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## Use of Telehealth in Home-based End-of-Life Care for Children in Rural Regions

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**USE OF TELEHEALTH IN HOME-BASED END-OF-LIFE CARE  
FOR CHILDREN IN RURAL REGIONS**

by

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A DISSERTATION

Presented to the Faculty of  
The University of Nebraska Graduate College  
in Partial Fulfillment of the Requirements  
for the Degree of Doctor of Philosophy

Medical Sciences Interdepartmental Area Graduate Program  
Graduate Program  
(Pediatrics)

Under the Supervision of Alfred L. Fisher, MD, PhD

University of Nebraska Medical Center  
Omaha, Nebraska

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This doctoral work is dedicated to Bravery Weaver.

## **ABSTRACT**

### **USE OF TELEHEALTH IN HOME-BASED END-OF-LIFE CARE FOR CHILDREN IN RURAL REGIONS**

Meaghann S. Weaver, MD, MPH, PhD  
University of Nebraska, 2021

Supervisor: Alfred L. Fisher, MD, PhD

A national shortage in pediatric-trained providers results in certain geographies, primarily rural, where children with special needs are not able to access home-based care at their end-of-life. Advances in technology have made the use of telemedicine a potential modality for palliative care subspecialty clinicians to provide clinical care and support for adult-trained hospice teams. This dissertation utilizes four approaches to consider telehealth as an unexplored opportunity in care delivery: (1) a systematic review of telehealth measures and instruments to select the Technology Acceptance Model as a validated metric of telehealth acceptance uniquely now applied to pediatric care; (b) a pilot study to assess telehealth acceptance from the perspective of dying children, family caregivers, and rural hospice nurses using the Technology Acceptance Model; (c) a qualitative exploration of rural hospice nurse perspectives on the quality of telehealth in end-of-life care for children due to the relatively lower acceptance ratings of telehealth by hospice nurses as compared to children and family caregivers; (d) a longitudinal assessment of the impact of a telehealth on pediatric physical and emotional symptoms, family impact, and location of end of life for children with cancer receiving end-of-life care in rural home settings. Care inclusion of pediatric palliative medicine specialist teams using telehealth modalities has potential to foster support for rural hospice teams, family caregivers, and children reaching end of life in a rural home setting.

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## **LIST OF ABBREVIATIONS**

COREQ - Consolidated criteria for reporting qualitative research

CSUQ - Computer System Usability Questionnaire

FIM - Family Impact Module

IRB – Institutional Review Board

PACT - Patient Assessment of Communication During Telemedicine

PEPPI-5 - Perceived Efficacy in Patient-Physician Interactions

PEQ - Patient Experience Questionnaire

PPC – Pediatric Palliative Care

PRISMA -Preferred Reporting Items for Systematic Reviews and Meta-Analyses

QOL – Quality of Life

MSAS - Memorial Symptom Assessment Scale

SUS - System Usability Scale

TAM - Technology Acceptance Model

TISQ - Telenursing Interaction and Satisfaction Questionnaire

TMPQ - Telemedicine Perception Questionnaire

TeSS - Telehealth Satisfaction Scale

TSQ - Telemedicine Satisfaction Questionnaire

TSUQ - Telemedicine Satisfaction and Usefulness Questionnaire

TUQ - Telehealth Usability Questionnaire



## INTRODUCTION

### *Current Problem*

A national shortage in pediatric-trained palliative care providers results in certain geographies, primarily rural, where children are not able to access home-based care at their end-of-life.<sup>1-3</sup> Neither hospital-based nor local community hospice services were available for pediatric patients receiving care at a quarter of the pediatric oncology centers in the United States in 2018,<sup>1</sup> creating a serious care access situation. Hospice coverage in rural communities, especially those non-adjacent to urban centers, represents the least available per capita coverage for this demographic in need of hospice services.<sup>4</sup> The limited number of hospice providers in rural regions and the time and expense associated with staff transportation between patient visits represent factors that continue to challenge the ability to provide rural home hospice care, particularly for children.<sup>5-8</sup> For those care settings that do have access to hospice services, the reliance is on adult-based hospice teams clustered around urban geographies.<sup>9, 10</sup> This crisis in access, heightened by the increasing number of families choosing to have their seriously ill child die at home,<sup>11, 12</sup> warrants innovative leverage of partnerships to ensure quality end-of-life care in the setting most preferred by the child and family, including home-based end-of-life care.<sup>13</sup>

Based on rural geography and shortage of pediatric palliative subspecialists in Nebraska, the current model of home hospice services in the state is one in which pediatric patients are managed by local adult-based hospice teams after discharge from the pediatric hospital. Adult-trained community hospice teams report feeling fearful about and uncomfortable with providing end-of-life services to pediatric populations, despite a strong desire to have the proper support to enable children and their families to return to their home setting.<sup>14, 15</sup> In a statewide survey of adult hospice nurses, over one-third reported feeling somewhat or very uncomfortable discussing hopes or goals of care with a child and over half felt uncomfortable discussing death or dying with pediatric-age patients.<sup>14</sup> Confidence in the ability to engage in pediatric advance care planning or goals of care conversations, inclusive of code status discussions, was notably low among adult

trained hospice teams despite high desire to provide quality care for children in the location of the child and family preference.<sup>15</sup>

### *State of the Science*

Recent advances in technological platforms and connectivity have fostered a cautious increase in telemedicine uptake in adult hospice cohorts over the past decade,<sup>16, 17</sup> with a sudden surge during COVID.<sup>18</sup> While evidence is limited, research suggests that telemedicine initiatives to expand hospice access in rural settings for adult patients may: improve symptom management; benefit communication; and enhance adult patient- and caregiver-reported satisfaction, while reducing costs.<sup>19-22</sup> Pre- and post-telehealth programmatic cost comparisons have revealed substantial cost savings for rural hospices.<sup>23</sup> Adult patients in rural communities have cited access to familiar providers as a primary benefit of telehealth with over half of the patients enrolled in telehospice believe that its usage had a positive influence on their end-of-life care.<sup>24</sup> Family caregivers have reported decreased caregiver burden, anxiety, stress, and improved caregiving knowledge, confidence, and coping as benefits to telehealth use.<sup>20, 22</sup>

The state of the telehealth science has not kept up with the surge uptake in telehealth during the pandemic. Prior to COVID-19, telehealth uptake in palliative care and hospice care for children was remarkably slow, translating into a lack of literature on the feasibility, acceptability, and outcomes. Literature described patient discomfort with accessing or utilizing technology for medical care, family caregivers' concerns about the usability of technology for adequate support, concerns about the difficulty of technology use or reliability, and fear about jeopardizing the integrity of the provider-patient relationship with a screen barrier as compared to face-to-face care.<sup>25</sup> Since COVID-19, the rate of telehealth use in palliative care now permeates 100% of palliative care programs in the United States despite nearly three-fourths of pediatric palliative care clinicians expressing concerns about care quality via telehealth.<sup>26</sup>

Prior studies have revealed reasons for palliative care providers' tangible concerns about telehealth: lack of training and lack of incentives,<sup>27</sup> lack of equipment availability or lack of

perceived ease of equipment use,<sup>28</sup> concern about technology functionality,<sup>29</sup> and uncertainty about patient eligibility criteria for telehealth.<sup>28</sup> User-friendly, reliable, accessible, secure technologies, and clear connectivity are well-established requirements in the literature for successful telehealth, as is provider training.<sup>30-32</sup>

### *Gaps in Existing Knowledge about Telehealth*

Telehealth services have been developed in adult hospice models as an attempt to extend support and reach into remote populations,<sup>33</sup> although attention toward telehealth services for pediatric hospice models has been under-explored. Data on the use of telehealth and its effect on the well-being of pediatric patients or their family caretakers is lacking,<sup>34</sup> including discontinuation of prior studies due to inability to enroll.<sup>35</sup> Clinicians discomfort with communication in virtual environments and technology use have been noted in qualitative interviews as reasons for low-uptake of home telehealth services by pediatric palliative care providers.<sup>36</sup> The five pediatric palliative telehealth research studies that do exist represent needs assessment, programmatic considerations, or descriptive studies focused on patient satisfaction and staff perceptions.<sup>34, 36-39</sup> Little evidence exists on the effect of telehealth support in palliative or hospice care on patient or caregiver outcomes such as symptom burden, family caregiver well-being, and location of death. This thesis advances the science of palliative telehealth care by applying relevant instruments to assess telehealth impact and experience from the perspective of the dying child, the hospice team, and the family caregiver.

### *Dissertation Objectives*

The purpose of this dissertation is to determine whether telemedicine represents a feasible and acceptable modality for palliative care subspecialty clinicians to provide clinical care and support for end of life care for children in rural regions. The dissertation progress through four chapters with sequential goals:

- Chapter 1 – The objective of this systematic review of existing telehealth survey instruments was to identify a measure for incorporation in patient, proxy, and hospice

staff assessments of telehealth use. The dissertation subsequently incorporated the selected Technology Acceptance Model tool into ongoing analyses of telehealth for rural children.

- Chapter 2- The objective of this chapter was to apply the Technology Acceptance Model to determine whether telehealth inclusion of a familiar pediatric palliative care provider during the first two home-based hospice visits was acceptable to children, families, and adult-trained home hospice nurses in rural settings during home-based care at the end of life.
- Chapter 3 – The objective of this chapter was to qualitatively explore reasons for hospice nurses' lower acceptance of telehealth as compared to patient and parent acceptance of telehealth as a means to inform palliative communication and improve telehealth palliative practices.
- Chapter 4 – The objective of this chapter was to explore physical and emotional symptom burden and family impact assessments for children with terminal cancer receiving home based-hospice care via telehealth support services.

The use of telehealth may serve as an extension of care for hospital-based pediatric palliative practitioners, offering patient-centric and family-supportive reach beyond the walls of the hospital and past the time of hospital discharge.

## CHAPTER 1 – SYSTEMATIC REVIEW OF TELEHEALTH SURVEY INSTRUMENTS<sup>1</sup>

### Introduction

Palliative care teams are navigating rapid telehealth uptake while also attending to the patient, family caregiver, and interdisciplinary team communication experiences during an exponential increase in telehealth use in clinical practice. An essential consideration in the goal of telehealth to extend care and communication reach with equity is to explore whether there has been inclusion of diverse populations for perspectives on telehealth experiences.<sup>40</sup> If telehealth is to serve as a partnership tool in palliative care, access and assessments of telehealth necessarily should reflect user input.<sup>41-43</sup>

A prior systematic review, aptly titled “telehealth in palliative care is being described but not evaluated,” recognized the lack of available evidence documenting perceptions about telehealth encounters for patients and family caregivers.<sup>44</sup> To move toward a robust understanding of telehealth communication experiences, palliative care teams benefit from awareness of the survey instruments currently available to assess patient care experience using telehealth modalities. The objective of this chapter was to locate survey instruments used to assess telehealth interactions, to determine the content and constructs covered by the available instruments, and to describe the patient populations previously surveyed by the existing instruments.

### Methods

#### *Search Strategy*

This systematic review and its reporting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines with the protocol registered in PROSPERO as CRD42020200468.<sup>45</sup>

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<sup>1</sup> The material (including tables and figures) published in this chapter was previously published in Weaver MS, Lukowski J, Wichman B, Navaneethan H, Fisher AL, Neumann ML. Human Connection and Technology Connectivity: A Systematic Review of Available Telehealth Survey Instruments. *Journal of pain and symptom management*. May 2021;61(5):1042-1051.

With the guidance of a medical research librarian (CS), a search strategy was formulated using keywords and related subjects inclusive of (“telehealth,” OR “telemedicine”) AND (“survey(s)” OR “questionnaire”) AND (“experience” AND “communication”) AND (“validity” OR “reliability”). Three databases were searched [PubMed, Embase, Cumulative Index to Nursing and Allied Health Literature (CINAHL)] for articles matching the inclusion criteria (Appendix A).

### *Study Selection*

Inclusion criteria included any paper that was published in English between 2005-2020 which contained the development or analysis of a telehealth survey. The year 2005 marked a transition time between telephonic-based to video-based telehealth.<sup>46</sup> Case report(s), editorial(s), letter(s), commentaries, and opinion documents were excluded.

Manuscripts were uploaded into EndNote for review of the potential inclusionary articles. The initial search generated 4,887 citations with 7 citations hand-selected from prior study team familiarity with the literature.<sup>47</sup> Duplicate studies were removed and the remaining 3,154 articles were screened in accordance to the established inclusionary criteria. Four authors assessed each manuscript for potential inclusion initially at the title/abstract level (JL, BW, HN, MW) and then at the full-text level so that each article was independently assessed by a minimum of two of the three participating reviewers (JL, BW, HN, MW). Inter-rater reliability was notably >85% across the reviewers at each stage of manuscript review (Figure 1).

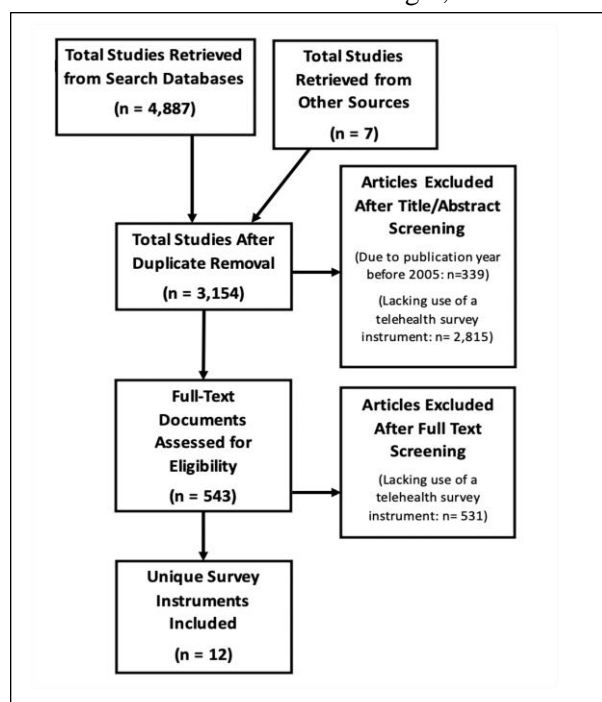


Figure 1. PRISMA Flow Diagram

### *Data Extraction*

Study team members (JL, BW, HN, MN, MW) abstracted data to a shared virtual spreadsheet fitted with the articles and outcomes with a primary data extractor and a blinded data check partner assigned per survey. The data extraction sheet was piloted on five surveys and revised based on study group discussion. Fields of data extraction interest included: survey item numbers, question types, target population (health provider, patient, or both); languages; constructs; communication experience (perception regarding the human interaction) or communication modality (perception regarding the technology interface) question measures; theoretical frameworks used in survey development; and prior hospice or palliative care survey use. Validity and reliability were each reported as a binary variable (yes/no) within the data extraction form with additional free-text for description of how psychometric properties were reported.

### *Diversity Snapshot*

To explore the populations previously included in telehealth survey research, PubMed was searched as a sole “snapshot” database using each survey name and acronym. Two study team members engaged in data extraction using a shared document designed and piloted by the study team (MN, MW). The following items were obtained for each manuscript using the telehealth survey: patient or family caregiver or other respondent; pediatric or adolescent (defined as age <19 years), adult, or geriatric (defined as age >65 years) participants; geographic location; description of diagnoses; gender diversity; survey language; rural or urban setting; socioeconomic summaries; and ethnic/racial representation.

## **Results**

Twelve telehealth communication assessment instruments were identified and agreed upon by the study team members. The constructs measured by the survey instruments and exemplary survey questions depicting the communication modality or human interaction themes are provided in Appendix B. Mean survey length was 20 questions (median 18, range 5-60

questions). Surveys consisted of Likert scale responses ranging from 3- to 11-point responses with mean 5-point scale. One survey was inclusive of space for free-text responses complimenting the quantitative responses (CSUQ) and one survey was qualitative (TISQ).

Three instruments (25%) inquired only into technology modality in terms of usability, connectivity factors, and the satisfaction with the video/audio interface (TAM, SUS, CSUQ). Four instruments (33%) solely explored the experience of human interaction in terms of the perceived quality of communication, visit content, therapeutic relationship, or care experience (PACT, PEPPI-5, PEQ, TISQ). Five instruments (42%) explored both the communication modality and the human experience with communication (TeSS, TSUQ, TMPQ, TUQ, TSQ).

Survey instruments were notably uni-directional with intention to assess a patient or patient family member's experience with telehealth rather than both provider and patient dyadic experience. Telehealth instruments could be applied to patient experience in 10 (83%) scales (TeSS, TSUQ, PACT, TMPQ, TUQ, TSQ, PEPPI-5, PEQ, CSUQ, TISQ). Only two (17%) scales were formatted for opportunity for both patient and provider comparative assessments of the telehealth encounter (TAM, SUS).

Theory was referenced in the development of three scales: Theory of Reasoned Action (TAM),<sup>48</sup> Theory of Planned Behavior (TUQ),<sup>49</sup> and the Integrated Model of Client Health Behavior (TISQ).<sup>50</sup>

Survey adaptation included the development of the TUQ scale created as a combination of questions from the TSW, TSUQ, and TMPQ scales. The original TAM was adapted into three survey editions (TAM3) relevant to telehealth.

Psychometric properties of the scales are reported in Appendix B. Cronbach's alpha is notably high for the available telehealth assessment instruments with recognition of generally high internal consistency reported for survey items. Validity reporting was notably diverse with many survey instruments describing validity as "good" or "reasonable" or "high" but lacking



quantified measures of validity (Appendix B). Validity was not described for the two surveys developed from prior validated survey items (PACT, TUQ).

All survey instruments were validated in English with Chinese (TAM, TSQ); Dutch (TSQ, PEPPI-5), Spanish (TSUQ), and Swedish (TISQ) as additional available languages. Manuscripts lacked mention of use of translators or interpreters during telehealth encounters or telehealth assessments.

Specific to the field of palliative care or hospice care, telehealth survey instruments have been applied in assessing the transition of adult rural<sup>51</sup> and pediatric<sup>52</sup> patients to home hospice (TAM) and palliative and hospice care patient symptom reporting usage (SUS).<sup>53</sup> These studies, notably with small sample sizes, depict telehealth as acceptable according to pediatric self-report, family caregiver insight, and adult cohorts based on the efficiency of the technology system and the effectiveness of the audio/video communication modalities.<sup>51, 52</sup> Technology-fostered interactions were deemed usable communication prototypes for facilitation of communication, shared decision-making, and self-management by eighteen surveyed adult palliative care patients.<sup>53</sup> Telehealth as a care and communication modality was notably more acceptable to children receiving hospice and their family caregivers than to hospice nurses,<sup>52</sup> warranting additional consideration of interdisciplinary team perspectives on telehealth.

### *Previous Populations*

Forty-five articles were assessed for populations included in prior telehealth research. Table 1 provides a summary of respondent demographics according to telehealth survey instrument use. Telehealth survey instruments have primarily been used to assess patient experience (n=41, 91%)<sup>49, 50, 54-90</sup> with less frequent use to assess family caregiver (n=7, 16%)<sup>54, 60, 63, 66, 91, 92</sup> or medical provider experience (n=8, 18%).<sup>49, 61, 66, 93-97</sup>

Table 1. Summary of Participant Diversity by Survey Instrument

Instrument	No. of articles	Study Population*			Study Age Group*			No. of articles in which diversity data is provided			
		Patients	Caregivers	Providers	Adults	Children	Geriatric participants included?	Gender	Race/ethnicity	SES	Urban/rural
TeSS	3	3	3	0	4	1	1	2	0	1	4
TAM	10	9	2	2	9	1	6	9	2	5	6
TSUQ	2	2	0	0	2	0	2	2	1	0	1
PACT	1	1	0	0	1	0	0	1	1	1	1
TMPQ	1	1	0	0	1	0	1	1	0	0	1
TUQ	6	3	1	4	6	0	1	3	2	2	3
TSQ	2	2	0	0	2	0	1	2	0	1	0
SUS	13	12	0	1	13	0	0	12	3	5	1
PEPPI-5	3	2	1	0	3	0	2	3	2	3	1
PEQ	2	2	0	0	2	0	1	2	0	0	0
CSUQ	1	1	0	0	1	0	unclear	0	0	0	0
TISQ	1	1	0	0	1	0	unclear	0	0	0	0
TOTAL	45	39	7	7	45	2	15	37	11	18	18

\*Could include more than one category

Telehealth surveys have been under-utilized to assess the experience of pediatric or adolescent cohorts with only two (4%) surveys used to assess the experience of pediatric care experiences or pediatric family caregiver experiences: TeSS for use in pediatric surgery telehealth communication<sup>98</sup> and TAM for pediatric telehospice care.<sup>52</sup> Fifteen studies (33%) included geriatric participants.

Demographic data for participants responding to the instruments is notably lacking in telehealth research papers with only 11 (24%) studies reporting on race or ethnicity, 18 (40%) reporting on some form of socioeconomic status, 18 (40%) reporting on geographic urban or rural representation, and 37 (82%) reporting on gender. For those papers reporting demographic data, the majority of telehealth survey instruments respondents across telehealth survey scale options are noted to be Caucasian, with a post-secondary education, and not low-income (Table 2).

## Discussion

Palliative care teams may consider employment of survey instruments to assess patient experiences with telehealth. Palliative care and hospice research has focused extensively on

descriptive methodologies to assess telehealth experiences.<sup>44</sup> While telehealth has been deemed usable and acceptable in palliative care outreach, the methodology to determine such has primarily been qualitative inquiry and small-scale studies.<sup>99</sup> Familiarity with the constructs assessed by available telehealth survey instruments is paramount in differentiating whether the focus is on the technology interface or the human interaction or both. The boundaries of the constructs do blur in certain question formats, such as in asking whether the participant experienced the telehealth interaction as equal to an in-person encounter. Not only do palliative care providers and researchers need to have familiarity with the constructs assessed, but they also benefit from understanding the strengths and weaknesses of the different assessment tools, including whether these tools are reliable and valid.

With respect to the inclusion of diverse populations in the validation and utilization of the various telehealth assessment measures (Table 2) , our team discovered that what *isn't* reported speaks just as loudly as what is. In fact, our review revealed a concerning lack of reporting on the demographic make-up of study participants in addition to a lack of diversity. Children and adolescents as well as geriatric age cohorts are notably under-represented and family caregivers are only rarely included in telehealth survey instrument reporting. Further, non-white or low-income populations and those without a post-secondary education are notably under-represented in studies utilizing the existing telehealth instruments. Educational exposures to varying technology interfaces, generational interpretation and comfort with technology, culture, geography, economic access to personally owned technology, and language are sure to impact perceptions of telehealth. Further, particularly with renewed calls for inclusion and the importance of listening to diverse voices in all facets of the public sphere, attentiveness to diversity and inclusion in eliciting feedback on telehealth experiences is critical. Lack of diversity reduces the generalizability of the existing telehealth survey findings.

Table 2. Summary of Diversity Inclusion by Survey Instrument

Instrument	Number of papers	If diversity information is quantified, percent represented in sample per group*				
		percent female	percent non-white	percent low-income	percent HS education or below	percent rural
SUS	13	70%	30%	x	21%	x
TAM	10	64%	38%	62%	55%	x
TUQ	6	58%	8%	x	25%	x
TeSS	3	49%	x	x	53%	58%
PEPPI-5	3	69%	25%	x	40%	x
TSUQ	2	51%	46%	x	x	x
PEQ	2	64%	x	x	x	x
TSQ	2	x	x	x	x	x
PACT	1	4%	4%	16%	x	x
TMPQ	1	57%	x	x	x	x
TISQ	1	x	x	x	x	x
CSUQ	1	66%	x	x	87%	x
*averaged across articles; categories defined by articles						

Limitations of this systematic review include the restriction to English-language manuscripts. The limited number of research-based telehealth manuscripts and the lower quality of the available studies further limit overall application of findings.

Logical next steps in telehealth research in palliative care include the development and then use of validated telehealth experience survey instruments with paired consideration of not only technology interface but also measure of human interaction.

Overall, this review revealed that instruments exist to measure patient and family caregiver perceptions of telehealth but the instruments are currently under-utilized. As a result of this systematic review, the Technology Academic Model was notably recognized as a validated tool with prior use in rural regions among patients with diverse socioeconomic backgrounds now with ready opportunity for application to pediatric populations.

## **CHAPTER 2 - Inquiry into the Acceptability of Telehealth from the Perspective of Children Receiving End of Life Care, their Family Caregivers, and Rural Hospice Nurses<sup>2</sup>**

### **Introduction**

The acceptability of telehealth as a means of offering pediatric palliative care visits in a child's home in rural geographies has been underexplored, primarily due to challenges with recruitment<sup>35</sup> and study retention.<sup>37</sup> The uninvestigated potential value of this communication modality in pediatric palliative care is striking; especially given the increasing number of families expressing preference for home for end-of-life care location.<sup>11</sup> Design and method decisions have contributed to a lack of study goals being achieved in prior pediatric palliative care telehealth studies,<sup>35, 39</sup> compelling this chapter on the acceptability of telehealth as a care modality.

Potential or perceived benefits of telehealth visits to extend care to children returning home to hospice in rural regions are relevant only if this visit modality is deemed acceptable by children, families, and home hospice nurses. This two timepoint, longitudinal case series study sought to explore the acceptability of telehealth pediatric palliative care consults for children receiving hospice care in rural communities from the child, family caregiver, and nurse perspectives. The goal of this telehealth intervention was to allow for continuity of pediatric-specific palliative care while introducing the child and family to their new in-home local home hospice provider. Intervention targets were thus the child and family as they transitioned home and the local home hospice nurse in fostering an introduction to the child and family with a familiar provider present via telehealth.

### **Methods**

#### *Participants and Setting*

This chapter specifically reports on the technology acceptance study aim of the IRB-approved protocol, registered as NCT03999957. The telehealth care model was one of a virtual

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<sup>2</sup> The material (including tables and figures) published in this chapter was previously published in Weaver MS, Robinson JE, Shostrom VK, Hinds PS. Telehealth Acceptability for Children, Family, and Adult Hospice Nurses When Integrating the Pediatric Palliative Inpatient Provider during Sequential Rural Home Hospice Visits. *Journal of Palliative Medicine*. May 2020;23(5):641-649.

presence pediatric palliative provider fostering a medically-informed and relationally-centered transition to home with the receiving in-person home hospice team (virtual transition). Participants were consecutively enrolled in the virtual transition to home program from July 2018 to July 2019. Eligibility criteria included any patient age birth to 18 years referred to the hospital-based pediatric palliative care team at the free-standing children's hospital, and enrolling on home hospice services within a rural zip code in the state of Nebraska at time of discharge from the hospital. Rural zip code was defined according to the Census Bureau Rural and Urban taxonomy.<sup>100</sup> Eligibility of the family caregiver included the person identified by the family as the primary hands-on caregiver of the child in the home based on existing family structure. Eligibility of the hospice nurse included the employed nurse assigned to serve as the child's primary in-home hospice care by the rural adult home hospice agency.

Study notification occurred through a conversation with the study coordinator who provided details on the study aims, methods, and the voluntary nature of participation. In-person written informed consent then occurred prior to hospice enrollment by the pediatric palliative care physician for the child and family participant and via telephone informed consent for the home hospice nurse. Family caregivers and children were told the intervention would include two telehealth interactions with a known pediatric palliative provider to help the receiving hospice team learn about the child and family. Family caregivers and home hospice nurses received written and <10 minute verbal instructions on how to access and use the Zoom Videoconferencing® telehealth platform prior to study enrollment.

### *Intervention*

Hospice referral and enrollment occurred through the pediatric palliative care nurse case manager with medical records faxed to the receiving hospice after signature of medical release. The hospice nurse case manager and the pediatric palliative care nurse case manager reviewed the medical and psychosocial care details at time of hospice enrollment. The patient enrolled in hospice after hospital discharge, meeting the hospice team for the first time in-person within 48-

hours upon arrival to home from the hospital inpatient setting (T1). The palliative physician and home hospice nurse did not communicate with one another prior to the first telehealth visit. This intervention was unique in utilizing an hospital-based palliative care provider familiar to the family in partnering with a rural, adult-trained home hospice nurse for the nurse's first two visits to the child's home after discharge from the free-standing children's hospital (T1 = first home visit within 48 hours of arrival to home from the hospital, T2 = 14 days later). This virtual transition model offered a review of the medical care plan and anticipatory symptom guidance inclusive of the family caregiver and child presence, emphasizing a relationally-based care handoff from the hospital to the home hospice setting.

Each study participant received a standard of care in-person visit with a home hospice nurse from an adult-trained hospice team within 48 hours of arrival to home after hospital discharge. The study intervention was the additional presence of the inpatient pediatric palliative care physician who had been following the child during hospitalization then joining the home hospice nurse's in-person visit as a telehealth presence using a facetime screen. The palliative physician was the palliative team member present for the transmission. The home health nurse was in the home with the child and family caregiver while the pediatric palliative care physician joined by screen for a combined care visit. The same intervention occurred at Day 14 at home. Standard of care in-person home hospice visits occurred as per each child's health need and home hospice agency service standard between these two structured telehealth visits with the hospital-based pediatric palliative care provider.

### *Measures*

A link to the study questionnaire was generated as the closing screen for the telehealth encounter. Questionnaire responses were accessed by the study team electronically through SurveyMonkey© collection.

The 15-item modified Technology Acceptance Model 2 (TAM2) surveys were completed by the home hospice nurse and by the family caregiver on the day of the first home hospice visit

and then again 14 days later at a second home hospice visit. The Technology Acceptance Model (TAM) was developed to gauge individuals' intentions and behaviors for technology usage.<sup>101</sup> Improved from the original TAM instrument, modified TAM2 incorporates social influence and cognitive instrumental processes by inquiring about perceived acceptability and behavior intention to use the technology format again.<sup>102</sup> The modified TAM2 instrument consists of nine domains: perceived usefulness, ease of use and learnability, intention to use, subjective norm, relevance, interface quality, reliability, satisfaction, and experience.<sup>103, 104</sup> Responses are on a five-point Likert scale (ranging from highly disagree to highly agree). Perceived usefulness has been consistently validated as a strong representation of usage intention, with internal consistency of the TAM instrument for perceived usefulness 0.91 and ease of use 0.96.<sup>105</sup>

The family caregiver additionally answered electronic survey questions on his/her age, highest level of completed education, primary language spoken at home, relationship to the child, distance from home to the hospital, child's age, level of respiratory support used by the child, and details surrounding the telehealth visit discussion content and attendees at the conclusion of the first telehealth encounter. The family caregiver endorsed the topics were discussed during the encounter from a nine-item list of potential topics at the conclusion of each telehealth visit. The home hospice nurse answered one question on prior telehealth use (yes/no) and prior pediatric hospice care experiences (quantified). Pediatric age participants were asked on the survey screen at both timepoints if they liked or disliked the use of telehealth with an optional open-text comments box for their thoughts on telehealth at the end of each visit: "Please share your thoughts about telehealth." Two blinded study team members used semantic thematic content analysis<sup>106</sup> to apply themes to the open-text comments. The unit of response was each "written phrase" shared by the child in the survey comments box and the unit of analysis was the "theme" assigned to the child's written phrase by the study team. Study team discussion occurred to reach consensus for thematic meaning. Themes were quantified by the number of participants whose free text comments depicted the theme.



The study team experience led to modification of a conceptual framework recognizing the role of family factors, external variables, technology quality, and user experience for future telehealth interactions.<sup>102</sup>

### *Statistical Analyses*

PC SAS version 9.4 was used for all summaries and analyses. The statistical level of significance was set at 0.05 for all comparisons. Likert scale data were summarized using mean, median, and minimum/maximum. These variables were analyzed using nonparametric analysis techniques: Mann-Whitney tests when comparing two groups of non-repeatedly measured data, Kruskal-Wallis tests when comparing three or more groups of non-repeatedly measured data, and the Signed Rank Test when comparing repeatedly measured data. Categorical data were summarized using frequencies and percentages. Fisher's Exact Tests were used to compare non-repeatedly measured categorical data. McNemar's tests were used to compare repeatedly measured categorical data. Spearman correlation was used to assess the correlation between Likert Scale responses to individual questions on the TAM2 Questionnaire.

### **Results**

All but one of the 18 families approached for participation agreed to enroll and had existing access to the internet at home (17/18, 94%). One family refused citing child's level of fatigue. One family enrolled but, sadly, the child died before the first hospice home visit and another family's child died prior to completion of the second survey and thus the data from the first survey was not included in analyses. The 15/17 (88%) enrolled who completed the two study visits are included in this analysis (Figure 1).

Child age was median 7 years (range six months to 15 years). The primary family caregiver enrolled in the study included eleven mothers (73%), two grandmothers (13%), and two fathers (13%) with median age of the family caregiver age 33 years (range 23 to 69 years).

No family caregiver had prior experience with telehealth. The 15 nurse participants, representing 9 different rural hospice agencies, were largely new to both pediatric populations

and to telehealth as a care delivery modality. One nurse had prior experience with telehealth in adult hospice care. Three of the home hospice nurses had prior experiences with caring for one pediatric-age patient in the prior two years, otherwise thirteen (87%) nurses reported the study participant to be their first pediatric-age hospice patient in twenty-four months.

Duration of the first telehealth visit was 52 minutes (range 40-75 minutes) and 55 minutes for the second telehealth visit (range 35-110 minutes). One telehealth visit was momentarily unintentionally disconnected but then reconnected within four minutes; otherwise no additional technological issues occurred.

Additional family members present for telehealth visits were: fathers (n=6), aunts (n=2), grandfathers (n=2), grandmothers (n=2), mothers (n=3) with one family including their local pastor in the visit. Only one telehealth visit included the child, family caregiver, and home hospice nurse alone. Twelve (80%) of family caregivers responded that the additional family member would not have been able to join the visit had the visit been an in-person return to the palliative care clinic.

Family home distance to the hospital averaged 172 miles with range 30-450 miles. Family caregivers reported an average of 8 hours of time saved by accessing telehealth encounter instead of an in-person return to see the palliative care team (range 1.5 to 24 hours). Only 4/15 (27%) of family caregivers stated they would have scheduled or kept an in-person follow-up appointment with the palliative care team if it meant a return to the pediatric hospital.

The family caregivers identified the reason for the telehealth inclusion of the pediatric palliative care physician as a routine “check-in” visit (n=8, 53%), a visit for symptom management (n=5, 33%), and a hospital discharge follow-up (n=2, 13%). Symptom review, medication review, decision making and code status discussions decreased and goals of care content increased between the two visit timepoints ( $p=0.025$ ). Goals of care conversations were noted by family caregivers to occur in 60% of Timepoint 1 conversations compared to 93% of Timepoint 2 conversations.

There was no association between code status content and family caregiver sense of telehealth being an acceptable format for the encounter ( $p=0.44$  and  $p=0.37$  for Timepoints 1 and 2). There was also no association between DNR/DNI being a topic of discussion using telehealth and overall caregiver satisfaction with telehealth ( $p=0.99$  for Timepoints 1 and 2), whereas nurses were less likely to express satisfaction with telehealth if code status was discussed in the first visit ( $p=0.01$ ). However, there was no association between code status content and hospice nurse satisfaction with telehealth at Timepoint 2 ( $p=0.99$ ).

Table 3 contains descriptive statistics of how the family caregiver and home hospice nurse perceptions of telehealth changed over time.

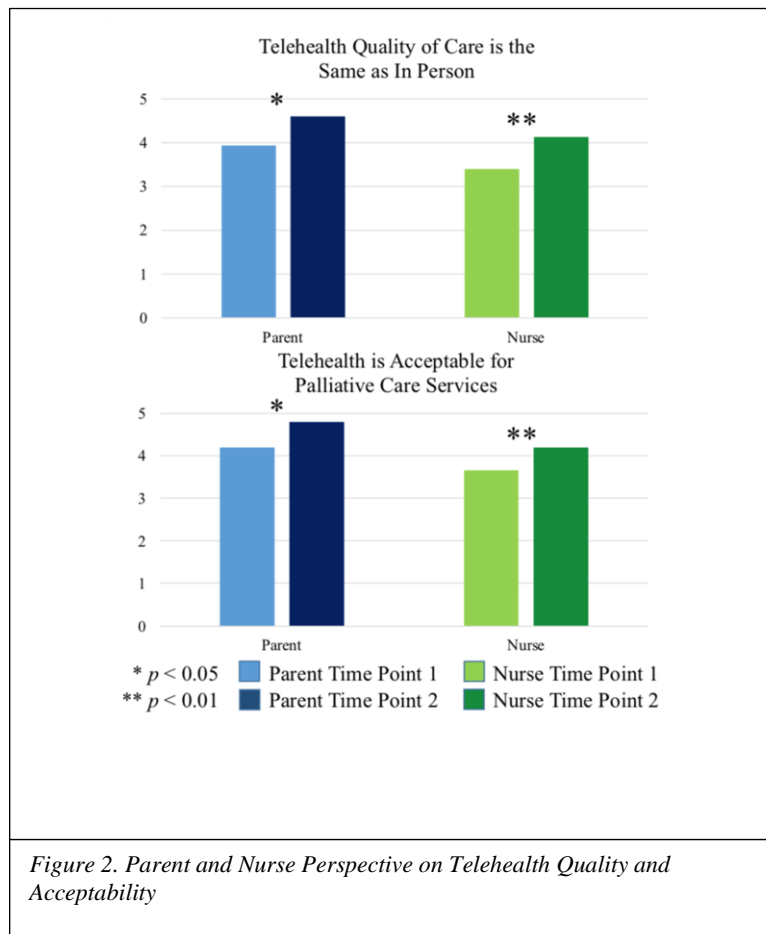
*Table 3. Family Caregiver & Nurse Experience at Timepoints 1 & 2*

Variable	FCG1 Mean	FCG2 Mean	Change in FCG perception p-value	NT1 Mean	NT2 Mean	Change in Nurse perception p-value
Telehealth improves my access to palliative care services	4.27	4.60	0.0156	3.60	4.13	0.0078
Telehealth was an acceptable format to discuss content of palliative care visit	4.27	4.87	0.0010	3.20	3.80	0.0469
It was simple to use this system	3.33	4.67	0.0020	3.40	3.93	0.0313
It was easy to learn to use this system	3.33	4.53	0.0010	3.33	4.07	0.0078
The way I interact with this system is pleasant	3.60	4.60	0.0234	3.33	3.80	0.0938
I like using the system as a way to communicate with the palliative care provider	3.87	4.60	0.0156	3.60	3.93	0.1875
I could easily talk to palliative care provider using telehealth system	3.73	4.53	0.5000	3.53	4.13	0.0156
I could hear the palliative care provider clearly using telehealth system	4.53	4.80	0.1250	3.47	4.13	0.0078
I felt I was able to express myself effectively	4.13	4.53	0.3750	3.60	3.93	0.2344
I felt like I was heard well during visit	4.53	4.87	0.0313	3.67	4.33	0.0156
I think quality of care over telehealth system is same as in-person visits	3.93	4.60	0.0156	3.40	4.13	0.0039
I feel comfortable communicating with the palliative care provider using telehealth	4.00	4.67	0.0156	3.60	4.20	0.0078
Telehealth is an acceptable way to receive palliative care services	4.20	4.80	0.0625	3.67	4.20	0.0078
I would use telehealth services again to communicate with the palliative provider	4.40	4.80	0.0156	3.67	4.20	0.0078

FCG = Family Caregiver; FCG1 – Family Caregiver Experience Time-point 1; FCG2 – Family Caregiver Experience Time-point 2; NT1 – Nurse Experience Time-point 1; NT2 – Nurse Experience Time-point 2

As the difference in The Signed-Rank test was used to determine if there was a significant change between time points; there were statistically significant improved perceptions found for all variables except “hear clearly”, “express myself effectively”, “heard well during visit”, and “would use again” for family caregivers. Similarly, for home hospice nurses; there were statistically significant differences found for all variables except “the way I interact with the system is pleasant”, “like using telehealth as a way to communicate”, and “able express myself effectively” survey items.

Figure 2 contains a visual representation of difference in perspective between Timepoint 1 and Timepoint 2 for both family caregiver and home hospice nurse perception of telehealth quality of care and acceptability. All items from nurse report and from family report showed improvement between the two timepoints.



There was no evidence of an association between family caregiver age or education level or primary language with “simple to use”, “easy to learn to use”, or “like of the system” survey items.

The mean number of prior in-person pediatric palliative care visits at the inpatient setting prior to telehospice enrollment was 4.2 (range 2-13). There was a statistically significant correlation of number of prior palliative care visits with the family caregiver’s perceived comfort communicating via telehealth (Spearman Correlation=0.86,  $p<.0001$ ) and the family caregiver’s reporting telehealth as an acceptable way to receive palliative care communication (Spearman Correlation=0.85,  $p<.0001$ ).

The mean number of in-person home hospice nurse visits between the Day 1 telehealth visit and Day 14 telehealth visit was 6.3 (range 4-11). There was a statistically significant correlation between number of nurse visits in between telehealth encounters and the nurse’s perception of comfort communicating via telehealth (Spearman 0.89,  $p<.0001$ ) and the nurse’s reporting telehealth as an acceptable way to receive palliative care communication (Spearman 0.89,  $p<.0001$ ).

The child was present in the telehealth room for all encounters. Of the fifteen pediatric participants, six (mean age 8.3 years) were developmentally and cognitively able to self-report their perception of telehealth at the end of the first visit and four (26.7%) were able to still self-report their perceptions at the end of the second visit with all pediatric-age participants reporting at both timepoints they “liked” rather than “disliked” the telehealth visit (100%). As depicted in Table 4; content analysis of the free-text comments entered by pediatric-age hospice enrollees revealed the following 6 themes fostered by telehealth: being remembered (4 patients) or being known (2 patients), medical knowledge and care plan (4 patients), comfort of home (3 patients), continuity of old team with introduction to new team (2 patients), and peace of mind (1 patient).

## Discussion

Using the Technology Acceptance Model, telehealth was noted to be an acceptable format of pediatric palliative care delivery for child, family caregiver, and home hospice nurse in rural settings. A hospital discharge to home hospice for children and families is a notably vulnerable time, as children and families adjust to new home-based care teams after intimate and often longitudinal familiarity with their pediatric longitudinal teams.<sup>107</sup> Familiarity with staff between transitions is noted to be a therapeutic offering for children and families enrolling in home-based hospice.<sup>108</sup> An assurance of continuity of care providers increases home hospice enrollment, compelling creative interventions focused on care transitions.<sup>109</sup> This study methodology was unique in utilizing a virtual transition to home model with a hospital-based palliative care provider familiar to the child and family partnering with a rural, adult-trained home hospice nurse for the nurse's initial visits to the child's home after discharge from the free-standing children's hospital. This virtual transitions model allowed for continuity of pediatric palliative care provision while the hospice adult nurse adjusted to the pediatric-age patient and family, as the pediatric-age patient and family settled into their home setting with a new care team.

Pediatric palliative care telehospice visits in the child's home may offer equity of access to services for the child and family while offering support for the home hospice nurse in a cost-feasible way.<sup>38</sup> The telehealth modality was notable for the valuable time and transportation saved for families. Telehealth offered expansion of care inclusive of the child and also welcoming of extended family members, as 80% of family caregivers reported inclusion of family members at the visit who would not have been able to join an in-person hospital visit. Telehealth brought a continuity in communication and medical services to children and families, welcoming of the social support closest to the family in a way deemed by the family as not feasible for in-person visits; revealing the role of telehealth to relieve disparity in service access while extending inclusivity to family members invited by the child and family.<sup>39</sup> This virtual transitions model has

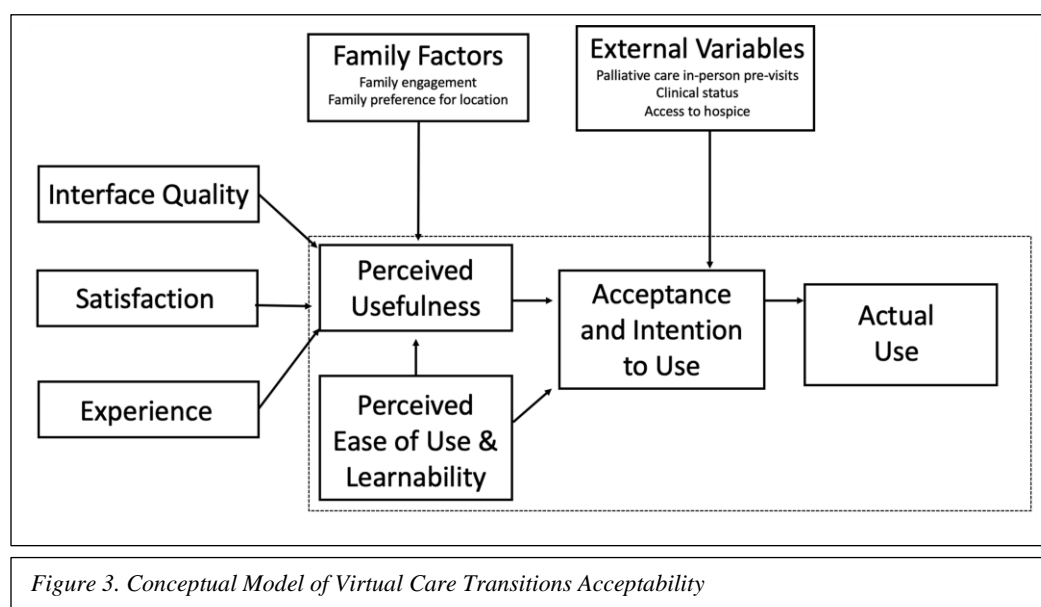
the potential to assist pediatric palliative care teams in achieving a greater degree of family-centered care aspirations.

While the child's perception of telehealth was consistent as "like" at both timepoints, family caregiver and nurse experience notably improved over time; a pattern of acceptance previously recognized in adult-cohort rural hospice telehealth studies.<sup>110</sup> This lends question as to whether an initial telehealth "practice run" interfacing with the technology without the depth of palliative care content would have more positively impacted outcomes. A future approach may include anticipating needs being addressed during the telehealth encounter in a pre-clinical care connection with the receiving home hospice nurse and the pediatric palliative provider. The findings from this study could be used to alert the home hospice nurse to the likelihood of comfortableness with the telehealth model of care increasing after the first use during a home visit.

An increased number of prior pediatric palliative care in-person visits correlated with increased parental comfort with and acceptance of telehealth. Similarly, an increased number of nursing home hospice visits between the two telehealth calls correlated with increased nurse comfort with and acceptance of telehealth. This finding indicates that the frequency of human interaction and relational familiarity between telehealth participants enhances comfort with and acceptance of this technology modality. These associations may help to explain the positive perceptions of the telehealth virtual care model as more prior interactions and familiarity between the family and pediatric palliative care team before telehealth encounter may contribute to the more positive family perception of the new model of care. Families may have agreed to be in the study secondary to the sense of continuation of care from their current care provider via telehealth.

Inconsistent receptiveness to telehealth implementation has sometimes been linked to the generation or education level of the participant.<sup>111</sup> This study did not reveal a correlation between family caregiver age or generation (parent versus grandparent), education level, or perception of

the usability of telehealth. This compels our study team to not discount telehealth as a feasible support model even for a traditional grandmother on a homestead; as the study data did not reveal a difference in comfort with technology based on gender, age, or formal education. A conceptual model for the factors relevant to perceived telehealth acceptability, modified and adapted from Venkatesh V and Davis FD work in 2000, is provided as Figure 3.<sup>102</sup>



The content of the conversations notably shifted from logistical topics (medication review, symptom review, code status clarification) toward goals of care at the second visit. Thoughtful concern has been raised about the use of telehealth for difficult news or sensitive conversational content,<sup>112</sup> seemingly due to the lack of physical proximity for the relational context of these conversations. This study specifically analyzed the acceptability of telehealth for visits that included code status conversations, determining acceptability by families but less perceived acceptability by home hospice nurses in the initial visit if code status were discussed. The newness of the home hospice nurse to pediatric-age patients may have influenced perception. The background of the familiar palliative care provider joining the family by telehealth, having



engaged in goals of care conversations in-person with the family prior to discharge to home hospice, may have impacted family receptivity and may have impacted the evolution of conversational content across visits.

Though sequential enrollments were achieved at the level of 94%, limitations in the study include single site, small case series without a comparison or control group. Lack of qualitative data from adult study participants is a noted limitation, having received such rich narrative from pediatric qualitative component. A strength of the study was the use of a validated technology acceptance instrument at two timepoints. A strength of the study was the inclusion of child voice in allowing the pediatric-age patient to report on their experience with the telehealth encounter. The reality that pediatric patients recognized a relational component to the encounter (“being remembered” theme in equal proportion to the practical implications of the visit (“medical knowledge and care plan” theme) speaks to the role of this modality for continuity of human connection in addition to care planning. The themes from the children convey their recognition of a care transition and their positive comments about the transition. The finding that nurses seemed less positive about telehealth than family caregivers and patients could be further explored through qualitative exploration.

### **CHAPTER 3 - Deeper Analyses of Hospice Nurse Perspectives on Telehealth as a Care Modality for End-of-Life Care for Children in Rural Regions<sup>3</sup>**

#### **Introduction**

Research highlighting the complex factors shaping the uptake of telehealth in the arena of palliative care and hospice finds that, while patients receiving palliative care and their family caregivers have reported mostly positive experiences with the utilization of telehealth,<sup>16, 22, 25, 113</sup> feedback from palliative teams has been less consistently positive.<sup>34</sup> Some research reports hospice staff enthusiasm toward telehealth as an enhancement of care reach,<sup>29, 114-117</sup> while other studies report staff discomfort due to equipment logistics and concerns about technology's impact on human relationships.<sup>27, 28</sup> Importantly, evidence suggests that medical personnel, particularly nurses and clinicians, function as gatekeepers to the utilization of telehealth services in palliative or hospice care.<sup>12,14,15</sup>

If telehealth is to be implemented in palliative care and hospice, feedback from these gatekeepers must be carefully considered and integrated into program design. Yet, largely missing from the current literature base are reports of the nurse perspective on their experience with telehospice. Our team was not able to identify a study explicitly investigating nurse experiences with the utilization of telehospice in their care for pediatric patients. This qualitative study helps to address this gap by providing experiential perspectives from adult-trained nurses utilizing telehealth to provide home-care for children receiving palliative care at end of life in a rural setting.

#### **Methods**

The IRB approved this qualitative work as an addendum to the original study protocol. Eligibility criteria included English-speaking hospice nurses who served as the primary in-home

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<sup>3</sup> The material (including tables and figures) published in this chapter was previously published in Weaver MS, Neumann ML, Navaneethan H, Robinson J, Hinds P. Human Touch via Touchscreen: Rural nurses' experiential perspectives on telehealth use in pediatric hospice care. *Journal of Pain and Symptom Management*. 2020 Nov;60(5):1027-1033.

nurse for children admitted to home hospice care in rural regions enrolled in a telehospice program from July 2018 to March 2020. The nurses were present in the child's home during routine hospice care encounters with inclusion of the pediatric palliative care specialist via telehealth connection. The nurse was present physically with the family while the palliative physician joined the nurse and the family via telehealth.

This study involved voice-recorded phone interviews with fifteen adult-trained hospice nurses. The nurses were employed with rural hospices serving primarily adult patients. The study method included interviewing all fifteen nurses enrolled in the larger telemedicine acceptance study,<sup>52</sup> regardless of the timing of study theme saturation. One open-ended statement was asked of each nurse at Month 3 of telehealth use or at the conclusion of their care (due to child's reaching end of life): "Please describe your experience with telepalliative use." This question was asked verbatim from a one-question interview guide. The nurse response was a mean of 16 minutes per nurse. Trained medical transcriptionists transcribed the interview content verbatim with a minimum of one study team member confirming accuracy.

Responses were analyzed using semantic content analyses.<sup>106</sup> Every phrase spoken by the nurse was entered into qualitative software program (NVivo). The interviewer created group classifications of phrases from the interview content to develop a code dictionary.<sup>106, 118</sup> The interviewer and another team member then used this grouped-specific codebook to review the content of the interview data. Team members further grouped the codes with overlapping meaning and co-occurrence into themes. The frequency of each theme was calculated by these three team members. Difference in code or theme perspective was resolved with discussion and consensus. A conceptual definition was then developed for each theme based on the interviewee's verbiage and the assessed meaning of the described theme according to "benefit" or "caution" relevant to telehealth use. For the final validation step, three rural hospice nurse study participants reviewed the manuscript and shared consensus opinion that the content was comprehensively representative.

## Results

All approached 15 nurses for the 15 children enrolled in the CALLiNGS study consented to participate. Nurses were female with mean age 38 (range 31-62 years). Nurse participants, representing 9 rural hospice agencies in one mid-Western state, averaged seven years in hospice nursing (range 1-18 years) but were largely new to both pediatric populations and to telehealth. One nurse had prior telehealth experience with adult patients. Three had cared for a pediatric-age patient in the prior two years, otherwise thirteen (87%) nurses reported the child to be their first pediatric-age hospice patient in twenty-four months.

Study saturation was reached at the thirteenth interview with new participants no longer eliciting novel themes not raised by the previous participants. Inter-rater coding reliability ranged from 86-100% for each theme.

Five themes emerged from the interviews (Appendix C): accessible support, participant inclusion, timely communication, informed and trusted planning, and familiarity fostered. Each theme was noted to contain a benefit paired with a caution.

Every interviewed nurse mentioned accessible support as a benefit (15/15) with a primary mention of accessibility for symptom management and the immediacy of communication regarding medical changes. This was balanced with a caution that the screen format bypassed the organic unfolding of symptom review which feels more natural in in-person format (5/15). Nurses cautioned that telehealth conversations carried “a certain immediacy less paced than in-person full symptom assessment,” sharing caution to pace the cadence of symptom review.

Most nurses acknowledged that telehealth allowed for participant inclusion with a wider support network included for palliative care encounters (14/15). The multi-face screen function allowed for co-parents or grandparents or other relatives, local pediatricians, and interdisciplinary palliative care team members to join. With this inclusion came a caution of creating a “mass presence” while missing the intimate, “personal touch” each family deserves. This sense of “personal touch” was depicted as physical hand-holding or hugging but also expanded to the

deeper “personal touch” of attentiveness and healing presence for each individual in the room. While the screen fostered a community gathering, this risked missing moments of attending to each participant’s personal needs. Nurses recommended finding ways to “check in” with each person who had been present at the telehealth visit after the visit, as one would in-person. Although this is a time commitment, this sense of personalized care was notably essential when using a less personal communication format.

While timely communication (11/15) represented a strength for goals of care discussions to include advance care planning, the nurse sitting next to the family depicted a sense of awareness of energy and emotion difficult for providers to capture on screen (4/10). One nurse described “Her [mom’s] hands were just trembling, trembling and I was so glad that I was there to hold her hands and steady them. She knew we had to talk about how the dyspnea was going to turn more agonal but it was so hard a topic for her to imagine the breathing even getting worse. She could hear the care through the computer. But, me sitting there next to her allowed me to help pace the conversation across the screen so that we could talk through it but I knew to pace it by how her hands were trembling. They couldn’t see her hands below the video camera.” Nurses recommended specifically checking-in on family readiness and pacing with clear communication cues as nonverbal gestures were more challenging to notice by screen.

Nurses valued that telehealth fostered an informed and trusted plan with clarity in messaging across providers, (10/15) but also expressed concern that the family confidence in the expertise of the telehealth team may inadvertently minimize the family’s sense of confidence in their own family caregiver intuition (4/15). The screen offered the security of an external voice of validation but perhaps risks minimizing the family’s own intuition or awareness: “Like it was safer for them to ask a screen than to hear their own sense of it and so I like when we said, “what is your heart telling you?” on the screen. Like, you know, you are in the room and so you tell us what you sense being as you are right there and we are all in this together.” Nurses recommended

strategic and purposeful inquiries about family perception, family intuition, and family experience as part of telehealth.

Telehealth fostered familiarity (9/15), which the interviewed nurses recognized as important for professional presence. The hospice nurses also recognized that a screen relationship can feel more superficial or less deeply trusting, as there remains “a sense of still being a bit on the outside, you know, distant”. One nurse phrased this as “the family may not be yet fully trusting of the technology and then there is a provider who they don’t yet personally trust so there needs to be that extra commitment to building trust through caring communication.” The nurses voiced that therapeutic relationships and personal trust “felt a little longer to really enter into with the screen.” Taking a moment for relational content and thoughtful pauses may form as a way to foster relationship, “asking about the pet in the room or just asking about hobbies or pleasures is extra important to make the place feel more personal.”

## **Discussion**

The deeper concern with telemedicine use in palliative and hospice care is the concern with whether this communication modality is a facilitator or a barrier for the relationality so core to the profession. A fear about virtual interaction is whether the communication format depersonalizes the team or family experience, particularly when discussing the sensitive topics relevant to pediatric end of life care. Palliative and hospice teams have shared concerns about the way telehealth impacts professional roles: telehealth’s impact to professional autonomy,<sup>29</sup> fear of decay in the quality of care provided,<sup>117</sup> and concern for risk of not being present to assist the patient such as in adverse medication reactions.<sup>117</sup>

Few studies have explicitly explored palliative or hospice nurse experiences with telehealth, although nurse perspectives on telehealth use should inform practice. In focus groups with nurses involved in piloting a multidimensional tele hospice program in Australia, Collier et al<sup>16</sup> found that nurses view themselves as central to successful implementation of telehealth programs, citing the potential for technology to enhance patient relationships and undermine trust

when technical difficulties arise. A study of video consults for rural pediatric hospice patients found a lower acceptance of telehealth by home hospice nurses than by family caregivers, but note that nurse attitudes toward telehealth improved after their first virtual meeting, including their acceptance of telehealth as a suitable way to receive palliative care services.<sup>119</sup> In a study on video consults for elderly rural patients, nurse experience with the program revealed nurse comfort and nurse perception that the encounter address patient needs as well as an in-person appointment, with most agreeing that they would utilize telehealth for similar situations in the future.<sup>120</sup>

Nurses in our study were able to accept and use the new approach to pediatric palliative care, could report the benefits, and yet were also able to share insightful cautions. The positives about telehealth seem to point toward benefits for overall care and specifically for the family (inclusion) and the patient (support for symptom management). The cautions related to the prioritization of the nurse-family trust relationship and the worry that this could be slowed, interrupted, or altered in some way with the use of telehealth. The nurses emphasized the need to support the primacy of the care relationship even with the use of technology. Each caution provides opportunity to consider purposeful attentiveness for recognizing the challenges introduced by technology use while striving to still offer quality care. A limitation of our study was that the methods included a nurse present physically in the room with the child and family while the physician joined by screen; thus, the findings cannot be extrapolated to a strict telehealth-only model.

Importantly, studies almost universally caution that telehealth should function as a *supplement to*, rather than an entire *replacement of*, in-person care, and that issues related to training and technical problems need to be considered prior to implementation.<sup>16, 116, 120, 121</sup> In a video consult set-up, there may be benefits associated with having a nurse in the home with a patient during the telehealth consult to help to navigate communication and technical issues, as well as to benefit from important insight from the clinician on care planning.<sup>119, 120</sup> Some evidence

also points to telehealth visits being more appropriate for follow-up visits than for initial appointments.<sup>119, 120</sup> Further telehealth research warrants following the experience over a longer period of time to learn more about communication, symptom burden, quality of life, and relationships longitudinally.

Technology impacts the relational and affective component of communication.<sup>121</sup>

Telehealth has triggered historic concerns about “shifts in working patterns including the way people relate to each other.”<sup>121</sup> Prior discomfort with telehealth in palliative care emphasized risk of being an impersonal modality<sup>122, 123</sup> with worry that telehealth minimized the importance the actual touch so core to our field.<sup>122, 124-126</sup> As we creatively offer palliative care in rural and underserved settings, telehealth may serve as a modality to foster relationships and togetherness although this does require special attentiveness to communication values. One of our interviewed nurses stated: “I find myself touching the screen, even if it is not a touchscreen. I just lean in and touch the screen. I need them to know I am reaching out. With everything I have, I am reaching out. We remain connected.”



## **CHAPTER 4 - Assessment of the physical and emotional symptom burden and family impact for children with terminal cancer receiving home-based end-of-life telehealth care in rural regions<sup>4</sup>**

### **Introduction**

Data on the use of telehealth and its effect on the well-being of patients or their family caretakers is lacking. The research that does exist is largely dated and represents needs assessment or descriptive studies focused on patient satisfaction and staff perceptions.<sup>33, 52, 127, 128</sup> Little evidence exists on the effect of telehealth support in palliative or hospice care on patient or caregiver outcomes such as symptom burden, family relationships, family caregiver well-being, and location of death.<sup>25</sup> Telehealth models may improve access to preferred location of death for children and families. While our study team does not have a reliable pre-intervention tracking of refused rural hospice enrollments, we programmatically documented an increase from 12 to 55 home-based rural end of life care for all pediatric diagnoses in the past five years during which our care offerings were developed and implemented (358% increase inclusive of non-oncology diagnoses). Not much is known about palliative care patient and caregiver experiences associated with the use of telehealth, particularly for pediatric palliative care for children with cancer and especially for end of life care in pediatric oncology.<sup>34, 129, 130</sup>

According to 103 bereaved parents, 89% of children with cancer suffered “a lot” or “a great deal” from at least one symptom in the final month of life.<sup>131</sup> Pain, fatigue, and poor appetite have been previously identified as prevalent symptoms in end of life care for children with cancer.<sup>132-135</sup> Evidence on a positive effect of the use of telehospice on patient symptom burden and translated quality of life is absent for children with cancer and is lacking in the adult oncology research base, but may be suggestive of some positive impact. Bakitas et al (2009) conducted a randomized control trial of a phone-based palliative care intervention for adult

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patients with late-stage cancer diagnoses,<sup>136</sup> which resulted in a higher quality of life score and less depressive mood with some evidence for a decrease in symptom intensity for those in the intervention group.<sup>136</sup> Laila et al (2008) conducted a small case study of adult oncology patients utilizing videoconferencing to connect with their providers, finding improvements in anxiety and depression scores.<sup>137</sup> Hebert et al. found no difference in quality of life and symptom management for adult palliative care patients receiving video-visits compared to those receiving standard care.<sup>138</sup>

The objective of this study was to provide longitudinal symptom assessments for children with terminal cancer receiving home-based hospice care from an adult-trained hospice team in rural settings with scheduled telehealth support from a remote pediatric palliative care team. Symptom frequency, quality, and intensity were correlated between child and proxy-report to include parent and nurse report of the child's symptoms. The secondary objective of the study was to assess family caregiver well-being over time.

## **Methods**

This paper specifically reports on the longitudinal symptom burden and family impact study aim of the protocol approved by the Institutional Review Board. The family caregiver answered initial demographic questions on his/her relationship to the child, the child's age, and the child's diagnosis. The study included independent completion of the Memorial Symptom Assessment Scale (MSAS 7-12) the child (if able) with completion of the proxy edition (MSAS Proxy 7-12) by the family caregiver and the hospice nurse every 14 days. Each party completed and submitted the survey instruments independently on an assigned iPad. The family caregiver additionally completed a family well-being scale, the PedsQL™ Family Impact Module (PedsQL™ FIM) every 14 days. Surveys were submitted every two weeks one day prior to the scheduled family meeting which was held via telehealth for 1-hour duration. Survey responses were accessed by the study team electronically through the SurveyMonkey© survey collection platform.

The MSAS instrument was developed for oncology patients to gauge patient-reported symptom profiles inclusive of each symptom's severity, frequency, and associated distress.<sup>139</sup> The validity, reliability, and responsiveness of the MSAS has been repeatedly demonstrated for evaluating symptom patterns experienced by cancer patients, including end of life symptomatology.<sup>140-145</sup> The original MSAS was notably developed for adult cohorts, requiring revisions for versatile and developmentally-appropriate symptom assessments in pediatric patients with cancer.<sup>146, 147</sup> The pediatric edition, the MSAS (7-12), contains 8 items (pain, fatigue, sadness, pruritis, worry, loss of appetite, nausea, and insomnia) to assess the physical and psychological distress experienced by children with cancer. The MSAS (7-12) has been systematically adapted to ensure the questions were appropriate for the reading and comprehension of a patient at seven years of age and has been approved for use through age 18 years.<sup>146</sup> The validity and reliability of this instrument has been confirmed in all three subscales with overall alpha coefficient  $>0.7$ , with only a minority of children requiring assistance for its completion.<sup>146</sup> On average, pediatric cohorts complete the MSAS (7-12) in under six minutes, demonstrating its appropriate length and difficulty.<sup>146</sup> The MSAS is partnered with a proxy-reported scale which can be completed by a family caregiver or a medical staff member reporting their perspective on the child's experience.

The 36-item PedsQL™ FIM is a measure of self-reported parental perceptions of their own physical, emotional, social, and cognitive functioning; communication; and worry. The PedsQL™ FIM further explores the impact of the child's diagnosis on family daily activities and family relationships. In initial validation studies, PedsQL™ FIM scales demonstrated Cronbach's coefficient alpha scores  $>0.82$ .<sup>148</sup>

### *Statistical Analyses*

SAS for PC version 9.4 was used for all summaries and analyses. Total symptoms at each time point were calculated by counting the number of symptoms present (pain, tired, sad, itchy, worried, loss of appetite, nausea, insomnia, and other free-text symptoms) for each

respondent at each time point. This variable was summarized with the mean, standard deviation, minimum/maximum, quartiles, and median for each respondent at each time point.

Binary variables are summarized using frequency and percentages and p-values from Fisher's Exact Tests are reported where comparisons are made. Ordinal variables are summarized using minimum/maximum, quartiles, and median. P-values from nonparametric tests are presented: Kruskal-Wallis when 3 or more groups are compared and Mann-Whitney when two groups are compared. Spearman rank correlation is used to examine the relationship between ordinal variables. Statistical analyses for the PedsQL FIM™ were conducted using scale scores as the main outcome measure. Each PedsQL FIM™ item was reverse scored and linearly transformed to a scale of 0 to 100 (higher scores reflected better family function or higher perception of family well-being). Items left unanswered and questionnaires left blank (not completed after the child's death) were not included in final statistical analyses.

## **Results**

A total of fourteen children were eligible for the study. One family declined participation due to caregiver fatigue and two children who were approached for study enrollment died in the hospital setting prior to ability to arrive home for home-based hospice enrollment. The average age for the eleven participants was 11.9 years (range 8-17 years).

Telehealth interactions with the pediatric palliative care team occurred at the scheduled 14 day intervals with an average of 4.8 telehealth interactions received in total (range 2-15). The average time from home hospice enrollment to death was 21.6 days (range 4-95 days). Eleven children were able to self-report symptoms at Timepoint 1 (Day 0), seven at Timepoint 2 (Day 14), and three at Timepoint 3 (Day 21). All attrition was due to death. All children enrolled in the study reached a natural end of life in the home setting with hospice present.

### *Symptom Burden*

All children were able to self-report their symptom burden at Timepoint 1 using the MSAS 7-12 survey instrument. The average number of symptom self-reported by the child at

Timepoint 1 was 5.9 symptoms (S.D. 1.4) while hospice nurses reported the child experiencing an average 5.4 (S.D. 1.7), mothers reported 4.1 (S.D. 1.9), and fathers reported 3 (S.D. 1) symptoms.

The most frequent symptoms self-reported by the child at Timepoint 1 included: feeling tired/fatigue (91%), pain (82%), sadness (82%), loss of appetite (73%), nausea (55%), worry (55%), insomnia (18%), and pruritis (9%). In free-text mention of additional symptom burden, children reported tingling (n=2), weakness (n=2), headache (n=1), blurry vision (n=1), bruising (n=1), rash (n=1), dyspnea (n=1), constipation (n=1), dizziness (n=1), and drowsiness (n=1). Hospice nurses most frequently reported the child experiencing fatigue (100%), pain (91%), sadness (91%), and worry (82%) at the time of the child's enrollment on hospice.

Children depicted their pain at time of hospice enrollment at 2.1 (SD 1.1) on the 3-point scale, while hospice nurses and mothers both rated the child's pain severity at 2.5 (SD 0.9) and fathers rating the child's pain severity 2.0 (SD 1.7). Children reported the bothersomeness of their pain at 2.2 (SD 1.2) on the 3-point scale, while hospice nurses and mothers both rated the bothersome nature of pain at higher: hospice nurses at 2.5 (SD 0.9) and mothers at 2.4 (SD 1.0). Fathers reported the bothersome nature of the child's pain as experienced by the child much lower at 1.7 (SD 1.5).

At the time of home hospice enrollment, children recognized their level of fatigue at 2.5 (SD 1.0) on the 3-point scale, while nurses perceived children were more fatigued (2.7, SD 0.5) and parents perceived their child less fatigued (2.3, SD 1.1). Children depicted feeling less bothered (1.4, SD 1.4) about being tired than nurses (2.5, SD 0.5) and parents (1.8, SD 1.0) perceived the child felt about the fatigued.

Children, hospice nurses, and maternal caregivers reported that the severity of the child's pain decreased over time while enrolled in hospice care, while the intensity and disruption of tiredness varied (Figure 4).

While parents recognized fatigue, physical pain, and loss of appetite as primary symptoms at the time of hospice enrollment, emotional burden experienced by the child in the form of sadness and worry were notably under-recognized by parental caregivers at all three timepoints (Figure 4). Nine (82%) of children described feeling sadness while only 4 (36%) of parents identified sadness as part of the child's experience at time of hospice enrollment. Parents who did identify sadness as part of their child's experience under-recognized the severity of this emotion at 0.73 (SD 1) on a 3-point scale while children self-rated their sadness as 1.6 (SD 0.9) on the same scale. Children reported feeling bothered by sadness at 1.3 (SD 1.1) while parents depicted the bothersomeness of sadness for the child at 0.73 (SD 1.1).

Fathers did not describe worry as a symptom experienced by their child at the time of hospice enrollment, while four mothers (50%) and six children (55%) self-reported feeling worried at the time of hospice enrollment. There was not a correlation between the parental perception of worry as a symptom experienced by the child on the Proxy MSAS 7-12 and the parent's self-report of worry on the PedsQL™ FIM (p-value 0.93).

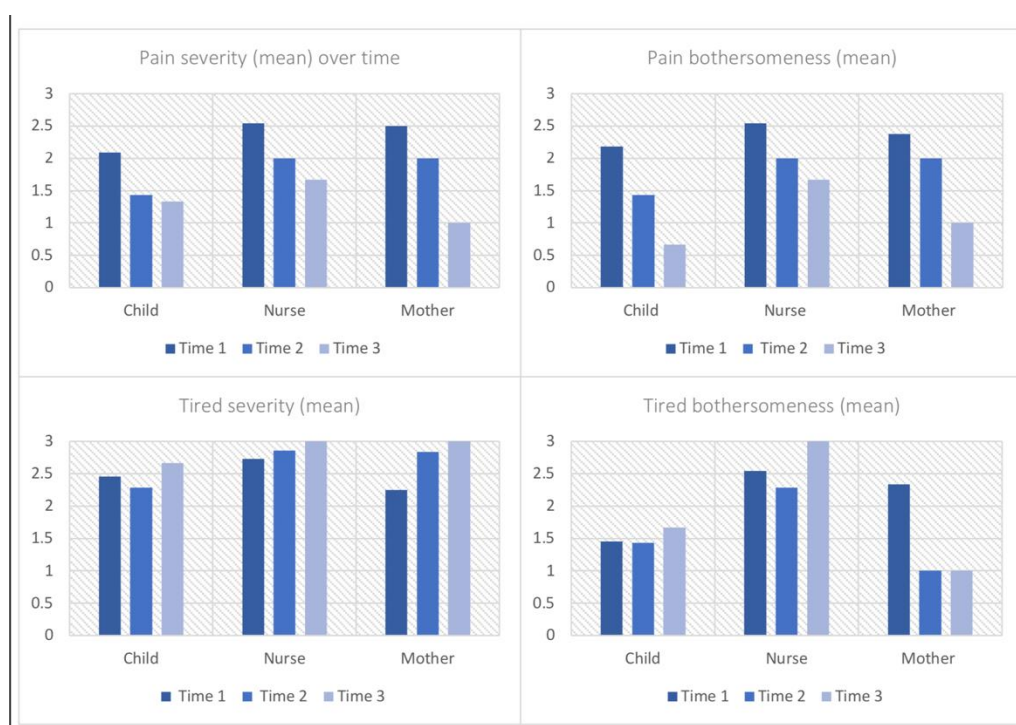


Figure 4. Symptom Development Over Time

At time of hospice enrollment, the total number of symptoms reported by the child correlated with the nurse's report of the child's symptom burden ( $p=0.035$ ). Fourteen days after hospice enrollment, the child's symptom burden correlated with both the hospice nurse ( $p=0.046$ ) and the mother's report ( $p=0.046$ ) of the child's symptom burden.

### *Family Impact*

The mean PedsQL™ FIM score (instrument score range 1-100 with higher score meaning better family well-being) at time of hospice enrollment was 46.4 (S.D. 18.7) with noted increase in family impact scores (improved family function) over the first three timepoints to 49.8 (S.D. 11.9) at Timepoint 2 and 50.7 (S.D. 6.9) at Timepoint 3. While this is not a statistically significant change, it is notably a clinically-relevant change.<sup>149</sup>

The Spearman correlation estimate for child's age and family impact scores was 0.62 ( $p$ -value 0.042), indicating as the child's age increases, family impact scores increase (higher wellness reported by the family). The  $p$ -value of 0.0422 indicates that the Spearman correlation is statistically significantly different from 0 for child's older age correlating with higher family well-being when enrolled on home hospice.

Parent gender and the child's type of cancer did not have statistically significant correlation with family impact scores in this small sample size. However, the median score for children with hematologic malignancies at time of hospice enrollment was 61.6 and for solid tumors was 46.9, while the neuro-oncology cohort was notably low at 36.9 mean family well-being score. The children of father respondents ( $n=3$ ) all had brain tumors with median paternal rating on the PedsQL™ FIM remarkably low at 19.4 while mothers of children with brain tumors ( $n=2$ ) reported median PedsQL™ FIM score 53.2 ( $p$ -value = 0.15).

## Discussion

Without a reliable link to providers trained in pediatric palliative care or hospice teams prepared to provide end of life care for children, end of life care in the home setting may not be feasible for children with cancer.<sup>12</sup> Children with cancer residing in rural regions are at risk of not having access to home-based care services, resulting in hospital-death regardless of child or family preference.<sup>1-3</sup> This study revealed a supportive role for telehospice in home-based end of life care for children with cancer residing in rural regions, specifically for physical symptom and emotional support. Symptom management, psychological/emotional aspects of care for the pediatric patient, and tangible care coordination have been identified as the most valued aspects of home-based hospice care by parents of children with life-shortening serious illness.<sup>150</sup>

### *Symptom Reporting*

This study revealed that many children with cancer are able to participate in symptom reporting, even at end of life and that children experience or report their symptoms differently than proxy perspective. Children with cancer depicted not only the presence of a symptom but also the experienced severity or bothersomeness of that symptom, fostering improved understanding about how that symptom translates into the child's actual quality of life at the end of life.

Despite data documenting that adult-trained hospice nurses have low baseline self-efficacy, confidence, and comfort in pediatric end of life care<sup>14, 151</sup>; the symptom summary of hospice nurses correlated closer with patient-reported symptom burden comparative to parent summary. Aside from the support of the telehealth model, adult-trained hospice nurses may provide instinctual childhood symptom recognition and care intervention better than they give themselves credit for despite minimal prior pediatric-specific experience. Certain symptom expertise and communication skillsets of adult-trained hospice nurses may transcend across ages, further leveraged by pediatric-specific training and professional partnerships.



Fatigue was noted to be the most prevalent symptom burden in this study. Child participants were less bothered by their fatigue than parents perceived the child to be. This may be because parents were seeking wakeful moments for memory-making and relational engagement.

Children with cancer experienced more physical and psychological symptoms than were noted by parents or staff at the time of home hospice enrollment, with notable under-recognition of the child's sadness and worry by those around the child. The marked difference in child report of sadness and parent recognition of sadness may have been family distraction by the child's excitement about getting to leave the hospital to return home (enthusiasm for home masking sadness of prognoses) or may represent a form of emotional protectionism within the family unit.<sup>152</sup> Prior investigation into agreement between child- and proxy-report of symptoms and functioning for children undergoing oncology treatment has revealed poor agreement for physical symptoms and psychosocial stress.<sup>153</sup> This warrants ongoing developmentally-informed inclusion of pediatric patients for self-report (as able) in identifying and recognizing physical changes, symptom burden, and particularly emotions.

The use of pediatric patient reported outcomes has been shown to be relevant and effective in assessment of the symptom burden in pediatric cancer populations.<sup>154-157</sup> Child-reported outcomes should be considered in end-of-life care to guide clinical decision and symptom management optimization.<sup>158</sup> Patient reported outcome tools may be considered even during end of life care in an effort to further improve patient-centered care.

The data from this small study parallels the symptom burden over time for children with cancer enrolled in other terminal care studies. Prior work has documented that suffering from pain is improved for hospitalized children with cancer with ongoing physician presence throughout end-of-life care<sup>131</sup>. By deploying telehealth, our team was able to achieve symptom-burden outcomes for children with cancer similar to both home-based and hospital-based models

<sup>131, 132</sup>.

### *Family Caregiver Experience*

The markedly low family wellness scores reported by fathers in this study and parents of children with brain tumors warrants further exploration as to parental gender or child diagnoses patterns and family function.<sup>159</sup> Although the father sample size is notably low and all included fathers had children with central nervous system tumors, fathers rated their child's quality of life scores much lower than mothers although they did not perceive a high degree of symptom burden in their child.

Overall, family impact scores were low at time of hospice enrollment in this study (meaning poor family wellness) with some improvement in family function over time. This may hint at the “compassionate care” benefit families receive from interdisciplinary home-based hospice teams companioning with the family in anticipatory grief, legacy making, and open communication.<sup>160</sup> Because family caregivers play a central role in the care of a patient receiving home-based hospice care, family caregiver support is a core function of pediatric end of life care.<sup>161</sup> Telehealth is one tool that may be utilized to support family caregivers.

While research does suggest overall satisfaction of family caregivers with telehealth in palliative practice, there is no consistent evidence for the effect of telehealth as an intervention on caregiver *outcomes* such as measures of quality of life and caregiver burden. O'Hara et al (2011) found no differences in family caregiver burden for those caring for patients receiving a phone-based palliative care intervention compared to patients receiving standard care, and note that family caregiver burden was strongly linked to patient well-being.<sup>162</sup> In an intervention designed by Demiris et al (2007), caretakers of adult patients on home hospice used videophones to communicate with hospice staff, and found that caregiver anxiety decreased significantly for participants; improvements in quality of life were non-significant.<sup>163-165</sup>

Dionne-Odom et al (2015) utilized an intensive phone-based palliative care intervention for cancer patients and found that an initiation of palliative care at the time of the diagnosis was associated with lower caregiver depression and stress burden later in the patient's disease

course.<sup>166</sup> Gagnon et al (2006) found no difference in quality of life and symptom management when comparing patients receiving conventional palliative care and patients receiving a combination of home visits and telehealth.<sup>167</sup> Kilbourn et al (2011) conducted a feasibility study of a phone-based counseling program for family caregivers of adult hospice patients and found that caregiver depression and stress scores decreased over the 12-week intervention period, while quality of life increased; interestingly, physical quality of life decreased.<sup>168</sup> Oliver et al (2010) did not find statistically-significant improvements in caretaker quality of life in their pilot study on the inclusion of family caregivers in interdisciplinary hospice team meetings via telehealth.<sup>169</sup>

Research on the utilization of telehospice and caregiver outcomes is even more limited in pediatric palliative care. Bradford et al (2012) conducted a pilot study to evaluate a home-based palliative care intervention and found no differences in quality of life between the control and intervention groups, which may at least in part be attributable to a small sample size and an unexpectedly high mortality rate among the recruited patients.<sup>37</sup> Young et al (2006) describes positive impacts on quality of life for families of children with complex health needs receiving a telehealth intervention.<sup>170</sup>

### *Tangible Impact*

Children residing in rural regions, particularly those with special health care needs, have a higher prevalence of unmet care needs as compared to children residing in urban regions and are notably at increased risk of worse health outcomes.<sup>171</sup> Interventions to decrease care barriers and to deliver high-quality health care to children in rural regions are necessary to improve existing disparity gaps.<sup>172, 173</sup>

Families of children receiving telehealth support for end-of-life care residing in rural residence describe extensive time and travel savings with centralization of care to home-setting.<sup>52</sup> Davis et al (2015) found that adult hospice patients participating in the telehealth intervention had a lower utilization of clinical services than their counterparts who were not participating in telehealth.<sup>174</sup> Another study using administrative data estimates substantial cost saving from the

use telehealth for in the place of some in-person visits for adult hospice patients.<sup>175</sup> With the modifications to telehealth billing practices during the coronavirus pandemic, palliative care providers may now recognize the clinical cost-effectiveness of telehealth outreach models.<sup>176-178</sup>

The willingness of pediatric teams to engage in telehealth-based support results in rural hospice teams previously unwilling to enroll children then willing to accept pediatric enrollments, thereby increasing child and family access to location of preference<sup>179</sup>. All of the children enrolled in this study reached end of life in the home setting. Whether the telehealth intervention enabled the child and family preference for location of death outside of the hospital (goal fulfillment) is not formally explored in this study. While child, parent, and provider preference point toward preference for home death in pediatric oncology,<sup>180</sup> inadequate home support is a recognized limiting factor in location feasibility.<sup>12, 181</sup> Future research may explore the ways telehealth may impact flexibility in location of health delivery for children with terminal diagnoses.

Limitations in this particular study include small sample size from a single center without a parallel comparator population. The pediatric family participants' familiarity with the palliative care team prior to use of telehealth may introduce reporting bias.

Challenges in research involving pediatric hospice include patient recruitment and attrition (secondary to death). The findings from this pilot study suggest the feasibility of telehealth to extend care reach into rural regions and to enable end-of-life care to occur at home. The under-recognition of physical symptom burden and especially psychological symptoms experienced by children further emphasizes the need to include patient reported outcomes even in end of life studies. This study revealed benefit for patient symptom experience and support for family caregiver well-being. As a now-bereaved parent participants shared in a letter to the study team, "she [*child*] really wanted to be home instead of the hospital and we weren't sure that would possible but this allowed us to remain on the homestead and to still feel together with each other and the team."

## DISSERTATION DISCUSSION

Telehealth has potential to extend clinical care and support to pediatric patients receiving end-of-life care in the home setting in rural regions. Using a trifecta approach of child, parent, and hospice nurse acceptance ratings; nursing staff qualitative feedback; and patient- and proxy-reported longitudinal symptom and impact outcomes – this longitudinal study revealed the potential of telemedicine to foster quality care in the location of preference for children with terminal cancer in a rural region.

### Gaps Filled

This research filled five important gaps in the existing literature:

- 1) *The measures* – The study included a review of existing measures and instruments to assess telehealth experience with attentiveness to prior use in rural cohorts. The study deployed a validated Technology Acceptance Model to explore telehealth acceptability across timepoints.
- 2) *The intervention* – The intervention *responded to the top three pediatric palliative research needs recently identified by a large Delphi study* (care coordination between health settings, symptom management, and quality innovation)<sup>182</sup>, in addition to the Institute of Medicine Dying in America priorities<sup>11</sup>, and the quality National Quality Form priorities<sup>183</sup>.
- 3) *The setting* – The study *recognized the role for team-based science and interdisciplinary collaboration in resource-limited settings with a focus on partnerships with rural hospice nurses to serving children in rural regions; it incorporated telemedicine in a humanistic way to foster transitions between care settings* (makes “home” a reality for families not able to access pediatric trained hospice providers in rural settings)<sup>184</sup>.
- 4) *The population* – This study specifically sought to study the potential to leverage telehealth to improve care for children with special healthcare needs. The proposed study

approach *honored the priority needs shared by bereaved family caregivers*<sup>185, 186</sup> for improved care for children at end of life.

- 5) *The perspectives* - This study advanced the science of palliative care by *identifying outcomes through triangulated inclusion of child, family, and team perspectives* with proactive use of child-reported outcomes in addition to proxy-report.

### **Limitations Recognized**

Limitations of the work include single state geography. While the study method would be strengthened by a cross-over approach, the unpredictable life timeline of pediatric patients enrolling in hospice does not allow for assignment based on futuristic survival. Respondent bias is a threat to the findings although use of a Research Assistant unfamiliar to participants for survey receipt may have been protective.

### **Future Direction**

The clinical impact of telehealth on symptom burden, time and travel, therapeutic relationship, and quality of life warrant ongoing research consideration. Telehealth may serve as a vehicle of meaningful clinical impact, fostering patient and family sense of connectedness in times of transition to home from the hospital or even enabling patients and families to remain at home, as the family experiences ongoing care interaction while the receiving local care team receives support. Ideally future telehealth research for patients receiving pediatric palliative care may consider methods which concurrently and longitudinally assess symptom burden, quality of life, and cost analyses via validated instruments.

### **Areas for Advancement in the Scientific Field**

Regardless of provider comfort with technology, technical difficulties in rural regions such as video connectivity and sound quality have also been identified as a frustration among rural telehospice users which, in turn, deters future use.<sup>187</sup> This study showed the ability to use

telehealth even in rural geographies in Nebraska, but caution should be paid to those encounters for which the connection may be slow or nonreliable. Lack of access to smartphone or computer services and the internet platforms required for telehealth use has further been under-studied,<sup>188</sup> raising concern about telehealth reach into under-served areas such as tribal homelands and rural regions.<sup>189, 190</sup> Additional research into ways telehealth may inadvertently further cause gaps in care equity based on technology access, internet connectivity, and user confidence and comfort with telehealth services are warranted. Caution should be taken to ensure telehealth support meets the cultural and educational needs of the communities which have not yet provided perspective on telehealth encounters. The lack of participant diversity in reporting on telehealth communication using telehealth survey instruments warrants attentiveness to inclusion to better understand perspectives on telehealth.

Telehealth, through its utilization of technology to connect medical professionals with patients and family caregivers, has been recognized as one potential solution to address critical access issues in hospice care<sup>191</sup> and is now set to turn into an essential tool in the face of the coronavirus pandemic.<sup>192</sup> The COVID-19 pandemic has resulted in a rapid surge of telehealth use in palliative and hospice practices.<sup>193-195</sup> Telehealth has historically been deployed to decrease distance between patients and palliative care professionals through the use of technology.<sup>196, 197</sup> Telehealth now creates physical distance, functioning to ensure access while affording an infection control barrier between patients and providers and preserving protective equipment.<sup>198,</sup><sup>199</sup> In recognizing the role for telehealth in the coronavirus pandemic and in the eventual post-pandemic world, the experience of palliative care patients interfacing with telehealth warrants urgent and deliberate attentiveness. As the COVID-19 pandemic has necessitated the rapid incorporation of screen modalities into palliative care, that suddenness warrants pause to consider the baseline barriers or discomforts with telehealth, particularly as they relate to the provision of palliative or hospice care.

After the pandemic both providers and patients may remain drawn to potentially attractive features of telehealth such as the ability to be seen at home, the ability to include family from other regions of the country in visits, and reductions in the need for physical office space. Patient and family caregivers deserve opportunities to provide feedback on whether telehealth encounters still maintain a sense of human connectedness and connectivity essential to the fields of palliative care and hospice care.

Under the Coronavirus Preparedness and Response Supplemental Appropriations Act, CMS specified that hospice providers may provide routine home care as well as face-to-face encounters for recertification via telehealth.<sup>200</sup> The Health and Human Services Office for Civil Rights “will exercise enforcement discretion and waive penalties for HIPAA violations”, allowing providers to communicate with patients and families via commonly utilized communication tools such as Skype and FaceTime.<sup>201</sup> The Children’s Health Insurance Program (CHIP), private insurers covering pediatric cohorts, and Medicaid reduced barriers to telehealth use for child and family caregiver behavioral health assessment and management, symptom-based care, and concurrent wellness care for children.<sup>202</sup>

In recognizing the impact of the coronavirus pandemic, there may be a norm-referenced shift in responses as survey questions regarding the “convenience” of telehealth as a communication modality are now confounded by not just time and distance saved but also perceptions of preventative public health measures. Even survey questions regarding “acceptability” are influenced by the now-normative approach to virtual interactions in non-medical settings (schooling, extended family connectedness, community gatherings) as a public health safety measure. Palliative care researchers thus warrant caution in comparing responses to current telehealth surveys in relation to a pre-set, pre-pandemic standard.

Historically, telehealth experiences and encounters have been described but not yet extensively evaluated by patients, family caregivers, or care teams. This study focused on child, family caregiver, and care team telehealth experience with attentiveness to telehealth



acceptability and impact on location of death, child symptom, and family impact. The current upsurge in telehealth use in palliative and hospice care warrants ongoing consideration of patient, family caregiver, and interdisciplinary palliative perspectives on telehealth modality and communication experiences.

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## APPENDICES

### APPENDIX A: Telehealth Systematic Review Search Terms

#### PUBMED Search:

(telehealth[Title/Abstract] OR tele-health[Title/Abstract] OR telemedic\*[Title/Abstract] OR tele-medice\*[Title/Abstract] OR telecare[Title/Abstract] OR tele-care[Title/Abstract] OR teletherapy[Title/Abstract] OR tele-therapy[Title/Abstract] OR telehospice[Title/Abstract] OR tele-hospice[Title/Abstract] OR telepalliative[Title/Abstract] OR tele-palliative[Title/Abstract] OR telerehab\*[Title/Abstract] OR tele-rehab\*[Title/Abstract] OR telegeriatric\*[Title/Abstract] OR tele-geriatric\*[Title/Abstract] OR telegerontolog\*[Title/Abstract] OR tele-gerontolog\*[Title/Abstract] OR teleoncolog\*[Title/Abstract] OR tele-oncolog\*[Title/Abstract] OR telepediatric\*[Title/Abstract] OR tele-pediatric\*[Title/Abstract] OR tele-paediatric\*[Title/Abstract] OR telepaediatric\*[Title/Abstract] OR telepsych\*[Title/Abstract] OR tele-psych\*[Title/Abstract] OR telecardio\*[Title/Abstract] OR tele-cardio\*[Title/Abstract] OR teleendocrin\*[Title/Abstract] OR tele-endocrin\*[Title/Abstract] OR telegastro\*[Title/Abstract] OR tele-gastro\*[Title/Abstract] OR teleneph\*[Title/Abstract] OR tele-neph\*[Title/Abstract] OR telepulm\*[Title/Abstract] OR tele-pulm\*[Title/Abstract] OR telerheu\*[Title/Abstract] OR tele-rheu\*[Title/Abstract] OR teleimmun\*[Title/Abstract] OR tele-immun\*[Title/Abstract] OR telepharm\*[Title/Abstract] OR tele-pharm\*[Title/Abstract] OR telenurs\*[Title/Abstract] OR tele-nurs\*[Title/Abstract] OR teledent\*[Title/Abstract] OR tele-dent\*[Title/Abstract] OR teletherap\*[Title/Abstract] OR tele-therap\*[Title/Abstract] OR telenutrition\*[Title/Abstract] OR tele-nutrition\*[Title/Abstract] OR telediet\*[Title/Abstract] OR tele-diet\*[Title/Abstract]) OR "Telemedicine"[Mesh])

AND

(survey\*[Title/Abstract] OR questionnaire\*[Title/Abstract] OR instrument\*[Title/Abstract] OR checklist\*[Title/Abstract] OR score\*[Title/Abstract] OR scale\*[Title/Abstract] OR index\*[Title/Abstract] OR likert[Title/Abstract] OR tool\*[Title/Abstract] OR "Surveys and Questionnaires"[Mesh])

AND

(comfort\* OR discomfort\* OR uncomfot\* OR satisf\* OR dis-satisf\* OR unsatisf\* OR content\* OR dis-content\* OR experien\* OR feel\* OR happ\* OR unhapp\* OR ambivalen\* OR attitud\* OR opinion\* OR belief OR believ\* OR percep\* OR perceiv\* OR assess\* OR evaluat\* OR usab\* OR useful\* OR unusab\* OR qualit\* OR accept\* OR pleased OR dis-pleas\* OR pleas\* OR rate OR rating OR rated OR excell\* OR adequate\* OR inadequate\*)

AND

(communicat\* OR heard OR hear OR hearing OR listen\* OR interact\* OR dialog\* OR biplay\* OR convers\*)

AND

(validity OR reliability OR consistency OR psychometric OR develop\* OR creat\* OR design\* OR generat\* OR build\*)

NOT

("case reports"[Publication Type] OR "editorial"[Publication Type] OR "letter"[Publication Type] OR "comment"[Publication Type])

#### EMBASE Search:

(telehealth:ti,ab OR 'tele health':ti,ab OR telemedic\*:ti,ab OR 'tele medic\*':ti,ab OR telecare:ti,ab OR 'tele care':ti,ab OR teletherapy:ti,ab OR 'tele therapy':ti,ab OR telehospice:ti,ab OR 'tele hospice':ti,ab OR telepalliative:ti,ab OR 'tele palliative':ti,ab OR telerehab\*:ti,ab OR 'tele rehab\*':ti,ab OR telegeriatric\*:ti,ab OR 'tele geriatric\*':ti,ab OR telegerontolog\*:ti,ab OR 'tele

gerontolog\*:ti,ab OR teleoncolog\*:ti,ab OR 'tele oncolog\*:ti,ab OR telepediatric\*:ti,ab OR 'tele pediatric\*:ti,ab OR 'tele paediatric\*:ti,ab OR telepaediatric\*:ti,ab OR telepsych\*:ti,ab OR 'tele psych\*:ti,ab OR telecardio\*:ti,ab OR 'tele cardio\*:ti,ab OR teleendocrin\*:ti,ab OR 'tele endocrin\*:ti,ab OR telegastro\*:ti,ab OR 'tele gastro\*:ti,ab OR teleneph\*:ti,ab OR 'tele neph\*:ti,ab OR telepulm\*:ti,ab OR 'tele pulm\*:ti,ab OR telerheu\*:ti,ab OR 'tele rheu\*:ti,ab OR teleimmun\*:ti,ab OR 'tele immun\*:ti,ab OR telepharm\*:ti,ab OR 'tele pharm\*:ti,ab OR telenurs\*:ti,ab OR 'tele nurs\*:ti,ab OR teledent\*:ti,ab OR 'tele dent\*:ti,ab OR teletherap\*:ti,ab OR 'tele therap\*:ti,ab OR telenutrition\*:ti,ab OR 'tele nutrition\*:ti,ab OR telediet\*:ti,ab OR 'tele diet\*:ti,ab OR 'telemedicine'/exp OR 'telemedicine')

AND

(survey\*:ti,ab OR questionnaire\*:ti,ab OR instrument\*:ti,ab OR checklist\*:ti,ab OR score\*:ti,ab OR scale\*:ti,ab OR index\*:ti,ab OR likert\*:ti,ab OR tool\*:ti,ab OR 'surveys and questionnaires'/exp OR 'surveys and questionnaires')

(comfort\* OR discomfort\* OR uncomfot\* OR satisf\* OR 'dis satisf\*' OR unsatisf\* OR content\* OR 'dis content\*' OR experien\* OR feel\* OR happ\* OR unhapp\* OR ambivalen\* OR attitud\* OR opinion\* OR 'belief'/exp OR belief OR believ\* OR percep\* OR perceiv\* OR assess\* OR evaluat\* OR usab\* OR useful\* OR unusab\* OR qualit\* OR accept\* OR pleased OR 'dis pleas\*' OR pleas\* OR rate OR rating OR rated OR excell\* OR adequate\* OR inadequate\*)

AND

(communicat\* OR heard OR hear OR 'hearing'/exp OR hearing OR listen\* OR interact\* OR dialog\* OR biplay\* OR convers\*)

AND

('validity'/exp OR validity OR 'reliability'/exp OR reliability OR 'consistency'/exp OR consistency OR psychometric OR develop\* OR creat\* OR design\* OR generat\* OR build\*)

AND

('article'/it OR 'article in press'/it OR 'erratum'/it OR 'letter'/it OR 'review'/it OR 'survey'/it)

AND

(English)/lim

NOT

(case report)/de

CINAHL Search:

(telehealth OR tele-health OR telemedic\* OR tele-medic\* OR telecare OR tele-care OR teletherapy OR tele-therapy OR telehospice OR tele-hospice OR telepalliative OR tele-palliative OR telerehab\* OR tele-rehab\* OR telegeriatric\* OR tele-geriatric\* OR telegerontolog\* OR tele-gerontolog\* OR teleoncolog\* OR tele-oncolog\* OR telepediatric\* OR tele-pediatric\* OR telepaediatric\* OR telepaediatric\* OR telepsych\* OR tele-psych\* OR telecardio\* OR tele-cardio\* OR teleendocrin\* OR tele-endocrin\* OR telegastro\* OR tele-gastro\* OR teleneph\* OR tele-neph\* OR telepulm\* OR tele-pulm\* OR telerheu\* OR tele-rheu\* OR teleimmun\* OR tele-immun\* OR telepharm\* OR tele-pharm\* OR telenurs\* OR tele-nurs\* OR teledent\* OR tele-dent\* OR teletherap\* OR tele-therap\* OR telenutrition\* OR tele-nutrition\* OR telediet\* OR tele-diet\* OR "Telemedicine")

AND

(survey\* OR questionnaire\* OR instrument\* OR checklist\* OR score\* OR scale\* OR index\* OR likert OR tool\*)

AND

(comfort\* OR discomfort\* OR uncomfot\* OR satisf\* OR dis-satisf\* OR unsatisf\* OR content\* OR dis-content\* OR experien\* OR feel\* OR happ\* OR unhapp\* OR ambivalen\* OR attitud\* OR opinion\* OR belief OR believ\* OR percep\* OR perceiv\* OR assess\* OR evaluat\* OR usab\* OR useful\* OR unusab\* OR qualit\* OR accept\* OR pleased OR dis-pleas\* OR pleas\* OR rate OR rating OR rated OR excell\* OR adequate\* OR inadequate\*)

AND

(communicat\* OR heard OR hear OR hearing OR listen\* OR interact\* OR dialog\* OR biplay\*  
OR convers\*)

AND

(validity OR reliability OR consistency OR psychometric OR develop\* OR creat\* OR design\*  
OR generat\* OR build\*)

NOT (editorial OR case study)

## APPENDIX B: Telehealth Instrument Constructs, Content, and Psychometric Properties

Scale	Constructs	Exemplary technology modality questions	Exemplary human interaction questions	Psychometric properties
Telehealth Satisfaction Scale (TeSS)	Quality, length of time to access, personal comfort, ease of use, privacy, attitude	"How satisfied were you with the voice quality of the equipment?"	"How satisfied were you with the thoroughness, carefulness and skillfulness of the health care team?"	Cronbach's alpha 0.9  Items reported as valid based on eigenvalue >1.
Technology Acceptance Model (TAM)	Perceived usefulness, perceived ease of use, attitude, intention to use	"It was simple to use this system"; "The way I interact with this system is pleasant"	NA	Cronbach's alpha 0.91  Items reported valid based on the high value of loading factor (>0.5).
Telemedicine Satisfaction and Usefulness Questionnaire (TSUQ)	Perceived usefulness, perceived effectiveness, perceived ease of use, attitude, intention to use, comparing telemedicine to in-person	"I can always trust the equipment to work"	"Provider engages me in my care"; "Provider gets a good understanding of my concerns"	Cronbach's alpha 0.92  Construct validity supported by a two-factor solution, Video Visits and Impact and Use, which explain 64% of variance.
Patient Assessment of Communication During Telemedicine (PACT)	Patient-centered communication, provider competence, interpersonal skills, convenience	NA	"How much did your doctor understand what you were going through emotionally?"; "Did you and your doctor decide together which of your concerns was most important to you?"	Cronbach's alpha 0.9  Developed based on a previously validated patient satisfaction instrument.
Telemedicine Perception Questionnaire (TMPQ)	Communication, privacy/confidentiality, time and cost savings, difficulty, accessibility, physical contact, trust in equipment, standardization for future, satisfaction	"I trust this equipment to work;" "My privacy is maintained with this technology"	"Clinician can get a good understanding of my medical problem"; "Can be as satisfied as if talking in person"	Cronbach's alpha 0.83  Robust face, construct, and content validity processes reported.
Telehealth Usability Questionnaire (TUQ)	Usefulness, ease of use and learnability, interface quality, interaction quality, reliability and effectiveness, satisfaction	"The system is simple and easy to understand"; "I could hear the clinician clearly using the telehealth system"	"I think the visits provided over the telehealth system are the same as in-person visits"	Cronbach's alpha 0.8  Due to development from prior validated scales, validity not reported.

Telemedicine Satisfaction Questionnaire (TSQ)	Satisfaction, technical quality, interpersonal manner, communication, financial aspects, time, accessibility and convenience	"I can hear my health-care provider clearly"	"Health-care provider is able to understand my health-care condition"; "I feel comfortable communicating with my health-care provider"	Cronbach's alpha 0.93  Three components with eigenvalues > 1.0, which together explained 68% of the total variance.
System Usability Scale (SUS)	Usability primarily; also technical quality, ease of use, complexity of use, and user confidence	"I do not think that I would need the support of a technical person to be able to use this system"; "I found the various functions of this system well integrated"	NA	Cronbach's alpha 0.92  Moderate convergent validity reported with other measures of usability.
Perceived Efficacy in Patient-Physician Interactions (PEPPI-5)	Efficacy primarily; confidence in ability to access care, make the most of visit, act upon conversation	NA	"How confident are you in your ability to ask questions? And, to get answers in this visit?"	Cronbach's alpha 0.92  High structural and construct validity reported.
Patient Experience Questionnaire (PEQ)	Communication experience, emotions, short-term outcomes, barriers, relationship	NA	"The doctor understood what was on my mind"; "It was a bit difficult to connect with the doctor"	Cronbach's alpha 0.7  Good construct validity described.
Computer System Usability Questionnaire (CSUQ)	System usability and capability	"The interface of this system is pleasant"; "This system has all the functions and capabilities I expect it to have"	NA	Cronbach's alpha 0.9  Correlation validity 0.4; reasonable concurrent validity reported.
Telenursing Interaction and Satisfaction Questionnaire (TISQ)	Perceived interaction; inclusive of affective support, health information, decisional control, professional/technical competence) understanding, satisfaction	NA	"Did you perceive that you were given the opportunity to ask all your questions?"; "How satisfied were you with the nurse's ability to support you affectively?"	Cronbach's alpha 0.82  Good content validity reported.

### Appendix C: Benefits and Challenges of Pediatric Telehealth Care According to Nurse Participants

Benefit Themes (n=5)	Benefit Description  <i>Caution Mentioned</i>	Participant Reporting Benefit and Caution n=___/15 (%)	Exemplary Quotes
Accessible Support	Enabled the family and nurse to access immediate support for symptom management or medical changes.  <i>Risks over-utilization.</i>	Benefit n=15 (100%)  Challenge n=5 (33%)	Benefit Quotes: “When he had a seizure, I felt most supported being able to call in real-time with an update and the family felt supported by the ready access.” “Discussing the pain plan together helped me to feel confident about our options and helped [the family] feel supported.”  Caution Quote: “Sometimes [child’s mom] wanted me to call the doc at the start of every visit before I even did my symptom assessment because she felt like the screen made the doc available any time even if there wasn’t really a question to ask yet.”
Participant Inclusion	Inclusion of additional team and family members.  <i>Risks missing a personal touch for the participants.</i>	Benefit = 14 (93%)  Challenge = 8 (53%)	Benefit Quote: “We were able to include both parents and grandparents and that wouldn’t have worked for their work schedules otherwise to all be together at one time.” “Our social worker could join in even though the commute time from her last home visit would have made it not possible otherwise.”  Challenge Quote: “More people can maybe access it but there still is something about a hug or a hand held. You know, that physical and actual presence which is hard to create unless there. . . Beyond a screen, the hands-on is part of the experience for them and also for me in my nursing touch.”
Timely Communication	Allowed for timely goals of care communication.  <i>Risks rushing content without “reading the room”.</i>	Benefit = 11 (73%)  Challenge = 4 (27%)	Benefit Quote: “I didn’t know how to really talk about death with him [adolescent] and so having someone who does this type of conversation with teenagers right there on the screen helped and [adolescent] was good with the technology and that made the conversation easier and better for all of us.” “The mom was acting like we were home health. So, the doctor being there on the screen talking about the benefits of hospice at the first couple visits helped us be able to talk right then more openly about the bigger goals and hospice-specific goals.”  Challenge Quote: “Being in the room, I can feel the body language and the general readiness of the parents to really get into these

			goals but I think from the side of the screen it probably feels like we are all ready at that moment. The mom may be actually giving off a subtle nervous vibe that is hard to see across a computer and can really only be felt sitting next to her on the sofa.”
Informed and Trusted Plan	<p>Fostered clarity of care plan together with larger medical team; built trust in communication and care.</p> <p><i>Risks family’s trust in their own intuition or the prior messaging.</i></p>	<p>Benefit = 10 (67%)</p> <p>Challenge = 4 (27%)</p>	<p>Benefit Quote: “Sitting together with the team on the screen gave [relative] a sense of confidence that this dose increase was worth the possible side effects. The telehealth times helped him trust and validated the care”</p> <p>“We were able to together come up with clear plans for terminal dyspnea. We discussed options and what to do in various scenarios and they knew that the entire medical team knew since we were all there on the screen right before he died.”</p> <p>Challenge Quote: “The family knew how long she had left by their own intuition but seemed like they wanted the safety of the screen instead of the power of their own intuition.”</p>
Familiarity Fostered	<p>Included team members already familiar to the patient and family.</p> <p><i>Risks delaying development of new relationships.</i></p>	<p>Benefit = 9 (60%)</p> <p>Challenge = 7 (47%)</p>	<p>Benefit Quote: “In telehealth, she was talking about how [the patient] did not historically respond to certain meds which are usually our first-line on formulary. [Parent] seemed relieved that their child’s history was known and shared in front of them on the screen.”</p> <p>“The fact that we knew the name of her favorite stuffed animal did seem to help on the screen to have a bit of “being known already” to help the screen be more personal.”</p> <p>Challenge Quote: “Professional validation was immediate because of the more familiar telehealth visits but a personal relationship took longer.”</p> <p>“The knowledge is immediate but the relationship and rapport are slower by screen.”</p>