Understanding Caregiving and Caregivers: Supporting Children and Youth With Special Health Care Needs at Home

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ABSTRACT

Caregiving encompasses the nurturing, tasks, resources, and services that meet the day-to-day needs of children and youth with special health care needs (CYSHCN) at home. Many gaps exist in the strategies currently offered by the health care system to meet the caregiving needs of CYSHCN. The work of family caregivers of CYSHCN is known to be extensive, but it is so poorly understood that it has been described as "invisible". This invisibility leads to poor communication and gaps in understanding between professional health care providers and family caregivers. To address these gaps, health care researchers must work with family caregivers to incorporate their expertise on caregiving and create meaningful and sustainable research partnerships. A growing body of research is attempting to remedy the problem of caregiving invisibility and lay better foundations for successful integration between health care settings, family caregiving, professional caregiving, and community supports for families of CYSHCN. We identify high-priority gaps in CYSHCN caregiving research and propose research questions that are designed to accelerate growth in evidence-based understanding of the work of family caregivers of CYSHCN and how best to support them.

KEYWORDS: caregiving; family engagement; home health; research agenda

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WHAT'S NEW

An expert team led by a family caregiver reviews what is known and what is not known about how family caregivers complete the work of caregiving in the home and makes suggestions for future research based on the priorities set by the CYSHCNet National Research Agenda.

BACKGROUND

CAREGIVING ENCOMPASSES THE nurturing, tasks, resources, and services that meet the day-to-day needs of children and youth with special health care needs (CYSHCN) at home. By definition, caregiving occurs outside of professional settings and is driven by the families of CYSHCN. However, our healthcare system has struggled to accommodate the basic implications of the home health setting, including the fact that doctors lack the authority and means to enforce "doctor's orders" within the family's sphere of control. Patients and their families may not have the will or resources to accomplish a doctor's orders, or they may have difficulty implementing them given the limitations of home health. One author on this paper (C.H.) remembers having a sterile field destroyed by a pit bull as the defining moment of her caregiving experience. Such an event would be inconceivable in the tightly controlled environments of most health care settings; whereas within the family home, a pet's ill-timed frolic is a normal event and possibly even welcomed as a distraction. Health care professionals are not taught that the essentials of quality health care are ad hoc training (illustrated in Fig. 1), whatever materials the home health agency happens to send that month, ice cream bribes, and making sure that the dog is locked in the bedroom. However, family caregivers *can* deliver quality health-care working with this toolkit, the very best healthcare available in some cases, given the current realities of
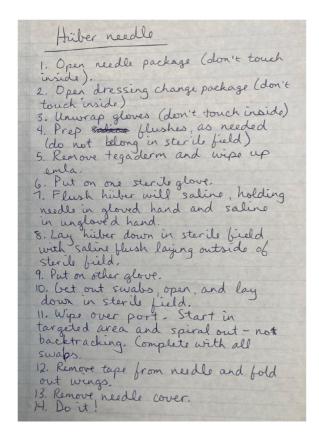
Figure 1. *Artifact of a family caregiver's training session with a home nurse.*

our healthcare system. To improve on what family caregivers already accomplish, we must start by understanding the all-terrain, under-resourced nature of family caregiving in the home setting.

CURRENT LITERATURE ON CAREGIVING

> ### WHAT IS KNOWN?
> 1. Family caregivers, by default, play a central, distinguishable role in caring for CYSHCN, and health care systems need to be designed to support that role.
> 2. CYSHCN and their families are impacted both by general disparities observed across the entire population of CYSHCN, and by intersectional disparities that are observed based on race, ethnicity, income, and living in rural areas.
> 3. The resilience and contributions of family caregivers are not adequately recognized and leveraged in established approaches for improving CYSHCN outcomes by improving caregiving quality.

As advances in technology continuously improve the clinical outcomes of CYSHCN, more families are quite suddenly inducted into the complex world of medicine. Life often takes on a frenetic pace—one not easily slowed —as families learn to navigate a decisively new culture, while at the same time trying to normalize life at home to integrate health care services and potentially replicate a formal health care setting at home without the staffing

support. Family caregivers work across all of the systems, networks, and services that their child connects with, and become highly specialized in providing all of the types of care that their child requires.[1,2] Family caregivers have a personal stake in their child's outcomes across the lifespan, through the transition to adulthood and beyond.[3] Recognizing the central importance of this role, the CYSHCN Research Network (CYSHCNet) National Research Agenda, using a family-engaged, multidisciplinary, mixed-methods process, recently identified, *"How can the optimal level of home supports (including home healthcare) that a family needs to improve child/family outcomes be determined and achieved?"* as a top-priority research need for systems and services serving CYSHCN and their families.[4]

NEEDS OF CAREGIVERS

Families in the United States deliver an estimated 1.5 billion hours of health care annually to their CYSHCN at home. The economic impact of this so-called "invisible" system[5,6] represents $17.6B in associated foregone earnings for these family caregivers. The unmet needs of CYSHCN caregivers are well-established.[7] Caregiving itself is hypothesized to have important effects on the health of caregivers.[8] Caregiving responsibilities for CYSHCN often come with a great sense of isolation and loss of traditional, more familiar supports. Employment and finances can be severely affected[9] because of the demands of caring for the child who may experience frequent hospitalizations, missed school, surgeries and subsequent recovery, or inadequate home health nursing. Families of CYSHCN are more likely to live in poverty and have higher rates of work loss, especially families whose children are more severely affected by their health condition(s).[9,10] Both mothers and fathers of CYSHCN more frequently report being in fair or poor mental and physical health than the parents of non-CYSHCN.[10] The COVID pandemic of 2020−2022 has brought new visibility to difficult experiences that are commonplace among CYSHCN, including being forced into homeschooling; being homebound; struggling to balance social and educational needs against competing health needs; and inequities in health care quality and outcomes linked to race or ethnicity. The stress of family caregivers can be reduced through supports that address logistical problems and promote connections with peers[11,12] and parent mentors working with Latino and African-American family caregivers have been shown to improve CYSHCN health outcomes[13] and healthcare access.[14]

HEALTH DISPARITIES FOR CAREGIVERS OF CYSHCN

CYSHCN disproportionately are of Black non-Hispanic race, live in homes headed by a single parent, and more commonly experience adverse childhood experiences.[10,15] Among CYSHCN, disability and poor health status are more common for children living in poverty and children of Black non-Hispanic race.[10,16] CYSHCN are also more likely to have forgone healthcare, and while 49.4% of non-CYSHCN receive care in a

medical home, only 42.7% of CYSHCN do.[10] Only 13.9% of CYSHCN receive care in a well-functioning health care system and the more complex their needs, the less likely CYSHCN are to receive healthcare in a well-functioning system.[10] These issues of access to health care are worse for children living in poverty, Black non-Hispanic children, children with medical complexity, and children living in rural areas.[10] Both health and health care are impacted by inequities in the larger society[17−20] and understanding the operation of racism within the health care system is an essential step toward understanding and supporting the caregiver role. The AAP policy on racism expresses the urgent need to address the impact of racism across clinical practice, workforce development, public policy, and research.[17] In recognition of these inequities, the CYSHCNet National Research Agenda identified social determinants of health as a key area of research focus (addressed elsewhere in this supplement). The CYSHCNet National Research Agenda also included a question addressing the specific issue of healthcare access and other barriers in rural areas: *"How does rurality uniquely affect CYSHCN, and what are effective interventions to support CYSHCN and families living in rural settings?"*[4]

FAMILY RESILIENCE

Families must practice resilience, leveraging their own particular strengths to respond to the challenges and inequities they encounter in caring for their CYSHCN. Research that casts family caregivers in passive roles (those who are done to rather than those who are doing) allows the amount and complexity of care that families provide to be underestimated or effectively invisible.[5,18] This is observed in interventions intended to modify caregiver behavior[21] and in adherence research.[22,23] Where it is studied at all, the work of family caregivers is often styled "caregiving burden," a phrase that some family caregivers argue is belittling to their children and the love that they have for them.[1] A shift away from attempting to quantify all care of CYSHCN as "caregiving burden", towards describing and understanding family caregivers as part of the healthcare workforce, will help us better understand how family caregivers do what they do.[1,24−26] For example, one study using this approach found that parents of children with tracheostomies reported issues with both emotional and logistical coping, and said that the training preparing them to take their child home was adequate but needed to be adapted to their individualized needs.[27] Family caregiving requires responding to all crises of all kinds, regardless of whether prior knowledge, evidence base, or established support services are available to help.[1−3,7,18] Medical professionals are more likely to see the instances where this goes badly, requiring professional intervention; whereas, family caregivers need to see, celebrate, and learn from each other's successes.[11] Research topics related to family resilience, addressing stress and burnout, and child thriving are relevant across a wide variety of family circumstances and provide a positive focus on contributions that families make to improve their children's health.[15,28]

CURRENT KNOWLEDGE GAPS

WHAT IS MISSING?

1. Health systems research lacks a top-level understanding of how family caregivers shape health care delivery systems, including estimates of how much health services rely on family caregivers as part of the health care workforce, and modelling that describes the link between family caregiving and health outcomes for CYSHCN.

2. Research needs to incorporate an understanding of the relationships among family caregiving, professional home-based health services, and services provided in health care settings, and is specifically lacking in family-driven frameworks for evaluating the quality, health outcomes, and success of these relationships for the child, family, and health system.

3. Existing research targeting underserved subcommunities of CYSHCN is sparse, and there is a need for high-quality interventional studies to establish an evidence-base on how best to support family caregivers, particularly people of color and those living in rural areas.

In Figure 2, we present a simple schematic for conceptualizing health care services and research based on whether they are family-centered, systems-centered, neither, or both. We use the term "family driven" to signify research that synergizes the best qualities of family-centeredness and systems-centeredness. The definition of "family driven" developed for the US Substance Abuse Mental Health Services Administration states that "family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation."[29(p177)] This definition expresses that the goals and needs of the CYSHCN and their families should be the driving force shaping integration of pediatric health care systems with family caregiving for CYSHCN.[18,30,31] While family-driven research and literature on caregiving of CYSHCN are expanding in terms of availability and sophistication, we have identified the following gaps that need to be addressed by future CYSHCN research.

MODELING THE IMPACT OF CAREGIVING

The absence of family-driven conceptual models that link family caregiving to the health care system and to child and family health outcomes is an important barrier to developing evidence-based approaches to family caregiving. Research teams need models that accurately depict the relationships between family caregiving and key health outcomes to design effective policies and interventions that support the volume, sophistication, and under-resourced nature of family caregiving at home.[32−34] A

Family-centered

	Absent	Present
Absent	Self-serving	Relationship-oriented
Present	Accountability-oriented	Family-driven

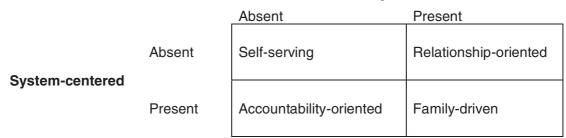**System-centered** (row label, leftmost)

Figure 2. *Family-centeredness and system-centeredness in research.*

family-driven model would recognize caregivers as a skilled and motivated workforce, providing the foundation to develop the needed tools to help them plan and conduct their work efficiently, effectively, and safely.[24,33,34] One potential strategy could be to blend well-known health system frameworks from fields such as human factors engineering (for example, the Systems Engineering Initiative for Patient Safety[35]) with CYSHCN-specific caregiving frameworks illustrating CYSHCN caregiving processes, experiences, and outcomes.[3,36−38]

INTEGRATION BETWEEN FAMILY CAREGIVING AND HEALTH CARE SYSTEMS

Central to improving integration between family caregiving and health care systems is a thoughtful approach to integrating systems-centered values and family-centered values into family-driven health care (Fig. 2), for example through family-centered assessment and measurement.[30,31,39] Optimal models of integration with specialists, educational systems, community partners, home health professionals, and insurance companies must be developed and studied.[31,38] Opportunities exist to enhance caregiving capabilities of families with training and improved hospital-to-home transitions as well as by leveraging technology.[30,40] Egocentric social network analysis offers one set of methods that could be used to synthesize data on how family caregivers blend health care with connections in other domains to meet the needs of their CYSHCN.[41] Such data should be interpreted with an eye toward understanding diversity as well as towards capturing commonalities to lay a solid foundation for addressing health inequities.

CAREGIVING INTERVENTIONS THAT SUPPORT HEALTH EQUITY

The conditions that children are born into, learn, play, and grow up in are the social determinants of health. These determinants need to be addressed in order for CYSHCN to achieve health equity (the fair and just opportunity to be as healthy as possible).[42] CYSHCN are diverse with intersecting identities.[43] They are not defined by their health conditions alone. Reducing inequities in health care access and disparities in health outcomes requires that upstream factors related to poverty and discrimination are addressed. This means dismantling racist policies and practices within the health care system while also addressing the impacts of racism on the health of CYSHCN.[17]

The absence of dissemination of programs and services that improve outcomes for children with disabilities and other special health care needs is well-documented.[44,45] Additional research is needed to determine how best to implement, revise based on unique community needs, and scale-up programs and approaches that work. The lack of dissemination and implementation of known strategies[2,14,20,46−48] to address disparities (including racism) and contextual barriers (including rurality) encountered by family caregivers in accomplishing their work is part of a larger pattern that impacts CYSHCN in general, underserved communities in general, and most particularly the intersection of the two. For example, rapid uptake of telehealth during the COVID pandemic simultaneously demonstrated the rising potential of technology to improve services for CYSHCN, raised serious concerns about disparities caused by the digital divide, and begged the question of why we had not accomplished more with telehealth sooner.[48,49] Telehealth can keep family caregivers connected with home nursing services,[50] maintain sophisticated monitoring of CYSHCN at home, improve access to services based in health care settings, and reduce unplanned hospitalizations.[49] However, interventional research will need to incorporate evidence-based lessons on health equity to make sure that innovative applications of telehealth are equitable, adaptable, and effective.[48]

RECOMMENDATIONS FOR FUTURE RESEARCH

SUGGESTED RESEARCH QUESTIONS
1. How can we model the interaction between health care providers, professional caregivers, and family caregiving to accurately reflect the roles and labor fulfilled by family caregivers, while honoring the cultural diversity of CYSHCN and their families and supporting health equity?
2. What are the relative impacts of different elements of the model developed for the previous question, and does quantifying these impacts provide validation for translating the model into practice?
3. What are effective, equitable, family-driven interventions to improve outcomes for CYSHCN by better supporting family caregivers in their caregiving tasks?

The "invisibility" of the work of caregiving is the result of widespread social factors as well as methodological factors within CYSHCN research. While we recommend some specific directions for research below, we note that a broader shift toward family-driven health care and research will be essential to the subsequent uptake and impact of any findings resulting from this research.

All of these projects, and the projects suggested in other articles in this supplement, should be carried out working with youth and family partners, and with the intent of being family driven.

1. Develop a conceptual model of caregiving that acknowledges the volume, sophistication, connections, and resources needed to care for CYSHCN at home. The model should define the roles of family caregivers in association with health care settings, in-home professional caregivers, and other professional and informal supports, and with the changing role of CYSHCN in their own care as they mature. This model must also depict the relationship between caregiving and key child and family health and well-being outcomes, accounting for social determinants of health and health inequities.

- Specific aim: Rigorously design and validate a family-driven conceptual model of caregiving for CYSHCN in home and community settings. This model would reframe the notion of "caregiver" from one that is health-system-centered to one that is a more holistic and accurate representation of home life.
- Approach: Group Concept Mapping involving a large and diverse group of national stakeholders will depict a consensus set of concepts (and their connections) that represent caregiving for CYSHCN in home and community settings. A systematic literature review of studies involving conceptual models that represent family caregiving can inform model refinement while highlighting key advancements from this study. Finally, qualitative analyses of care maps developed during delivery of services (see Kuo et al[2]) and of rigorously conducted focus groups with diverse stakeholders would further refine and validate the group concept mapping and literature review results. The final product will be a conceptual model reflecting the consensus of CYSHCN, their families, and key stakeholders.
- Feasibility to conduct: These studies can be conducted rapidly, and they are routinely used to develop conceptual models and depict model relationships. Engagement with many stakeholders, likely through key stakeholder organizations (for example, Family Voices, American Academy of Pediatrics) will be necessary.
- Implications: To date, research progress is hampered by the absence of an accurate, comprehensive, prevailing theory of caregiving for CYSHCN in the home and community. Creating this model is an essential step to design the most relevant and high-impact studies to improve the health of CYSHCN going forward.

2. Quantify the relationships and paths of this conceptual model, uncovering relative contributions of model elements on key CYSHCN health outcomes using social network analysis. We assume that the conceptual model for CYSHCN caregiving outlined above will hypothesize how the interaction between health care providers, professional caregivers, and family caregivers involved in a child's life has direct links to key CYSHCN health outcomes.

- Specific aim and hypothesis: Validate structures of the social networks of CYSHCN associated with health-related quality of life and family trust in health care systems. Researchers will test the hypotheses suggested by the caregiving model with better health-related quality of life for the child and higher trust and better relationships between family caregivers and health care professionals.
- Approach: Cross-sectional survey of a national sample of families of CYSHCN oversampled to maximize diversity and redress health inequities. The survey could integrate questions that characterize the people and resources in the CYSHCN's social network, as well as evaluate the CYSHCN's health-related quality of life and family trust in key aspects of the health care system. The survey instrument will also collect data on other constructs from the model as well as important demographic and clinical covariates. Analyses will determine whether the observed variables reliably reflect the model's latent constructs with confirmatory factor analysis. This study will also reveal the specific variables representing the conceptual model constructs, and those significantly associated with health-related quality of life outcomes and family trust in the health care system.
- Feasibility to conduct: Although survey data is a feasible approach to conduct this type of analysis, achieving high response rates and a nationally diverse sample is challenging. If this type of data collection was integrated into existing large-scale data collection efforts with families of CYSHCN, this study would be substantially more feasible. Alternatively, smaller scale surveys targeting specific aspects of the caregiving model could implement a piecemeal approach to validating the model as a whole while examining its applications in specific diverse communities.
- Implications: Studies of this type provide important validation to theory-driven conceptual models. Additionally, using large samples to identify the latent constructs from a conceptual model can generate useful tools for future research, for example, questionnaires and scales that reliably and validly represent the concepts from the model. Finally, by quantifying the prevalence of given concepts and their relative influence on key outcomes, stakeholders can design interventions and advocate for policies that promise to have the highest impact.

3. Approaches for remedying health inequities by supporting the work of diverse family caregivers need backing from a strong evidence base. Many of these approaches will ultimately prove generalizable to CYSHCN as a whole, with communities of color, rural communities, and other communities impacted by health inequities driving the innovations that will shape the future of caregiving for CYSHCN. Modelling and social network analysis, as described above, may help identify the most promising interventions to pursue within the existing body of interventional research relating to caregiving for CYSHCN.

- Specific aim: Determine the efficacy and effectiveness of interventions that support the work of diverse family caregivers. Test the impact of the interventions on health-related quality of life and family trust in health care systems among CYSHCN and their families.
- Approach: Intervention development will draw on approaches that are promising but do not have proven efficacy within a particular community. These may include innovative strategies originating from within the community, widely used strategies that have not been successfully adapted to the community, or blends of the two. Studies will be completed as randomized, controlled trial at multiple sites and will incorporate adaptive components (such as revising materials at each site based on input from a local Advisory Council). The study evaluates the intervention's impact on health-related quality of life and family trust in health care systems among rural CYSHCN.
- Feasibility to conduct: Clinical trials are challenging and time-consuming to implement; however, they provide high-quality evidence. Flores et al have demonstrated that relatively small clinical trials can yield statistically significant results with the potential to impact racially and ethnically diverse CYSHCN.[13,14]
- Implications: Most research among CYSHCN is observational and yields relatively low-quality evidence. Well-designed experimental studies are critically needed to help families, clinicians, policymakers, and researchers understand where to invest time and energy. Experimental studies should build on existing qualitative and small-scale quantitative work to maximize impact for communities of color, rural communities, and other communities affected by health inequities.

CONCLUSIONS

Partnerships with diverse family partners are the key to developing an evidence base that is relevant to family caregivers and the full spectrum of CYSHCN. Specifically, we have proposed family-engaged research to develop a conceptual model of CYSHCN caregiving and its role within the health care system, validation of this model that includes quantifying the contributions of different aspects of the model to the overall wellbeing of CYSHCN, and interventional research to determine the

effectiveness of specific mechanisms for supporting diverse family caregivers of CYSHCN. By uncovering the essential caregiving constructs from the perspective of an inclusive group of stakeholders, researchers will be able to quantify the various relationships within the conceptual model and design and test theoretically grounded interventions. Interventions rooted in such a model, and targeting suspected inflection points within the model, will be substantially more likely to succeed. Moreover, defining the parameters of the currently invisible health care delivery system run by families in their homes and communities is an important contribution of this effort. Additional impacts include more successful and equitable dissemination of evidence-based practices for home-based health care; better general understanding of the role of family caregivers leading to higher levels of confidence in this role for both family caregivers and health care professionals; and reduced conflict between family caregivers and health care professionals leading in turn to reduced stress for family caregivers. This work will advance health care systems toward recognizing and supporting family caregivers as valued and contributing members of the health care workforce and improve the quality of health care and health outcomes for children with CYSHCN.

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