Home Health Care Research for Children With Disability and Medical Complexity

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abstract

Pediatric home health care represents a vital system of care for children with disability and medical complexity, encompassing services provided by family caregivers and nonfamily home health care providers and the use of durable medical equipment and supplies. Home health care is medically necessary for the physiologic health of children with disability and medical complexity and for their participation and function within home, school, and community settings. While the study of pediatric home health care in the United States has increased in the last decade, its research remains primarily methodologically limited to observational studies. Dedicated funding and research efforts are needed to transform American home health care research to address multifaceted outcomes valued by families and providers as well as payers and government programs. In this paper, we review the recent literature in pediatric home health care and then propose an actional agenda that could address its missing evidence base. We posit that pediatricians should partner with family caregiving experts and patients to advance knowledge about child and family health outcomes, home health care use, new models of care, and optimal approaches to education and training while also considering meaningful approaches to address disparities. The creation of an American pediatric home health care data-sharing consortium, patient registry, and reproducible access and quality measures is also needed. Most importantly, efforts should center on patient- and family-centered health priorities, with the goal of ensuring equitable outcomes for every child and family.

OVERVIEW

While many people first think of a hospital or clinic when they think of health care delivery, the home and community settings are where most children receive their daily medical care.[1] Home health care (HHC) is defined as the delivery of services, equipment, and supplies in a person's home and community to treat their chronic medical condition, disability, and acute illness.[2,3] HHC holds particular importance for the health and function of children with disability (CWD), especially the subgroup of children with medical complexity (CMC) who have disabling chronic conditions, rely on medications and intricate respiratory, digestive, and other organ-system care regimens, and are assisted with medical equipment

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and supplies for daily survival.[4,5] The population has increased in America, with approximately 1 in 20 children discharged from a hospital to home with specialized durable medical equipment (DME) or HHC service.[6,7]

Despite CWD/CMC relying heavily on HHC for their daily health and functioning, American pediatric research focused on the home setting has lagged behind other health service research areas. While home is a core setting of life, HHC often appears to be a forgotten health care sector that, we argue, is deserving of increased attention. In this paper, we cover the American historical and legal context of pediatric HHC for CWD/CMC, including how it came to be that children are legally entitled to HHC as a public service. We also review the known American nonbehavioral HHC literature, which demonstrates how inadequate financing and training has led to a national workforce shortage in pediatric HHC, nonmedically necessary hospitalization, delays in equipment, and family stress, injury, and financial insecurity. We finish with proposing a research agenda with specific questions and example studies that, if undertaken, we believe can transform multifaceted health outcomes for these children and their families.

INTRODUCTION TO PEDIATRIC HHC

As with all other medically necessary health care, HHC is covered under Medicaid by Early and Periodic Screening, Diagnostic, and Treatment and may be covered by a commercial health insurance plan. In many ways, the description of "home" in HHC is misleading, as this care is meant to enable the child's broad participation in family and community life. The American Academy of Pediatrics guidelines recommend that pediatricians create a daily home care plan to cover medically necessary care that may be delivered over the day and night at home and in the community, including within the school setting.[8] Care plans are typically created in a collaborative effort with the child, family, and interdisciplinary health providers, which may include primary and subspecialty physicians, advanced practice nurses, respiratory therapists, and habilitative therapists. Within each care plan, services, equipment, and supplies are prescribed and detailed. In addition to addressing nutrition, a care plan may include support for other activities of daily living like dressing, transfers, and toileting. HHC services may then be delivered by a range of health professionals, including registered nurses (RNs), licensed practical nurses (LPNs), certified nursing assistants, personal care assistants, home health aides, and therapists, based on the skill level needed for a child's care tasks. Notably, however, in current common practice, care tasks of all skill types are delivered in part or even in whole by family caregivers, typically unpaid and without work-hour restrictions.[9]

HISTORICAL AND LEGAL BACKGROUND OF PEDIATRIC HHC

CWD/CMC populations have increased and aged over the last 50 years due to medical advances that have improved pediatric survival from prematurity, rare conditions, and injury.[4,10,11] Specifically, innovation in transportable technologies such as portable ventilators has made discharge from the hospital possible for children requiring continuous technological support and expanded the conditions managed outside hospital walls.[12]

By the 1980s, the increase in the need for HHC services and equipment to address children's highly technical and labor-intensive care was present but without a clear avenue for insurance payment. Patient and family advocates lobbied for access to Medicaid coverage through new waivers (eg, "Katie Beckett waivers") and specialized programs.[13,14] Subsequent passage of the Americans with Disabilities Act in 1990, along with the Olmstead Supreme court decision in 1999, expanded public actors' obligations to ensure children with disabling conditions have access to care in the home and community.[13,15] Together, these precedents created a legal standard in that CWD/CMC should be able to access health care to live at home.

As investments in pediatric hospitals and research expanded in the 1990s and 2000s, pediatric HHC infrastructure did not similarly expand, primarily due to relatively lower reimbursement. Currently, nonfamily pediatric HHC is typically provided by external agencies that are independent from the tertiary pediatric health systems.[7,16] As we continue through the 21st century, despite most families' preference for their children to receive their health care at home and in the community, large gaps persist in pediatric HHC delivery and research.[1,8,16–18]

PRIMARY EXISTING SCHOLARLY AREAS WITHIN THE EXISTING PEDIATRIC HHC HEALTH SERVICES LITERATURE FOR CWD/CMC

Access to High-Quality and Integrated HHC

Most of the peer-reviewed research in HHC over the last several decades has documented a "leaky pipeline" of HHC access gaps along the care continuum in which nursing access is lost (Figure 1; Table 1)[19–32]. Figure 1 demonstrates how financial and coverage policy gaps lead to insufficient access of HHC for children, in which the gap led to decreasing access to nonfamily medical HHC. First, wait lists for public coverage or a lack of home care coverage in commercial plans reduces insurance coverage for pediatric HHC.[14,32] The use of nonvalidated score tools and generalized cutoffs (eg, requiring "technology dependence" or 16-hour maximum allocation rules) for eligibility determination and hour allocation further erodes HHC coverage.[32–34] Even when hours are approved, family caregivers often cannot get HHC to take their child's case, and if they do, providers may not be satisfactorily trained on the child's

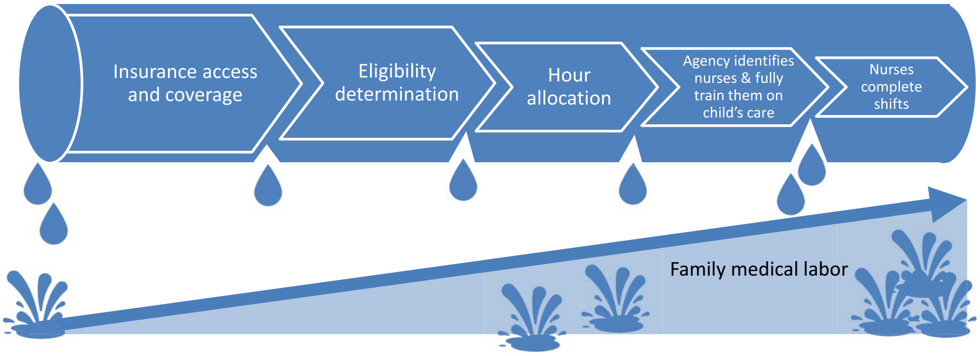

FIGURE 1.
Pediatric home health care “leaky pipeline.” Illustrates where the “pipeline” of health care has documented “leaks” or gaps in the policies and programs for children with disability and medical complexity that lead to reduced access to medical home health care. As one goes farther along, the number of hours of unpaid medical labor that family caregivers contribute to a child’s care accumulates.

level of care needs and/or often miss shifts. As one goes farther along, the number of hours of unpaid medical labor that family caregivers contribute to a child’s care accumulates. One published example of 38 children who were supposed to receive HHC found that the average child missed 40 hours/week of care.[27] Similar research has recorded gaps in access not just to HHC services but also critical HHC equipment such as wheelchairs and airways supplies.[35–37] Published research also has underscored a persistent gap in pediatric experience among workers in pediatric HHC, including their safety and experience using pediatric DME/devices.[26,27,38–58]

Peer-reviewed research has also demonstrated fragmentation in HHC delivery, including poor information sharing and coordination between pediatric health systems, HHC agencies, and DME suppliers. One recent 3-year study at a children’s hospital found that 188 children with private duty nursing needs were discharged to 35 *different* home health agencies at a total of 44 *different* sites, of which none shared electronic health records or ordering with the hospital or across agencies.[7] Qualitative findings in other studies have similarly documented fragmentation and error risk due to a lack of record sharing between HHC agencies, suppliers, and pediatric health systems.[59–61]

Child Health and Development

With the enormous documented gap between high-quality service and need, it is no surprise that the literature reports broad negative impacts on CWD/CMCs’ health and safety. Under-recognition of home safety events is widespread, with one study of in-home medication errors observing that family caregivers and prescribing physicians were unaware

TABLE 1. Main Existing Scholarly Areas Within the American Pediatric Home Health Service Literature for Children With Disability and Medical Complexity

Area	Main Research Findings
Access to high-quality and integrated HHC	• High-quality HHC is linked to spending reduction and reduced hospital days.[28,29,41,135,136] • Low availability of HHC providers with pediatric expertise persists nationally.[26,27,38–58] • Prolonged hospital discharges occur because of insufficient HHC access.[19–29] • Delays exist in access to needed equipment such as wheelchairs and airway supplies.[35–37] • Inadequate integration between service agencies, equipment suppliers, and pediatric health systems leads to errors and communication problems.[7,59–61,137,139,140]
Child health and development	• Inadequate HHC can impact child health and lead to hospitalizations, emergency room visits, additional medical procedures, and nonmedically necessary hospitalization.[19–29,59,61,65] • Unreported medication errors and device complications occur frequently at home.[62–64] • Vulnerability exists for worse development outcomes for children using HCC.[68–70,141]
Family caregiver health	• Inadequate HHC causes caregiver stress and is linked to mental health conditions.[27,71–80] • Negative health impacts occur for family caregivers through direct injury, inadequate sleep, and their own foregone health care needs when HHC care for their children is inadequate.[27,71,72,74,75,82,83]
Family financial health	• Inadequate HHC services impair family employment and financial capital.[59,87–92] • Negative financial impacts on families of CMC exacerbate existing social stressors like food or housing insecurity.[59,93]
Maintenance of intact families	• Internationally, CMC/CWD are disproportionately represented in the child welfare system.[94–99] • CMC account for approximately 10% of children in US foster care yet less than 1% of all children.[11,101,102]

Abbreviations: CMC, children with medical complexity; CWD, children with disability; HHC, home health care of 47% and 80% of home medication errors, respectively; another recent study found that 30% of CMC's emergency department visits were due to home device complications and errors.[62–64] Numerous qualitative studies have linked inadequate HHC to poor health outcomes including emergency department visits, additional medical procedures, and nonmedically necessary hospitalization.[19–29,59–65] Family caregivers of CWD have also reported an under-referral to HHC and barriers to the receipt of HHC, especially therapies and equipment or supplies, which negatively impacted their child's function and neurodevelopment.[66,67]

Nascent research is also unveiling the downstream impacts of inadequate HHC on the neurodevelopmental trajectories of CWD/CMC, a population at high risk for severe disabilities across developmental domains.[68] Already neurodevelopmentally vulnerable due to the double jeopardy of medical complexity and long hospital stays,[69] CWD/CMC's gaps in HHC can reduce their school attendance and force their family caregivers to engage in nursing and medical caregiving rather than typical parenting activities; these differential experiences likely contribute to worse disability profiles and social, emotional, or educational outcomes.[70]

Family Caregiver Health

Impacts of the care of CWD/CMC on family caregivers, most often mothers, have been relatively well studied, with results showing how HHC gaps result in significant parental stress and negative health consequences and are predictive of child health care utilization.[27,71–81] Poorer physical health can stem from both direct care tasks (eg, back injury from lifting without adequate equipment) and a forgone care of family caregivers' own health because of time constraints and caregiving fatigue.[27,71–74,82,83] Specifically, these studies have demonstrated how caregivers can often feel overwhelmed and unsupported by a persistent lack of HHC and DME access, even becoming socially isolated, which further worsens their caregiving capacity. Key limitations in this area of HHC research are the lack of a life-course timeline to capture the challenges unique to aging parents and children and the lack of inclusion of diverse family perspectives. Most research to date has primarily focused on non-Hispanic white and English-speaking families of younger children.[33] However, at least one efficacy study using telemedicine to support the mental health of family caregivers has shown benefit and potential for expansion.[84] Yet, other studies have shown that new technologies have expanded the ability for providers to monitor care at home.[85,86]

Family Financial Health

Existing research has also documented alarming patterns of how inadequate HHC financing can magnify existing health and financial disparities.[32] With a current HHC system that defaults most, if not all, in-home care to family caregivers, this situation significantly impairs families' abilities to further education, remain employed, and build financial capital.[59,77,87–91] A recent national-based study found that families of children with special health care needs—a broad population that includes CWD/CMC—lost an average of $18 000/year per family to care for their child's medical needs; moreover, impacted families were more likely to have a lower income, be Hispanic, and spend more than $5000/year on out-of-pocket costs.[89,92] The "interwoven nature" of medical and social needs means that families of children with more complex health care needs may experience higher rates of poverty, inadequate housing, poor caregiver health, divorce, and food insecurity, demonstrating the vital role that HHC access plays in equity.[93]

Maintenance of Intact Families

The financial and psychosocial stressors that result from inadequate HHC can impact a family's ability to meet their child's daily medical care needs, and concerns for maltreatment (ie, neglect, abuse) may arise. Prior research shows CMC/CWD are disproportionately represented in the child welfare system.[94–99] A Canadian study found that nearly 1-in-4 CMC had involvement with the child welfare system, and over 1-in-3 of those children were placed in out-of-home foster care arrangements (as opposed to receiving in-home prevention services).[100] In the United States, CMC account for approximately 10% of children in foster care yet less than 1% of all children.[11,101,102] This raises questions as to what degree families are being penalized, even split apart, because of inadequate HHC access (that notably falls short of legal standards) and what obligations the pediatric health care system and policymakers have to ensure all families are supported and equipped to care for their child's medical needs at home prior to child welfare involvement.[103–106]

RESEARCH AGENDA TO TRANSFORM HHC RESEARCH FOR CWD/CMC

The aforementioned research has provided some guidance on the current state of HHC, but there is still much to learn. Interventions that improve HHC and address child health, family quality of life, hospitalizations, and family financial strain are as yet undiscovered. A recent 40-year systematic literature review found that while the number of pediatric HHC peer-reviewed manuscripts has increased, studies of this health care sector remain primarily descriptive, cross-sectional, and regional and rarely evaluate quality in reproducible ways.[33] Another systematic literature review in 2023 that focused on interventional studies to improve pediatric home- and community-based care identified only 25 tested interventions, all of which were limited in scope to caregiver education, support, or self-efficacy rather than improvement or expansion of the services themselves.[99]

More focus in HHC research is needed to understand how to improve child health, functional, developmental, family psychosocial, and financial outcomes affected by health care occurring at home and in the community.[68] We believe the transformation of pediatric HHC is possible with (1) family partnership driving research priorities, (2) dedicated HHC funding to support rigorous methods that evaluate multifaceted outcomes, and (3) follow through by insurers and government programs to enact the evidence-based findings into practice. When the collective motives are high, evidence-based improvements in the access and quality of HHC to improve outcomes for children, families, health systems, and payers are possible.

Additional Research Needed to Improve HHC for CWD/CMC

We propose the following actionable agenda that applies this conceptual framework to future research projects relevant to the American health care system. Across this portfolio of work, pediatricians and pediatric researchers must partner with families and other essential key stakeholders—patient-family advocacy organizations, HHC providers and agencies, DME manufacturers and suppliers, health care provider systems, educational systems, employers, and payers—to address the practices and policies needed to enact evidence-based care. The field must also elevate HHC as an essential form of health care delivery in our medical and nursing societies, both to draw funding and talent toward this area but also to facilitate an integration of HHC with other health care sectors.

We suggest that research for this population focus on the following additional areas: (1) child and family outcomes across the life course, (2) health service use, (3) models of HHC care provision, (4) education and training, (5) measurement of HHC access and quality, and (6) identification and mitigation of disparities. Table 2 presents these areas, each deserving of distinct, dedicated funding streams, to move forward a child- and family-centered and anti-ableist HHC scholarly agenda. Table 3 then provides examples of prospective, intervention-based studies that could be proposed across these scholarly areas. Each example study includes at least one patient- and family-centered outcome, while also considering outcomes that matter to health care systems and payers, organized by the National Academy of Medicine's (NAM) framework of quality across the domains of effective, safe, patient-centered, timely, equitable, and efficient care.[26,59,107] Proposed projects' designs also emphasize the importance of child and family engagement in codesign when developing new HHC interventions. Lastly, while each study is listed within a primary NAM quality domain, we note that many studies cross quality domains (eg, effectiveness and safety) and address multiple HHC research scholarly areas (eg, workforce training, models of care).

Child and Family Outcomes

First, research is needed to evaluate the clinical effectiveness of HHC, including impact on CWD/CMC health, function, and participation (Table 2). Research examples (Table 3) include robust efficacy and effectiveness trials. Examples of clinical effectiveness studies could include the (1) integration of home-based nutrition support to

TABLE 2. Additional Research Needed to Improve American Home Health Care for Children With Disability and Medical Complexity

Area	Research Questions
Child and family outcomes	• How does HHC impact child health, function, and participation? • Which HHC will improve family caregiver physical, mental, and financial health? • What do pediatric patients and their families prefer for settings of care?
HHC use and access	• Who currently needs and who is prescribed HHC? • Who are the providers serving pediatric patients using HHC? Do providers differ by region? Health condition? Patient characteristics? • How frequently is approved HHC not being received across states and patient groups?
HHC models of care	• What strategies best integrate care between dispersed HHC team members in homes and schools with pediatric specialists and medical homes? • Which medical treatments and digital technologies can be used to manage care effectively and safely at home? • How is HHC best coordinated and monitored? • What can we learn from HHC models in other countries?
Education and training	• What strategies support expanding and maintaining the nonfamily HHC workforce? • What are the best methods to train, maintain, and monitor HHC skills? • How can in-home skills training be standardized and improved?
Disparities	• What disparities in care exist in HHC receipt and family experience? • How can ableism, racism, and classism be addressed to ensure equitable HHC?
Data and measurement	• How can we efficiently and reproducibly measure HHC access, quality, and costs? • How can we specifically track and reinforce receipt and timeliness of service delivery? • How can we conduct adverse event and safety detection and reporting at home?

Abbreviation: HHC, home health care.
Table shows exemplary scholarly questions relevant to the science of pediatric home health care areas.

TABLE 3. Proposed Home Health Care Research for Children With Disability and Medical Complexity

National Academy of Medicine Quality Primary Domain	Potential Research Studies Across Areas of Pediatric HHC
Effectiveness	• Trial randomizing pediatric HHC nurses to a "virtual peer" to increase effectiveness of symptom monitoring at home as measured by reduction in pain and feeding symptoms, reduction in emergency visits, and reported confidence providing care by nurse and caregiver • Codesign and evaluation of a scalable virtual simulation training to reduce skin ulcers and improve feeding tolerance for pediatric HHC children • Randomized control trial of integrated home-based nutrition support to improve growth and nutrition-related outcomes in children receiving HHC • Prospective step-wedge intervention to evaluate the impacts of consistent nursing teams on family employment and child community participation • Prospective study that follows the effectiveness of paid caregiver programs to improve child days at home and reduce family financial stressors
Safety	• Observational prospective study measuring in-home safety events in children receiving HHC that compares safety rates with staffing level, nursing training experience, and ordering provider communication followed by an interventional study to improve those safety rates • Pilot evaluation of a "train-the-trainer" simulation course for home nurses caring for children on home mechanical ventilation to practice ventilator emergency scenarios • A study to assess whether a hospital-based home visit to ensure nursing care, equipment, and safety protocols are in place as a CMC is discharged home results in increased patient safety and an increase in caregiver and home health professional confidence to provide care. • User codesign and then prospective evaluation of a home environment safety checklist to be used by families and nursing agencies to prepare for emergency situations • Randomized control trial of pediatric pharmacy support with at-home symptom monitoring for children receiving HHC to reduce medication errors or adverse drug events
Patient centeredness	• Codesign and then prospective evaluation of caregiver-led HHC planning for holistic child-centered care, including outcomes such as child engagement, development, and caregiver satisfaction with care • Codesign and then prospective evaluation of communication and value-assessment tools to facilitate decision-making and regarding using or declining HHC for their child, including use of nursing services, equipment, and home modifications • Codesign and then prospective evaluation of caregiver-friendly care management resources (eg, auto-populated dosing calendars, administration instructions, and diagrams) to reduce caregiver stress and improve self-efficacy
Timeliness	• Prospective observational study that tracks delays in insurance and requirements for pediatric equipment and medications, including costs of the delay, followed by quality improvement intervention to reduce wait time to pediatric equipment receipt • Codesign and then prospective evaluation of proactive (earlier) at-home identification of treatable symptoms (eg, constipation, feeding intolerance) to improve child symptom control and reduce acute health care evaluations • Randomized control trial pairing pediatric home nurses from children's hospitals with children eligible for home nursing with underfilled hours, with outcomes comparing emergency department rates among those with partial versus filled home nursing hours • Randomized control trial that assigns dedicated discharge nursing/coordinator team to children prescribed home nursing to evaluate if hospital-based recruitment to fill home nursing shifts decreases the time from medical readiness to go home to actual discharge with home nursing hours filled
Equity	• Prospective multisite step-wedge design to evaluate hospital and HHC agency collaborative to improve access to care at home in the family's language for children whose family uses a language other than English • Codesign and then prospective evaluation of pediatric curriculum anti-ableist HHC designed to improve care delivery experiences and reduce safety events • Context study to identify areas of intervention to improve CMC nursing needs on the ability of children to attend school, including access for 1:1 care • Creation of workforce intervention to enhance workforce recruitment and retention in in minoritized and/or rural communities
Efficiency	• Implementation study to identify the most effective and efficient approaches to HHC case/care coordination and management efficiency with providers and families followed by application of those strategies across multiple sites • Codesign and then prospective evaluation of an electronic shared care plan between primary care, specialty care, families, nursing agency, and DME company that outlines to reduce family coordination effort, including call time • Health deteriorations for children receiving HHC are expected, yet health care systems are often siloed. Virtual communications with subspecialty care teams that quickly modify care plans in response to clinical data may improve health outcomes. • Prospective evaluation of whether electronic health record sharing between prescribers, agencies, and suppliers reduces duplicate orders and call time

Abbreviations: CMC, children with medical complexity; DME, durable medical equipment; HHC, home health care.

Table shows examples of home health care in pediatrics with outcomes of relevant interest organized by the National Academy of Medicine's 6 quality domains. These examples demonstrate opportunities for implementable intervention-based studies that move beyond observation of the problems alone. Each study is listed with a primary quality domain, but many studies include outcomes across domains (eg, effectiveness and safety) and address multiple areas of home health care research scholarly areas (eg, workforce training, models of care).

improve growth and nutrition-related outcomes in children receiving HHC or the (2) codesign of a scalable virtual simulation training program for HHC to reduce the risk of skin pressure injury and improve enteral feeding tolerance for CWD/CMC. Research should also address which HHC interventions will improve family well-being (physical, mental, and financial health), for example, by prospectively evaluating the effectiveness of the new state-based paid caregiver programs and how they can reduce family financial stressors and improve family health.

HHC Use and Access

Research should enable a better understanding of which children are using HHC and how their clinical needs and allocations vary nationally, including (1) what treatments are being delivered, (2) who is providing them (ie, RNs, LPNs, family), (3) who *should* be providing them (ie, matching care asks with scope of practice), and (4) how HHC use is mechanistically linked to acute health care in the emergency department and hospital (Table 2). We encourage this work to address not only the care received but also to consider other NAM quality-of-care domains such as timeliness and family centeredness. An example of such a study is a prospective observational study that tracks delay in insurance and approvals for pediatric equipment and medications (including delay costs) paired with a quality improvement intervention to reduce wait time to pediatric equipment receipt. Interventional research to improve home health service access is needed, such as a quasi-experimental trial pairing pediatric home nurses from children's hospitals with children eligible for home nursing but with underfilled hours to address outcomes of timeliness and efficiency (Table 3).

HHC Models of Care

Research should advance the understanding of what tools, skills, or other interventions could make HHC provision effective at treating patients' chronic symptoms as well as preventing mortality, costly emergency care, or hospitalizations (Table 2). For example, what strategies best integrate care between dispersed HHC team members in homes and schools with pediatric specialists and medical homes? Research in this area may include the development and evaluation of digital tools and remote patient monitoring to support home-based clinical decision-making, given little knowledge exists on how to integrate such emerging technologies into HHC (Table 3). More research is needed to understand how to replicate, scale, and ensure payment for innovative models of care—like those providing integrated remote supports for children with chronic respiratory failure—in other settings and clinical groups.[108,109] Quasi-experimental and implementation science study designs are particularly positioned for utility in this research area.

One specific HHC challenge well suited to innovation is managing health crises in the home and community. The use of inclusive, evidence-based participatory codesign methods can be pursued with families and HHC providers to design interventions to improve care during acute exacerbations.[110–125] In addition to the depth of personal knowledge family caregivers have about a child's health, family caregivers can proactively identify and rapidly intervene at the onset of concerning symptoms that predict acute care use.[116,117] Interventions focused on bolstering family capacity and access to resources through HHC likely play a more critical role in treating symptoms and preventing acute care visits than clinic-centric strategies.[118] Given their multiple components and need for customization to address the unique needs of each event and individual, these approaches can be viewed as complex health interventions.[119] To produce a scalable implementation of complex interventions with high-quality evidence, experimental designs might include just-in-time adaptive intervention designs and hybrid effectiveness implementation trials.[120–124]

As HHC models in the United States evolve, proactive and preventive evidence-based strategies must be implemented to ensure safety of care. One example relates to managing the safety of complex medication regimens in the home setting.[125] Any solution must be acceptable to, and inclusive of, family caregivers from all levels of health literacy and should minimize additional caregiving tasks. One example intervention might be to include pediatric pharmacists experienced with CMC to proactively identify and monitor in-home medication-related problems, support HHC and family caregivers, and communicate with the child's larger health care team.[126] Other solutions could leverage technology-based[86] symptom monitoring for children receiving HHC to preemptively detect adverse symptoms that could signal medication-related problems or adverse drug events.[127] If proven to be effective, these types of approaches could be applied more broadly to other aspects of HHC to enhance safety at home.

Education and Training

The best practices in training, monitoring, and maintaining HHC skillsets—for either HHC providers or family caregivers—have yet to be established (Table 2). Any future agenda in pediatric HHC must address the need for higher quality training that is evaluated for effectiveness. An example may include a trial randomizing pediatric HHC nurses to a "virtual peer" to increase the effectiveness of symptom monitoring at home as measured by a reduction in pain and feeding symptoms, a reduction in emergency visits, and a reported confidence providing care by nurse and family caregivers (Table 3). We also need to conduct economic- and policy-based research to identify evidence-based strategies for supporting the expansion of the much-needed HHC workforce, including how to achieve fair and equitable compensation for families filling the care gap with high levels of training and skills.[128–130]

Disparities

Research in HHC should be conducted beyond English-speaking, white children and families to advance understanding of the range of needs and preferences of HHC across diverse populations (Table 2).[33] HHC research focused on disability and its intersection with structural ableism, racism, and classism is critically needed. Pervasive ableism exists in health care, especially payer assessments, often constructing desired outcomes in terms such as "likely to benefit" or with requirements to demonstrate improvement in function rather than reduced decline.[66] Investigators ought to be alert to this existing bias, and HHC research should be embedded in anti-ableism, which favors a social model of disability.[66,131–133] One research example in this area is the codesign and evaluation of an anti-ableist curriculum to improve care delivery experiences and reduce safety events in CWD (Table 3). Outcome measurement in this research should include focus on links between access to HHC and school, recreation, and social engagement.[68,134] Another example is a prospective, multisite step-wedge clinical trial to evaluate how a hospital and HHC agency collaborative might improve access to care at home in families that speak a language other than English (Table 3).

Data and Measurement

Reproducible measures of access and quality of HHC are needed to conduct effective research. Measurement science should be conducted to establish valid and reliable measures meaningful to child health and family quality of life and should hold health care payers, providers, and policy makers accountable for high-quality HHC. Research should measure—and ideally benchmark—access and quality measures across the NAM domains, such as total hours assessed/approved, hours received/filled, timeliness of care, and patient-centered HHC.[2] For example, an agreed-upon definition of HHC "access" is needed to conduct a prospective step-wedge intervention to evaluate the impacts of consistent nursing teams on family employment and child community participation (Table 3). Another example is a development of a reproducible approach to systematic report pediatric HHC-based safety errors and adverse events, including deaths.

Data-Sharing Consortium and Patient Registry

Due to the highly heterogenous and fractioned delivery of HHC in the American health care system, optimizing HHC research will require creating comprehensive datasets that support the synthesis of HHC trends and address research gaps. Creation of a pediatric HHC research consortium that links (1) family-led and community-based organizations supporting and advocating for CWD/CMC and (2) US pediatric hospitals, HHC agencies, and payers that oversee CWD/CMC home care services could collectively facilitate data sharing and address subgroups of children with rare conditions. Such a consortium would encourage collaborative research that leverages adaptive and quasi-experimental design to inform pediatric health systems and policy makers about care at home in the "real world." Part of the work of this consortium could be to develop standardized electronic data structures to ensure pediatric HHC data are reproducible across electronic health records, including improved specificity regarding HHC services, supplies, and equipment.

To additionally accelerate the collection of data of CWD/CMC and the families receiving HHC, a national patient registry could be developed that would allow children and families to enroll themselves with parent-reported data on quality and access to care. The potential avenues for future research would be substantial, and it could be a place to enable families to not only learn about or participate in scholarly research opportunities but could help to direct and actively partner in codesigning studies based on real-time emerging needs and trends.

CONCLUSION

The home and community are where most health care occurs for children, and the complexity of HHC need has expanded rapidly in the United States over the last 40 to 50 years. Opportunities for research and innovation in pediatric HHC have the potential to change the landscape of US HHC dramatically. The transformation and optimization of HHC are possible with dedicated funding to address multifaceted outcomes valued by children and families as well as insurers and government programs. To achieve meaningful impact, a partnership with family caregiving experts in home care to advance knowledge about in-home care delivery is essential. We posit that researchers should partner with family caregiving experts and patients to advance knowledge about child and family health outcomes, HHC use, new models of care, and optimal approaches to education and training while also considering meaningful approaches to address disparities. The creation of a pediatric HHC data-sharing consortium, a patient registry, and reproducible access and quality measures are also needed. Most importantly, child health and family quality of life and care delivery priorities must be the center of any HHC research agenda, with the goal of ensuring equitable outcomes for every child and family.

ABBREVIATIONS

CMC: children with medical complexity
CWD: children with disability
HHC: home health care
LPNs: licensed practical nurses
NAM: National Academy of Medicine
RN: registered nurse

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