

COMMENTARY

CRISIS AS AN ENGINE OF CHANGE

MATTHEW SADOFF, MD^a

Coronavirus disease 2019 (COVID-19) is a novel contagious respiratory illness caused by a virus thought to spread mainly between people through respiratory droplets produced when an infected person coughs or sneezes.¹ Heeding the CDC advice for social distancing, we health care providers have been forced to look at our daily practice to find new ways to care for our patients without unduly exposing them to infection. As this current health crisis drives innovations to safely and efficiently care for children with medical complexity (CMC), we are compelled to reexamine the way we practice, creating opportunity to gather evidence that can transform care.

Across the country there may be shifts driven by a need to rapidly adapt and evolve to heed the imperative to keep children away from health care settings unless absolutely necessary. A great deal of rapid cycle testing and prototyping of new approaches to old problems has arisen, catalyzed by interim liberalization of telehealth rules by federal or state authorities. This provides an opportunity to pilot new approaches and assess their value and impact.

Certain existing programs show promise of what success looks like. During a webinar entitled “Telehealth for CMC in the Pandemic” hosted by the Academic Pediatric Association Complex Care Special Interest Group, multiple complex care programs reported preliminary data of improved patient outcomes and patient satisfaction while using telehealth.² Those who participate in the care of CMC best take note of salient examples.

In the past decade, a number of studies in many different settings have demonstrated that care coordination when properly structured can improve the quality of life for CMC and their families and lower cost.^{3,4,5,6,7,8,9}

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Published reports have also demonstrated that telehealth-based care coordination does not adversely affect care and may improve upon the experience of families. In a randomized controlled trial of 148 families with CMC between the ages of 2 and 15, investigators used the Consumer Assessment of Healthcare Providers and Systems survey as an outcome measure at baseline and after 1 and 2 years. They found that participants in the intervention group had higher ratings on measures of the child's provider, provider communication, overall health care, and care coordination adequacy, compared with control subjects.¹⁰ A second RCT of 168 patients from the same center compared Health Related Quality of Life HRQL as measured by the PedsQL. This study compares telehealth care coordination to office-based care coordination in families' existing medical homes. They found no difference in outcomes and patient satisfaction between the two groups.¹¹

Telehealth can represent a range of services. Encounters may involve a simple telephone call, a video-assisted call using the patient's smartphone and a secure video chat application, or it can include devices that monitor the patient and auscultate the patient noninvasively. A new pediatric telehealth research network, Supporting

Pediatric Research and Outcomes and Utilization (SPROUT) is conducting ongoing prospective research to promote evidence-based practice as this new modality grows to scale.¹²

The technology available for home monitoring of CMC, still quite underdeveloped for pediatrics, is a potential area that is ripe for research and development. A recent focus group of family caregivers on the use of mobile health (mHealth) suggests that the ideal application should include: symptom tracking, an optimized user experience with real time text and email messaging options to post a video and/or photograph of the child to allow a visual assessment by the healthcare provider.¹³

Now as medical providers across the country are converting from office-based care to video and audio telehealth to provide care and lower the risk of infection,^{14,15} we in pediatrics need to acknowledge that patients may come to expect this practice to continue after the current health crisis. We also need to ensure that if the transformational effect of this crisis endures that it allows patients and families to feel cared and not just taken care of.

It may be helpful to look at this change through three different lenses; the patient,

the provider/care team, the health system.
This is depicted below in Table 1.¹⁶

	Benefits	Potential Harms
Patient and family perspective	Convenience Reduced transportation barriers Better access to specialty care Less time missed from work Improved patient provider connection Lower infection risk Better DME access	Perceived lack of caring Limited knowledge of local landscape Decreased patient provider connection Increase health disparity and enhanced digital divide
Provider and care team	Improved access to families Improved show rates Lower infection risk Improved patient provider connection Closed loop communication	Poor video quality/Poor connectivity Absence of in person nonverbal cues with cultural miscommunication Lack of physical exam Limited ability for diagnostic testing Decreased patient provider connection Open loop communication
Population health/ health system	Improved access to specialty care Lowered transportation barriers Improved no show rates Lowered health care utilization costs	Lowered demand for in person visits Increase health disparity and enhanced digital divide Decreased quality of care Impaired antibiotic stewardship

Table 1. Potential changes caused by telehealth through three different lenses

While there are many benefits from the families' and patients' perspective, there remains potential for unintended harm. Inequitable access to internet based services abounds, and a lack of universal telehealth may unintentionally worsen health disparity. Large telehealth "call centers" may not possess adequate knowledge of local resources applicable to CMC and may lack the personal connections required to build an adequate community of caring for individual patients and families.

While telehealth has existed in some health systems for decades, others are working to catch up and understand what gaps they need to address to fully implement this in

practice. A holistic assessment will be critical. Current documentation requirements relating to prescribing of medications, treatments, durable medical equipment and homecare may need to be reexamined to improve access. For CMC, the needs may be correspondingly complex, including integrating forms or templates that enhance care coordination and care management. Electronic prescribing may need to be expanded or modified, moving home care documentation (485 forms), DME requests, from open loop paper and fax systems to online closed loop systems with shorter turnaround times and more rapid feedback loops. As we look to enhance our efficiency, we may also need to consider shifting the current paradigm and have documentation driven by medical need instead of billing requirements. How much documentation is really needed for care? How much needs to be physician driven and how much can be team driven? How can the EMR be simplified and redesigned around this?

The current pandemic has created a crisis of resources and a need for healthcare systems to reexamine how care is best delivered for all patients in an environment of resources under stress and high demand. In this crisis comes a great opportunity that is best seized upon as a chance to look at how we can provide care that is safer and

more efficient for patients and providers. Some changes will be rapid and some will take longer. To be successful we must continue to re-examine our approach to everything, and to apply creative solutions, assess their impact while focusing on what is primary: the needs of families and patients during this time of transformation.

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FIGURES

	Benefits	Potential Harms
Patient and family perspective	<ul style="list-style-type: none"> Convenience Reduced transportation barriers Better access to specialty care Less time missed from work Improved patient provider connection Lower infection risk Better DME access 	<ul style="list-style-type: none"> Perceived lack of caring Limited knowledge of local landscape Decreased patient provider connection Increase health disparity and enhanced digital divide
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