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Telemedicine use in neonatal follow-up programs – What can we do and what we can't – Lessons learned from COVID-19

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ABSTRACT

Little empirical data support the use of telemedicine to provide medical and developmental follow-up care to preterm and high-risk infants after hospital discharge. Nevertheless, the COVID-19 pandemic temporarily rendered telemedicine the only means by which to provide essential follow-up care to this population. In this article we discuss our institution's experience with rapid implementation of telemedicine in a multi-site neonatal follow-up program as well as benefits and limitations of the use of telemedicine in this context. Finally, we discuss the current problems that must be solved in order to optimize telemedicine as a tool for providing comprehensive, multidisciplinary medical and developmental care to high risk infants and their families.

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Telemedicine is an evolving technology with countless potential applications. In neonatology, telemedicine has been studied to support inpatient care in resource poor settings; for example, to facilitate screening for retinopathy of prematurity when pediatric ophthalmologists are not available in person.^{1,2} Similarly, it has been used as a means for inpatient physician-to-physician consultation.^{3,4} Such uses of telemedicine are discussed in the current issue of *Seminars*. In addition, providers and organizations, such as the American Academy of Pediatrics, increasingly recognize telemedicine as a potentially valuable means to increase access to certain outpatient services, such as pediatric subspecialty care.⁵ Some have warned about possible disadvantages of telemedicine in this context, such as potentially disrupting the patient-clinician relationship.⁶ In a qualitative study assessing caregiver perspectives on the use of telemedicine to

provide subspecialty pediatric care, families expressed a preference for using telemedicine to complement, rather than replace, in-person care.⁷

After discharge from the neonatal intensive care unit (NICU), infants will have a wide variety of ongoing medical and developmental needs. A small 2016 randomized trial assessed the use of telemedicine as an adjunct to home nursing for infants discharged from the NICU with home health care in Sweden.⁸ Infants randomized to the telemedicine group had fewer scheduled visits to the hospital and fewer emergency visits per day of home health care. Importantly, only about two-thirds of eligible families agreed to participate in this trial. Even though most participating families reported that they had extensive experience using computers, 3 of 47 infants in the telemedicine group did not receive any video calls because of problems with internet connectivity. On the

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other hand, families generally reported that participation in telemedicine made them feel more secure in caring for their babies. In a pilot project in Cleveland, all patients discharged from a single NICU were offered a 20-minute telemedicine visit which was scheduled to occur after the first pediatrician visit.⁹ Seventy percent of visits were completed successfully and 68% of the participating families had medical questions that were answered by the neonatologist during the telemedicine visit. Most recently, telemedicine has been used to assess for evidence of evolving infection after discharge in infants born to mothers with confirmed or suspected COVID-19 infection.¹⁰ While these studies have demonstrated a possible role for telemedicine in addressing the medical needs of both high and low risk infants after NICU discharge, none of these studies evaluated the role of telemedicine in addressing the developmental needs of NICU graduates.

Neonatal follow-up programs are an essential service for high-risk infants discharged from the NICU. They provide family support, care coordination, developmental assessment and guidance, and medical care focused on sequelae of prematurity or critical neonatal illness. At this time, no empirical data support the use of telemedicine to provide multidisciplinary developmental follow-up care after NICU discharge. Nevertheless, the COVID-19 pandemic temporarily rendered telemedicine the only means by which to provide essential developmental follow-up care to this population. Below we discuss our recent local experience with rapid implementation of telemedicine in a neonatal follow-up program, benefits and limitations of the use of telemedicine in this context that we identified during the pandemic, and future directions for telemedicine in neonatal follow-up programs.

Local experience of implementing telemedicine in neonatal follow-up

At Children's Hospital of Philadelphia (CHOP), our in-person Neonatal Follow-up Program was suspended effective March 16, 2020 in response to the COVID-19 pandemic. Subsequently, between March 30 and June 16, 2020 our program was conducted exclusively via telemedicine. Resumption of in-person care blended with telemedicine began June 17, 2020. In light of the evolving pandemic, our blended in-person and telemedicine program continues today. During the hiatus from in-person visits we learned several important lessons regarding the successful conduct of neonatal follow-up via telemedicine.

All scheduled patient visits were immediately converted to telemedicine visits. Providers were trained how to use the telemedicine application in the electronic medical record (EMR). Simultaneously, families were contacted to inform them of the change and determine whether they were both willing and able to participate in the telemedicine visit. A detailed process was created for scheduling patients for telemedicine visits (Appendix 1). For some families, internet connectivity was an obstacle; for others, bringing care providers virtually into the home environment was a concern. Some families opted for a telephone encounter rather than telemedicine. Per organizational policy, telephone encounters were not an option for new patient visits, but were permitted

for established patients who did not feel comfortable with telemedicine.

After scheduling the telemedicine visit, we provided parents with a guide for the visit. First, parents were instructed how to download the MyChop mobile application, which is a patient portal that allows parents to communicate with their child's providers and to access portions of their child's electronic medical record. MyChop access is also required to access telemedicine visits (Fig. 1). The guide included suggested toys to have on hand during the visit, but also emphasized that any of the child's toys would be appropriate. Clinic coordinators used the following telephone script to instruct parents about how to prepare for the visit:

"So that our providers can get an idea of how your baby moves and interacts, the medical provider would like to see how your child does during floor time. If you could please have a blanket and some of his/her favorite toys available during your video visit, the provider will ask you to put your baby on the floor with the toys. They may watch your baby play, and want to see how he/she does in different positions on the floor, so that they can give you tips on activities you can do to support your baby's development."

Response if a parent responds that they don't have toys: "That's ok! The provider will still be able to watch your baby on the floor and give you tips on how to use what you have to support your baby's development."

For infants less than 12 months of age/corrected age as well as older children with previously identified motor needs, physical therapists participated in the telemedicine visit. Medical providers joined visits with physical therapists in order to observe evaluations and participate in recommendations. Parents often proved to be remarkable partners in conducting this aspect of the visit, eager to better understand their infant's progress as well as identify areas of concern. With scripted instructions, parents assisted in demonstrating such assessments as head lag in pull to sit, head control, scarf sign, popliteal angle, ankle dorsiflexion and adductor angle. Portions of the Hammersmith Infant Neurological Examination (HINE) were performed through family instruction. However, not all elements could be routinely assessed (i.e., reflexes). These maneuvers that were performed were quite useful in determining abnormalities requiring further follow-up, particularly when the abnormalities were not of a subtle nature. Importantly, the HINE is not yet validated for telemedicine use and HINE telemedicine training was not available at the time that this was implemented in our program, so findings were interpreted with an abundance of caution. At completion of the visit the physical therapists, in partnership with the participating physician, provided individualized care recommendations to the families.

For infants/toddlers 12 months and older, developmental evaluations were carried out by our behavioral health team, most of whom are early childhood psychologists. In preparation for telemedicine, the behavioral health team had several telephone/ virtual meetings to discuss best practices for telehealth assessments. They collaborated with our institution's neuropsychology team to enhance their understanding of

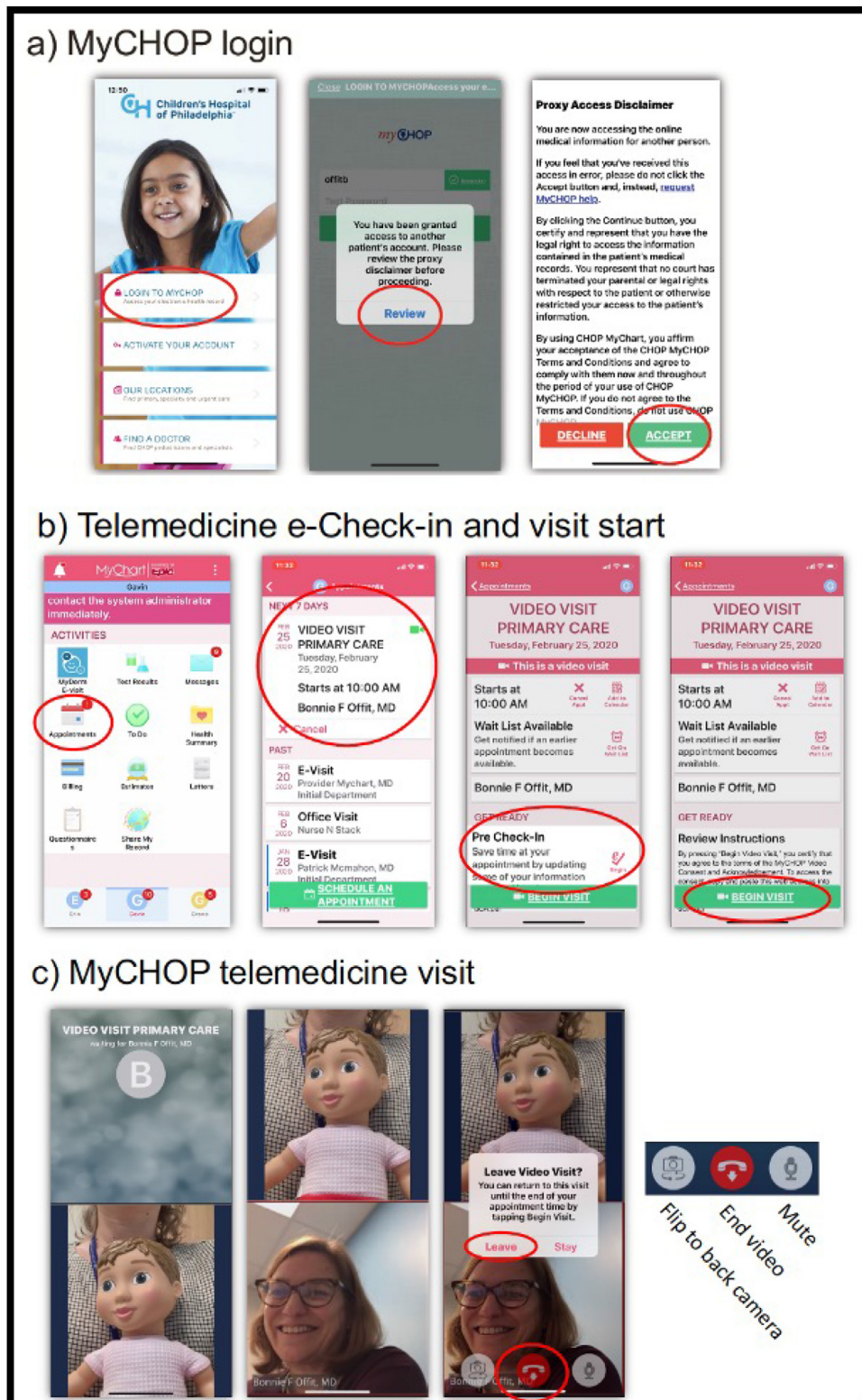


Fig. 1 – Patient/family views of MyCHOP telemedicine encounter. (Images provided by the CHOP Office of Digital Health.)

telehealth billing, documentation, ethics, and issues around licensure. In addition, they collaborated with the developmental pediatric group to discuss approaches to performing global developmental and autism assessments on telemedicine. The behavioral health team developed a set of recommended

prompts to facilitate parents’ demonstration of their children’s developmental skills (Fig. 2). The developmental portion of the visit was generally conducted first, with time built into the visit for the psychologist to communicate impressions to medical providers prior to their portion to the visit. This provided

Target Age – 12 months	Developmental Concepts to Observe and Related Toys	Clinician Prompts to Caregiver
Toys/Materials Container with blocks or small toys Toy car/truck Doll or Stuffed animal Play dishes or cups Pop up toy or music box Crayon and paper Board book Ball	Cognitive Skills	
	<u>Imitation – truck or car</u> Observe whether child imitates parent’s actions	“Please roll a truck or car across the ground near your child. Then give your child the truck or car and ask them to do it.” “Please clap your hands or make a face.”
	<u>Interactive Play – ball, social game</u> Observe whether child plays, engages with parent	“Please roll a ball back and forth while sitting on the floor facing your child, and encourage your child to play with you.” “Please initiate a social game such as peek-a-boo or pat-a-cake with your child.”
	<u>Attends to story – board book</u> Observe child’s attention to book, whether child looks at pictures, flips pages	“Please read the board book to your child.”
	Communication Skills – Expressive Language	
	<u>Imitates words</u> Observe whether child imitates parent	“Please make animal sounds or other familiar sounds like “ah oh” or “Bye-bye.”
	<u>Uses finger to point to express needs</u>	Observe or ask parent
	Communication Skills – Receptive Language	
	<u>Understands “No” – toy of interest</u> Observe whether child stops, does not pick up toy	“Please put a toy in front of your child but then tell your child “no” before they pick it up.”
	<u>Understands words for familiar objects</u> Observe whether child looks at, points to, or retrieves the object	“Please ask your child a question they would know the answer to (e.g., where’s bottle?).” “Please read to your child and ask him/her to point to objects in the book.”
	Motor Skills – Fine Motor	
	<u>Writing grasp –crayon</u> Observe grasp and ability to make marks on paper	“Please show your child to make marks with a crayon .”
	<u>Stacking - blocks</u> Observe how child picks up and stacks blocks	“Please show your child how to make a block tower with two blocks.”
	Motor Skills - Gross Motor	
	<u>Rolls, stands from laying down</u> Observe how child gets up	“Please place your child on his/her back and let them get up.”
<u>Takes steps without holding on – object of interest</u>	“Encourage your child to walk towards you or towards an object of interest.”	
<u>Throws ball with a forward motion – ball</u>	“Demonstrate throwing the ball and then ask your child to throw it.”	

Fig. 2 – Example of Guidelines for Behavioral Health Providers to Assess Development. Parents were sent a list of possible toys to have available during their telehealth visit. In this figure are listed a few key milestones in each domain for a 12-month visit (excerpted from a more comprehensive list) that the behavioral health provider could observe and ask a parent to help demonstrate. Similar lists were also developed for 6 months, 18 months, 24 months, 30 months, 3–4 years, and 4–5 years.

opportunity for discussion and consensus regarding recommendations for interventions and follow-up.

During each telemedicine visit, the medical providers reviewed medical history, intercurrent illnesses/hospitalizations,

medications, subspecialty visits, nutrition, sleep and other issues. A physical and neurological ‘examination’ was conducted by the provider with the clear caveat of limitations of such an examination. Once again, parents utilizing a camera were able to

provide more information to the care provider during the evaluation. For example, in younger participants, eye movements and response to sound stimuli could be assessed. Retractions could be visualized, with parental input solicited regarding whether this finding was stable, more than usual, or less than usual. Similarly, dermatologic problems could be assessed, with parents providing visual and narrative information as to whether hemangiomas were increasing in size, decreasing or remaining the same. At the conclusion of each visit, the medical provider communicated back to the clinic coordinator whether the child should be rescheduled for an in-person visit as soon as possible or according to our usual clinic cadence, which is every 3–12 months depending on the child's corrected age.

In the initial week of telemedicine, we scheduled only 18 visits. In ensuing weeks, however, as many as 36 visits per week were scheduled. The show rate ranged from 40% initially to as high as 95%. Our overall show rate for telemedicine visits during these first few months was 72%, which is approximately similar to our show rate for in-person visits in our Neonatal Follow-up Program. Even though we did not see our typical numbers of visits, we were able to see about 74% of our usual in-person patient volume during this period of exclusive telemedicine. In retrospect, the majority of our providers and families concluded that these visits were "not so good as in person, but so *much better* than no visit."

Benefits of telemedicine

Telemedicine provides an effective alternative to address the multiple barriers that may limit families' ability to attend Neonatal Follow-up Program clinic in person.¹¹ In prior qualitative work, these barriers have been broadly categorized related to time, logistics, knowledge, and emotional stress. For example, telemedicine overcomes barriers related to the financial costs and time commitment for long-distance travel to clinic. As noted above, in-person developmental care was not permitted at our institution or at most institutions during the first wave of the coronavirus pandemic. Telemedicine allowed us to provide this care remotely.

Often, parents will report that a child is capable of performing developmental skills that the child does not demonstrate during an in-person visit. When developmental visits are conducted via telemedicine, the provider is able to view the child in his or her own environment. Children are naturally more comfortable in their home environment, and therefore may be more likely to demonstrate some of these skills. Furthermore, the child, parent, and provider are not required to use personal protective equipment such as gloves, masks, face shields, or gowns during telemedicine encounters, potentially making the interactions more personal and less intimidating, especially for the child.

As described above, it is possible for medical providers to perform a sufficiently comprehensive medical assessment and examination via telemedicine to inform clear recommendations. Behavioral health providers can use telemedicine as an opportunity to provide family support, observe developmental progress in the home environment, and provide recommendations about needed developmental supports and interventions.

Lastly, at this time, some families are nervous about the possibility of acquiring sars-CoV-2 during a healthcare encounter and are therefore reluctant to return to in-person care. Having telemedicine as an option ensures access to care for those families.

Limitations of telemedicine

Despite the many benefits of telemedicine in a neonatal follow-up program, it is not a panacea. As noted above, the Hammersmith Infant Neonatal Examination (HINE), which is an essential component of the infant neurologic examination, was adapted for use via telemedicine during the pandemic. However, the reliability and validity of the HINE in this context have not yet been established. Furthermore, *none of the standardized developmental assessments utilized in our program are validated for use via telemedicine.* The Bayley Scales of Infant Development, the gold-standard measure of development for infants ages 16 days to 42 months, requires the child to directly interact with a specific set of manipulatives and toys.¹² Similarly, the Autism Diagnostic Observation Schedule (ADOS) requires direct social interaction and observation.¹³ Therefore, during telemedicine visits, our behavioral health team members are unable to administer these assessments and provide structured feedback about a child's developmental performance relative to age-based expectations or specific diagnoses such as autism. Such data are essential for eligibility for some community support services and communication with educators. Furthermore, these data are often critical endpoints for ongoing neonatal clinical trials. Widespread failure to acquire timely developmental outcomes data on research participants during the COVID-19 pandemic could threaten the integrity of important neonatal research.

Several challenges may interfere with a provider's ability to successfully complete a telemedicine encounter. Technological connectivity issues experienced by both provider and family are frequent and often lead to multiple re-connections and delays. When only one parent is available to participate in the visit, it can be difficult for that parent to provide a requested developmental stimulus to the child while simultaneously holding the camera focused on that child. Our providers have consequently spent considerable time observing floors, ceilings, lamps, and shoes rather than the patient. Distractions inherent to the home environment, such as interruptions from other siblings, pets, doorbells, and telephones sometimes prolong or even derail clinical encounters.

From a clinic operations perspective, scheduling and coordination of a multidisciplinary telemedicine program is riddled with challenges. When one provider finishes a portion of the visit, the family must wait while the first provider communicates off-line with the second provider. This hand-off requires that the accepting provider has completed their own prior patient visit and is ready and available for the discussion at that moment. In the CHOP Follow-up Program, we often recommended to parents that they use this time to recharge their device and give the child a snack.

Lastly, legal and regulatory hurdles complicate the conduct of telemedicine in all fields, including neonatal follow-up. The providers participating in the visit must have a license to

practice their specialty in both the state in which they are physically located and the state in which the patient is physically located. Therefore, families must be instructed that they should not plan to travel and then attend the visit from another state without notifying the providers in advance. In response to COVID-19, many states relaxed licensing requirements for telemedicine for limited time periods and emergency out of state licensing was obtained by our clinic providers. These declarations expire at different times but most commonly whenever the state of emergency in each state has ended. A few states (e.g. New Jersey) require that providers obtain temporary licenses to practice in their jurisdiction, which includes practicing telemedicine from or with patients residing in those states. When scheduling and confirming patient visits, our clinic staff consults with the Federation of State Medical Boards (<https://www.fsmb.org/siteassets/advocacy/pdf/state-emergency-declarations-licenses-requirements-covid-19.pdf>) to ensure that reciprocity agreements have not expired. In non-pandemic times when these agreements are no longer in place, it may become more difficult to conduct telemedicine across state lines. This would have a significant impact on our program, which receives referrals from a wide catchment area.

All insurance providers do not cover telemedicine, and some will reimburse for medical but not behavioral health visits. Some will only permit telemedicine within a narrow network of providers or telemedicine companies with whom they have contracts. In addition, institutional guidance about which patients are appropriate for telemedicine visits has varied throughout the COVID-19 crisis and varies by institution. Similarly, guidance about proper documentation of a telemedicine encounter has evolved and requires close attention.

The future of telemedicine in neonatal follow-up

Despite the lack of evidence to directly support the use of telemedicine in neonatal follow-up, the COVID-19 pandemic demanded that we rapidly implement telemedicine into our local follow-up program. The only alternative would have been to cease providing care to our high-risk families until in-person care was determined to be safe. However, neonatal follow-up is critically time sensitive. Early detection of cerebral palsy and early intervention for children at high risk for cognitive and motor delays are associated with improved outcomes.^{14,15} In addition, our program serves as a safety net for parents of NICU graduates. Parents of NICU graduates are at high risk for anxiety and depression. Our clinic social worker provides both mental health and social welfare resources to our families during neonatal follow-up visits. Thus, lack of follow-up care could have had potentially disastrous consequences for our patients and families.

If we are to continue providing neonatal follow-up in this manner, several aspects of this model require careful assessment and creative solutions to identified barriers need to be developed. Examples of future directions that will improve the utility of telemedicine in neonatal follow-up include:

- Providers must ensure that telemedicine is, in fact, meeting families' needs. Ideally, stakeholders would be involved in

assessment of the most appropriate use of telemedicine in the post-NICU population, particularly if it will at times be used to replace rather than solely to supplement routine care in case of emergencies. Ultimately, it may be that telemedicine cannot be used as an equal replacement for comprehensive face-to-face developmental assessment. An alternate approach may be to use telemedicine to optimize the value of in-person care, as a communication tool before and after the visit, in order to ensure best use of the family and providers' time and resources during the in-person visit.⁷ In addition, when switching between in-person and virtual models, the program must aim to ensure continuity of care with providers and consistent messaging about the goals of program participation.

- While telemedicine is often promoted as a means to reduce disparities in access to care, there may be unintended consequences when marginalized groups have limited access to or skill managing the technology needed to fully participate in telemedicine. For example, more than 40% of Medicare beneficiaries do not have access to a computer with internet and more than 40% do not have a smartphone with a data plan.¹⁶ Those living below the poverty level with lower education levels, a disability, or a Black or Hispanic background are less likely to have digital access.¹⁶ Whether the same is true for families of children eligible for neonatal follow-up is unknown. Thus, efforts must be made to ensure that families with ready access to technology do not disproportionately benefit from the availability of telemedicine programs.
- The telemedicine platform must be optimized to support the needs of the participants. In prior studies, both providers and patients have noted the need to improve technology to enable clear communication.^{7,8} As noted by Robinson, et al: "For telemedicine to work, it is necessary to have patients and healthcare staff who are able and motivated to use information and communication technology."⁸
- New developmental assessments appropriate for use in the virtual environment are needed. Alternately, existing measures will need to be thoroughly validated for use in this context. Without such tools, the utility of telemedicine for neonatal follow-up is inherently limited.
- Ongoing program evaluation is necessary to determine whether the assessments conducted on the telemedicine platform are adequate to capture any evolving developmental delays or medical problems in this high-risk patient population.

In conclusion, we report a novel experience of rapid implementation of telemedicine in a multidisciplinary neonatal follow-up program during the COVID-19 pandemic. While telemedicine is not yet poised to completely replace in-person neonatal follow-up care, this was a positive experience for both families and providers. Telemedicine allowed continued contact with at-risk infants and children, a platform to provide interventions and recommendations, and an opportunity to observe the participants in their natural environment during the unprecedented constraints wrought by the COVID-19 pandemic. Further improvements will ensure that the quality of telemedicine visits rises to that of the exceptional care that is provided face-to-face.

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None.

Declaration of Competing Interest

The authors have no conflicts of interest to declare.

Appendix 1

Coordinator Script for Telehealth Visits

“Hello! <patient name> is scheduled for an appt with us on <date/time>. Because of the COVID-19 concerns, we are contacting families about changing appts to a video visit. Would you be interested in having a telehealth video visit?”

“During this COVID emergency, CHOP is offering telemedicine services. It is our intention that for these telemedicine visits you will not be financially responsible for more than you would be if you had an in-person visit.” (What Dept of Peds provided. Use as needed)

*If YES to VIDEO visit and has an active MyCHOP account:

1. “Great! (Review date/time and provider(s) info with the family).”
2. We also have a few reminders to review:
 - a. Please log in to your MyCHOP account prior to your scheduled visit to complete questionnaires that may be assigned.
 - b. (If BH/med visit): “After your video visit with <provider’s name> has ended, please exit the visit (details if needed→ by tapping the screen and tapping the red phone icon). You’ll then need to join the next visit with <provider’s name> 10 min before the scheduled time of <time>.”
 - c. “Please be sure that <patient’s name> is present for the visit.”
 - d. “Please make sure your phone is fully charged. If you have more than one visit with us, you may need to recharge your phone in between.”
 - e. “It may be helpful if you have someone else present during the visit to help hold the phone while you assist <patient’s name> with some of the activities during the exam portion of the visit.”
 - f. “Try to have some favorite toys, books, and maybe a blanket ready to use for some floor time activities during the video visit. The providers will want to see how <patient’s name> plays and moves.”
 - g. “If you get disconnected, please try to log back into the visit.”
 - h. “If you are having trouble with the sound, try holding the phone rather than laying it on a surface.”
 - i. “If you run into too many challenges with getting the video visit to work, call us (xxx-xx-xxxx) or text us (xxx-xxx-xxxx) to let us know and we can try to switch to a telephone visit.”

■ You may want to reserve h. and i. if they contact you about connectivity issues.

- j. “Please bear with us if we run into technical difficulties or challenges related to this visit. This is an entirely new process for all of us. Thank you!”
3. Ask about SW needs: “Would it be helpful if our Social Worker gave you a call?”

*If YES to VIDEO visit but does NOT have an active MyCHOP account:

1. I can help you with that (refer to the MyCHOP Instant Activation pdf on O drive and provide the family with their activation code)
2. Review reminders above (See #2 – a-j, above)
3. Ask about SW needs: “Would it be helpful if our Social Worker gave you a call?”

*If NO to VIDEO visit but YES to TELEPHONE VISIT:

1. Confirm the phone number to reach the family
2. Confirm an email address (so that the After Visit Summary can be emailed to the family—we won’t have the capability to physically mail correspondence to the family at this time).
3. Confirm date and time of the appt
 - a. Change visit type
 - i. TELEPHONE VISIT [2152]
4. Ask about SW needs: “Would it be helpful if our Social Worker gave you a call?”

*If Cancelling because prefers In-Person appt:

1. “Thank you. We understand your decision and will go ahead and cancel this appt. Because of the frequently changing status of the COVID-19 issues, we will not be able to reschedule the appt at this time. To avoid multiple rescheduling, will give you a call in the future to reschedule once we have a date to begin rescheduling patients.”

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