

# Shared Care of Childhood Cancer Survivors: A Telemedicine Feasibility Study

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**Purpose:** With an increasing number of childhood cancer survivors (CCSs), determining the best model of survivorship transition care is becoming a growing priority. Shared care between pediatric oncology and adult primary care is often necessary, making survivorship a time of transition, but effective standard models are lacking. We sought to provide a more integrated approach to transition using telemedicine.

**Methods:** Recruited primary care provider/CCS dyads were instructed to log-in to a password-protected virtual meeting room using telemedicine equipment at the time of a regularly scheduled office visit. Dyads were joined by a pediatric survivorship clinic team member who conducted the telemedicine portion of the transition visit, which consisted of the review of an individualized treatment summary and care plan. Postquestionnaires were developed to evaluate key points such as fund of knowledge, satisfaction with the visit, and effectiveness of this electronic tool.

**Results:** There were 19 transition visits conducted, 13 of which used the telemedicine equipment as planned. Those that did not use the equipment were primarily unable to do so due to technical difficulties. Postquestionnaires were overall positive, confirming increased knowledge, comfort and abilities, and patient satisfaction in survivorship care. Negative comments were primarily related to equipment difficulties.

**Conclusions:** A gap still remains in helping CCSs transition from oncology to primary care and this pilot study offered insights into how we might better bridge that gap through the use of telemedicine. Further research is needed to refine the transition process for CCSs, including evaluation and testing models for standard of care.

**Keywords:** survivorship, late effects, telemedicine, primary care, transition, childhood cancer

## Purpose

AS OF 2010, there were ~380,000 survivors of childhood and adolescent cancer living in the United States.<sup>1</sup> That number will continue to increase as overall survival rates have drastically improved from <20% in the 1960s to more than 80% as of 2010.<sup>2,3</sup> For this reason, determining the best model of survivorship care is becoming a growing priority. Childhood cancer survivors (CCSs) are known to have higher early mortality rates<sup>4</sup> and report a life-long higher rate of illness owing to chronic health conditions with more than 25% experiencing a severe or life-threatening condition.<sup>5</sup> Cancer survivorship care is a time of transition: Concern regarding risk of relapse diminishes, whereas concerns related to long-term follow-up care, management of late effects, and health promotion predominate.<sup>6</sup>

In 2005, the Institute of Medicine (IOM) recognized the importance of optimizing delivery of care to survivors in its

report *From Cancer Patient to Cancer Survivor: Lost in Transition*. This highlights the need for coordination of care between specialists and primary care providers (PCPs) to avoid compromising the quality and timeliness of care needed to minimize late effects and optimize wellness in CCSs.<sup>7</sup> Survivorship care of CCSs includes shared care between pediatric oncology and adult primary care, including personal communication and organized transfer of knowledge, particularly in the form of a treatment summary and individualized plan of care.<sup>7</sup>

Despite the belief of many PCPs that survivorship care should be a shared responsibility,<sup>8</sup> effective standard models of partnership are still lacking. Research has shown that by 18 years postcancer diagnosis, <15% of CCSs report receiving follow-up care at a cancer center, but nearly 90% report receiving general medical care in the past 2 years,<sup>9</sup> suggesting that survivorship care is being sought out in the primary care setting. PCPs are nearly ten times more likely to discuss

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survivorship care with CCSs when they receive a treatment summary from the treating oncologist. Unfortunately, as many as 86% of PCPs fail to receive this critical document, despite the recommendation from the IOM.<sup>10–15</sup>

Before the creation of our survivorship clinic in 2008, our institution followed what has been described as the comfort model<sup>16</sup> in which CCSs continued to be followed by the primary oncologist indefinitely. This model results in patients eventually becoming lost to follow-up by attrition over time. With the implementation of a dedicated survivorship clinic, we began seeing many patients who had completed treatment decades earlier. We recognized the need to incorporate a transition process that begins at survivorship entry, promotes a shared care model throughout, and culminates in final transition to PCP care; ideally at ten years post-treatment (beyond the point of any expected disease recurrence) or postcollege age, whichever comes last.

There is a burgeoning trend toward promoting the use of telemedicine and telehealth due to its cost effectiveness and potential to improve quality of care and patient satisfaction in transition care.<sup>17,18</sup> However, much of the current literature on the use of telemedicine in the transition process has been done in subspecialties such as diabetes,<sup>19–21</sup> but has not been replicated in the survivorship population. The majority of our CCSs are young adults; a tech-savvy population willing to participate in health-promoting programs.<sup>22</sup> Telemedicine technology provides a novel mechanism to explore ways in which to engage this population and enhance care in the process of transition.

Thus, the overarching purpose of our study was to test feasibility of a more integrated approach to CCSs transition from pediatric oncology care to adult primary care through a collaborative effort between the survivorship team, the PCP, and the survivor, using telemedicine. The specific aims of the project were to (1). explore PCPs perception of ability and comfort level in providing care to cancer survivors; and (2). explore CCSs satisfaction with transition of care, through the use of telemedicine. The investigational aspect of the project was one of feasibility and exploration of the potential benefit of creating a model utilizing telemedicine.

## Methods

This cross-sectional, observational, pilot study was approved by the University of Pittsburgh IRB. Recruitment occurred over a 16-month period, primarily when CCSs presented for their annual follow-up visit to a pediatric hospital-based survivorship clinic.

### Participants

Eligibility criteria for CCSs were: 18 years of age or older; 10 or more years postcancer treatment; and having established care with a PCP who also consented to participate in the study. Exclusion criteria for CCSs were: PCP (or practice) unwilling/unable to participate; and PCPs located out of state, as this is the current standard of practice for the telemedicine department at our institution due to billing and insurance restrictions. Once an eligible CCS expressed interest in participating, their PCP was contacted to discuss the study and obtain verbal consent, if willing.

### Procedure

Once consents were obtained, the CCS was instructed to schedule an office visit with their PCP. Offices were asked to allow an additional 20 minutes to accommodate the telemedicine portion of the visit. Equipment, including web camera and speakers, was shipped to the PCP office to be installed for the transition visit if they did not already have equipment in place to accommodate this. Offices were also asked to download Vidyo™ software, which provided a virtual meeting space that is Health Insurance Portability and Accountability Act (HIPAA) compliant, secure, and has consistent high-definition quality video from any location with internet access.

The CCS presented to the PCP office and underwent the standard history and physical. With the CCS still in the room, the PCP logged-in to the password-protected Vidyo virtual meeting room, where a provider from the survivorship team was waiting to conduct the next portion of the visit. The transition visit consisted of a review of the individualized CCSs treatment summary, which includes the oncology treatment details, potential late effects of treatment, and screening and surveillance recommendations set forth by the Children's Oncology Group in their clinical practice guidelines, Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (public access found at [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)).<sup>23</sup> After reviewing the information, the connection through telemedicine allowed the opportunity to ask questions and voice concerns in a more personal way. In the event that there was difficulty with the technology, the visit was conducted through conference call instead.

### Instruments

**Visit information.** The survivorship team member conducting the transition visit documented the length of the visit as well as who participated in the visit.

**Demographics.** Patient demographics were collected through extraction from the medical record and included gender, race, age, diagnosis, chemotherapy history, radiation history, oncology surgery history, age at cancer diagnosis, date of therapy completion, and years since completion of cancer therapy.

**Intensity of treatment rating.** All CCSs were assigned an intensity of treatment rating (ITR) score using the ITR-3 scale, which has been shown to be valid and reliable in groups of pediatric cancer survivors.<sup>24</sup> The scale assigns each CCS into one of four intensity of treatment categories ranging from level 1, least intensive treatment, to level 4, most intensive treatment, depending on treatment modalities, diagnosis, and staging.

**Postvisit questionnaires.** Postquestionnaires were distributed through email using online survey software to the PCP, CCS, and survivorship team member who participated in the visit, and were intended to be completed immediately following the visit.

**PCP questionnaire.** The primary aim of the PCP questionnaire was to explore the perception of ability and comfort level in providing care to CCSs in their practice, as well as to help assess feasibility. The PCP questionnaire consisted of seven 5-point Likert scale questions with answer choices ranging from

strongly agree to strongly disagree. They were also asked the open-ended question, “What would have improved this visit?”

**CCS questionnaire.** The CCS questionnaire had nine 5-point Likert scale questions, as well as three additional “yes/no” questions with regard to whether they would participate in a visit like this again, recommend a visit like this to someone else, and “did this visit make it EASIER for you to communicate with your PCP about your cancer history?” Additionally, CCSs were asked to “Please provide any additional comments related to your visit.”

*Data analysis*

Given the exploratory nature of this observational pilot study and the small sample size, only simple descriptive statistics were calculated. For nominal and ordinal data, frequencies and percentages were reported. In the case of ratio data, mean and ranges were reported.

Due to the number of dyads who were unable to use the telemedicine equipment as planned, PCP and CCS questionnaire responses were divided into a “telemedicine standard (TLMD-STD)” group and “telemedicine-modified (TLMD-MOD)” group.

**Results**

*Visit information*

During the 16-month recruitment period, 301 CCSs were considered for inclusion in this study. Applying inclusion and exclusion criteria, 46 CCSs were eligible for the study and were approached about their willingness to participate. The majority of CCSs were excluded because of age or lack of an identified PCP. There was PCP refusal or lack of response for 24 of those who were eligible, resulting in 22 fully recruited and consented PCP/CCS dyads. One of the dyads withdrew after the PCP practice’s IT department declined participation. Ultimately 19 transition visits were completed, as two additional consented dyads were unable to participate due to PCP office scheduling limitations. Of the 19 completed transition visits, the majority ( $n = 13, 68.4\%$ ) used the telemedicine equipment as planned. Six offices did not use the equipment, primarily due to technical issues. Five of those visits were conducted by telephone conference call and one was conducted using the sound portion only of the equipment without the video. Visits were reported to last from 5 to 20 minutes and were attended primarily by the CCS, PCP, and survivorship team member ( $n = 14, 75\%$ ). A parent(s) or other support person attended the remaining visits.

**Demographics.** See Table 1. The majority of CCSs were female ( $n = 14, 73.6\%$ ) and Caucasian ( $n = 18, 94.7\%$ ), and the most common diagnosis was leukemia ( $n = 9, 47.4\%$ ). All participants received chemotherapy and nearly half also received radiation therapy ( $n = 8, 42.1\%$ ). There was an average of 16.84 years that had elapsed since completion of treatment (range: 10–28 years) with an average current age of 26.52 years (range: 21–41 years) and the average age at diagnosis was 7.8 years (range: 1–15).

*ITR*

Participants scored in each of the four ITR-3 categories, but the majority scored a level 2 ( $n = 6, 31.6\%$ ) or 3 ( $n = 6,$

TABLE 1. DEMOGRAPHICS

	Total transition visits (N=19) n (%) or mean (range)
Telemedicine equipment usage	
As planned (TLMD-STD)	13 (68.4)
Audio without video (TLMD-MOD)	1 (5.3)
Phone conference call (TLMD-MOD)	5 (26.3)
Survivor demographics	
Sex (Female)	14 (73.7)
Race (Caucasian)	18 (94.7)
Age (years)	26.52 (21–41)
Age at cancer diagnosis (years)	7.8 (1–15)
Time since completion of therapy (years)	16.84 (10–28)
Cancer diagnosis	
Acute lymphoblastic leukemia	6 (31.6)
Acute myelocytic leukemia	3 (15.8)
Hodgkin’s lymphoma	3 (15.8)
Wilm’s tumor	2 (10.5)
Osteosarcoma	1 (5.3)
Ewing’s sarcoma	1 (5.3)
Medulloblastoma	1 (5.3)
Treatments received	
Chemotherapy (yes)	19 (100)
Radiation (yes)	8 (42.1)
Oncologic Surgery (yes)	4 (21.1)
Hematopoietic stem cell transplant (yes)	3 (15.8)
Intensity of treatment	
Level 1	2 (10.5)
Level 2	6 (31.6)
Level 3	6 (31.6)
Level 4	5 (26.3)

TLMD-MOD, telemedicine modified; TLMD-STD, telemedicine standard.

31.6%), indicating moderately intensive or very intensive treatments, respectively.

*Postvisit questionnaires*

**PCP questionnaire.** See Table 2. The PCP response rate to the postvisit questionnaire was 94.7%. In the “TLMD-STD” group, 85% of respondents agreed or strongly agreed that their ability to take care of the CCS was enhanced by the visit, compared with 100% of the “TLMD-MOD” group. The results were similar when asked if the visit improved their knowledge about the care of CCSs and if it improved their comfort level in caring for CCSs, in which 85% of both groups either agreed or strongly agreed. Unfortunately, the results were less favorable when asked if the telemedicine equipment worked well, where only 47% of the “TLMD-STD” group agreed or strongly agreed. When asked what would have improved this telemedicine visit, all negative responses were related to installation and use of the equipment (see Table 4).

**CCS questionnaire.** See Table 3. The CCS post-questionnaire response rate was 89.4% and responses were

TABLE 2. PRIMARY CARE PROVIDER QUESTIONNAIRE

<i>PCP survey results</i>					
	<i>Strongly disagree</i>			<i>Strongly agree</i>	
	1	2	3	4	5
The videoconferencing (telemedicine) equipment worked well.					
TLMD-STD	1/13	3/13	3/13	4/13	2/13
TLMD-MOD	0/5	1/5	2/5	0/5	2/5
It was easy for the patient, the survivorship team, and me to communicate as a team.					
TLMD-STD	0/13	1/13	2/13	7/13	3/13
TLMD-MOD	0/5	0/5	0/5	1/5	4/5
My ability to take care of this patient was enhanced by this consultation.					
TLMD-STD	0/13	0/13	2/13	6/13	5/13
TLMD-MOD	0/5	0/5	0/5	2/5	3/5
I was able to address the patient's concerns.					
TLMD-STD	0/13	0/13	1/13	6/13	6/13
TLMD-MOD	0/5	0/5	1/5	1/5	3/5
This session improved my knowledge about the care of childhood cancer survivors					
TLMD-STD	0/13	0/13	2/13	5/13	6/13
TLMD-MOD	0/5	0/5	1/5	2/5	2/5
This session improved my comfort level in caring for childhood cancer survivors					
TLMD-STD	0/13	0/13	2/13	5/13	6/13
TLMD-MOD	0/5	0/5	1/5	2/5	2/5
As a result of the telemedicine visit, I feel that I have more resources for childhood cancer survivors available to me.					
TLMD-STD	0/13	2/13	0/13	8/13	5/13
TLMD-MOD	0/5	0/5	1/5	2/5	2/5

PCP, primary care provider.

overall positive. In both groups, 94% of respondents agreed that this visit made it easier to communicate with their PCP about their cancer history. In the "TLMD-STD" group, 94% of respondents agreed or strongly agreed that because of the visit, they felt more confident that their PCP could address their needs. In the "TLMD-MOD" group, 100% of respondents agreed or strongly agreed with this statement. Again, the CCS responses were less favorable with regard to the telemedicine equipment, in which only 70% of the "TLMD-STD" group agreed or strongly agreed the connection was clear.

CCSs were also given the opportunity to leave comments (see Table 4) related to the visit, not just recommendations for improvement as in the PCP questionnaire. Negative comments were generally related to technical difficulties with the equipment. Positive comments shared a common theme of appreciation of feeling their health is valued and they liked the ability to talk to both the PCP and survivorship team simultaneously.

## Discussion

Transition from pediatric to adult care has typically been driven by pediatric providers who lack adult counterparts with expertise in pediatric chronic conditions, leading to gaps in care across subspecialties. More children with special health needs are surviving into adulthood, and effective transition into the adult healthcare system is crucial to maintaining their health.<sup>25</sup>

However, standard models of transition are still lacking. Through an empirical literature review, Davis et al<sup>25</sup> confirmed the lack of rigorous research available to guide the transition process and evaluate current programs, regardless

of the strong conceptual agreement on the importance of transition and the negative impact it may have when not accomplished adequately. Patients with diabetes, sickle cell disease, and those who have undergone organ transplant are among those with the most evidence-based research with regard to transition.<sup>25</sup> A thorough review of the literature demonstrates an absence of studies evaluating telemedicine as a potential tool in the transition of adult CCSs.

Warner et al<sup>26</sup> found rural CCSs to be anxious over the quality of healthcare available in their areas of residence. They suggest the use of telemedicine to increase the quality and appropriateness of survivorship care, while also improving trust of the CCS in their local provider.<sup>26</sup> CCS respondents in our study reported feeling more confident in their PCP after the visit and PCP respondents reported increased comfort and ability in caring for CCSs. These pilot study findings suggest that a mutually more trusting relationship may be established following a transition visit using telemedicine. However, the TLMD-MOD group actually had similar to slightly higher overall patient satisfaction according to the CCS questionnaire results. This may be due to small sample size, but one must also ask if the use of telemedicine equipment actually had significant impact on the visit experience.

We recognize that the use of telemedicine technology adds yet another intervention to the transition literature, but we believe it has great potential to enhance the transition process. Unfortunately, our study results did not strongly support the feasibility of its use as implemented. There seemed to be an underlying discomfort with using telemedicine equipment in PCP offices (resulting in low response rate; 24 of 46

TABLE 3. CHILDHOOD CANCER SURVIVOR QUESTIONNAIRE

<i>CCS survey results</i>					
<i>Did this visit make it easier for you to communicate with your primary care physician about your cancer history?</i>					<i>n (%)</i>
Yes					16/17 (94.1%)
No					1/17 (5.9%)
<i>Would you recommend telemedicine to your family and friends?</i>					
Yes					17/17 (100%)
No					
<i>Would you choose to have another telemedicine visit in the future?</i>					
Yes					16/17 (94.1%)
No					1/17 (5.9%)
	Strongly disagree				Strongly agree
	1	2	3	4	5
<i>The video/audio connection was clear</i>					
TLMD-STD	0/13	3/13	1/13	4/13	5/13
TLMD-MOD	0/4	0/4	2/4	1/4	1/4
<i>It was easy to talk with the PCP and the survivorship team</i>					
TLMD-STD	0/13	1/13	0/13	4/13	8/13
TLMD-MOD	0/4	0/4	0/4	0/4	4/4
<i>Things were explained in a way I could understand</i>					
TLMD-STD	0/13	0/13	0/13	3/13	10/13
TLMD-MOD	0/4	0/4	0/4	0/4	4/4
<i>I got important information or advice to help me</i>					
TLMD-STD	0/13	0/13	1/13	3/13	9/13
TLMD-MOD	0/4	0/4	0/4	1/4	3/4
<i>I felt comfortable asking questions.</i>					
TLMD-STD	0/13	0/13	0/13	2/13	11/13
TLMD-MOD	0/4	0/4	0/4	0/4	4/4
<i>I feel confident that my telemedicine visit is confidential.</i>					
TLMD-STD	0/13	0/13	0/13	3/13	10/13
TLMD-MOD	0/4	0/4	0/4	1/4	3/4
<i>The visit lasted the right amount of time</i>					
TLMD-STD	1/13	1/13	0/13	3/13	8/13
TLMD-MOD	0/4	0/4	0/4	0/4	4/4
<i>Because of this visit, I feel more confident that my PCP will know what I need as a cancer survivor.</i>					
TLMD-STD	0/13	0/13	2/13	3/13	9/13
TLMD-MOD	0/4	0/4	0/4	0/4	4/4
<i>Overall, I was satisfied with this visit</i>					
TLMD-STD	0/13	2/13	1/13	1/13	10/13
TLMD-MOD	0/4	0/4	0/4	0/4	4/4

CCS, childhood cancer survivor.

eligible dyads), and incorporating its use was more cumbersome than we initially anticipated (resulting in poor compliance; 13 of 19 completed visits used the equipment as intended). This was most apparent when there was no IT staff on-site to assist in the process of installation. Much of the difficulty likely relates to the fact that most PCP participants were setting up the equipment for a one-time visit with only one patient. The same barrier may not exist if there were multiple visits performed over a period of time, or with multiple patients, in which case, ease of use would be expected to improve. In future models, we would propose to identify PCP practices who are seeing multiple CCSs and aim to better assist in initial equipment set-up, possibly even with an in-person visit to establish the regular use of telemedicine visits within those identified practices. This may also be beneficial to CCSs given that a barrier to study enrollment,

and to transition in general, is a lack of an identified PCP. Identifying strategic PCP partners could greatly enhance and permit scale-up of this model.

Limitations of this study include a small sample size so results may not generalize to the wider CCS population. We did not use a transition readiness tool as it did not fit with our primary aims in this small pilot study, but such a tool would be important to use in future studies to promote a more uniform transition process. Data collection to include PCP demographics, such as geographical location, training, and practice size may also provide valuable information to help guide future interventions. Finally, the study design did not include a control group so it is difficult to quantify whether this particular intervention improved patient satisfaction and PCP comfort relative to a PCP simply receiving a treatment summary without the telemedicine intervention.

TABLE 4. ADDITIONAL QUESTIONNAIRE COMMENTS

*Comments from childhood cancer survivors*Feedback on technical/equipment aspects

- “[There were] some initial technical difficulties setting up the conference.”
- “It was a little rough setting up telemedicine the first time.”
- “My PCP could not get the video chat to work.”
- “It was hard for PCP to understand.”

The importance of connecting patient, primary care provider, and survivorship physician

- “It was nice to see the doctor’s concern to make sure my health history is conveyed to my new provider.”
- “I liked how I could talk to both of them and they were both concerned about my health and is there to help in any way they can.”
- “The opportunity to teleconference let my PCP ask her specific questions.”
- “I love that my survivorship team and my PCP are communicating.”
- “This teleconference was wonderful, it really bridged the gap between transitioning from oncology care to primary care.”
- “Informing my PCP on my history, treatment and prognosis reassures me and gives me comfort.”
- “It was as if we were all together in the same room.”

Attentiveness to health

- “thankful for the concern of my health”
- “I felt like my history of ALL was given special treatment and recognized as an important part of my medical history.”
- “The visit was very informative and useful.”

Comments and Recommendations from Primary Care ProvidersFeedback on technical/equipment aspects

- “The speaking part of the visit was poor. I had difficulty hearing and being heard during the visit”
- “My clinic has shotty wireless and no computer that is hard wired with camera.”
- “The equipment did not work.”
- “Sorry I didn’t get equipment hooked up.”
- “We had difficulty with the initial setup of the equipment. Once it was set up it was working appropriately.”

Time considerations

- “It does take a little extra time for the appointment, but had time to prepare for appointment so more time was scheduled.”
- “In the end it took 3 HOURS of admin. staff time to set up the software for the visit.”

Recommendations

- “Larger screen access or other equipment would allow for enhanced viewing.”
- “Electronic sharing of records in addition to electronic face to face. Not every EHR has direct messaging capabilities. But a video chat for transition of care and an electronic transfer of records would be a perfect world!”

Accepting the limitations described above, this study provides critical information to determine the feasibility and applicability of a telemedicine intervention to aid in the transition process. Despite concerns raised over technical difficulties, our results remained overall positive: PCPs

reported increased knowledge, comfort, and ability in caring for CCSs and CCSs reported greater confidence and comfort with their PCP assuming their survivorship care. This is significant given the great need for a formal transfer of care to the PCP and the trust that must be instilled within this relationship. Additionally, to our knowledge, this is the first study to examine the effectiveness of a transition intervention that connects the CCS, PCP, and survivorship team simultaneously through the use of telemedicine.

Future research with a larger sample size is needed to confirm findings of our study, including improved CCS satisfaction and improved PCP comfort and confidence. Additionally, exploring a way to limit the technical difficulties in utilizing telemedicine will be crucial to continuing its use in future participating community practices.

**Conclusions**

A gap remains in helping CCSs transition from oncology care to primary care. This pilot study further elucidates barriers and potential solutions to bridge this gap. Both the CCSs and PCPs deemed the experience to be overall beneficial. However, the technical difficulties proved to be a hindrance, significant enough to question if the use of telemedicine in this setting is indeed feasible or if it may simply require a different implementation process. The study demonstrated value to the use of telemedicine in the CCS population and additional study is warranted to improve its ease of use in the setting of transition. Future directions will include an emphasis on identifying strategic PCP partners who may be willing to see multiple CCSs. Ultimately, this study provided a framework in which to evaluate a novel model of transition and collaboration in providing survivorship care.

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