Child Health, Vulnerability, and Complexity: Use of Telehealth to Enhance Care for Children and Youth With Special Health Care Needs

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ABSTRACT

Telehealth, or the use of telecommunications technology and infrastructure to deliver health-related services and information that support patient care, has the potential to improve the quality of care, particularly deficiencies related to access and patient experience of care. Telehealth may also reduce disparities for children and youth with special health care needs (CYSHCN) with barriers to accessing in-person care, for example, those residing in rural areas and children with medical complexity who are particularly fragile. While important foundational work has been done to study telehealth's effectiveness and implementation, key gaps remain regarding its use for CYSHCN. The CYSHCNet national research agenda development process, described in a companion article, identified as key priority areas for future research telehealth as an innovative care delivery model for all CYSHCN and as a mechanism to address rural-urban disparities in health care access. Here, we review the current knowledge around telehealth, identify populations for whom telehealth could be especially beneficial, discuss the important gaps identified, and make recommendations for specific studies that will move the field forward. There are ample opportunities for telehealth to improve health and patient/family experience of care and quality of life for CYSHCN while requiring less time and resources from families accessing this care. Innovative research to inform best practices around incorporation and implementation of telehealth will improve its efficiency and effectiveness and achieve optimal outcomes.

KEYWORDS: children with special health care needs; health equity; telehealth; telemedicine

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WHAT'S NEW

Despite evidence supporting telehealth to improve health care access, little research is specific to children and youth with special health care needs (CYSHCN). We address research gaps in adoption and implementation of telehealth, effect on health outcomes and utilization, and personalization of telehealth interventions for different categories of CYSHCN.

TELEHEALTH REFERS TO the use of various telecommunications technologies to exchange information and deliver health-related services that support patient care, administrative activities, and health education.[1,2] For children and youth with special health care needs (CYSHCN), telehealth has the potential to serve as a highly useful tool for communicating with providers, managing care, and monitoring symptoms. Telehealth interventions take many forms, which are evolving as technology is advancing (Table 1).[3,4] Telemedicine is considered by most to be a subtype of telehealth in which videoconferencing software allows providers and patients to communicate remotely in real time, typically in lieu of in-person office visits or transferring patients from one facility to another. Another type of telemedicine includes asynchronous electronic messaging among providers that allows for efficient and timely provider-to-provider consultations. Patient portals to electronic health records allow caregivers and patients to view aspects of their medical record and exchange messages, documents, and photographs with providers. Telehealth also includes medical devices that transmit data wirelessly and applications for patient-entered data on mobile devices in which symptoms, vital signs, laboratory data, and adherence to treatment are communicated to providers.

Table 1. Example Categories of Telehealth

Category	Definition	Example
Telemedicine	The remote diagnosis and treatment by means of telecommunications technology	Conducting an ambulatory visit with a patient/caregiver using videoconferencing
		Sending photos of exam findings from a patient's phone to a provider using a practice's patient portal
		Communicating asynchronously among providers within an electronic medical record system about a patient's care plan
mHealth	Management of care using applications on a patient's tablet or mobile device	Patient use of an app to track exercise and nutrition goals
		Patient use of an app for medication and appointment reminders
Remote patient monitoring	Collection, transmission and evaluation of patient health data through electronic devices	Wireless transmission of data to health care providers depicting a patient's use of continuous positive airway pressure devices for sleep apnea
		Wireless transmission of blood glucose levels from a device worn by the patient to health care providers

SUMMARY OF THE CURRENT LITERATURE AND RESEARCH PROGRESS AROUND TELEHEALTH INTERVENTIONS

Box 1 What's Known: Summary of Existing Knowledge on Telehealth and CYSHCN

1. Many subsets of CYSHCN face barriers to access to care. Rural children face additional barriers to care, especially specialty care, due to transportation burdens, geographic availability, and higher rates of poverty.

2. Many elements of health care can be delivered by telehealth with equivalent health outcome.

3. The global pandemic has accelerated adoption of telehealth.

4. Standards and infrastructure supporting research on telehealth are being developed.

Studies and reviews of multiple telehealth interventions in adults and children have generally found, when delivered in the right context, health care quality and clinical outcomes are equivalent or improved, compared to in-person care.[5,6] For example, researchers have found that remote intensive care unit consultations likely reduce mortality; specialty telehealth consultations reduce patient time in the emergency department; telehealth consultations in emergency services likely reduce heart attack mortality; remote consultations in outpatient settings improve access to specialty care. In addition, there is evidence to support the effectiveness of telehealth for remote patient monitoring for patients with chronic conditions; communication and counseling for patients with chronic conditions; and psychotherapy as part of behavioral health. Nevertheless, some observers have continued to question the evidence base for the benefits and cost effectiveness of telehealth, particularly for children and adolescents in specific clinical contexts.[7,8]

In addition to videoconferencing technology in lieu of in-person care, patient self-management tools using mobile technology (mHealth) have emerged as a promising adjunct to traditional care for chronic conditions. Examples of mHealth tools include applications whereby patients with mental health conditions can track symptoms and receive positive messages consistent with cognitive-based therapy principles; remote monitoring technology to collect and collate data on blood glucose levels in diabetes; and applications designed to promote adherence to medication therapy (eg, inhaled steroid use in asthma) or physical activity. Several systematic reviews have shown positive outcomes in symptom severity and adherence to therapy,[6] with some areas noted to be more challenging (eg, interventions for children with autism and children with obesity).[7,9]

Recognizing a need for more investigation, especially in children and adolescents, a pediatric-focused research network supporting research on outcomes and utilization of telehealth was established in 2015 by the American Academy of Pediatrics.[10] While supporting research on outcomes and utilization of telehealth intends to study telehealth generally and not specifically for CYSHCN, the focus of much work on telehealth gravitates naturally to CYSHCN. From that network has come strategies for evaluating telehealth interventions, highlighting domains of health outcomes, patient/provider experience of care, health care utilization, and telehealth implementation.[11]

TELEHEALTH AS A WAY TO MITIGATE BARRIERS TO ACCESSING CARE

Historically, telehealth services have been often conceived as a way to mitigate patients' difficulty with accessing specialty services located far from home. Several subsets of CYSHCN experience barriers to accessing direct, in-person services from medical and mental health providers, including children in rural areas, those with medical complexity and children who lack reliable transportation (Table 2). For each of these subsets, different

Table 2. Subsets of CYSHCN With Barriers to Accessing In-Person Health Care Services

Subset	Nature of the Barrier(s)
By socioeconomic factors:	
CYSHCN living in rural areas	Lack of locally available specialty workforce
	Family's time and financial resources needed for travel to tertiary centers
CYSHCN whose caregivers lack reliable, efficient transportation	Difficulty with scheduling appointments to accommodate transportation constraints
	Difficulty attending appointments in a consistent way
	Family's time needed to utilize inefficient public transportation even for short distances
CYSHCN whose caregivers are employed in jobs with low wages and/or few workplace protections	Lack of paid sick leave/loss of income due to time away for appointments
	Lack of workplace culture that supports employees' time off for medical appointments
	Difficulty making appointments with unpredictable work schedules
	Cost of travel to appointments
By condition type:	
CMC with extreme fragility	Risk of contracting infections in health care settings
	Risk of missing necessary care (eg, medications, respiratory treatments) when left at home or deferred due to lengthy appointments
	Risk of medical complications during travel outside of the home
CYSHCN with autism and behavior complications	Difficulty tolerating health care settings and/or disruption in routine
CYSHCN with mental health conditions	Stigma surrounding attending appointments at a mental health facility
	Lack of locally available specialty workforce
	Need for frequent appointments (eg, for psychotherapy, medication adjustments)

CYSHCN indicates children and youth with special health care needs.

(but sometimes overlapping) barriers to care exist, and telehealth has the potential to address many of these barriers.

Studies of telehealth interventions in rural-dwelling children have shown the potential to ameliorate specific disparities in access to care for a high-risk population.[12,13] Rural children are uniquely vulnerable from a socioeconomic standpoint.[14,15] In addition, the child health care environment and workforce are different in rural areas, particularly for specialty care: Children in rural areas are more likely to see an adult specialist,[16] and slightly more than half of all rural counties lack a pediatrician.[17] Compared to children in urban areas, children in rural areas are less likely to receive preventive medical and dental care,[18] are less likely to see a behavioral health specialist, more likely to be obese, and more likely to be hospitalized for asthma.[19,20] Studies of caregivers of CYSHCN in rural areas highlight frustration with local health care resources, social isolation, a lack of coordination and planning for specialist-informed emergency care with local hospitals.[21,22] Rural primary care providers, too, see a benefit to telehealth to expand access to specialty providers.[23] The early focus for telehealth studies on rural populations was natural, and the majority of the evidence supporting equivalence in quality of care and benefits to patients (eg, improved access to care, reduced family travel burden) has been in this group.[12,24,25]

Telehealth has been less well studied for children with medical complexity (CMC), a subset of CYSHCN who have conditions that require substantial health services, and often affect multiple organ systems and lead to disabilities.[26] However, CMC, regardless of where they live, are safest and most comfortable in their typical home, school, and community environments where modifications, routines, and supports have been made to accommodate their needs. Telehealth visits in lieu of in-person visits avoids unnecessary travel, time away from their safe environment, and exposure to nosocomial pathogens; supplanting telehealth visits instead of phone calls allows providers visual assessment of the child and the home environment.

TELEHEALTH ADOPTION THROUGH CORONAVIRUS DISEASE 2019

Coronavirus disease 2019 (COVID-19) greatly accelerated the use of telehealth across populations[27,28]; nonetheless, before this pandemic, some efforts were underway to increase its use. Prior to February 2020, policies to increase reimbursement for and decrease regulatory barriers to telehealth visits had been implemented in over 40 states, and these policy changes were associated with increased use of telehealth.[29] Still, until the novel coronavirus pandemic, its use in individual practices and patients' homes was limited. In 2016, only 15% of US physicians reported working in practices using telehealth for direct patient care, and 11% were in practices that use it for provider-to-provider interactions.[30] Patient-level adoption was also lacking; an analysis from one state's claims data in 2015 found less than 1% of patients received telemedicine services despite policies supporting it.[31] Several surveys revealed concerns about using telehealth, including patient privacy, technology burden, quality of the service, access to the internet, and lack of insurance coverage.

The COVID-19 pandemic created a scenario in which telehealth was the safest, most feasible, and sometimes only mechanism for patients to receive medical care for acute and chronic conditions. This was particularly important for CYSHCN, who have demonstrated an increased risk for severe complications of severe acute respiratory syndrome coronavirus 2 infection.[32] Telehealth fulfilled other aims related to the pandemic, namely, to achieve social distancing in health care settings, protect staff, and

mitigate personal protective equipment shortages, all while maintaining a level of health care delivery necessary to treat patients. The Centers for Medicaid and Medicare Services, on March 30, 2020, removed many of the regulations that had been previously identified as barriers to implementing telehealth.[33] This action, coupled with patients' preference to reduce their own risk of exposure, led to faster, more widespread use of telehealth than what would have been achieved through traditional evidence-based implementation strategies.[34]

In summary (Box 1), important foundational work to establish the potential for telehealth to mitigate barriers to accessing care for CYSHCN has been done. With the urgent need for safer care, telehealth during the pandemic was implemented rapidly but with an uneven attention to equity for patients with limited literacy skills and limited English proficiency. Similarly, concerns about patient privacy, provider experience, and the appropriateness of telehealth based on clinical context were viewed differently through the COVID-19 lens, compared to before. Much remains to be learned about how to best to use telehealth to deliver health care outside of research settings and in a post-pandemic era, and its effects on health outcomes, patient self-management, patient and provider experience of care, access to health care and utilization, and disparities have yet to be fully examined.[35]

GAPS IN RESEARCH FOR TELEHEALTH AND CYSHCN

Box 2 Highest Priority Topics Related to Telehealth in the CYSHCNet Research Agenda

- What are feasible and acceptable telemedicine interventions and what is their influence on child and family outcomes?

- How does rurality uniquely affect CYSHCN, and what are effective interventions to support CYSHCN and families living in rural settings?

- What are effective strategies for using technology to reduce disparities?

Box 3 Gaps: Summary of Knowledge Gaps in Research on CYSHCN Populations and Telehealth Interventions

1. Effect of different implementation strategies on the adoption of telehealth, and the components of clinical contexts that promote sustained use of telehealth interventions.

2. The effectiveness of telehealth in different populations of CYSHCN.

3. Effect of differential access to high quality internet and video devices on receipt of telehealth services.

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4. Effect of widespread implementation of telehealth on disparities among CYSHCN.

5. Optimal incorporation of remote self-monitoring and other telehealth tools to promote self-management and collaborative management among CYSCHN, caregivers, and providers.

Research priorities for CYSHCN were recently established and published based on feedback from over 800 members of expert-nominated stakeholder organizations including families, health care providers, researchers, and policy makers using a multistakeholder approach. Telemedicine implementation, the use of technology to reduce disparities, and rurality's influence on health and care were among the topics given the highest rank (Box 2).[36] A 2016 agenda regarding telehealth research across populations highlighted gaps in knowledge around implementation and adoption, as well as identifying the need for studies of models personalizing telehealth to individuals' clinical and social contexts.[37] The COVID-19 pandemic accelerated implementation of some aspects of telemedicine, which provides opportunities to answer key questions in several areas, including real-world effectiveness and adaptations needed to best serve CYSHCN. Although it is unclear how many of the changes implemented during the pandemic will persist, it is likely that telehealth will continue to play an increasing role in health care delivery.[35]

Important, immediate research questions surround implementation and effectiveness of telehealth as it was rapidly implemented as a result of the pandemic, and the adaptation and sustainability of this model postpandemic (Box 3). For example, what factors contributed most to adoption of telehealth during the pandemic, and to what degree will use be sustained in the future? Under which clinical, social, and technological circumstances is telehealth superior to in-person care for CYSHCN, or inferior? In what ways should these technologies be sustainably incorporated into care of CYSHCN? The experiences and perceptions of groups that implemented telehealth rapidly could inform models of sustainability and policies around appropriateness of telehealth use for CYSHCN. In addition, studying lessons learned from rapid application of telehealth to a variety of clinical contexts could lead to the creation of innovative models of care where telehealth is an important component. This is especially important for CMC and other clinically vulnerable groups (eg, children who are immunocompromised) for whom telehealth may reduce exposure to infectious diseases in health care settings.

A second overarching research question, particularly noted during the national research agenda development process, asks whether and how telehealth reduces inequities in health care access and quality. Studies have indicated a potential for telehealth to address the onerous travel and cost burden for patients seeking specialty care as well as geographically-based workforce shortages of both pediatric specialty providers and mental health

therapists.[5] A population-based, retrospective analysis of health care utilization patterns related to this pandemic, during which telehealth is more widely available, could identify where disparities exist in access to telehealth (eg, due to lack of wireless internet, quality devices, or interpreter services) and whether disparities in access to specialty and other care due to geography are reduced or exacerbated.[27] Examining telehealth use post-pandemic, with telehealth instituted as routine in at least some aspects of health care, could examine where use persists because it addresses barriers to care (eg, in rural populations and CMC) and how health outcomes fare with telehealth in real-world settings.

Finally, a third research gap examines if high-level, complex models that personalize telehealth to certain clinical or social contexts benefit CYSHCN, particularly those using multiple modalities of telehealth, such as technologies that proactively monitor symptoms and promote interactive self-management between patients and care team members.[37] These complex models have particularly high potential impact for CYSHCN due to their focus on chronic condition management, and they represent the next phase of how telehealth technologies can be applied to health and health care. However, because of the imperative for telehealth to be implemented quickly at the onset of the COVID-19 pandemic as a direct substitute for in-person care, such models were generally not included in the pandemic-related acceleration of telehealth implementation.

SPECIFIC PROJECTS

Box 4 Research Approaches: Summary of Recommendations for Future Research

1. A mixed methods study examining implementation, effectiveness, and sustainability of telehealth for CYSHCN to date.

2. Examination of the effect of telehealth expansion on patterns of health care use/access for CYSHCN using claims data or other datasets that include health care utilization, with particular attention to patterns of use and disparities in use for vulnerable subcategories of CYSHCN.

3. Foundational studies to examine perspectives on incorporating remote patient monitoring to manage chronic conditions in CYSHCN to inform intervention design.

We conceive the following 3 studies as examples of those that might begin to close the gaps identified above (Box 4).

1. *Implementation, effectiveness, and sustainability of telehealth adapted in response to COVID-19 pandemic for CYSHCN.* Here, studies leveraging the natural experiments in telehealth conducted as a result of COVID-19 would have a direct impact on identifying strategies for optimization and sustainment of telehealth, both for routine use and in the event of future health care crises, and would prime the research pipeline for comparative effectiveness studies on telehealth in the postpandemic environment.

Aims: 1) To examine implementation strategies that were effective for CYSHCN to rapidly transition practices and families from in-person to virtual care. 2) To examine clinical, social, and technological factors particularly salient for CYSHCN that affect the appropriateness, perceived effectiveness, and patient/family experience of telehealth as a substitute for in-person care. 3) To identify mechanisms and supports at the practice and system levels needed to sustain effective elements of telehealth. Specific to CYSHCN populations, these research activities would focus on telehealth as it relates to management of chronic conditions in both primary and specialty outpatient settings.

Methods: For these Aims, we anticipate a mixed methods approach,[38] which integrates qualitative and quantitative methods into a single design. The sample population would include primary care practices in select communities and their referral centers for specialty care. Quantitative data collected would include utilization data that examined practices' transition to telehealth following lockdown procedures and data from surveys of practice administrators and medical directors regarding implementation of telehealth. Qualitative data would include focus groups or interviews of providers, staff and families in these practices regarding their initial and ongoing experiences with telehealth. Drawing from these data, surveys for providers and families using vignettes could be developed and administered with the goal of determining appropriateness and quality of care if telehealth were applied in different contexts. Lastly, utilization data from these same practices in the post-pandemic period could be examined to determine contextual factors that promote sustainability of telehealth.

Impact: Telehealth as a care delivery model will evolve over time, and careful and deliberate decisions and policies informed by this research will ensure proper sustainment and use proportional to need to optimize care received by CYSHCN.

2. *Association of telehealth availability and patterns of health care utilization to assess disparities for vulnerable subcategories of CYSHCN.* With the rapid expansion of telehealth during 2020, the opportunity to examine its impact on patterns of health care use among CYSHCN has become enhanced. This aim of this study would be to determine the effect of the availability and use of telehealth on differences in receipt of outpatient primary and specialty (including mental health) care of chronic conditions for CYSHCN, particularly those at risk for limited access to in-person care, such as those dwelling in rural areas and those with medical fragility.

Methods: We would use claims data, such as all-payer claims databases for this study. The population would be patients < 21 years, who could be further categorized by medical complexity and disability status. A large database would allow further analysis by conditions or condition groups, eg, mental health conditions, diabetes and asthma. Sociodemographic populations of focus would include CYSHCN residing in rural areas and patients with lower socioeconomic status in neighborhoods with limited public transportation, which can be identified in many datasets. Outcomes would be receipt of primary care, mental health, and specialty care. Differences between comparator groups would be measured, controlling for other patient demographic factors (eg, age) and allowing for regulatory changes that affected telehealth as a result of the pandemic. The use of telehealth outpatient care would be examined as a contributing factor to changes in disparities seen; examining differential use of telehealth among sociodemographic groups could further elucidate where disparities persist.

Impact: If a reduction in disparities is found, this would support efforts to expand and enhance telehealth services, and would also substantiate studies to assess reduction of disparities in health outcomes between these populations.

3. *Perspectives on incorporating remote patient monitoring to manage chronic conditions in CYSHCN.* Interventions to remotely monitor individual patients and/or to promote tracking and self-management of symptoms (ie, mHealth interventions) have been studied in adults, but less work has been done in this area in children and youth, including CYSHCN. The technology is expanding for widespread use: Some electronic health records have the capability to collect and collate patient-entered symptom data and data from devices measuring pulse oximetry, blood pressure, serum glucose and use of positive airway pressure devices. The aims of this study would be 1) to explore perspectives of patients, caregivers, providers and staff regarding the incorporation of remote symptom monitoring in care management for CYSHCN and 2) to adapt current tools for 2 groups of CYSHCN: CMC and children/youth with mental health conditions. Data collected would be applied toward designing a pilot study of the feasibility and acceptability, as well as assessing study procedures for use in larger trials. The rationale for focusing on CMC is that chronic conditions that define CMC often start to flare at home, and early detection by both caregivers and providers may help prevent emergency department visits and hospitalizations. In addition, greater involvement of medical providers at the start of symptoms may help manage caregivers' anxiety around such flares. The rationale for focusing on children with mental health conditions is similar—flares often start at home, but not intervened upon until symptoms worsen. However, key differences in these populations also justify inclusion of both groups separately—medical complexity is rare, heterogeneous, and typically managed by large teams of providers; mental health conditions are common and often managed in primary care with school or community therapists.

Methods: We would recommend qualitative methods for the first aim, using primarily focus groups that explore domains of adoption, usability, added benefit, workload/burden, privacy, and individualized adaptions. Caregivers would also be asked about these tools for self-monitoring of symptoms. Adapting existing tools would involve expertise by technology developers with input from caregivers and providers. Together, these efforts would set the stage for a larger trial, as well as next steps for the design of comprehensive, collaborative, patient-focused care management systems that include remote monitoring as a key component.

Impact: Remote symptom monitoring can be used to augment personalized care and track populations of CYSHCN, especially when incorporated into a complex model of care delivery focused on managing chronic conditions.

CONCLUSION

Significant gaps exist in our knowledge regarding the effects of telehealth on the care of CYSHCN, and in particular those with conditions or socioeconomic factors that make it more difficult to access in-person care. We noted specific areas where additional studies are needed. The proposed studies, whether conducted within CYSHCNet or elsewhere, will further the understanding of how best to incorporate these evolving technologies into the complicated and nuanced care of children with chronic conditions to mitigate known disparities. This technology is changing rapidly, and telehealth use will likely persist, regardless of whether research is performed to understand its potential; thoughtfully planned investigation will ensure that use of this technology optimizes health and health care of this vulnerable population.

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