

# The Benefits and Challenges in Delivering Telehealth in Pediatric Pulmonary Hypertension

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## BACKGROUND

The COVID-19 pandemic has had an extraordinary impact on the health care system in the United States, including the rapid adoption and implementation of telehealth in many subspecialty clinics, including pediatric pulmonary hypertension (PH). Pediatric cardiology has been a leader in the telehealth field with home and remote monitoring through the use of blood pressure cuffs, oxygen saturation monitors, weight scales, feeding logs, cardiac implantable electronic devices, remote interpretation of electrocardiograms (ECGs) and echocardiograms, yet replacing routine clinic visits with virtual telehealth appointments is a new experience for most pediatric PH providers.

Pulmonary hypertension in infants and children is associated with idiopathic and heritable pulmonary arterial hypertension as well as a diverse group of pulmonary, cardiac, and systemic diseases.<sup>1</sup> Despite advances in medical therapies, there continues to be significant morbidity and mortality in infants and children with PH.<sup>1</sup> As there is no cure for PH, treatment is aimed at improving symptoms, exercise tolerance, and slowing the rate of disease progression. Disease management in PH often requires complex care involving pharmacologic and nonpharmacologic therapies, laboratory testing, symptom monitoring, and diagnostic imaging. However, most PH symptoms and adherence to the medical regimens have the potential to be observed with telehealth or remote monitoring.

Given the unprecedented demand on the health care system during the COVID-19 pandemic and to minimize

the risk of exposure to patients and caregivers to the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), telehealth should be explored as a tool in treating infants and children with PH. This article examines the current systems and resources as well as the challenges, benefits, and future direction of telehealth in pediatric PH.

## TELEHEALTH DEFINITIONS

Telehealth is the use of technology and devices such as computers (laptop or desktop), telephones, smartphones, and tablets to connect patients and health care professionals. The term telemedicine has been in use since the 1960s when closed circuit television was used for psychiatric consultations.<sup>2</sup> Telemedicine is a subset of telehealth that refers to direct patient care, and the distinction between telemedicine and telehealth is similar to the comparison between medical care and health care.<sup>3</sup> The modern era of telehealth services can be separated into the timing of the interaction, termed asynchronous or synchronous services.<sup>4</sup> *Asynchronous* telemedicine does not require real-time patient interaction. For example, teleradiology is asynchronous, wherein images are sent to a radiologist to review and interpret on their own.<sup>5</sup> On the other hand, live video conferencing is considered *synchronous* telemedicine, or real-time interactions between patients and health care providers.<sup>3</sup>

## TELEHEALTH PLATFORMS

As COVID-19 surged in the United States in spring 2020, the Department of Health and Human Services issued

a notification of enforcement discretion that health care providers were permitted to use widely available communication applications and platforms without the risk of penalties imposed by HIPAA.<sup>6</sup> This has allowed health care providers to serve patients in “good faith” when using various telehealth platforms. Health care providers may now use popular nonpublic-facing applications to deliver telehealth. Examples of nonpublic-facing video chat applications include Apple FaceTime, Facebook Messenger video chat, Google Hangouts video, Zoom, and Skype. Under this notice, health care providers may not provide telehealth on Facebook Live, Twitch, TikTok, or any other platforms that are public facing. Many large health care systems in the United States already had HIPAA-compliant telehealth platforms in place before the COVID-19 pandemic, and the chosen platform varies at each institution. See Table 1 for a list of HIPAA-compliant telehealth platforms.

**Table 1.** HIPAA-Compliant Telehealth Platforms

Updax
Doximity
Doxy.me
Zoom for Healthcare
Skype for Business/Microsoft teams
VSee and Google G Suite Hangouts Meet
Amazon Chime
GoToMeeting
Cisco Webex Meetings/Webex Teams
Spruce Health Care Messenger.

## TELEHEALTH LICENSING AND BILLING/REIMBURSEMENT

The COVID-19 pandemic has also prompted changes to telehealth reimbursement and licensing. On March 17, 2020, the Center for Medicare & Medicaid Services changed health care providers' reimbursement so that all telehealth services provided for Medicare patients are reimbursed at in-person office visit rates indefinitely, yet it remains unclear how long this rate of reimbursement will continue, and some private health insurance companies that followed the government's direction could go back to paying a fraction of the cost for telehealth visits.

As of March 2020, health care providers may now also furnish telehealth and other services using communications technology wherever the patient is located, including at home, even across state lines.<sup>7</sup> However, individual state laws and regulations influence pediatric telehealth programs more than national guidelines. Little standardization exists among states in pediatric telehealth and licensing board requirements, and telehealth practices vary widely from state to state. The Center for Connected Health Policy retains lists of each state's laws, regulations, and reimbursement in regard to telehealth.<sup>8</sup> Additionally, the Telehealth Resource Centers are another resource for state and region-specific telehealth information.<sup>9</sup> Finally, the American Academy of Pediatrics offers a comprehensive list of coding for telehealth services.<sup>10</sup>

## CONDUCTING A TELEHEALTH ENCOUNTER

### *Telehealth Consent and Documentation*

Before beginning the telehealth encounter, consent from the patient or parent/caregiver must be obtained and on file. Common language around telehealth consent states:

I performed this consultation using real-time telehealth tools, including a live video connection between my location and the patient's location. Before initiating the consultation, I obtained informed verbal consent to perform this consultation using telehealth tools and answered all

the questions about the telehealth interaction.

### *Interpreters*

If the family or caregivers are not fluent in the same language, it is important to have a medical interpreter available for the entire telehealth visit.

### *History*

Obtaining a patient history and review of symptoms is not location dependent and can be easily achieved during a telehealth encounter. The home environment may prompt a better history or symptom recall. Additionally, adherence to the medications or the medical regimen can be reviewed. Providers can examine medication vials and bottles to confirm correct dosage and administration.

### *Physical Exam*

Although a patient's heart and lung sounds cannot be auscultated, or a liver edge and pulses palpated, the general appearance and mental state can be ascertained during a home telehealth exam. Providers may also inspect for pallor or cyanosis, labored breathing, edema, clubbing, and evidence of syndromes or genetic diseases. In addition, prostacyclin infusion insertion sites (central venous or subcutaneous catheter) may be observed over telehealth.

## TELEHEALTH CHALLENGES

Although there was rapid adoption of telehealth within pediatric PH, several barriers in implementing and delivering telehealth exist.

### *Vital Signs*

In most cases, vital signs cannot be obtained in the home environment. However, some medically complex patients may have home monitoring equipment, such as pulse oximeters. During a telehealth visit, such devices may allow for collection of vital signs, including heart rate, respiratory rate, and pulse oximetry. Parents may also be instructed to count pulse and respiratory rates. Additionally, if a home health nurse is available, he or she can obtain a full set of vital signs and growth measurements. However, at times, this in-home technology is not

available, creating the challenge of obtaining important biometric data points.

### *Diagnostic Imaging and Testing*

One of the biggest challenges of telehealth is the inability to perform diagnostic imaging, such as echocardiograms, ECGs, cardiopulmonary exercise testing, and pulmonary function testing at the time of service. In some cases, there may be an option for the patient to have imaging and/or testing completed and available to the provider before the telehealth appointment. This may be completed at their home institution or a satellite clinic. However, when this is not an option, telehealth visits should be reconsidered, as these studies are crucial to track progression of disease and develop a treatment plan.

### *Ancillary Services*

Ancillary services that are vital to the multidisciplinary team, such as nutrition, respiratory therapy, pharmacy, social work, and behavioral health, may or may not be available to participate in a telehealth appointment. This will vary at each institution and may require follow up at a later date.

### *Patient/Caregiver Presence*

In some instances, the ability for the health care encounter to occur in the home setting has given the misconception that either the caregiver or the child does not need to be present, but just as if they were in a specialty clinic, both patient and legally approved caregivers need to be present for telehealth appointments. If either the caregiver or patient is not available, the appointment will need to be rescheduled.

### *Technological Barriers*

Both providers and patients or caregivers must have access to technological devices (ie, desktop computers, laptops, tablets, smartphones) and a stable Internet connection. Although numerous school districts in the United States are working to close the digital divide, this may continue to be challenging for low-income and rural patients and caregivers. Some communities, such as the Amish or the Mennonites, do not partake in technology for religious reasons.

## TELEHEALTH BENEFITS

While there are numerous barriers to telehealth, there are several attributes that may enhance the quality of care a pediatric PH patient receives. Telehealth has the potential to increase accessibility of health care and education to patients, allow for better assessment of the home environment, and enrich the patient-provider relationship.

### *Accessibility*

Many pediatric PH centers are regional programs, and it is not uncommon for patients and their caregivers to travel great distances to receive comprehensive care for their disease. As a result, significant financial implications for attending an in-person clinic appointment include the cost of gas and hotel rooms. There may also be missed work and the need for arrangement of childcare for siblings. The ease and convenience of telehealth allows the patient to receive quality care on a virtual platform in his or her own home, thus reducing the cost and burden associated with travel. This has the potential to reduce missed appointments and may result in earlier detection of disease progression or barriers to care.

### *Assessment of the Home Environment*

Through telehealth, patients provide a virtual invitation into their home, which deepens providers' understanding of their patients and their home environments. Providers have the insight into a patient's level of resources that may not be gained in a traditional in-person office visit. This can assist the health care team in identifying barriers that may affect their patient's health and ability to adhere to his or her medical regimen. The visual sweep of a patient's home also puts into context the day-to-day life that a patient lives. It highlights the resiliency of families that have adapted their personal lives to make mini-hospital rooms for their patients with feeding tubes, monitors, and ventilator support. Being able to see the patient in his or her living room or bedroom is also a reminder that many more things define the patient aside from his or her PH.

### *Enhanced Patient/Provider Relationship*

Patient and caregiver involvement are very important to the health care team, as they provide information surrounding overall well-being, symptoms, side effects, and the feasibility of treatment plans in a child's life. Telehealth may change the dynamics between the patient and provider, as it affords the health care team the ability to see a patient in the environment in which they are most comfortable. Children have a better sense of control at home versus in the clinic. They may be more relaxed, less reserved, and eager to share their favorite things over the video conference with their health care team. Similarly, caregiver involvement may change when participating in telehealth from their home, and telehealth may empower caregivers to take a more active role in developing a treatment plan. Telehealth can level the playing field between the patient and provider and move away from the asymmetric relationship that occurs inside a traditional clinic setting.

## FUTURE DIRECTIONS OF TELEHEALTH

At this time, telehealth in pediatric PH is largely focused on clinical evaluation and replacement of in-person clinic appointments. However, there is an opportunity to explore several other interventions delivered over telehealth, including education, social support, and home monitoring devices.

### *Education*

There is an opportunity to advance the education of pediatric PH patients and their caregivers on PH physiology, disease management, medications, and transition to adult PH services. Multiple studies have shown increased patient knowledge of disease and improvement in objective clinical outcomes when telehealth is used in patient education.<sup>11</sup> Providers may also feel like they have more time to focus on patient and caregiver education over telehealth rather than a rushed clinic setting.

### *Social Support*

Patients, siblings, parents, and caregivers all experience the physical and mental challenges from living with or caring

for a child with PH. Telehealth offers a platform to obtain support from providers and peers. For example, support groups may be offered by social workers or clinical psychologists over telehealth for patients, siblings, and caregivers. The barriers that might restrict support group attendance, such as time and distance, may be overcome when telehealth modalities are used.

### *Monitoring Devices*

While many adult subspecialists have begun using home monitoring devices, they are not yet widely adopted by pediatric PH providers. As technology advances are made, pediatric PH patients may be able to use devices that transmit data such as activity, weight, blood pressure, pulse oximetry, and ECG waveforms. These monitoring devices may enhance the telehealth encounter and overcome the barriers that providers view in the providing telehealth services.

## CONCLUSIONS

The use of telehealth during the COVID-19 pandemic will likely have a lasting impact on the delivery of pediatric PH healthcare. During the current pandemic, legal restrictions such as reimbursement and out-of-state licensure issues have been alleviated, allowing pediatric PH programs to explore the use of telehealth in this patient population. However, it remains unclear how long these changes will remain in place. Additionally, having telehealth capabilities does not mean that every patient encounter is required to be through a virtual platform. A hybrid approach of in-person clinic visits and the use of telehealth may balance the challenges and benefits of each modality. Every pediatric PH center should identify the telehealth procedures that are ideal for their practice and patients to determine the best approach to care.

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