



Satisfaction with Telehealth Psychoeducational Intervention in Paediatric Palliative Care: A Pilot Study

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Abstract

Objective: Assess pediatric patients with life-limiting conditions and their parents' ratings of comfort and satisfaction with using telehealth modalities for a pilot psychoeducational skills intervention.

Methods: Pediatric palliative care patients and their families were enrolled in a six-month long psychoeducational skills building pilot study. Pediatric patients met individually and as a group with their parents via a zoom telehealth platform with two trained mental health practitioners to learn coping and relaxation strategies as well as improve communication about distressing symptoms. Parents and children completed a satisfaction survey and participated in a semi-structured exit interview. The interviews were transcribed and analyzed using a grounded theory approach. **Results:** Overall, parents and children were satisfied with the telehealth aspect of the intervention, however, children were significantly more comfortable with the concept in general. Qualitative analysis of the interviews yielded similar results with parents and children both reporting satisfaction with telehealth services, but parents also advocating for periodic in-person sessions. Upon review of the free-response section of the satisfaction survey, it became apparent that children had a greater preference for individual meetings than parents.

Conclusions: Results provide evidence that telehealth services increase access to care for families of children with life-limiting illnesses. The positive response to the telehealth modality of this pilot study suggests that a larger follow-up study be conducted to determine best practice models in delivering mental health services to this vulnerable population.

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Introduction

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement [1].

As pediatric palliative care services increase in availability both in-person and virtually using telehealth, there yet has been the same availability of mental services tailored to meet the needs of this vulnerable population. Mental health care plays a key role in reducing symptoms and suffering of critically-ill patients [2,3] as well as promoting adherence to medical regimens [4]. In turn, preventative mental health interventions provided via telehealth in the comfort of a pediatric patient's home, such as anxiety management and symptom communication training, can lead to a reduction of ER visits and other costly medically based services.

Patients and their families have reported that virtual, pediatric palliative care has been comparable, if not better than in-person care [5,6]. Patients and their families receiving telehealth also have been found to benefit from decreased travel times, decreased costs, improved communication, and some have experienced improved outcomes compared to in-person visits due to telehealth [7,8,6,9]. Thus, virtual appointments may be an especially attractive alternative for more vulnerable, physically compromised pediatric patients lacking adequate transportation or seeking treatment at distant facilities.

Despite having many advantages, telehealth in pediatric palliative care may also have drawbacks. For example, although telehealth may significantly improve accessibility, it also prevents healthcare providers from capturing whole body language and performing physical exams [10]. It is also unclear how comfortable vulnerable pediatric patients with life limiting conditions are about communicating their feelings and other sensitive information over a computer screen. The purpose of the current study is to evaluate the satisfaction and comfort of pediatric patients with life-limiting conditions and their parents' comfort and satisfaction with utilizing telehealth for mental health type services in their homes.

Material and Methods

The research highlighted in this paper belongs to a larger pilot psychoeducational skills training program, called Project CARE. Project CARE (standing for Comfort and Reflective Expression) provides interventions aimed at improving coping and symptom communication between parents and their children with life-limiting illnesses. Through Project CARE, children with life-limiting illnesses and their primary caregiver received 6 months of weekly psychoeducational skills interventions consisting of communication training as well as dyadic coping skills and relaxation training, all aimed at improving biobehavioral outcomes for these families. Since families with critically ill children rarely have opportunities to seek specialized mental health services outside of the home, a key objective of Project CARE was to offer these interventions in the home both via in-person and telehealth services. The current study assesses the feasibility of administering the intervention via telehealth services. Parents and their children participated in the study following written parental consent and child assent. All partici-

pants were recruited through UCLA Health and the study protocol was granted Institutional Review Board approval. It should be noted that the program was initially a mix of in-person and telehealth visits, however due to COVID-19 it was adapted to be fully telehealth. Of the twelve parent-child dyads who enrolled in the study, nine completed participation and contributed to the qualitative and quantitative data analyzed in this report. Two dyads withdrew from the study, and one was removed due to the child's severe anxiety interfering with their ability to participate. The demographic make-up of the study participants is displayed in Table 1.

Two psychologists, one working with parents (age range: 34-55) and another working with the children (age range: 9-21), implemented the intervention, administered questionnaires, and performed semi-structured interviews over the telecommunication platform, Zoom. The program included sessions where the psychologists and parent-child dyad all met together. A comprehensive battery of psychosocial questionnaires (medical demographics, pediatric symptoms, pediatric quality of life, parent psychological distress, coping resources, satisfaction with communication, family environment, spirituality/religiosity, and child PTSD inventories) were administered separately to parents and children at different time points, which included a telehealth evaluation survey and a semi-structured exit interview aimed at assessing their satisfaction with the program. The interviews provided participants with the opportunity to expand upon their responses to the telehealth evaluation survey (see Figure 1). Interviewers prompted participants with guided questions to ensure all pertinent concepts were addressed. The guided questions for parents were:

1. What were your feelings about the time commitment required by the program?
2. In general, what changes, if any, did the program have on your satisfaction with the communication you have with your child about his/her symptoms? What about the impact you feel it may have had on your child's quality of life? Your family's quality of life?
3. Throughout the program, what have your experiences been when discussing physical versus emotional symptoms with your child?
4. What symptom or symptoms bothers your child the most? What effect, if any, did the intervention have on your satisfaction with your communication with your child about this symptom?
5. What other parts of the program stood out to you? Were you able to use some of those skills in your everyday life? How?
6. How did you feel about the telehealth portion of the study?
7. What recommendations would you offer to improve the program? Interview questions for parents and children were similarly worded.

Qualitative Data Analysis

Participant interviews were audio and video recorded and transcribed verbatim into a standard format. All interviews went through two rounds of reliability checking with the exception of one parent-interview conducted in Spanish. The mean length of parent interviews was 158.89 lines (range: 56-307).

The mean length of child interviews was 95.33 lines (range: 46-139). A grounded theory approach was used to analyze the data in NVivo, a qualitative coding software program, to allow for the identification of themes organically occurring in the data [11]. Research assistants and the research coordinator independently reviewed the first three pairs of interviews and came together to identify a base list of concepts observed in the initial review of the data. Those concepts were organized into a preliminary codebook with the semi-structured interview prompts providing the higher order thematic scaffold. Definitions and select agreed upon examples were added to the codebook to facilitate coding, promote reliability, and minimize rater bias. When appropriate, data could be double-coded and marked as such. Regular meetings were held to resolve discrepancies in coding and to make adjustments to the codebook as needed. Lastly, a research assistant and the research coordinator independently coded three individual interviews (two parent and one child), and upon reaching .80 or higher interrater reliability, the finalized codebook was used to analyze each transcript independently by the research assistant and the research coordinator. Percent agreement and kappa values were calculated for each code and the principal investigator acted as a tiebreaker for any remaining discrepancies. Refer to Table 5 for a breakdown of interrater agreement and qualitative code frequencies regarding satisfaction with the telehealth aspect of Project CARE.

Results

Participant Characteristics

Pediatric patients ranged in age from 9 years to 21 years (mean age 14.67). Medical diagnoses were categorized primarily as muscular dystrophy (89%) and having multiple organ transplants (11%). 78 percent of the patients were male. More than 55% of the parents self-reported race/ethnicity as Latine (55.5%, *n*=5), 22% were Caucasian, and 22% were Pacific Islander. All understood written and spoken English; however, one parent used Spanish as the primary language to converse with the interviewer. The most common level of education was partial college or specialized training. Families resided from a distance of 7.6 miles to 89.9 miles (*M*=28.82 miles) from the UCLA Medical Center Campus (Table 1).

Descriptive Analysis of Quantitative Telehealth Evaluation

On a quantitative measure of telehealth satisfaction (Table 2), pediatric patients rated the highest mean satisfaction with the technical feasibility of the telehealth aspect of the program (*M* = 4.56, *SD* = .527) and the least satisfied with their comfort of telehealth use (*M* = 4.11, *SD* = .782). All pediatric patients rated telehealth satisfaction items relatively high (overall mean score = 4.306, on a likert scale of 1 lowest to 5 highest, *SD* = .464). Parents also rated overall telehealth satisfaction relatively high (*M* = 4.267, *SD* = .679). Parents rated that they would most likely use telehealth again (*M* = 4.56, *SD* = .527) although comfort with telehealth was rated lowest out of the group of satisfaction variables (*M* = 3.78, *SD* = 1.093). There was significant disagreement ($\kappa = -0.397, p < .05$) regarding comfort with telehealth between pediatric patients and their parents (Table 4).

On a free response subsection of the quantitative evaluation (Figure 1), pediatric patients and parent participants recorded additional feedback as part of the telehealth evaluation (Table 2). Comments generally supported the adjunctive use of telehealth and found it to be an effective method for psychoeducational skills training.

Qualitative Data Regarding Telehealth Usage

A qualitative exit interview was conducted with both the pediatric patient and parent separately regarding program satisfaction and thoughts for future program improvement. Table 5 summarizes the telehealth aspects covered. Overall, there were more endorsements of being satisfied with the use of telehealth (27 endorsements) than those endorsements indicating that in-person was preferred (7 endorsements) or that there were issues with feasibility (3 endorsements).

Table 1: Project CARE Participant Demographics.

Characteristic	Child	Parent
	No. (%), <i>n</i> = 9	No. (%), <i>n</i> = 9
Distance (mi), mean (range)	28.82 (7.66-89.90)	
Annual Household Income*		
\$10,000-\$19,999	2 (22.22)	
\$20,000-\$39,999	0	
\$40,000-\$59,999	3 (33.33)	
\$60,000-\$79,999	1 (11.11)	
\$80,000-\$99,999	1 (11.11)	
\$100,000-\$149,999	1 (11.11)	
Age, mean (range)	14.67 (9 - 21)	42.14 (34 - 55)**
Child's Gender		
Male	7 (77.78)	--
Female	2 (22.22)	--
Child's Diagnosis		
Muscular Dystrophy	8 (89.89)	--
Multiple Organ Transplant	1 (11.11)	--
Receiving Schooling & Aid		
Schooling	7 (77.78)	--
Special Ed	5 (55.56)	--
Special Services in the Home	6 (66.67)	--
Fluent in English	9 (100)	8 (89.89)
Ethnicity		
Latine	5 (55.56)	5 (55.56)
Caucasian	2 (22.22)	2 (22.22)
Asian/Pacific Islander	2 (22.22)	2 (22.22)
Participating Parent		
Mother	--	8 (89.89)
Father	--	1 (11.11)
Highest Level of Education of Participating Parent		
Less than 7th grade	--	2 (22.22)
Partial high school	--	0
High school graduate	--	0
Partial college or specialized training	--	4 (44.44)
Bachelor's degree	--	2 (22.22)
Graduate/professional training	--	1 (11.11)

Note: Displayed demographics feature only dyads that completed participation in Project CARE. Direct distance, in miles, calculated from provided latitude and longitude to UCLA Ronald Regan Medical Center's latitude and longitude in Excel. * Missing data from a dyad. ** Missing data from two parents.

Table 2: Project CARE Telehealth Evaluation Free Response

Prompt	Child Responses	Parent Responses
<p>If you were going to do something different with the USE of telehealth within the program, what recommendations would you make?</p>	<p>"Have some of the meetings in person, if it wasn't COVID." "Not really. Maybe more games and video making." "It gave us the opportunity to talk." "The zoom comfort got better over time, some of the emotional stuff is harder."</p>	<p>"If going to use it, you guys used it well. However, I would prefer it in person." "Everything is ok; it feels better in person but it is ok. It felt safe with COVID, would like in person but this felt safe with COVID." "Everything was good and easy." "Would have been the same with in person and telehealth." "I don't have any because didn't have problems. Everything worked well." "Go to in-person." "I don't have any; it has worked very well."</p>
<p>Do you have any suggestions for us as a new telehealth program that might be useful as we continue to build and implement Project CARE?</p>	<p>"More alone time on the zoom and not so much with other family members." "None, just more meetings with zoom. Wants to stay involved." "After COVID is over, to have in-person visits mixed with zoom." "More visits, longer time." "Additional time with program."</p>	<p>"I think the survey may be completed and returned rather than done online during a telehealth session. I would rather spend time with you versus doing this questionnaire. Easier if I could record answers, then could discuss further and discuss content that interest us as doctors." "Not really any suggestions." "None so far, all good." "No everything was good with email ahead of time it is all good how we are doing it." "Honestly, I don't." "Some modules interactive record answers instead of typing pre-defined forms different analytical tool so you can see trend save manual efforts he is here to help with that." "No I think it has gone very well; I like the breakout rooms."</p>
<p>Tell us about your experience using the telehealth modality for individual versus group/family sessions.</p>	<p>"I preferred the alone meetings compared to meeting with other family members being part of the meetings." "I liked the time I met alone with you better than when we met together with my family." "It was a good mix of having both. I liked when we did group meetings." "It was a good balance. I also liked when my dad and sister were able to join." "Liked having combination of individual and group." "I liked both." "Liked the individual breakout rooms better than the group meetings because more focused on him and quieter." "Thought both parts were equally helpful and needed parts of the program." "I liked both. I liked having my own time for the individual part and the group part was more familiar to me."</p>	<p>"I think it is more effective for an individual session because of sound delays and more than one person talking at a time happens." "It was good, we get [Sibling] gets her own private it was ok start all together then break it was ok. Hard for people who don't know how to use electronics." "Individual was good to voice opinions feelings and any questions we might have it was easy. Group family it was also good the experience was good." "It was good because you have breakout rooms can have family therapy and also individual therapy – not difficult." "Maybe sometimes may want to have the in person- both would be helpful." "Never had a session like this, so she liked having something like this." "Yes, absolutely, I really liked that. It was more comfortable with me and [Child] in the separate meetings with [Interviewer 2] and [Interviewer 1]. Very beneficial, would highly recommend." "More private individual and able to express myself more freely than in group because we have different opinions or we disagree. I felt supported and listened to. Groups were helpful; I heard her side because she does not provide that as easily to me."</p>

Note: Missing or one word responses have been omitted. The prompt "How **easy** was it to use the telehealth program on your electronic device" was also omitted due to know qualitative responses. Participant and interviewer names have been redacted.

Table 3: Project CARE Telehealth Evaluation Descriptive Statistics.

Variable	Child Report		Parent Report	
	M	SD	M	SD
Comfort with Telehealth	4.11	0.782	3.78	1.093
Satisfaction Compared to In-Person	--	--	4.22	1.093
Effectiveness of Telehealth Communication	4.33	0.707	4.22	1.093
Technical Feasibility	4.56	0.527	4.56	0.527
Would use Telehealth again	4.22	0.833	4.56	0.527
Total Telehealth Rating	17.22	1.856	21.33	3.391
Average Telehealth Rating	4.306	0.464	4.267	0.679

Note: Variables were measured using a likert scale (1 = not, 2 = a little, 3 = somewhat, 4 = quite, 5 = very). The variable, "Satisfaction compared to in-person" was omitted for child report due to it being beyond their comprehension.

Table 4: Parent-Child Agreement on Project CARE Telehealth Evaluation.

Variable	R Value	Kappa Value
Comfort with Telehealth	0.033	-0.397*
Effectiveness of Telehealth Communication	-0.108	-0.038
Technical Feasibility	0.55	0.55
Would use Telehealth again	-0.032	-0.102
Average Telehealth Rating	0.245	-0.025

Note: * Indicates significance at $p < .05$.

Table 5: Qualitative Interview Frequencies of Telehealth Endorsements

Qualitative Code	Description	Total N = 18	Child Endorsements** n = 9	Parent Endorsements* n = 9	Qualitative Coder Rating Agreement	
					(%)	Kappa Value
Dissatisfaction with Telehealth	In-person is better.	7	1	6	100.00	1.00
General Telehealth Comments	Comments acknowledging Telehealth, but not impact on experience.	6	4	2	99.20	0.90
Satisfaction with Telehealth	Advantages about using telehealth.	27	15	12	100.00	1.00
Technical Difficulties	Feasibility issues with telehealth.	3	0	3	100.00	1.00

Note: Overall unweighted kappa value for coders is .98 (calculated by paragraph because of formatting used in transcription process). * Frequencies indicate the number of times a topic was endorsed across parent qualitative interviews. ** Frequencies indicate the number of times a topic was endorsed across child qualitative interviews.

ID #: _____ Date: _____

Project CARE Telehealth Evaluation – PARENT VERSION
(Highlight the # that best matches how you feel)

CONCEPT
1. How *comfortable* were you with idea of *telehealth* services being incorporated into the program?
1-----2-----3-----4-----5
Not comfortable a little comfortable somewhat comfortable quite comfortable very comfortable
If you were going to do something different with the USE of telehealth within the program, what recommendations would you make?

CONTEXT
2. How *satisfied* were you with the telehealth follow-up *in comparison to in-person visits*?
1-----2-----3-----4-----5
Not satisfied a little satisfied somewhat satisfied quite satisfied very satisfied

COMMUNICATION
3. How *effective* do you feel the communication was using the telehealth modality?
1-----2-----3-----4-----5
Not effective a little effective somewhat effective quite effective very effective

TECHNICAL
4. How *easy* was it to use the telehealth program on your electronic device?
1-----2-----3-----4-----5
Did not easy a little easy somewhat easy quite easy VERY easy

COMMENTS _____

SUGGESTIONS
5. Do you have any suggestions for us as a new *telehealth* program that might be useful as we continue to build and implement Project CARE?

FUTURE SESSIONS
6. How *likely* are you to use *telehealth* services for supportive and/or mental health care type services?
1-----2-----3-----4-----5
Not likely a little likely somewhat likely quite likely very likely

7. May we contact you for additional questions in case we need additional input to sustain/improve this service?
- YES - NO

INDIVIDUAL/GROUP SESSIONS
8. Tell us about your experience using the telehealth modality for individual versus group/family sessions.

BARRIERS
9. Do you think the telehealth program helped to remove cultural and/or language differences as a barrier to receiving quality care?
- YES - NO - N/A

THANK YOU FOR COMPLETING THIS IMPORTANT SURVEY!

FINAL Version 2019-E. Evan

Note: Children received a similarly worded and formatted version of the same evaluation form.

Figure 1: Project CARE Telehealth Evaluation Form.

Discussion

A pilot sample of children with life limiting illnesses and their parents who participated in the Project CARE program were, overall, satisfied with the telehealth aspect of the program and found telehealth to be an effective modality in receiving psychoeducational intervention services. When pediatric participants were asked to comment on their experiences using telehealth for the program, some examples of comments were: "It gave us the opportunity to talk," "None (re: to improve on), just more meetings with zoom. I want to stay involved," and wanting "Additional time with the program." Similarly, parents did note regarding telehealth use: "...I didn't have any problems. Everything worked well," "...I like the breakout rooms." Overall, there was a higher number of endorsements for telehealth and a lower number of endorsements for in-person being preferred.

Although there were more positive reports on the quantitative ratings, participants provided more detailed feedback in areas of the evaluation that asked for additional comments/free responses. When mentioning in-person services in comparison to telehealth, they mostly favored incorporating in-person time with telehealth as a hybrid approach (e.g., "After COVID is over, to have in-person visits mixed with zoom"). The pilot of our intervention study during the main quarantine period of the COVID pandemic from 2020-2021, provided us with an interesting historical snapshot of the needs of children with life-limiting conditions. Namely, the scarcity of medical resources (including home care staff availability), social distancing and quarantine limitations before the availability of a vaccine, which in turn,

lent to additional feelings of distress and isolation in an already vulnerable medical population, created a unique opportunity to pilot a telehealth mental health intervention. Other studies evaluating telehealth satisfaction and efficacy during COVID demonstrate similar results, which support the benefits of using this modality [12,13,14]. It would be important to continue the study of telehealth for mental health services in pediatric palliative care during less dire historical circumstances and evaluate if consumer usage is as valued in its impact on patient care.

When comparing child to parent endorsements of comfort in utilizing telehealth, parents voiced less comfort with this newer modality of service delivery. It could be that the scant resources of in-person contact during the COVID pandemic prompted parents to wish for further service provider contact during the quarantine period. Current literature reveals positive feasibility and satisfaction ratings among pediatric patients, caregivers, and clinicians who utilize telehealth for psychology and psychiatry services [15,16,17,9]. Furthermore, ongoing research does not reveal a significant difference between pediatric patient and caregiver satisfaction ratings, and both groups typically report they would use telehealth again [15,18,19]. As a result, further studies in this field may provide valuable insight to help support and expand telehealth through improving patient and caregiver satisfaction while maintaining the feasibility of this type of service delivery. Children and parents endorsed a balance with regards to preference of individual versus group meetings during their course of participating in the intervention program. The literature also supports the preference of either individual or group therapy sessions via telehealth [20,21]. Depending on topic, age group and patient population. This could translate to further investigation of group versus individual telehealth therapy efficacy and satisfaction in a pediatric palliative care population depending on disease severity, family involvement and other factors affecting youth confronting serious illnesses and their parents.

Another important dynamic we noted involved the cultural implications of the pilot intervention on our Spanish-speaking population. One family in particular noted that it was easier to include their Spanish-speaking father in a family group session using telehealth from their home because being in his own home minimized the stigma for him of mental health intervention and created a “safe” space for this father to speak more freely about his emotions. With more ethnic-minority groups having limited access to highly specialized mental health services, studies have examined how telehealth has improved accessibility to services [22,19], however, it would also be critical to evaluate how telehealth can be used to capture the content and methods necessary to be sensitive to the needs of ethnic minority pediatric palliative care patients and their families. Future study of this novel and timely area of mental health care using telehealth for pediatric palliative care families could include review of this service with a larger and more diverse (e.g., diagnostic group diversity and cultural diversity) sample size of participants and investigating which elements of the intervention may be best conducted in person and what parts were best capitalized by the use of telehealth, in both individual and group therapy formats.

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