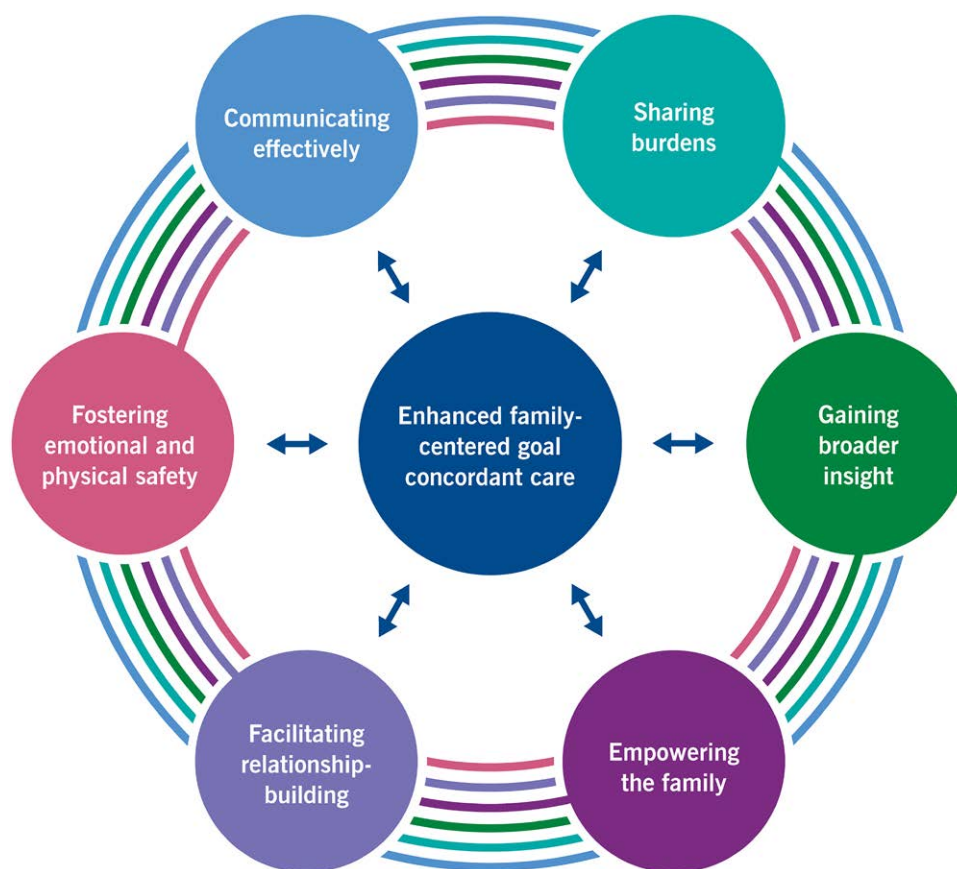


Fig. 1. Conceptual model depicting caregiver perceptions of the value of pediatric home-based hospice care or PC.

you're on my territory." Participants from racial minorities expressed greater freedom to have issues addressed in culturally sensitive ways. One person stated, "Most Black people deal with mental health. We don't communicate that. I do feel they address it differently when they address it at home than when you're in the office." Participants reported having their efforts as their child's caregiver validated during HBHPC and appreciating that experience. Parents described HBHPC as an expression of respect for themselves and their culture.

Gaining a broader insight

HBHPC offers value for the child's health care by enabling providers to experience a more holistic appreciation for the child's life. Participants described how much more "themselves" their children were at home compared with the clinic. This feeling resulted in a more comprehensive physical assessment with a more cooperative child, leading to an enlarged understanding of the child's condition. Seeing the physical environment allowed providers to offer practical suggestions rather than simplistic, impractical ones, such as suggesting a wheelchair too wide for a home's doorways or shower carts in bathrooms too small to accommodate them. Participants also commented that providers seemed less distracted and thus more thorough and detail-oriented than in the clinic.

Sharing burdens

HBHPC provides value by reallocating the level of the burden borne by parents and providers. Having providers travel to the child's home minimizes the burden on the child, avoiding the disruption of their daily routine and increased stress for the child. It minimizes the time burden parents experience, with participants noting that a 30-minute ambulatory PC appointment at the hospital or health center could easily equate to a half-day experience of preparation, travel, stress, and cost, including sick time or missed work. HBHPC also maximized efficiency by having multiple providers arrive simultaneously without waiting to see them serially in the clinic. No participant felt home visits increased their burden by generating a need to prepare or clean their house. One commented, "My attitude with most is, you're young, you'll get over it." Participants denied concern that a home visit would lead to being investigated. On the contrary, they perceived greater privacy threats in clinics due to being overheard or their custody threatened specifically by agreeing to limits to nonbeneficial life-prolonging interventions such as do-not-resuscitate orders.

DISCUSSION

This study identified 6 caregiver-identified domains of value in pediatric HBHPC. On the surface, having a

Table 2. Exemplar Quotations Supporting Themes

Number	Major Theme	Subtheme	Exemplar Quotations
	Communicating effectively		Home visits really facilitate good conversation about what to do for my daughter and getting a good plan in place for her. Just being at home made it so much easier for us to process and accept hospice and think about <i>N.</i> 's death and how it could happen.
	Fostering emotional and physical safety	Avoiding missed treatments due to travel or waiting	Their coming (to my) home (meant there) was no worry for me to how I'm going to feed her during the travel (to and from clinic). If our appointment is too early, we might not have access to the full 20-minute breathing treatment.
		Feeling safer emotionally at home	Being in your own comfort zone lends to more...better head space than being in clinical setting. At clinic, it's just that sterile, it's a lot going on, but when you're at home, it's personal and you don't worry
		Reducing travel risk enroute	if she starts choking, I'm literally not going to be able to do anything about it. I'm stuck on the highway. It's a concern because of the wheelchair, and if anything were to happen on the road, it would be very difficult if the vehicle broke down, or if there were an accident.
		Reducing risk of being at hospital	even though they're coming into the home you're still having less exposure to than to the number of people than if you were coming into this hospital, so that certainly is helpful. Pre-COVID, when things would get busy, I wouldn't like, you know, standing in line with people or having to walk through crowded areas, or sitting close to people if the waiting area was busy.
	Building and maintaining relationships	Setting the tone for the future	We associated that first home visit with the practice, not the individual. That initial visit set the tone for everything going forward.
		Maintaining the relationship by doing home visits	Our comfort level in discussing things has changed because of that relationship. The focus of the visit isn't just on [<i>N.</i>] and her health status per se, it's about all of us, and everything that is going on,
		Maintaining the child's social network	In a bedroom with the door shut, and if she did not have a nurse there, she was totally alone. I feel like the bigger her circle of people is, the better.
		Considering a home visit as entertainment	I consider a home visit an entertainment. You are a guest in my home. Even the nurses come once a month...I talked her leg off... <i>N.</i> doesn't answer me back, so it's nice to have someone to spar with...the engagement is nice.
	Empowering the family	Empowering the parent	We address mental health differently at home than when you're in the office...most Black people deal with mental health...(but) we don't communicate that... In the clinic, it's almost like there's a little power difference. You're in an unfamiliar environment, like their professional place of work.
		Respecting the family	They always respected our questions, and they answered them clearly. It made us comfortable that yes, they are the right people. We follow Hinduism. They did make sure that every part of our cultural belief is addressed.
		Validating what the family is doing	It wears on you after a while, and when someone gives you a pat on the back and says, "Hey, you're doing the right thing," it helps. Helps a lot. More than they will ever know. Home visits are more goal-consistent...they leave here with me feeling like I have somebody in my corner that knows I'm working hard.
	Seeing the bigger picture	Being our true selves	After an hour ride each way, he is not as alert as he would be when you are here. Our son is non-ambulatory, and seeing the setup in the home is, I think, better understood.
		Going deeper in conversation and relationship	It's easier to get into more in depth conversations, and really they get, dig deeper into the issues and problems than it might be at the outpatient. You do have a sense of like, total attention being put on your child. And that is like paramount to parents like us.
		Being culturally sensitive	I want you see you know where <i>N.</i> lives and her environment, what influences her. Having him come out, having him see us, why we chose hospice, why we wanted to bring <i>N.</i> home, maybe gave him a better understanding of who we are as a family and who <i>N.</i> is. And I think that helped open up our hearts more to him and trust in his care more.
	Sharing burdens	Maximizing efficiency	With a special needs kiddo, there's always something that you can do at home if you are waiting Usually, it's like a doctor and a nurse. Sometimes a social worker, a pastor
		Providing post-mortem assistance and guidance	And once he did pass, there was a lot of stuff we didn't have to think about, like the death certificate and stuff like that. They came out afterwards and helped us out a lot because like I had no idea how to destroy the drugs. So, you know, we had leftover Ativan leftover morphine.
		Reducing burden on the child	She's always afraid that we're going to have to stay so her heart rates and blood pressures are always higher than they are at home. For <i>N.</i> , maybe the burden for her is like, her routine gets disrupted.
		Reducing family travel burden	It takes like 2 hours to get <i>N.</i> ready. To get him loaded up. Like it was a half day of work I would have to take off for maybe a half hour appointment.

physician or advanced practice provider devote several hours to travel may seem unproductive compared with more efficient settings with lower costs and higher reimbursement. However, emphasizing a more global definition of value in health care broadens the conversation from purely financial to considering quality and experience. Providing family-centered goal-concordant care is a cornerstone of pediatric health care. HBHPC's value lies partly in how children and families experience care as value-added over ambulatory or inpatient care delivery.

Winston Churchill said of the bomb-damaged Houses of Parliament, "We shape our buildings, and afterwards, our buildings shape us."²⁵ This pithy statement captures the perception that clinical encounters outside the "sterile" clinic exam room or inpatient unit facilitate communication. Participants in the present study experienced goals of care discussions differently, often preferentially, when they occurred in the home. They attributed that difference to the shifting power dynamics between the home and clinical environments. Not only was communication experienced as being more effective, but there was also evidence that the home setting enhanced cultural sensitivity, improved the provider's clinical assessment, and resulted in more practical family environment-centric recommendations regarding resources.

Participants appreciated the cultural sensitivity more clearly experienced in HBHPC. Differences in available cultural cues in the home versus ambulatory settings may increase providers' opportunities to enquire about cultural issues in the child's health care during home visits. Participants in the present study, as well as in that of Boyden et al¹⁴, value the care of their child's physical needs. Participants in the present study valued the provider's ability to see the child's full self, abilities, and clinical needs, as well as their psychosocial concerns, significantly enhancing the perceived value of the clinical care.

The socially isolating nature of a child's significant chronic condition is well known.^{26–28} The present findings provide evidence that HBHPC provider visits may be an intervention, providing, however temporarily, an antidote against the ill effects of isolation. Home visits offer value for the caregiver and the caregiver's perception of their child's social inclusion. While promoting social inclusion would not be the primary goal of a home visit, the findings support recognizing it as an enhancement over clinic/hospital-based care. This observation is consistent with adult HBHPC findings, in which value is experienced more by providing social services and practical assistance.⁶ Additionally, we hypothesize that home visits can build the child's dignity and personhood, cementing their position of value in the discipline and practice of HBHPC, especially as a child approaches their end of life, as well as for their caregivers in the immediate postmortem period.²⁹

Social components and the emotionally safe environment the caregivers described may prepare for and facilitate future decision-making conversations. When

providers assume the travel burden and meet children and families in their environments, demonstrating a personal relationship with the child and family, caregivers can recognize the providers' valuation of their child and themselves to a greater degree than in ambulatory or inpatient settings. Such recognition and engagement often translate to trust, demonstrating the provider's comprehensive whole-person view in approaching the child. The enhanced trust provides an additional sense of safety, facilitating openness for the provider to initiate emotionally difficult topics about disease trajectory, care options, and their implications.^{30–32}

This pathway is consistent with prior research. Pestian et al⁸ noted trust as a pediatric HBHPC issue. Kaye et al³³ found that therapeutic alliances were fostered by the provider's (oncologist) presence and the development of personal connections with children and adolescents with a cancer diagnosis. Sanders et al³⁴ presented a model in which fostering provider-patient (and caregiver) relationships builds trust and increases the likelihood of goal-concordant care. The present study's findings suggest that interactions occurring in seemingly unrelated areas—between socialization for the child and promotion of goal-concordant care—facilitate increased trust and vulnerability, allowing providers to explore emotionally taxing concepts.⁸

The findings presented here overlap the 5 Institute of Medicine quality domains: health care that is effective, equitable, patient-centered, safe, and timely.⁴ Similarly, the results are largely consistent with the Quadruple Aim (health care delivered at a lower cost, with high-value patient-centered outcomes, patient satisfaction, and provider satisfaction). However, the present study did not enquire about provider satisfaction.³⁵ Lower cost in this context refers to costs beyond billed charges; it costs the parents less in terms of their time, effort, and energy. The results also broaden the conversation about cost and revenue to the less tangible, but no less real, costs to the child and family—e.g., disruption of the child's routine and decreased loss of wages from missing work. In particular, several participants mentioned the value of having their time burden decreased due to not traveling to a clinic appointment, thus preserving income that would otherwise be lost.

This study has the following limitations. First, both sites are located in one state, lowering opportunities for significant racial, ethnic, or cultural diversity. Second, both sites have established programs with significant resources, which may limit smaller or less-resourced pediatric PC programs' ability to fully integrate the findings into care delivery. Third, the study included only caregiver perspectives; many pediatric PC and/or hospice care recipients do not communicate verbally or are developmentally unable to participate. Finally, potential recall bias may impact the results. While some participants recalled home visits occurring pre- and postpandemic, the fact that there were no differences in how they perceived the value of the home visit suggests that recall bias may be low.

Nonetheless, the study provides important conclusions. From the perspective of parents of children receiving hospice care and/or PC who consented to the study, HBHPC enables enhanced family-centered, goal-concordant care beyond what is available in the hospital or clinic. Future research may include understanding the child/adolescent voice and their value to home-based care. Opportunities offered by telehealth modalities and their impact on HBHPC are worthy of future research. Children receiving HBHPC have complex conditions, and their caregivers have significant burdens. Pediatric HBHPC provides high-value care that participants experienced as communicating effectively, providing safety, building and maintaining relationships, empowering the family, seeing the bigger picture of the child and family unit, and sharing the health care burdens. Together with goal-concordant medical outcomes, these are the means, and the ends, of pediatric health care.

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DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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