

***Virtual Modalities Including Telehealth in  
Pediatric Palliative/Hospice Care***

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**NHPCO**

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# Pediatric e-Journal

## Pediatric Palliative and Hospice Care

### Issue #63; May 2021

#### Issue Topic: Virtual Modalities Including Telehealth in Pediatric Palliative/Hospice Care

Welcome to the 63rd issue of our Pediatric e-Journal. It is important to note here that this issue was planned many months ago, but we still could not have imagined the world in which we currently find ourselves with the coronavirus pandemic. Although older adults have suffered the brunt of the infection, the challenges this pandemic has created affect all of us. Not only have we had to create different ways of living our everyday lives, we have also had to create different ways to provide care and services to all populations. For many, there have been significant disruptions.

This issue's collection of articles on various aspects of employing virtual modalities, including telehealth, in connection with pediatric palliative, hospice, and end-of-life care has been produced at a time when huge and unprecedented numbers of people are dying from this disease. It is also a time when the disease continues to give rise to many different challenges and to a few opportunities that touch on the interests of this publication and its readership. We hope the contents of this issue will provoke fruitful discussions about employing virtual modalities including telehealth as we move into the future.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Suzanne Toce. **Chuck Corr is our Senior Editor.** Archived issues of this publication are available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics such as disparities and inequities in relation to pediatric palliative and hospice care, and glimmers of hope for our next two issues in 2021. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at [christytork@gmail.com](mailto:christytork@gmail.com) or Suzanne Toce at [tocess@gmail.com](mailto:tocess@gmail.com).

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## Issue #63: Virtual Modalities Including Telehealth in Pediatric Palliative/Hospice Care

Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.

### *What, Why, and How: Leaning in to Virtual Technology to Extend and Expand High Quality Pediatric Hospice Care* p. 5

**Chantal Curell, RN, CPN, CHPPN**

This article explores why and how the COVID-19 pandemic has driven providers of pediatric palliative and hospice care to turn to virtual technology to extend and expand their services. The author also discusses the successes, challenges, and opportunities encountered by her pediatric program.

### *Telehealth Use in Pediatric Palliative Care & Patients with Chronic or Life-Threatening Illness* p. 9

**Katharine Brock, MD, MS, and Danielle Faye Jonas, MSW, LCSW**

In this article, the authors explain why the COVID-19 pandemic has led to increased use of telehealth throughout health care, but also recently in pediatric palliative, hospice, and oncology programs. They offer 15 tips when using telehealth in pediatric palliative care.

*Remote Patient Monitoring: Are We Ready in Pediatric Palliative/Hospice Care?* p. 13  
**Tina Gustin, RN, CNS, DNP**

*Remote Patient Monitoring in Pediatric Palliative/Hospice Care: A Physician's Perspective* p. 17  
**Ami Mehta, MD**

*Remote Patient Monitoring Impact on Health Care Usage in Pediatric Pain and Palliative Care Patients* p. 21  
**Erin Brawner, RN, SRNA, BSN, DNP Candidate, and Tina Gustin, RN, CNS, DNP**

*Remote Patient Monitoring from the Parent/Caregiver's Perspective* p. 24  
**Lacey Bloy, RN, BSN, SRNA, DNP Candidate, and Victoria Goode, PhD, CRNA**

These four articles emerge from a pilot program exploring remote patient monitoring and evaluating its use. The first article explains what the program understands by telehealth and remote patient monitoring with special attention to pediatric patients and palliative care. The second article offers the perspective of the physician in this project. The third article compares small groups of children who used remote patient monitoring versus those who did not. The fourth article offers a brief report based on an email survey contrasting the perspectives of those parent/caregivers who received remote patient monitoring and those who did not.

*The Virtual Doctor is In: E-Connecting to Psychosocial Care* p. 26  
**Nancy Lau, PhD, and Abby R. Rosenberg, MD, MS, MA**

According to these authors, under the threat of the COVID-19 pandemic, the "Psychosocial standard of care has transitioned from in-person to telehealth delivery to protect the health and safety of patients, families, and providers." However, "Despite the accelerating pace of eHealth adoption for psychosocial symptom monitoring and treatment, little is known regarding the scientific evidence supporting the technological health care revolution." Accordingly, based on their review of the current situation, they offer three key lessons learned and three recommendations for clinical practice.

*Use of Telehealth for Pediatric Palliative Care and Counseling during COVID-19* p. 31  
**Ruth Shapiro, LCSW**

This author explains how, under the threat of the COVID-19 pandemic, one pediatric program adapted its palliative care and counseling services by incorporating telehealth to a much greater degree than previously employed. She notes, "It is possible this shift will last much longer than the current pandemic," and concludes, "When it comes to the very special world of palliative care and mental health...we can combine the benefits of Telehealth while also promoting in-person visits to maintain the quality of care that comes from seeing a patient's facial expression or completing a physical examination. During this unique time, we have discovered that there is space for both in quality medical and mental health care."

*Pediatric Palliative Care Music Therapy: Adapting and Changing Pace During COVID-19*

p. 34

**Amanda Maestro-Scherer, MA, MT-BC, and Jessica Sturgeon, MT-BC, HPMT**

Music therapy was among many services in pediatric palliative care impacted by COVID-19. However, “As time went on, the impact of increased isolation on the patient and family’s emotional wellbeing became clear, and many music therapists were brought back onto their teams and transitioned to Telehealth work, or resumed services with enhanced precautions.” This article describes how many music therapists adapted to the new situation, with particular attention to challenges and benefits in music therapy via telehealth. The article concludes with 11 tips for music therapists during COVID-19.

*Virtual Grief Support Groups in the Era of COVID-19*

p. 39

**Gina Kornfeind, MSW, MS, and Ratna Behal, MD**

When twice-monthly, in-person support groups for grieving family members became impossible because of the COVID-19 pandemic, personnel at this children’s hospital turned to virtual platforms to launch a virtual support group. This article describes in detail the steps undertaken to provide this new form of bi-weekly support group. While conceding that “the shift from in-person to virtual support groups initially created a great deal of stress,” the article concludes that, “Despite these challenges, there have been many ‘pandemic positives’ about this new format” and lists several of them. Above all, “The feedback from parents and families has been overwhelmingly positive.”

*A Transformative New Care Model “Bridge” to the Future for Pediatric Palliative Care at Home: What’s Possible*

p. 44

**Ann Fitzsimons, BS, MBA**

This article describes a new model of care implemented in the Canadian province of Ontario that has served pediatric patients over the last 11 years. The model’s aim has been “replacing and/or reducing the length of hospital stays for medically-fragile and/or mechanically-dependent children.” This innovation is “built on the concept of an enhanced ‘share care’ model among families and the health system. Utilizing a comprehensive technology platform called eShift™, this new model leveraged the knowledge and skills of the health care providers (i.e., a team of nurses, primary/specialized medicine physicians, health care aides, etc.) to facilitate improved access to care for families at home. This technology platform enabled a delivery format which could then link medical providers in a health system or community clinic to clinicians, technicians, and nursing assistants who were in the home with the child, resulting in a new way to deliver ‘real time’ patient- and family-oriented care to more children, more efficiently and a lower cost.” Read the article to learn how this model works, how it departs from traditional models of community-based care, and how it has been successful.

## WHAT, WHY, AND HOW: LEANING IN TO VIRTUAL TECHNOLOGY TO EXTEND AND EXPAND HIGH QUALITY PEDIATRIC HOSPICE CARE

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### **The Why:**

Since March 2020, the COVID-19 pandemic has upended the lives of all Americans. As a pediatric hospice provider, we routinely support families whose lives have already been upended for months-or sometimes years. Yet, the pandemic has presented *Jo Elyn Nyman Anchors Programs for Children* a unique set of challenges in offering holistic, person-centered care that meets CMS requirements and keeps patients, families, and staff safe.

The challenge of meeting our patients' needs amid the barrage of rapidly changing guidelines from local health departments has prompted creative solutions to augment care via virtual visits. Working closely with our field clinicians, quality/compliance team, generous donors, and, most importantly, patients and families, we've been able to harness the power of virtual technology not to replace, but to expand upon the extraordinary care our hospice clinicians provide each day to children and their families across the Lower Peninsula of Michigan.

### **The How:**

They say it takes a village to care for a child—but when that village becomes virtual, it is even more essential that each member has the tools and resources to play their part. As a not-for-profit organization, our commitment to providing equal access to care assured that the necessary technology would be available to every patient and their family. We sought funding to ensure that families who either did not have the means to acquire a video-capable device or who did not have the data/internet connection to support telehealth visits received via these necessary resources.

Through a generous community of donors, including funding from disease-specific community resources and a donor-supported Quality of Life Fund, sufficient funds were raised to purchase new, Zoom-capable tablets, and also cover improved data/internet access to alleviate these concerns, thus allowing each family to become open to virtual visits to take advantage of this new opportunity.

The next step was to secure buy-in from staff, patients, and families on how this technology would be used to improve—and complement—their experience. Fortunately, as a pediatric

program, it was clear that many of our patients already had an affinity for tablet use and a familiarity with virtual learning. Older school-age and teenage patients were much more willing and able to engage virtually than younger children or many adult family members. Further, it was important to ensure to families that a system was in place to protect their privacy while conducting visits electronically. Zoom’s business license addressed the security concerns, and embedded passcodes added an additional layer of safety to meeting virtually. It was most important to reassure all families that when they needed us to be at the bedside, we would be there—*no questions and no exceptions*. However, if they preferred to minimize exposure, or if symptoms were managed, this virtual technology offered a convenient way for families to meet with their care teams without having to worry about one more person in the home. The virtual technology also offered the capability of extending visits to other providers who wouldn’t “typically” be present at a routine visit—looping in physicians, music therapists, and volunteers from our art program and other disciplines who could provide a more rounded interdisciplinary experience and decrease the amount of separate calls families received throughout the week.

Finally, understanding the regulations regarding which types of visits could be conducted virtually, and what would be most useful, was essential. This is where guidance from our quality/compliance team, who stayed up to date with Michigan legislation, was invaluable. Virtual visits were allowed for non-telehealth purposes (such as art or volunteer visits), for visualizing a patient and family to assist in symptom management by nursing and physicians, and for follow-up with social workers, spiritual care, or grief support counselors to provide a friendly face during difficult conversations. Virtual visits could not replace care that required an in-person assessment physically, emotionally, or spiritually, such as a patient experiencing a symptom crisis, new admissions or deaths, for assessment of suicidal ideation, or at any time when a family requested in-person care. It was important to remind families that we remain present and available to them in any way that is meaningful to them, and the ability to do so virtually was simply an extension of our care.

### **The What:**

### **Successes:**

The significant adoption of virtual communication during the pandemic will undoubtedly trigger many studies on the benefits of incorporating this technology into a comprehensive hospice plan of care. In the near term, I can elaborate anecdotally on what successes, challenges, and opportunities *Jo Elyn Nyman Anchors Programs for Children* has faced as we have piloted and implemented virtual visits into our day-to-day services. These include:

#### *Access to immediate video assessment for symptom management*

There is no denying that timeliness of care during an emergency is a struggle faced by all in-home health care providers. Pediatric hospice is no exception. Although having phone triage nurses helps, being able to visualize a patient while a nurse is on the way, or for those moments where a parent will say, “I’m not sure if I need a visit, I just wish someone could lay eyes on

him,” makes having virtual video access irreplaceable. The ability to pull the physician into that video call so that parent, nurse, and physician can collaborate for immediate assistance has been an incredible benefit for families. Being able to visualize the symptom a patient is experiencing—instead of putting the sole responsibility on the parent to describe it—can help provide more timely treatment. This access also has been beneficial during collaboration with other providers, making virtual “care conferences” an exciting new possibility for our pediatric patients who often are followed concurrently with many specialists.

### *Overcoming challenging geography*

As the only statewide pediatric hospice program of its kind, *Jo Elyn Nyman Anchors Programs for Children* covers the vast majority of the Lower Peninsula of Michigan. While patients are largely gathered around each children’s hospital, we have seen growing census in more rural areas and believe that every child should receive the same high-quality care, even if pediatric patients in that area may be few and far between. Patients in these areas, thanks to virtual technology, can receive the benefits of volunteer art visits and music therapy sessions no matter if they live 5, 50, or 150 miles away from the closest available volunteer or music therapist. Their local team has access to our pediatric physicians and dedicated staff. No matter where they are in the state, the pediatric specialists of *Jo Elyn Nyman Anchors Programs for Children* are only a click away. And finally, as we expect another harsh Michigan winter (COVID notwithstanding!), having immediate virtual access will be critical to improving timely and comprehensive care.

### *Improved communication with patients and families...and each other*

Virtual technology has also helped overcome practical barriers for those who struggle with telephonic support or face hearing challenges. For instance, for patients and caregivers with hearing challenges, video allows the ability to lip-read, something that is not possible when wearing a mask during a traditional in-person visit or with telephonic support. It also was a way to put a “friendly” face to the care team, who—during COVID-19—may only be seen covered in PPE. Virtual visits also improved the ability to visualize “teach-back” with caregiver education instead of verbal confirmation of understanding only over the phone, providing more confidence to caregivers and patients that they have everything they need when we are not present with them.

Additionally, the ability to expand access to pediatric-specific end-of-life education grew by leaps and bounds when forced to get creative with how we conducted internal processes. The creation of a pediatric end-of-life curriculum for all RNs and interested field clinicians was borne out of the unique access that video visits provide. From one central hub, we are able to reach clinicians throughout the state of Michigan and beyond to provide knowledge and advice specific to the unique needs children and families face at end of life. Using the same platform with which we conduct virtual visits, we’re able to gather for a time of learning and Q&A as well as record the sessions for clinicians who want to view them at a later time.



## **Challenges:**

### *Participation barriers*

By and large, the biggest barrier to virtual visits has been the comfort level with participation from both families and staff. As with any new opportunity, virtual visits via any platform can be an intimidating prospect for families who are in a very sensitive season of life. While virtual visits with pediatricians, specialists, and consulting physicians are becoming more common, familiarity with hospice care supplemented through virtual means has still not become mainstream. We have found that clear communication regarding virtual visits as a tool to improve access to care, but not replace traditional hospice care, has taken away from this challenge in part. For staff, frequent education, training, and practice has alleviated the bulk of the concerns regarding performing virtual visits.

## **Opportunities:**

Adding virtual visit capabilities provides an endless amount of opportunity for future benefit to patients and families. Opportunities include building in a live chat (in a proprietary platform) with providers to schedule virtual “check ins” and prevent emergent needs, and expanding the range of certain volunteer services such as companionship, story-telling and music. In addition, extending available complementary therapy services such as guided imagery and the ability to record patient stories for legacy building are just around the corner. For organizations willing to think outside the box, access to virtual care is an exciting new frontier to create an even more holistic and comprehensive end-of-life experience.

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## TELEHEALTH USE IN PEDIATRIC PALLIATIVE CARE & PATIENTS WITH CHRONIC OR LIFE-THREATING ILLNESS

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The COVID-19 pandemic has placed unique burdens and challenges upon the health care field, notably on palliative care clinicians reliant on facial expressions, a supportive emotional presence, and the ability to provide therapeutic touch. Although telehealth had been available prior to the pandemic, this mode of care delivery greatly accelerated in 2020 with numerous hospitals, clinician offices, therapists, and hospices growing into the telehealth space after changes in guidance and legislation related to the location of the patient/provider, physical exam requirements, and prescribing allowances were modified. Telehealth is synchronous audio/video-based communication, similar to Zoom or Facetime, conducted over a HIPAA-secure platform, giving patients the ability to remain in their home while connecting to their medical teams. Although many palliative care clinicians may worry about having difficult conversations via video or about reimbursement for services, there are unique advantages to the telehealth platform in the palliative care and hospice populations. Visits are discussion focused, are less reliant on physical exams/labs/technology, allow the patient to remain in a comfortable setting, and avoid the burden of a clinic visit. As palliative care volume has increased and the interdisciplinary team has less time to perform home visits, telehealth offers the opportunity to virtually go to a patient's home, no matter the geographic distance. These in-home visits have provided opportunity for increased intimacy, as providers are able to better understand what everyday life is like for patients and families.

Telehealth within pediatric palliative care can assist families who have transportation challenges (who often spend excessive time getting their child ready and into the car for a visit) or a child who is too sick and limited in their mobility to travel to clinic. Some children struggle with significant pain and anxiety related to transport and clinic/hospital visits. Telehealth provides families an in-home alternative for care. Compared to the clinic setting, this platform allows parents and children to be unmasked while in a safe and comfortable space. Parents can be in separate rooms from their child and allow for privacy and easier expression of their concerns and emotions. Multi-party video visits can also include pediatricians, additional

relatives, supportive community members, or other interdisciplinary providers or hospice nurses.

With regard to interactions with children, teenage, and young adult patients, telehealth can offer added benefits for rapport building and comfortability. Pediatric patients have reported that it feels helpful to be able to have difficult conversations from the comfort of their own home. Pediatric providers have noted an added layer of authenticity and comfortability as patients eagerly share aspects of their lives to which providers have not been traditionally exposed. Furthermore, some pediatric patients have noted their comfort in communicating with the assistance of technology and have used features like the chat box or turning off their video when discussing particularly challenging or intimate topics. For example, providers have noted that some patients feel more comfortable discussing sexuality or end-of-life preferences through the chat box or with their cameras off.

Telehealth can also be utilized for hospitalized children whose parents have a challenging time being at the bedside due to physical distance, lack of resources or time off from work, or competing family obligations at home. This allows families to participate in virtual care conferences with the interdisciplinary teams involved in a child's care. Some hospitals, palliative care programs, and grief camps have transitioned memorial services and grief and bereavement programming to virtual groups, while still ensuring a healing environment and high levels of participant engagement. Additionally, bereavement counselors have transitioned individual therapy and bereavement support groups to promote ongoing access to these crucial services during a time when social isolation and physical distancing have impeded usual sources of support.

Research has shown telehealth to be feasible, acceptable, and cost-effective in adult oncology, hospice, and pediatric palliative care. Recent clinical efforts and research studies have also expanded services to pediatric hospices. Nonetheless, challenges include technical failures, administrative and technical support needs, difficulties for non-English speaking families regarding accessing interpreting services, ensuring privacy for patient conversations, non-universal access to technology or the internet at family homes, or lack of familiarity and comfortability by families. Pre-COVID challenges like a lack of institutional support or reimbursement challenges have been lessened.

Despite challenges, many pediatric palliative care programs have experienced lower "no show" rates when comparing telehealth visits to in-person visits. This improves clinician efficiency and billing revenue. Due to the pandemic, changes in insurance regulation and telehealth billing have allowed for increased utilization and reimbursement. Telehealth laws have generally been changing on a state-by-state basis and it is unknown whether the changes that promoted access and physician acceptance will persist post-COVID. Federal legislation is being introduced proposing continued telehealth expansion and payment reform for physicians and other billable interdisciplinary services.

Consider the following tips when using telehealth in pediatric palliative care:

- Dress professionally
- Plan for a break between sessions to use the bathroom, stand up and stretch, debrief with colleagues, etc.
- Remove mask/goggles if you are in a safe and private location
- Be cognizant of your background visuals and sounds, and have a good front-facing light
- Be in a location that is private with a reliable internet connection
- Center your face in the screen and note your facial expressions
- Look at the camera and not at the screen
- Start the visit by asking patient/family to plug in their device and set an agenda, including the time allotted
- Ask the patient/family what their goals are for the session and include this in your agenda setting
- Assure their privacy by asking if they are in a place to speak and who else is around
- If patients are not in a space where they can speak freely, encourage the use of the chat box function as a means of discussing private or delicate topics
- Let families know if you will be looking at additional screens to perform medication reconciliation or write instructions/prescriptions, etc.
- Ask children or families to show you around their room and/or show you a favorite toy in their room as a means of rapport building
- Signal when the visit is coming to an end, i.e.: “We have about five minutes left in our appointment, is there anything else you wanted to discuss today?”
- Use screen sharing as a clinical tool—for results, advance directives, 5 Wishes/Voicing My Choices, POLST

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## REMOTE PATIENT MONITORING: ARE WE READY IN PEDIATRIC PALLIATIVE/HOSPICE CARE?

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### **Telehealth and Remote Patient Monitoring**

Telehealth is a rapidly growing method for delivering care to patients who might not otherwise have access to care (Rutledge et al, 2017). Prior to the coronavirus (COVID-19) pandemic, it was estimated that care delivered through telehealth would grow at an annual rate of 16.8%; instead, this growth exceeded an annual of increase of 80% in 2020 (Arizton, 2020). Recent reports predict that 30% of all health care visits will be delivered through telehealth post pandemic. Additionally, as many as 65% of health care consumers plan to use telehealth post COVID-19 (Annis et al., 2020; Drees, 2020). As the COVID-19 pandemic accelerated throughout the country, many hospitals, specialty care practices, and primary care practices pivoted their care to remote patient monitoring (RPM). In simple terms, RPM uses a tablet with peripheral devices such as stethoscopes, high resolution cameras, oximeters, scales, and glucometers that collect patient data and transmit it via the internet to a care team. RPM equipment is designed to allow patients to remain in their homes. Data collected through RPM devices allow the care team to monitor changes in the patient's vital signs and/or reported symptoms and act accordingly. A benefit of RPM is that providers can link to the patients and caregivers directly through the tablet. The RPM tablets are designed for easy access, decreasing the patient's need to go into either an email or phone text to link to the provider. Most RPM devices also allow providers to load and send patient education materials in print and video to patients. Many RPM tablets are also equipped with SIM cards that can be used by families in areas with limited broadband connection. Research has shown the use of RPM technology prevents the worsening of illness and decreases emergency room visits and hospitalizations, while also reducing health care costs for both patients and hospitals (Malasinghe et al., 2019). Remote patient monitoring consistently demonstrates improved patient outcomes. With RPM, providers and nurses can leverage data to help give patients better feedback regarding their condition(s) and treatment.

### **Remote Patient Monitoring for Pediatric Patients**

Despite the successful use of RPM for chronically-ill adults, it has not been fully utilized for chronically-ill pediatric patients. Clearly pediatric patients would benefit from the same technologies. The problem with widespread use is reimbursement. While Medicare has reimbursed for services provided through RPM, most state Medicaid programs have not.

Because of this limited revenue in the pediatric space, most of the technology companies that develop, manufacture, and sell RPM equipment and services have not focused product development on the unique needs of the pediatric population. For example, the Bluetooth devices are not designed for the smaller pediatric patient. Oximetry probes are sized for adults; neonatal oximetry probes are not available through most companies. Infant scales are not standard options, and blood pressure cuffs are sized only for small to large adults.

Despite these limitations, RPM shows promise in several pediatric domains. Hospitals have successfully monitored neonates discharged from neonatal intensive care units with limited travel to the clinic for appointments. Providers can observe the baby and parent within the home. Instead of using adult monitoring devices, parents have manually loaded biometric data such as weight and oximetry readings into the tablet's dashboard. This allows both the parent and provider to track the neonate's trends.

Providers and parents have found this type of virtual connection has helped the parents better manage complicated medication regimes and treatments (Sasangohar et al., 2018). Other successful pediatric RPM use has been seen with transplant patients, children with implantable cardiac devices (Dechart et al., 2014; Tsao, 2019), and complicated diabetics. During the COVID-19 pandemic there has been a surge in pediatric RPM delivery. Much of these results are in pre-review and should be published over the next several months. Of note, both providers and families have reported satisfaction and ease in the use of RPM.

### **Palliative Care and Remote Patient Monitoring**

Remote Patient Monitoring has shown early promise for pediatric patients receiving palliative and hospice services. For pediatric palliative patients, RPM can leverage care coordination; it allows for easily available educational and informational resources, and it provides symptom and medication management that is critical to improving quality of life and preventing adverse health events. Telehealth and RPM services can offer patients and their families the advanced care necessary to ensure their needs are met. Collecting patients' biometric data in real-time enables palliative care teams to continuously assess patients' health, inform additional care providers of patients' status, and triage patients—all while keeping the patient in the comfort of home.

Beyond biometric data, the care team can leverage medication management and symptom survey tools available via telehealth and RPM platforms. Collecting this information is critical to proper symptom, pain, and medication management. This data provides the care team further insight into their patients' daily health and wellbeing. Remote patient monitoring devices also allow the palliative care team real-time virtual visits directly from the device. This type of visit has decreased the need for the medically fragile palliative care patient and family to travel to clinics for in-person visits. It has also limited the need for care teams to visit patients in their homes, as these home visits are conducted virtually. Another benefit of this type of virtual visit is the ability to have multiple providers available during the visit.

## **Reimbursement for Remote Patient Monitoring**

Historically, reimbursement for RPM has been a challenge. On November 2, 2020, however, the Centers for Medicare and Medicaid Services (CMS) (2020) finalized new reimbursement guidelines for RPM. Providers may now bill for RPM services when an established physician-patient relationship has been previously developed. The following monitoring is now reimbursable: remote weight, blood pressure, pulse oximetry, and respiratory flow rate. Non-physician staff may also bill for setting up the RPM with patients and teaching them how to utilize it. For reimbursement, the RPM devices must be valid, reliable, and transmit the data electronically and automatically, rather than having the patient self-report. (It should be noted that this guideline may negatively affect pediatric patients and their families that are using this equipment.) As discussed earlier, most RPM companies do not have equipment sized for small children. Parents need to manually load their data into the systems. As the policy is written, providers will not be able to bill for monitoring and reporting on this type of data. The direct supervision and video visits conducted through the RPM equipment may also be billed (CMS, 2020). Another important guideline is that patients must transmit data through the device at least 16 days during the month and all treatment must be documented in the patient's electronic medical record. These billing guidelines have been adopted by Medicare, Medicare Advantage, and commercial payers. States are currently evaluating these guidelines for Medicaid reimbursement.

## **The Future of Pediatric RPM and Palliative Care**

It is essential that pediatric palliative care teams make themselves aware of RPM and how these technologies may benefit their patients and families. Pediatric home care agencies and hospitals should begin to build RPM costs into their patient delivery models and fiscal budgets. It is projected that 33% of hospital executives will deploy RPM in 2021 (CareSimple, 2020). Policy makers must continue to lobby for Medicaid reimbursement at the state level. Providers and parents of children with chronic and terminal illnesses should work with RPM companies in the development of pediatric devices. Researchers must continue to research RPM outcomes as this data will further drive reimbursement and use. This innovative equipment should be offered to all palliative care patients living at home.

Palliative care is an invaluable service that provides pediatric patients and their caregivers a lifeline to a variety of services and specialists during a very difficult time in their life. Telehealth and RPM can improve care quality and thus quality of life for both patients and families. For palliative providers, telehealth and RPM can ease communication difficulties, inform care planning to improve care quality, and enhance services offerings to patients and their families.



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## REMOTE PATIENT MONITORING IN PEDIATRIC PALLIATIVE/HOSPICE CARE: A PHYSICIAN'S PERSPECTIVE

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Taking care of complex patients with palliative needs is one of the favorite parts of my practice. We see a variety of children in my clinic, with a wide range of diagnoses, from chronic pain in a healthy teenager to newborns with neuro-degenerative/genetic diseases who will not see their first birthdays. The nature of this work requires that I see patients frequently; consequently, when the concept of remote patient monitoring (RPM) was introduced to me, I was immediately interested in how it could change the tenor of the care delivered.

Prior to our integration of RPM, we were trying to see patients in person every two months. Some of my palliative patients, or those with complex medical needs and a circus train of equipment (wheelchair, trach, vent, feeding tube, central line, etc.), required home visits every few months. Despite the amount of time these visits took from my day (travel time plus visits at least an hour in length), they were (and still are) one of my favorite ways to see a patient. These visits allow me to see the child and family “in their own habitat.” Other families struggle to come to clinic for various other reasons, including failure of Medicaid transportation, distance issues, guardian work conflicts, and the child’s medical fragility. Our clinic makes a practice of trying to see patients when they are at clinic appointments with other subspecialists. This cuts down on the number of trips back and forth. Even with each of these interventions, families are still having to take off work, take siblings out of school, and bring a roadshow of medical equipment to receive medical care multiple times each month.

### **Our Remote Patient Monitoring Project**

In response to these barriers, our team implemented an RPM pilot study with 20 of our most fragile patients. The project took place over 12 months with the hope of having enough information at the conclusion to support the hospital’s investment for other populations. The goals of this project included increased access, rapid video visits, and a decreased need to travel to the patient’s homes, as well as tracking of patient biometric data for the improvement of care management.

The logistics of getting this small project up and running proved to be challenging as there were many steps to the process, including: finding a company that provided devices at a price point our health system could accommodate, identifying patients willing to commit to the one-year project, Wi-Fi or broadband connection, developing new workflows within the electronic

medical records to log RPM visits and patient data, getting devices in patients' hands during a pandemic, adapting our clinic schedule to fit in telehealth visits, and determining how best to document and capture charges for our visits.

The project was planned prior to the pandemic when telehealth was still a new concept, at least in terms of my own practice. We did not truly know what to expect with RPM but pictured an idealistic care style in which patients could access us easily, allowed me to have a good pulse on the health of our patients on a weekly basis, and facilitated a quick video visit that not only allowed me to assess the patient, but provide a snapshot of care in their homes. Our hope was this type of visit would be like the quality of interaction during a traditional home visit.

### **Benefits**

The greatest benefit to this project seems to be the family's connection to our practice. They were able to visit with me without the need to travel. This proved to be critical during the early months of the pandemic. While I do not believe we changed treatment because of RPM, we did provide scheduled and as needed virtual visits that (hopefully) did not add more stress to the family. One mother, who was often a bit prickly when I saw her in the office or at her home, started to open a bit more about her feelings around having a child with a life-limiting heart condition. I think having the knowledge that she could hang up on me at any time gave her control over the situation and allowed her to feel safe enough to have those hard conversations with me. Another mother, who often presented a very strong front most of the time, became emotional while we spoke. When I told her I could not see her because her screen had frozen, she replied, "Good, I don't want you to see me crying anyway!" and we laughed together.

I have discovered that my visits via telehealth are often shorter. In some ways this is good, as I can see a patient in 5-20 minutes and get all necessary topics addressed. This format has allowed me to see my patients more often and this means that we have fewer topics to address and less interim "catching up" to do. However, sometimes I miss that easy chatter of being in the physical presence of a patient and a family. As a provider who asks patients to come from long distances to my clinic, I try to make their visit worthwhile. Not only do we talk about the child and their medical issues, we talk about siblings, family members, coping, mental health, nursing hours, hospitalizations, the weather, upcoming vacations, favorite TV shows, and any number of things that do not directly matter to the child's medical care, but help me to know the family, understand who they are, and build a long-term relationship. Some of this banter is lost in a virtual visit. It remains whether this is a benefit or a barrier to this form of care. Perhaps as a provider I can and should mindfully integrate those types of conversations into telehealth visits as well as in-person visits.

### **Barriers**

As with most new projects, our RPM pilot was not without barriers or problems. Unfortunately, we did not have the participation from the families that we had hoped for. Some families that eagerly agreed to using the devices did not submit the weekly data. This lack of data made it

difficult to remotely manage their care. While the device that we selected had a built-in cellular connection, the quality of this connection was less than ideal. Often the virtual connection with families would freeze or drop. The video quality at times was jerky and blurry. Despite troubleshooting with devices and connectivity, we struggled to get some of these devices to work effectively. I often had families show me their child at the start of the visit as the RPM tablet worked best for the first two to three minutes of the call. If the tablet froze, I would convert the visit to a phone call.

We originally hoped that we would have a better grasp on our patients' health, week to week, by asking them to submit weekly vitals and questions related to their child's health status. Instead, the data submission was irregular from most of our families. This irregular submission resulted in incomplete data that was not able to inform care.

Because this was a pilot study, we did not link the RPM data to the EMR. This has created more time for the nurse transferring data from the dashboard to the EMR. The nurse has also spent quite a bit of time calling families to remind them to enter data. This data component, while helpful in theory, has turned into a burden for my team, and gives us minimal useful data.

### **My Perceptions as a Physician**

My perception of telehealth may be unique, but bears sharing. When I see a patient via telehealth, I miss that relationship-building. I also find that I am more tired when I am doing telehealth appointments. I think this is due to a combination of factors including the increased effort required to read body language through a screen, the technical difficulties we often face, and the "concentrated" medical talk that is a stark contrast to the more leisurely in-person clinic visits I am accustomed to. I miss hearing about their lives and their families. I miss seeing my patients and their families in person. The care that I am able to deliver is more efficient, but is it better? I am not sure. I worry that I may have missed something in a family's haste to finish the call and get back to their lives. Often, when we are in person, we will meander through conversations, and parents have time to remember all the topics they wanted to discuss. There is definitely a higher number of after-visit calls to my nurse, asking one last question they forgot to ask during our visit.

### **Lessons Learned**

Despite all these frustrations, I think our families like the concept behind this device. I believe they like knowing they have access to us and can ask for a video visit later in the week if needed. However, more than the device itself facilitating a closer connection, I think that the schedule we have set up, which includes visits every 4-8 weeks for most patients, has been the best part of this pilot. Seeing my patients and families regularly has been a huge blessing. I think knowing that we have an appointment scheduled for every few weeks has been a comfort to families, who often have said to me, "I've been wondering about this for a few days, but knew we'd see you next week, so I didn't worry too much about it." I have been able to work around families' schedules for these visits easier than if they were in person. I have been able to meet

other caregivers who are normally working during clinic visits. We have found that all our visits should not be done virtually. Our more complex families need to see us in-person, too. Scheduling both in-person and RPM virtual visits is an ideal blend for these families.

Using RPM for this population has proven to be beneficial and has a place in delivering good patient care. RPM should be used as an “in addition to” and not instead of in-person visits. During the last 9 months, two of our palliative care patients have died. One lived far away (and didn’t want home visits), so was amenable to using the device close to the end-of-life period to share symptoms and to do frequent video visits, though of course this didn’t replace frequent phone calls and real-time symptom management. The other family stopped using the device close to the end of their daughter’s life, and instead preferred that we came out and made multiple home visits. Both families took some comfort in knowing that the device was available, but not intended to replace in-person care, and that they were still able to have a physician involved (to whatever degree they wanted).

### **Future Direction**

Remote patient monitoring has a place in pediatric palliative and hospice care. As a result of the COVID pandemic, RPM companies have advanced technologies and are quickly developing equipment and adapting to the unique needs of the pediatric population. Medicare and Medicaid are evaluating RPM reimbursement. This project was pioneering not only at our hospital, but for pediatric palliative and hospice care nationally. We look forward to seeing how we can continue to expand care while maintaining good quality of care delivered.

We are endlessly grateful to the families that took part in our pilot.

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## REMOTE PATIENT MONITORING IMPACT ON HEALTH CARE USAGE IN PEDIATRIC PAIN AND PALLIATIVE CARE PATIENTS

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Pediatric palliative care improves the quality of life for children with life-limiting conditions (Snaman et al., 2020). The care required for these complex children requires comprehensive care from specialty providers. Studies have shown that children who are followed by palliative care services have lower health care costs as they approach death compared to children that were not cared for by a palliative care team (Smith et. al. 2015). To date, there has not been a study that also evaluates health care utilization or cost for children cared for by palliative care services that incorporated remote patient monitoring into the practice.

### **RPM and Telehealth**

Remote patient monitoring (RPM) is a telehealth modality that uses digital technology to connect providers with their patients from a distance. Unlike traditional telehealth visits, patients are provided a tablet that allows for a quick and easy real time virtual visit. Patient biometric data such as weight, temperature, and oxygen saturation is transmitted through peripheral devices that are connected to the tablet to the provider. Patients can also communicate asynchronously with the provider using the tablet through text. Photos can be exchanged easily allowing the provider to assess things like skin wounds and rashes. RPM empowers both patients and health care providers by improving the quality of care while driving down costs. Care provided to adults through RPM devices has been shown to decrease hospitalizations, readmissions, and overall length of stay (Center for Connected Health Policy, 2021). However, we don't know if the use of RPM devices has a similar impact on the pediatric palliative care patient population.

## **Purpose of the Study**

Remote patient devices were provided to 20 children cared for by the pain and palliative care team at the Children's Hospital of The King's Daughters. From this larger study, several smaller pilot studies were conducted. This study evaluated the differences in health care services utilized between children that had the RPM equipment from those that did not. More specifically, we looked at the difference in the number of touch points (communication with either the physician or palliative care nurse through text or phone call), scheduled visits, unscheduled visits, missed visits, emergency room visits, hospitalizations, and length of hospitalization. It should be noted that this study took place during the COVID-19 pandemic, so all the visits were virtual for both groups. The sample size consisted of 7 participants (4 in the RPM group and 3 in the Non-RPM control group). Data was collected retrospectively from the patient's charts six months between April 1 and October 1, 2020.

## **Results and Discussion**

The descriptive statistics revealed that most of the children in the study were male. The RPM study group was composed of 75% males and 25% females. The Non-RPM control group was composed of 100% or all males with no females. The average age for the RPM group was 5.5 years of age, while the control group's average age was 12.3 years. Seventy-five percent of the children in the RPM group had private insurance and 25% had Medicaid. All the children in the control group had both private insurance and Medicaid. It should be noted that all the participants had some form of a neurodegenerative or significant life-limiting illness.

The touch points (email and texts) were significantly different between the groups. The RPM group had 54 touch points while the control group only had 7. The RPM group had 13 scheduled visits, and 41 unscheduled visits while the control group had only 7 scheduled visits, and no unscheduled visits. The RPM group had 2 emergency room visits and the control group had 3. Interestingly, the emergency room stay was shorter for the RPM group with an average of 326 minutes and the control group had an average of 725 minutes. Hospitalizations were similar between groups with one in the RPM group and two in the control. The RPM group's length of hospitalization stay was only 2 days, while the control group's average stay was 12.5 days.

Despite the small sample size, this study suggests that the use of RPM in this population provides an opportunity for increased communication between parents/caregivers and the pain and palliative care team. This increased communication may decrease unnecessary emergency room visits and shorten hospitalizations. The high volume of RPM use also suggests that the parents/caregivers were comfortable using the devices.

As RPM programs are implemented, practices must plan for the increased workload of managing the increased communication with families. Protocols should be implemented to assure that providers and staff can accommodate the increased number of touch points. This high telehealth usage could lead to provider burnout if health care facilities are not

appropriately prepared for increased communication. When incorporating RPM devices into practice, it is very important that health care teams have enough staff and are prepared to manage the overall increased number of touch points compared to non-RPM communication.

The results of this study are important to caregivers, patients, providers, and administration. RPM devices may help to support families and decrease unnecessary emergency room visits and hospitalizations. This study should be replicated with a larger sample size.

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## REMOTE PATIENT MONITORING FROM THE PARENT/CAREGIVER'S PERSPECTIVE

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Caregivers of pediatric patients undergoing palliative care face burdens that can result in negative outcomes for both child and caregiver. Innovative support is needed to alleviate caregiver burden for these parents. We sought to examine the use of remote patient monitoring (RPM) from the parent/caregiver's perspective. We hoped to determine differences between caregiver burden scores among families utilizing an in-home RPM system compared to those families without an in-home RPM system. We used an online survey to assess caregivers' thoughts on the RPM. In addition, we hoped to determine the caregiver's perception of collaboration with the health care provider.

The caregivers received an email link to a short survey regarding the research questions of interest. The participants included seven caregivers from the RPM group and six caregivers from the control group, for a total of 13 responses. Our findings determined the caregiver's mean age was 42 years old and most respondents were female. The caregivers in the RPM group reported little change in their perceived "nervousness or depression" in the past six months, while respondents in the control group reported an increase in nervousness or depression. The caregivers who utilized RPM (83.3%) reported feeling an increase in collaboration with the patient's provider over the last six months, compared to the control group (66.7%) who reported the same amount of collaboration with providers over the same time period. We hope these findings encourage health care providers to utilize RPM as an important part of telehealth care for patients.

The presence of RPM in the home seemed to improve communication. One caregiver reported, "It has been helpful to report symptoms and information to my son's doctor," while another

responded, “I think being able to video conference with the doctor and answering questions helped keep the doctor aware of what was going on.” Concerning the COVID-19 pandemic, one parent commented, “I think if we didn’t have the device then we would have felt the effects more because going to [the hospital] for appointments would have been more difficult, but because we had the device, we still meet with Dr. Mehta once a month for a video conference.”

This research has shown enhanced communication for both caregivers and Dr. Mehta. The findings of this project have given depth to the needs of parents with unique health care needs for their children. The current state of the pandemic has increased provider and patient concerns as we strive to prevent transmission of the virus. The expansion and use of telehealth are increasingly necessary and thus this project may help guide further implementation of RPM for caregivers. In this uniquely burdened population, caregivers deserve all the help they can get.

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## THE VIRTUAL DOCTOR IS IN: E-CONNECTING TO PSYCHOSOCIAL CARE

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The COVID-19 pandemic is “a serious threat to public mental health globally,”<sup>1</sup> leading to adverse impacts in healthy and clinical populations alike. 200+ countries with overwhelmed health care systems lack the resources to respond to this large-scale human disaster and mental health crisis.<sup>1,2</sup> Vulnerable populations such as children with medical conditions are known to experience maladaptive coping; decreased quality of life; and anxiety, depression, and post-traumatic stress.<sup>3-6</sup> The ongoing pandemic has only served to exacerbate underlying mental health symptoms and increase awareness of need for palliative and supportive care in this high-risk group.

Psychosocial standard of care has transitioned from in-person to telehealth delivery to protect the health and safety of patients, families, and providers.<sup>3</sup> This technological health care revolution may have staying power beyond pandemic times with \$250 billion of health care spending projected to be digitally deployed in the United States alone.<sup>7</sup> eHealth is an emerging field in health care which subsumes internet-based interventions, videoconference platforms to connect patients and providers for virtual visits, and smartphone applications. Digital interventions and tools are cost-effective due to reduced personnel and infrastructure requirements and increased access to care for patients and families in remote areas.

eHealth-based supportive care may be particularly well-suited to children, adolescents, and young adults as “digital natives” who were born and grew up during the technological boon of computers, smartphones, and the internet. In fact, the internet serves as a primary communication platform and means of health-related and mental health-related information-seeking for youths.<sup>8</sup> Despite the accelerating pace of eHealth adoption for psychosocial symptom monitoring and treatment, little is known regarding the scientific evidence supporting the technological health care revolution.

Our recent research has focused on the systematic synthesis of the state of the science of digital psychosocial interventions with a particular interest in pediatric patients with medical conditions. Here, we share three key lessons learned and close with our recommendations for clinical practice.

**Lesson #1: An overwhelming majority of mobile health (mHealth) for mental health apps available to consumers are not evidence-based.**

How do you, as a provider, make recommendations to your patients on which apps to use? How do you, as a fellow consumer and smartphone user, make informed choices on which apps to download? Over 50 million people use health-related smartphone apps. Apps promoting mental health, behavioral health, and coping skills are especially popular. Research suggests that patients and providers are interested in incorporating mobile health technologies that are supported by research into clinical practice.<sup>9,10</sup> However, more often than not, we are left making professional recommendations based on unscientific metrics such as brand recognition, word of mouth, media buzz, and “Top 100” lists. With an oversaturated market in which consumers are inundated with seemingly limitless options, you may be left wondering which mental health apps, if any, work.

We answered this question in a recent review of over 1,000 mental health-related smartphone apps available for free public download.<sup>11</sup> Search results for smartphone users are populated based on popularity and proprietary algorithms. Although there is a surfeit of smartphone apps that you and I can readily download on our phones, we found that only a handful have been rigorously tested in research settings. Less than 1% of mainstream consumer apps have published peer-reviewed studies demonstrating improved outcomes resulting from app use. Additionally, less than 1% were designed for individuals with medical conditions and only 4% targeted youths and/or young adults. In summary, an overwhelming majority of mental health app users are *not* receiving evidence-based care.

**Lesson #2: The state of the science on digital self-guided psychosocial interventions for youths with medical conditions is in its nascent stages.**

Do computer-based and smartphone app-based self-help interventions work? Research in the past decade has focused on translating evidence-based treatment content of face-to-face psychosocial interventions for various illness populations into self-guided digital formats. There are certain advantages to such undertakings. Young people are reluctant to seek psychological services due to mental health stigma, are uncomfortable discussing personal problems with clinicians, and prefer the anonymity of self-help.<sup>12</sup> With its appeal for this age group, you may be left wondering whether removing clinician guidance may be a viable alternative to traditional therapeutic approaches.

We answered this question in a review of the literature from 2008 to 2019 on self-guided eHealth and mHealth psychosocial interventions for youths with chronic illnesses.<sup>13</sup> We identified 12 unique interventions developed in six countries (including the United States). The most common therapeutic approach was cognitive-behavioral therapy, which teaches techniques to challenge and reframe negative and unrealistic thought patterns and to identify and change maladaptive behaviors. We found evidence of improvements in psychosocial and physical health outcomes and maintenance of treatment gains over time. Of note, the majority of self-guided interventions still involved some connection with a person (i.e., research staff or

psychosocial clinician) in the form of emails, texts, phone calls, or online message boards. In summary, early evidence suggest that digital self-guided care may be a viable alternative mode of treatment *and* such forms of treatment still benefit from some level of clinician assistance.

### **Lesson #3: Tele-mental health has universal appeal but there is limited evidence of efficacy for children, adolescents, and young adults with medical conditions.**

How does telehealth compare to traditional face-to-face treatments? During the COVID pandemic, telehealth has necessarily displaced in-person psychosocial care. The year 2020 saw a 50 to 175 times increase in the number of patients seen via telehealth.<sup>7</sup> The rapid adoption of telehealth has helped expand access to and ensure continuity of care. With its large-scale implementation in current standard of psychosocial care, you may be left wondering whether virtual visits may serve as a sustainable alternative to in-person care post-COVID.

We answered this question in a review of the literature from 2008 to 2020 on tele-mental health interventions for children, adolescents, and young adults.<sup>14</sup> We identified eight unique tele-mental health interventions developed in three countries (including the United States). Navigating videoconferencing platforms (i.e., Skype, Cisco WebEx, and Zoom) did not present significant technological barriers to attendance or engagement for patients and their parents. Studies showed tele-mental health interventions are feasible, acceptable, and appropriate for pediatric patients and their parents. Findings from early efficacy studies were mixed. Additionally, in a subset of randomized trials utilizing active comparison conditions, there was little evidence of treatment effects across a range of psychosocial outcomes. In summary, pediatric patients and their parents may find tele-mental health to be universally appealing *but* there is limited evidence that they work.

### **Summary and Clinical Practice Implications**

In the digital age, the explosion of technological innovations has resulted in the seamless integration of internet-based devices into our personal and professional lives irrespective of gender, race and ethnicity, and socioeconomic status.<sup>15</sup> Digital health is universally appealing to providers and pediatric patients and their families. We are similarly enthusiastic about the potential to leverage digital health interventions and tools to advance the dissemination and implementation of evidence-based pediatric palliative and supportive care. However, we caution against “putting the cart before the horse.” There is a research-practice chasm such that the accelerating adoption of eHealth, mHealth, and telehealth implementation in clinical practice far exceeds the slow pace of research development and testing.

We close with recommendations for pediatric palliative and supportive care providers on digital health adoption:

Routinely check in with patients and families to assess engagement, usability, and symptom monitoring. What is working? What isn't? You may need to iteratively adapt your approach to individual needs and preferences. Just because an evidence-based strategy has been proven to

be effective when delivered face-to-face does not mean that it will work as well, or at all, when translated to a digital format. Flexibility within fidelity is key.

Forming a human connection matters. Self-guided interventions are popular, but the majority of digital interventions developed for pediatric patients with medical conditions involve some form of contact with a provider. Ask questions. See what mode and frequency of connecting works best for the patient and family, and be responsive to their needs. Is it a regularly scheduled check-in to continue to build a therapeutic alliance and for the patient and family to feel heard? Is it a phone call or text message when they're struggling?

Think ahead to sustainable practices post-COVID. Begin to think about the right balance between digitally deployed and in-person psychosocial care. What are the strengths and weaknesses of virtual care that you have observed for yourself as a provider and from the perspective of your patients over the past year? What lessons learned will you implement now to improve care while telehealth remains the norm? What will you carry forward with you when in-person care returns?

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## USE OF TELEHEALTH FOR PEDIATRIC PALLIATIVE CARE AND COUNSELING DURING COVID-19

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Among the enormous changes our home-based palliative care and counseling teams have adapted to during COVID-19, one that stands out is the significant increase in the use of telehealth. At Coastal Kids Home Care, our palliative care social workers, nurses, and counselors are accustomed to visiting a patient in their home, as often as every day when necessary. Pediatric patients often have compromised immune systems related to their complicated medical conditions. Most also have three or more specialty medical teams serving them, so when the stay-at-home order began, it was imperative that we integrate telehealth visits into each care plan. Social workers identified families' needs and engaged schools and community groups to assist our most indigent or rural families obtain internet access and technology. This new form of connection was essential, not only to stay connected to friends, family, and school, but now with their medical teams.

Palliative care patients living in the most rural areas have seen the greatest benefits from telehealth services. Previously, many families faced obstacles to obtaining internet service or finding a local library or community center that had internet access. The move toward distance learning and a renewed community emphasis on internet access for all children has provided rural families greater connection. Palliative care social workers collaborated with the schools to help families with setup and continued education regarding how to access and use the internet. With collaboration and persistence, all families now have internet and at least one device to perform school tasks, social connection, and access telehealth.

As a result, these families can see their child's pediatric specialists more quickly and without a long drive to a Bay Area hospital by using secure telehealth programs such as Doxy.me or MyChart. Since shelter-in-place began in our counties in March 2020, most of these secure programs have been offered at reduced cost, with increased time limits for appointments, or no cost for basic services. This has made telehealth practices financially manageable for small non-profits and large health care systems alike.

For families who live in one of the four counties we serve, telehealth has also increased the amount of in-home nursing their child may receive. Specialty physicians have increased orders for home nursing to protect immuno-compromised patients from the pandemic dangers of clinics and hospitals. The resulting increase in home visits reflects an understanding that a single nurse, social worker, or therapist in a fragile child's home presents a lower risk of exposure to COVID than then traveling to a clinic.



Coastal Kids' registered nurses and nurse practitioners have been coordinating with pediatric specialty teams from three Bay Area specialty children's hospitals and local clinics to utilize in-home nursing and telehealth, when appropriate, to monitor and address pain and symptoms and perform home-based treatments that can be as simple as a blood draw or may involve chemotherapy infusions that take many hours. Since most of these treatments, and other services like physical and massage therapy, cannot be performed by telehealth, the majority of our visits, and all new patient admissions, still occur in the home. We increase safety by performing some of the follow-up or check-in visits by telehealth. Most specialty physicians have been performing primarily telehealth visits with their own medically fragile patients and, upon request, one of our home care nurses will be present in the home to support the family in understanding complex medical information, continuing treatments that will be supervised by the nurse, or assisting with conversations concerning medical choices.

Many children experience high anxiety when they go to a hospital or clinic, often because they have had hard or scary experiences there. Telehealth allows children to remain in their home, where their anxiety is presumably the lowest, promoting clearer communication regarding things that can be hard to discuss. For example, discussions regarding complicated treatments or life-sustaining measures may feel less intimidating when sitting in your own kitchen.

The lower anxiety level that telehealth allows also lends itself well to mental health services. COVID-19 has created a need for distance learning, social restrictions, elimination of most team sports, and myriad changes for kids. Patients, their siblings, and parents are reporting words and behaviors that express stress, frustration, fear, sadness, and other complex emotions. Hopelessness is present in many homes and communities as parents are unable to go to work or must go to work in unsafe environments. Our social workers, therapists, and expressive therapist have used creativity to connect via telehealth:

- The child life specialist drops off sanitized art and play supplies so she and the patient can do a project together via computer.
- The music therapist assisted a sibling to write a song regarding his feelings. The music therapist recorded the song and sent it to the sibling, who shared it with his family, bringing a greater understanding about what the sibling was going through.
- The bereavement counselor and sibling survivor write a story together on the computer. During the next session the counselor and child read aloud, over the phone, and continued to add to the story of the sibling's life.

In our age of technology, children over the age of ten are so comfortable with the technology that some are more willing to participate in therapy via phone or computer. It is possible they feel more comfortable talking openly in their bedroom than in a counseling office.

Communicating via technology can also reduce feelings of pressure or nervousness that can arise when we are alone in a room with someone new. This is why most of us find it less intimidating to have a hard conversation over the phone than in person.

However, many therapists would consider the reduced intimacy created through virtual means a *limit* of telehealth when used for mental health services. Therapists value the intimacy and trust that forms when meeting in person. Additionally, there are some therapeutic tools that are either more effective or safer when performed in person. Therapists can also observe whole body communication more easily and often when meeting in person. Finally, kids under the age of ten often have a hard time staying focused without the therapist present in the room. This can lead to very short sessions or sessions that include a parent, which negates the important part confidentiality plays in the therapeutic relationship.

Since the beginning of COVID-19 and shelter-in-place regulations, Coastal Kids Home Care's palliative care and counseling teams have made enormous changes in our policies and practices to include a significant increase in telehealth services. From consent forms that can be sent and signed by text message to telephone alerts regarding power outages and other emergencies, our agency is functioning in a much more virtual world. It is possible this shift will last much longer than the current pandemic because of some of the above-mentioned benefits. When it comes to the very special world of palliative care and mental health, including the privilege and responsibility of serving kids who are sick, we can combine the benefits of telehealth while also promoting in-person visits to maintain the quality of care that comes from seeing a patient's facial expression or completing a physical examination. During this unique time, we have discovered that there is space for both in quality medical and mental health care.

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## PEDIATRIC PALLIATIVE CARE MUSIC THERAPY: ADAPTING AND CHANGING PACE DURING COVID-19

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Since March 2020, the landscape of our daily lives as a palliative care community has changed drastically. The work we provide as music therapists is included in this. Pediatric palliative care music therapists typically work at the bedside with patients, providing music to comfort, soothe, grieve, and preserve legacy. This work can be beautiful and challenging, holding space for families to process and grieve through the music, providing opportunities for children to express themselves in songwriting or improvisation, assisting with pain management and anxiety reduction through responsive bedside playing, or even providing support during a death. The music therapist's role in pediatric palliative care is integral to the team and valued by all who have a chance to experience it.

When COVID-19 shutdowns began happening, many music therapists found themselves in the position of being considered "non-essential," with services furloughed or even terminated. As time went on, the impact of increased isolation on the patient and family's emotional wellbeing became clear, and many music therapists were brought back onto their teams and transitioned to telehealth work or resumed services with enhanced precautions. While not all music therapists saw an interruption or termination of their services, all have since had to adapt to the changing needs and challenges we are currently facing. Many music therapists even started conducting sessions outside of patients' windows at the beginning of the pandemic, and we saw how adaptable and creative music therapists were, rising to meet the challenge of continuing to provide a crucial service for patients and families during a global pandemic.

During this time, clinicians have had to alter their approach in providing services to children and families in hospice and palliative care. Music therapists, who function on the dual interaction with their clients, have had to adapt and change their practices to function in a pandemic world. The adaptations include operating through telehealth platforms, finding access into facilities, increasing infection control standards, and keeping up to date on literature referring

to the emotional and psychological trauma being seen in children due to isolation, inconsistency, fear, and change. Telehealth holds both advantages and disadvantages during this time, especially in relation to the work being done by music therapists in pediatric palliative and hospice care.

### **Challenges in Music Therapy via Telehealth**

Many professionals, music therapists included, were thrown into providing their services virtually very quickly when the pandemic began in March 2020. All of a sudden, professionals and their patients were needing to learn the limitations and possibilities of the technology in real time. The challenges, for many, were overwhelming and presented themselves in nearly every interaction with patients, families, and colleagues.

#### ***Therapeutic presence***

The challenges of music therapy telehealth work can feel overwhelming for a clinician trying to transition to an online platform from providing in-person services. Connecting with a patient and their family and offering a safe, grounded therapeutic presence proves difficult behind a screen. Allowing for silence in a session might feel uncomfortable or be quickly attributed to technology issues rather than a place for pause and reflection when in-person. The therapeutic presence offered by clinicians also feeds off of energy, which is limited if not void through a computer or tablet screen.

#### ***Music engagement***

Music therapists almost always utilize singing in sessions, and singing has now been deemed a “super-spreading” activity, due to the high rate that respiratory aerosols are generated during singing, despite research that has been published indicating this is inaccurate. Because of this, many music therapists providing in-person sessions are limiting how much they are singing. Music therapists are also facing restrictions with what can or cannot be brought into a home or room and are having to limit the instruments used in sessions. Limiting both singing and instruments in a music therapy session may lead to the work being less effective, and the therapist may feel frustrated with these limitations decreasing the quality and efficacy of the work they are able to provide. With children, the limited capacity to engage with a wide variety of tools has resulted in less efficacy in engagement.

#### ***Observing physiological responses***

A pediatric palliative care music therapist is always paying close attention to the physiological effects of the music on the patient, closely watching for changes in breathing, muscle relaxation, and facial affect, among other things. Observing these elements through a screen can be challenging, and is reliant on another person providing adequate positioning of the device. Even if a device is placed properly, often these physiological changes can be very tricky to observe through a video feed, and clarity is dependent on the speed of the internet connection. Music therapy is the most effective when the music can be altered in response to the visual changes seen.

### ***Audio lag***

The work of active music making through online platforms poses many challenges during the current world of telehealth. There is often a lag in the audio feed, which makes making live music with a patient very difficult. The therapist often has to adjust and anticipate this lag while playing and/or singing. Internet speed factors into the severity of the lag. Even something as simple as accompanying a patient while they sing is difficult when faced with an audio lag and can be frustrating for both patient and therapist. The connection, support, and community created through active music making has been stunted as a result.

### ***Assisting patients***

Many children who receive palliative care might need extra assistance to participate in an online music therapy session. Their attention span might be short in regards to attending to a screen vs. an in-person music therapist. Parents or caregivers might not always be available to provide this support, as many families are juggling their own work while assisting with school, therapies, etc. Caregivers or family members may not feel confident in their ability to manage technology. Although home health personnel may be involved, their involvement is not guaranteed and should not be expected as they often have their own protocols and boundaries to follow within their organization. Additionally, the limited training home health care workers receive in child-based therapy and behavior can make it difficult for them to engage in an appropriate and assistive manner. Any crucial or necessary hand-over-hand assistance may not be able to be provided.

Often, children in palliative care and hospice programs will have additional developmental, physical, and cognitive impairments that impact their ability to interact and engage in a one-on-one setting within the community or hospital. With telehealth, this provides a more apparent barrier in the therapeutic process as individuals with higher needs aren't able to be redirected as efficiently or effectively. There may also be heightened confusion or fear. Because of these reasons, many pediatric patients receiving palliative care might not be good candidates to receive music therapy services virtually.

### ***Strain, stress, and fatigue***

Providing services via telehealth often requires that someone else be present to set up the technology session and assist the patient in accessing the session. This puts a strain on other team members and asks of them to do more beyond their typical job duties. This additional strain can also be difficult for the music therapist to reconcile, knowing that their team members who must be present in-person with patients are already overwhelmed, stressed, and under a great deal of pressure. Other services that may have transitioned to telehealth such as social work or chaplaincy may also be vying for screen time access with patients when an RN or aide is present to assist with setting up the technology, and this places additional strain on staff who feel they must justify their work and compete for time.

### ***Internet accessibility***

With many children now doing online school, we are seeing that many are overwhelmed with screen time and have "Zoom fatigue," as almost all of their teachers and providers are online.

Access to the internet is also a privilege, and not all households have devices or internet connection. Many families might previously have used libraries to access the internet, however, most such places have now closed due to the pandemic. With many services transitioning to online, the inequity of internet access has been brought to light and is something music therapists must consider when moving into telehealth.

### **Benefits of Music Therapy via Telehealth**

Although the challenges have been apparent in utilizing virtual and telehealth platforms, there is still a sense of gratitude that the option even exists for connecting with patients and families. Telehealth has been a viable option for music therapists and other clinicians because there are quantifiable benefits to the use of video/audio integration and interaction. First and foremost, telehealth provides the option for services to be offered rather than putting them on hold or discontinuing services altogether. There is a sense of safety for both parties, and there can be additional benefits to the now on-the-job training many clinicians have received to be utilized once the pandemic has resolved.

#### ***Safety***

The most obvious benefit of providing services via telehealth is preserving the safety of both client and therapist. Limiting in-person exposure reduces risk for all involved. As pediatric palliative care patients are often immunocompromised, limiting exposure could save lives. In addition, patients who are COVID-19 positive, those in quarantine or self-isolation do not have to experience an interruption of services. Without instruments being shared in a session, the possibility of spreading the virus on surfaces is eliminated, and it also allows music therapists to protect their instruments from repeated cleaning with harsh chemicals.

#### ***Access to services***

With more providers using telehealth as an option, we are seeing that more people have access to services that they otherwise would not. This is a positive outcome for families who live in more rural areas, or even those living in states without many music therapy practitioners who otherwise would need to travel very far for their child to receive services. Telehealth has also allowed pediatric families to remain engaged with clinicians from their preferred pediatric hospital or connected to their home hospice/palliative care team.

#### ***Comfort in the home environment***

Receiving services in the comfort of their own home can be more effective for some children. With enhanced PPE required for all people providing in-person care, it is important to note that service providers who are virtual may be the only people that a child is able to see without a mask on. With more parents and caregivers working from home, this also provides more of an opportunity for them to see their child engage in music therapy.

### **Additional Considerations**

Despite all these challenges, music therapists have proven to be creative and resourceful throughout this pandemic, providing services in less-than-ideal situations, outside a patient's window while over the phone with them, or with enhanced PPE measures in place, such as group members spread out very far from one another, or very far away from the patient if at bedside, justifying the sacrifice of intimacy for the overall experience, as well as adapting to technology and virtual services.

### **Tips for music therapists during COVID-19**

1. Find new ways to use technology—think outside the box! Reach out to other music therapists doing this work and get ideas from one another.
2. Get creative with interventions. Can't use instruments or sing? Take the opportunity to try out new ideas, like a guided relaxation to recorded music, or electronic beat creation.
3. Make sure you are using a platform that allows for audio sharing from your device (such as Zoom) so you can utilize recorded music with better sound quality.
4. When providing services via telehealth and a staff member or family member is present, don't be afraid to ask how the patient is breathing, if they seem relaxed, etc. Through your questions, you can advocate for yourself, and make sure all parties know you are not just entertaining.
5. Keep in mind that it's okay to make mistakes, and it's okay to be learning as you go! This pandemic is new to everyone; we have to be gentle with ourselves.
6. Migraines or eye fatigue from excessive screen time providing telehealth work? Try blue light filtering glasses, or a computer screen protector that filters blue light. Make sure you are taking the time to set up your workspace to be comfortable for you, with ergonomic considerations. Sitting in front of a screen is not something we are used to doing as music therapists, so listen to what your body needs.
7. Having a mic and a battery-powered amp can help if providing distanced services in-person or outside. It can sometimes be hard to hear when you are far away, and this can help prevent vocal fatigue as well.
8. Working from home shouldn't mean you never stop working! Give yourself a start and end time to your day. If you can, schedule things in manageable chunks or assert this need to your management. Make sure you are taking adequate breaks, eating, hydrating, and resting.
9. Provide family members with ideas of ways they can use music to support their child outside of music therapy.
10. Make sure you are prioritizing your self-care. This is essential. Check out this link for more considerations and ideas to keep your head above water.  
<https://www.selfcareinstitute.com/self-care-support/covid-19/>
- 11. Remember that the need to connect through music is stronger than ever right now, and even if situations are not ideal, you are making a difference.**

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## VIRTUAL GRIEF SUPPORT GROUPS IN THE ERA OF COVID-19

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Amidst too many COVID-19 casualties, we have discovered several “pandemic positives” as our pediatric palliative care team continues to care for seriously ill children and their families during the pandemic. Although COVID has fundamentally changed the way we deliver care, it has also inspired us to creatively utilize technology and virtual platforms to reach our patients. Apart from providing an extra layer of support to children and families coping with life-limiting illnesses, a core aspect of our team lies in the unique ability to provide bereavement support to families after their child’s death. Our pediatric palliative care social worker and bereavement coordinator, Gina Kornfeind, created and facilitated online virtual grief support groups, which have been truly transformative in terms of how our team delivers clinical services to our bereaved families.

Support groups enable parents and caregivers to express their deepest and most raw feelings and thoughts about the unthinkable and “unbearable loss” (Dr. Joanne Cacciatore) — that of the death of their child. In a society that remains early in its evolution to become “grief-literate,” we know that across cultures people need the support of others to grieve with them. Hugs, finding healthy role models and mentors who might be further along in their grief, and having a reason to get up out of bed or out of the home are what coming to our grief support groups can provide.

As a clinician who has a passion for walking alongside grieving families who have experienced the death of a child, Gina has always considered it a privilege to provide in-person family grief support groups twice monthly for the past nine years at UCLA. Trained by the experts at The Dougy Center and equipped with her experience at Heartlight (affiliated with Children’s Memorial Hospital in Chicago, now Lurie Children’s), she ensured that our twice-monthly support groups were filled with love and healing. This model provided a space where we came together at a local church to begin with dinner as a group (to help the new family constellation), which was followed by breaking into two concurrent support groups: one for parents and the



other for grieving siblings (ages infant and up). After meeting for 1 hour and 20 minutes, we came back together for a “Closing Circle,” which included a poem, a “love squeeze” of passing the squeezing of hands, and many hugs that continued well into the night and into the parking lot while staff cleaned up inside. The in-person support groups truly sustained our grieving parents and siblings who often attended group for 4-5 years on average.

When the COVID-19 pandemic emerged, we found that our grieving parents lost their vital community support, especially if they were not able to have a public funeral or memorial for their child. Many described this as “soul sickening.” The word “bereavement” is derived from an Old English word that means “rob,” “deprive,” and “seize.” Our grieving parents shared this sentiment and further expressed a feeling of being doubly robbed after experiencing the most unimaginable loss of their child and then losing the in-person support group as well. This was further exacerbated by the pandemic, which led to additional isolation and grieving alone. The question for us quickly became: What can we do as a Pediatric Palliative Care Program to care for our bereaved families during this time? Although the pandemic forced us to cancel all in-person support groups at the end of March 2020, we found alternate ways to help support our pediatric parents with their grief process.

Just as we have adjusted and adapted to new funeral and memorial rituals, finding virtual ways to come together to provide grief support needed our utmost creativity and flexibility. We realized that we could still offer our emotional presence and reliability. Using virtual platforms such as Zoom with the assistance of our UCLA IT department, our Comforting Hearts Family Bereavement Group transformed and launched our first virtual grief support group on April 6, 2020! We “meet” virtually every other Monday and also provide a monthly virtual Sibling Support Group called “The Den,” which has a similar format although different content and themed activities. The siblings love it and are having fun with their space and sharing quite a bit.

Making the switch to a virtual format for the group was fairly easy. Here are the steps we engaged in to provide this important virtual service:

1. The Bereavement Coordinator sends an email to the current list of families on the Wednesday before the Monday evening group, which included the Zoom invitation link (our hospital asks us to enable a passcode and waiting room feature for HIPPA compliance), a few support articles from other organizations, the upcoming month’s birthdays and death anniversaries, and an invitation to share an item or photo of their child with personal significance—which varied each time.
2. Creation of the agenda for the group leaders (printed out in hard copy to have during the group). Agenda items include:
  - Opening Poem/Quote—sets the tone
  - Welcome and Introductions of any new parents/families
  - Review guidelines/agreements including confidentiality, muting yourselves when not talking, maintaining a non-judgmental space, and being mindful of giving group members adequate time to share

- Acknowledgment of significant days (i.e., recognition of birthdays of living members and birthdays and anniversaries of children who died)
  - Check-in with group members, followed by discussion of a predetermined theme from an existing list. These topics include:
    - **“What is a quality or qualities that your child had that you want to carry with you as you go through life?”**
    - **“Where do you go to cry? What is your crying room or space like?”**
    - **“How do you handle the return to school and meeting people who don’t know your story or narrative?”**
    - **“Who or what has been most supportive to you and in what way were they or was it helpful?”**
    - Often, we start with **“What do you bring to group tonight...what is on your mind and heart?”**
3. We send out another email reminder on the morning of the group. Grieving parents appreciate reminders on the day of group.
  4. We dress in professional clothes even at home to present ourselves in a professional manner. This also serves as a way for us to maintain professional/personal boundaries that allow us to leave our professional selves at the “virtual office.” As the primary facilitator, Gina sets up her desk 30 minutes before group and lights a votive candle placed next to a ceramic cherub near her computer. She also has a bulletin board of memorial photographs of the children present during our in-person groups. She ensures that this board is within the camera frame so members can see this as part of our virtual group. This helps to create a sacred space and a sense of continuity transitioning from the in-person group to our virtual group. She keeps a notebook, pen, cough drops, and water next to her as well.
  5. Group facilitators log on to Zoom 10 minutes early in order to make sure that the internet connection is stable.
  6. At 7:00 pm, we admit people from the waiting room to join the group and make sure they mute themselves. We ask participants to keep their cameras on, if possible. We usually wait about 5-7 minutes for parents to join. At times, parents join mid group if they were putting younger children to bed. We welcome them any time during the group which can be anywhere from 1.5-2 hours in duration. We monitor time allowed for each parent to share and check in with each parent aloud, also respecting those who prefer to listen and observe.
  7. With 10 minutes left, we begin to close the meeting and Gina summarizes themes and strategies, and highlights strengths shared. We always close with a poem or quote that focuses on hope and something they can do to help themselves.
  8. We end the meeting and co-facilitators often debrief via phone afterwards when time and energy allow. Screen fatigue is all too real and sometimes we are totally exhausted after the group and do not debrief.

The shift from in-person to virtual support groups initially created a great deal of stress, including profusely sweating due to unexpected technological snafus. Despite these challenges, there have been many “pandemic positives” about this new format. These include:

- Improving accessibility of the group to families who live over an hour away (especially in Los Angeles traffic), which previously presented a potential barrier to attending the group.
- Parents do not need to get babysitters in order to attend.
- Groups help with isolation from both grief and the pandemic.
- Some parents appear more comfortable talking and sharing from their own homes.
- Parents seem less inhibited on Zoom and perhaps from behind a screen.
- Parents are easily able to access photos and memorabilia of their child from their home, including sharing their room or sacred area with pride.
- For the clinician/group facilitator, the setup is much easier compared to a 2- to 3-hour set-up of a church or space with many rooms and dining area for many families. We can focus all of our energies on the actual clinical work of the group. Often, the quality of the interaction is improved as leaders have more energy to facilitate the group.

There are certainly challenges in providing virtual grief support groups. In our experience, we do not like group members using the chat box feature on Zoom and try not to use it. It potentially increases stress and can be distracting. The potential for group members to write things privately to leaders or to one another during the group is detrimental to the openness and transparency in this vulnerable space. Another issue lies within the critical notion of boundaries. Doing these intense and emotionally heavy groups from our home offices is challenging as we do not have a “commute” home during which to decompress. Facilitators attempt to debrief with one another, but everyone is usually tired and screen fatigued. One of the toughest challenges of virtual support groups is the inability to hug one another and provide human touch for connection and healing. The yearning and craving for physical connection are strong and the inability to have this connection within the virtual group can be heartbreaking and frustrating.

The feedback from parents and families has been overwhelmingly positive. They express immense gratitude, have asked to have group every other week, and share that it feels really good to be together even in a completely different modality. The pandemic has brought much isolation, fear, and anxiety in that many of their coping mechanisms have been lost or altered. They share that having this virtual group is their lifeline, is something they look forward to, and is a place where they are reminded that they are not alone. They have been able to join from the car, from being out of town, and even from a different time zone. Parents have been able to share important emotions as they cry, laugh, and share anger. We have learned to hug ourselves on the screen when we want to hug someone in the group virtually and they share that they “feel” it.

It has been quite remarkable to witness the strength and flexibility of these grieving families. Having been together virtually for over nine months, it feels to them and to us like this is our new norm within their new norm. We are contemplating continuing the virtual format when we return to an in-person group. This would allow more people to continue to participate and allow for greater flexibility in serving this population.

Together, we are all bearing more loss in new ways, and what better and most inspiring people to be with to venture into new and brave spaces for healing! Their children we remember would be so proud.

In closing, we offer this poem that we often read during our virtual grief support groups to center us:

### **HOPE IS NOT CANCELLED**

**“Hope is not cancelled  
Love is not cancelled  
Coping is not cancelled  
Growth is not cancelled  
Integrity is not cancelled  
Learning is not cancelled  
Gratitude is not cancelled  
Kindness is not cancelled  
Laughter is not cancelled  
Connection is not cancelled.”**

**-###-**

## A TRANSFORMATIVE NEW CARE MODEL “BRIDGE” TO THE FUTURE FOR PEDIATRIC PALLIATIVE CARE AT HOME: WHAT’S POSSIBLE

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### **We know the statistics:**

- The U.S. Department of Health and Human Services estimates that 23% of US households have a child with one or more chronic health conditions.<sup>1</sup>
- As advances are made in pediatric medical/surgical care, the number of children living with life-threatening conditions is increasing.<sup>2</sup>
- And children with chronic medical conditions and complex health needs are living longer.<sup>3</sup>

### **We know the trends:**

- Children with chronic health conditions account for a disproportionate number of in-patient days and hospital charges relative to the incidence of these children.<sup>3</sup>
- There is already a nursing shortage in the United States, with this shortage projected to intensify as aging Boomers tax the health care system with their health care needs.<sup>4</sup> There are/will not be not enough nurses available to care for these children in health systems or at home.
- More complex care is increasingly being pushed out to the home, in part due to technology and payer/reimbursement structures.

### **Lastly, we know what families want:<sup>5</sup>**

- Wishes honored
- Inclusion in the decision-making process
- Support and help at home
- Transportation, medications, equipment
- Access 24 hours/day, 7 days/week
- Honest information
- To be listened to... and more

**So the “BIG Question” is, “What do we do about it?”** How do we get out in front of this crisis in caring for our children with chronic medical conditions at home to a “better place” that can address the trajectory of where all this is going? How do we put the family’s needs first and deliver the standard of patient- and family-centered care we all aspire to be able to provide?

While there is no one silver bullet, there are some paths that start to get us there.

One such path is that we need to find the right balance of “high touch AND high tech.” That is, we need a system which leverages today’s exploding technological service delivery mechanisms in concert with real people who can deliver the kind of at-home monitoring and guidance required to ensure these children with medically complex conditions stay safe and well-looked after while at home. (And maybe that can provide some respite and peace of mind for Mom, Dad, and the rest of the family, too.)

As fear of COVID exposure kept adult and pediatric patients away from overcrowded health systems and care for pediatric patients with complex medical conditions shifted more to at-home care, telehealth or virtual models of health care began to fill the void of these no in-person pediatric patient visits. A health care provider could connect with the child’s parent(s) and do a check-in via self-report from the parent(s) while maybe looking at the child through a smartphone or tablet, and it worked. There is no question that in the absence of anything else, telehealth was, and continues to be, a necessary “stop gap” measure as long as COVID is present. But, should it be our final vision for how ongoing, continuous, virtual, relational care and monitoring could be delivered to our pediatric patients? Is it enough? Should we be wanting, and thinking about, how to do more with the available technological tools?

The answer is yes, and our neighbors in Canada may have an answer.

Although Canada has a different health system than we do in the U.S., the country’s needs for caring for and monitoring its pediatric palliative care patients, many of whom are on medical interventions like trachs and vents, is the same. Canada also faces similar struggles with respect to nursing staff shortages in their health system, lack of qualified in-home caregivers for pediatric patients, poor coverage in rural areas when children go home from the hospital, and more children with medically complex conditions than health systems can often adequately care for. All of this forces the inevitable, which is more of this acute care for and monitoring of these kids needing to now be delivered at home. And while in the end, home is often the best place for these children to be, it only works well with *adequate* supports. So what is Canada doing that we can learn from?



Medically-  
Complex  
pediatric care

In the Ontario Province of Canada in 2010, a new model of care was trialed by the Ontario Ministry of Health with pediatric patients, with the aim of replacing and/or reducing the length of hospital stays for medically fragile and/or mechanically dependent children. This new, disruptive model was built on the concept of an enhanced “share care” model among families and the health system. Utilizing a comprehensive technology platform called eShift™<sup>6</sup>, this new model leveraged the knowledge and skills of the health care providers (i.e., a team of nurses, primary/specialized medicine physicians, health care aides, etc.) to facilitate improved access to care for families at home. This technology platform enabled a delivery format which could then link medical providers in a health system or community clinic to clinicians, technicians, and nursing assistants who were in

the home with the child, resulting in a new way to deliver “real time” patient- and family-oriented care to more children, more efficiently and at a lower cost.

**So how did the model work?**

- A family would be referred to the program by a nurse or medical provider, often while the child was hospitalized. The child’s care team then evaluated the child to determine their fit for the program.
- Once the child was transitioned home, a pediatric nurse from the health system called the family to welcome them to the program and to schedule their first visit, often for the next day.
- The next day a specially trained pediatric technician (e.g., nurse’s aide in the US) well-versed in the use of the technology platform would then arrive at the house to begin their shift at home with the child and family. (Note: When first trialed, this program was set up to provide respite for these families, so the technicians really were reporting for multi-hour overnight shifts with the child.)
- The technician would log onto the platform with a smartphone to let the directing pediatric nurse remotely overseeing the shift know he/she was there. Now digitally connected, the pediatric nurse specialist would then oversee the child’s/family’s care, working with the technician/aide to do so. Under the direction of the nurse specialist, the technician would then follow the recommendations and tasks assigned for the child’s care and collect all necessary observations and critical report data (see below) as prompted by the platform on his/her smartphone, while following the care plan created by the child’s care team.

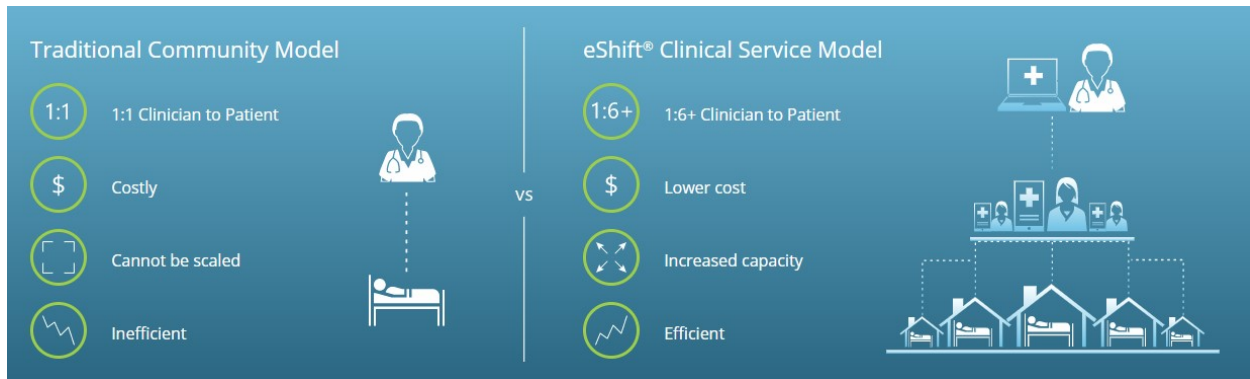
<u><b>OBSERVATIONS</b></u>	<u><b>CRITICAL REPORTING</b></u>
<p>The observations would include checklists customized for the child, and his/her specific medical condition(s)/health issues. These checklists were pre-programmed and could then be accessed with the tech’s smartphone and included things like being prompted for:</p>	<p>The in-home technician would also check for (again, as appropriate/relevant for the child) the following:</p>
<ul style="list-style-type: none"> <li>✓ Vital signs</li> <li>✓ Comfort care</li> <li>✓ Respiratory</li> <li>✓ Gastrointestinal</li> <li>✓ Cardiovascular</li> <li>✓ Neurology</li> <li>✓ EENT</li> <li>✓ G-Tube Medical Administration</li> <li>✓ Care Indicators</li> <li>✓ Complex Care Kardex...among others</li> </ul>	<ul style="list-style-type: none"> <li>✓ The child’s pain level</li> <li>✓ Any critical events, e.g.:               <ul style="list-style-type: none"> <li>❖ Equipment issues</li> <li>❖ Adverse events</li> <li>❖ Symptom escalation</li> <li>❖ Exacerbations</li> </ul> </li> <li>✓ Palliative Care Kardex Updates</li> <li>✓ Skin Integrity/Wound Care</li> <li>✓ Seizure activity, etc.</li> </ul>

- This shift data collected during the home visits was then sent in “real time” to the nurse specialist. In addition to the clinical data entered into the platform via smartphone, these reports also included self-reported data collected from the family caregivers on their burden or stress levels. Because the data was sent in “real time,” the nurse specialist (or care team if monitoring or alerted to any issues) could then facilitate responsive health care action to address what was happening with the child and/or family in the home as it was happening. This data was also regularly reviewed and evaluated by the child’s whole care team (who also had access to the platform); adjustments and modifications would then be programmed into the child’s chart for future technician visits.
- It should be noted that the directing nurse specialist, who worked remotely from the technician in the home, had a dashboard that she could access from her laptop that enabled her to receive communications and reports from multiple technicians in-home with children at the same time. It also provided a communication network upward to the child’s physician, clinical case manager, etc., enabling a cascading care direction downward from the highest level of clinical decision-making through the child’s entire circle of care, including the in-home caregivers.

This model was a departure from a traditional community-based model of care in Canada in several ways:

- It was run by a nurse clinician (e.g., nurse practitioner) experienced in pediatrics who then oversaw, directed, and delegated key care responsibilities to technicians and nurse assistants/aides specially trained in skills for working with, observing, and reporting out on various aspects of the pediatric patient’s care, and in how to use the e-platform.
- It increased the capacity of the number of medically complex children who could be overseen and continuously monitored at home from a ratio of 1:1 to 1:6.
- It helped to start to address the problem of nurse shortages by delegating the in-home check-ins, observations, and reporting to a safe and lower level of professional training (i.e., nurse’s aides) with a safety net of a real time, live feedback loop from the technician at-home with the patient back to the directing nurse specialist. (Note: Research on this model of “shared care” with an adult population has shown that the technicians/aides (also a scarce human resource) felt like a valued and important member of the care team, enhancing workplace retention of these employees.)
- It was not episodic or time-limited. That is, this in-home monitoring and care system was not just put in place when “something happened,” but instead, was a continuous support and reporting in-home safety system for the child, and the parent, for as long as it was needed.





This Ontario trial with medically fragile and mechanically dependent children utilizing this comprehensive technology platform, in concert with directing nurse specialists remotely overseeing the child’s care/monitoring and in-person trained technicians in-home with the child, resulted in many successful outcomes including:

- Being able to provide ongoing virtual care and clinical oversight to help ensure the child’s safety.
- Creating access for parents/families to trusted and evidence-informed health information in the care of their child while at-home.
- Allowing opportunities for families to ask questions about their child’s care and get timely/immediate responses from trusted pediatric sources.
- Increasing capacity for the number of children who could be cared for and monitored at one time.
- Facilitating real-time data collection on what was happening with the child at-home as it was happening.
- Reducing hospital readmissions as it could help identify signs of change in the child’s condition and course-correct under the direction of the nurse specialist before it became a health issue requiring hospitalization.
- Cost savings (i.e., avoiding unnecessary hospitalizations or the use of expensive registered nurses in the home).
- More coordinated care throughout the child’s entire care team (all who all had access to the in-home observations/reports via the e-platform).
- Sleep and rest for weary parents (if utilized for overnight respite) knowing there was a skilled technician monitoring their child who was virtually supported by a nurse specialist (like a nurse practitioner) if anything were to happen.

This model, now fully operational, has provided this type of care and monitoring through this eShift™ e-platform with no adverse events for 11 years. And as the program has grown in Canada, the Ontario Health System has also come to realize the additional capabilities this new system offers for extending specialized pediatric nursing care into rural areas, as well as into respite day shifts with the onset of COVID. The e-platform is also being used now in the adult areas of palliative/end-of-life-care, chronic disease management, and rehabilitation programs.

This is all done while ultimately providing an improved patient experience for its pediatric patients (and their families), as well as their adult patients. And while it may not be the “end all, be all” in pediatric palliative at-home care, it takes current telehealth medicine as we know it now into a new, more comprehensive realm of care, monitoring, and communication. That is, to a service delivery model that truly becomes an extension of the health system or community clinic caring for these medically complex kids when they return home — a sort of virtual and relational hospital unit at-home — through the use of an advanced technology platform encompassing the entire circle of care around the child and his/her family.

And who knows, maybe down the road, as regulations potentially relax and change with the ongoing growth of telehealth and related care technologies in the U.S., maybe “Dr. Mom” could even replace the technician or nurse’s aide, utilizing technological tools like eShift™ to directly be connected to a pediatric nurse practitioner or other medical providers remotely looking at and receiving the data being sent real time to them about their child from her at home with her medically complex child. We know “there’s no place like home,” so let’s start thinking outside the box of “what’s possible” in harnessing all the new technological innovations being developed to help better care for the medically complex children in our care when they go home, and while they are at home, for as long as they can safely and adequately stay there.

#### References:

- <sup>1</sup>US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2009-2010*. Rockville, Maryland: US Department of Health and Human Services.
- <sup>2</sup>Berry JB, et al. Inpatient growth and resource use in 28 children’s hospitals: A longitudinal, multi-institutional study. *JAMA Pediatrics* 2013 eb; 167 (2): 170-7.
- <sup>3</sup>National Hospice and Palliative Care Organization. ChiPPs White Paper: A call for change: Recommendations to improve the care of children living with life-threatening conditions. October 2001.
- <sup>4</sup>American Association of Colleges of Nursing. Fact sheet: Nursing shortage. Retrieved: <https://www.aacnnursing.org/Portals/42/News/Factsheets/Nursing-Shortage-Factsheet.pdf>.
- <sup>5</sup>Tolle SW, Rosenfeld AG, Tilden VP, Park Y. Oregon’s low in-hospital death rates: What determines where people die and satisfaction with decisions on place of death? *Ann Intern Med*. 1999 Apr 20;130(8):681-5. doi: 10.7326/0003-4819-130-8-199904200-00015. PMID: 10215565.
- <sup>6</sup>Sensory Technologies. Retrieved: <https://www.eshiftcare.com/en-ca>.

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## ITEMS OF INTEREST

In each issue of our Pediatric E-journal, we offer additional items of interest.

### 1. NHPCO Palliative Care Online Resources:

NHPCO has a variety of pediatric hospice and palliative care resources available at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics). Also, more palliative care resources are available at [www.nhpc.org/palliativecare](http://www.nhpc.org/palliativecare), including:

- Community–Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus, more for NHPCO members

### Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. **Join NHPCO Today!**

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

### 2. Pediatric Hospice and Palliative Care Resources:

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. [www.caringinfo.org](http://www.caringinfo.org)
  - *When Your Child is in Pain*
  - *Talking with Your Child About His or Her Illness*
  - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
  - *When a Child Dies: A Guide for Family and Friends*
  - *Helping Children Cope with the Loss of a Loved One*
- **NHPCO's Palliative Care Resource Series** includes pediatric palliative resources like:
  - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
  - *Consideration for Complex Pediatric Palliative Care Discharges*
  - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*
  - *Nonpharmacological Pain Management for Children*
  - *Sibling Grief*
  - *Pediatric Pain Management Strategies*

- *Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations*

### 3. Trends in Pediatric Palliative Care Research

Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit [their blog](#), [browse in their library](#), or join the [Zotero group](#). [View the New Citation List in their library](#).

### 4. Pediatric Hospice and Palliative Care Training:

- [Upcoming Webinars](#) provided by the Pediatric Care Coalition:
  - June 22: Including and Supporting Siblings in Non-traditional, Multicultural Families
  - July 20: Pediatric Concurrent Care: Research Updates
  - August 17: Increasing Sensitivity in Clinical Practice with the Transgender Population

### 5. Telemedicine Resources from Family Voices

Family Voices offered a Telehealth Academy in the Fall of 2020 as part of a CARES-Act-Telehealth for Family Engagement Grant. Available resources include:

- [Telehealth Academy](#)
- [Telehealth Curriculum](#)
- [Family-Centered Telehealth](#)
- [Planning for a Successful Telehealth Visit](#)
- [Preparing for a Successful Telehealth Visit worksheet](#)

### 6. Promoting Telehealth

The [American Academy of Pediatrics website on telehealth](#) features videos, graphics, and articles that can be used for promoting telehealth offerings in a user-friendly way for children, adolescents, and families.

### 7. Pediatric Resource on Medication Coverage:

In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled [Determination of Hospice Medication Coverage in CHILDREN](#).

### 8. Subjects and Contributors for Future Issues of This E-Journal

We are currently discussing topics such as disparities and inequities in relation to pediatric palliative and hospice care, and glimmers of hope for our next two issues in 2021. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at [christytork@gmail.com](mailto:christytork@gmail.com) or Suzanne Toce at [tocess@gmail.com](mailto:tocess@gmail.com).

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