SURVIVORSHIP: BRIEF REPORT







Virtual visits as long-term follow-up care for childhood cancer survivors: Patient and provider satisfaction during the **COVID-19** pandemic

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Abstract

Telemedicine can potentially meet objectives of long-term follow-up care (LTFU) for childhood cancer survivors (CCS) while reducing barriers. We surveyed providers at our institution about their satisfaction with video-conference virtual visits (VV) with 81 CCS during COVID-19 restrictions. The same 81 CCS (or parent proxies) were surveyed about their experience, of which 47% responded. Providers and CCS were highly satisfied with VV (86% and 95% "completely/very satisfied," respectively). CCS rated VV "as/nearly as" helpful as in-person visits (66%) and 82% prefer VV remain an option postpandemic. High levels of survivor and provider satisfaction with VV support ongoing investigation into implementation for LTFU.

KEYWORDS

childhood cancer survivor, COVID-19, telemedicine

1 | INTRODUCTION

Life-long, risk-based, follow-up care is recommended for all childhood cancer survivors (CCS) to monitor for cancer-related health issues and provide education about potential future health risks. Survivorship care is often cancer center based and includes screening by physical examination and testing. 1-3 Access to center-based survivorship care may be limited by both patient and healthcare system barriers.^{4,5} Telehealth is a proposed alternative to center-based long-term followup (LTFU) care, but reported experience has been limited to risk education,⁶ behavioral-health interventions,⁷ and care transitions.⁸ In response to restrictions on in-person visits (IPV) imposed by the COVID-19 pandemic, our survivorship clinic implemented virtual-

Abbreviations: CCS, childhood cancer survivor; IPV, in-person visits; LTFU, long-term follow-up; VV, virtual visits

visits (VV) using video-conferencing to continue to provide LTFU care for CCS. 9,10 This rapid and unanticipated shift in care delivery provided a unique opportunity to evaluate CCS and providers' satisfaction with VV for LTFU, to explore factors associated with satisfaction, and to evaluate content of LTFU care delivered by VV.

2 | METHODS

From April to June 2020, when IPV for routine LTFU were not scheduled at our institution due to COVID restrictions, our survivorship clinic began offering VV by live video-conference to CSS due/overdue for their routine LTFU visit and deemed appropriate for a VV by their provider. In preparation, providers were orientated to the video-conference platform but received no additional

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TABLE 1 Responses to provider satisfaction surveys

	n	%
Patient characteristics ($N = 81$)		
Patient gender		
Female	46	42
Male	34	57
Other	1	1
Patient age (years)		
<18	28	35
18-29	31	38
30+	22	27
Diagnostic category		
Hematological malignancy	50	62
Solid tumor	27	33
Other	4	5
Visit characteristics ($n = 94$)		
Week of visit		
1-5	31	33
6-7	27	29
8-10	36	38
Provider VV volume*		
Low (<10 VV)	4	57
High (20-30 VV)	3	43
Risk for late effects [¥]		
Low	29	31
Moderate	29	31
High	36	38
Visit content†		
Late effects and recommended follow-up		
Focal topic	77	82
Nonfocal topic	14	15
COVID-related symptom		
Focal topic	36	38
Nonfocal topic	36	38
Psychological well-being		
Focal topic	22	23
Non-focal topic	71	76
Symptom (treatment related)	, 1	, (
Focal topic	20	21
Non-focal topic	10	11
	10	1.
Symptom (not treatment related) Focal topic	14	15
·	27	
Nonfocal topic Concorn about recurrence	21	29
Concern about recurrence	,	,
Focal topic	6	6
Nonfocal topic	17	18

TABLE 1 (Continued)

	n	%
Follow-up		
Follow-up imaging/laboratory tests		
Urgently	4	4
At next follow-up	15	16
As soon as restrictions are lifted	67	71
None	8	9
Follow-up visit plan‡		
Urgent evaluation	7	7
Nonurgent PCP	9	10
Survivor clinic as soon as restrictions lifted	12	13
Survivor clinic at regular visit interval	68	72
Other medical specialist	9	10
Satisfaction		
Overall satisfaction		
Completely	35	37
Very	46	49
Moderately	10	11
Slightly	3	3
Not at all	0	0
Met clinical care objectives		
Yes	42	45
No	51	54

Abbreviations: PCP, primary care provider; VV, virtual visit.

*Four providers with <10 VV classified as low volume; three providers with >20-30 VV classified as high volume.

 $^{\, \Psi}$ Provider rated late-effect risk as high (i.e., treated with radiation, stem cell transplant, high-dose alkylators or anthracyclines >250 mg/m²; current surveillance for any cancer; recent onset or multiple late effects; hereditary cancer predisposition), moderate (i.e., anthracyclines <250 mg/m², low-dose alkylators, age <25 years, off therapy <10 years, any psychosocial morbidity), or low (i.e., all others).

†Topics that were a visit focus rated as "focal"; other topics discussed rated "non-focal"; topics rated "not discussed" are not shown.

training in telemedicine. During this period, 81 CCS off therapy ≥2 years with noncentral nervous system cancers followed in our clinic had 94 unique LTFU visits with one of seven clinic providers (pediatric-oncologists, nurse-practitioners, internist, endocrinologist) using video-conferencing. After each of the 94 visits, the provider completed a 10-item on-line survey. Provider survey items included patient characteristics, visit content, follow-up recommendations, and satisfaction. After the VV, the same 81 patients (parents/guardians if <age 18) were invited to complete an anonymous, 10-item, online survey about their VV experience; 25 survivors and 13 parents/guardians (38/81, 47%) participated. CCS survey items included demographics, visit content, and satisfaction. Logistic regression and Fisher's exact test were used to explore correlates of provider and patient satisfaction, respectively. Use of these data for research was IRB approved.

 $^{^{\}ddagger}\%$ total to >100% as participants were able to select multiple responses.

 TABLE 2
 Relationship of high provider satisfaction ratings with patient and VV characteristics

Visit characteristic	n	High satisfaction \dagger (n = 81) (n, %)	Low satisfaction $(n = 13) (n, \%)$	OR	95% CI
Patient gender					
Female	53	45 (85)	8 (15)	Reference	
Male	41	36 (88)	5 (12)	1.28	0.39-4.25
Patient age (years)					
<18	30	26 (87)	4 (13)	Reference	
18-29	37	33 (89)	4 (11)	1.27	0.29-5.57
30+	27	22 (82)	5 (19)	0.68	0.16-2.84
Diagnostic category					
Hematological malignancy	61	54 (89)	7 (12)	Reference	
Solid tumor	29	25 (86)	4 (14)	0.81	0.22-3.02
Other	4	2 (50)	2 (50)	0.13	0.02-1.07
Week of visit					
1-5	31	23 (28)	8 (62)	Reference	
6-7	27	23 (28)	4 (31)	2.00	0.53-7.58
8-10	36	36 (44)	1 (8)	12.17	1.43-103.93
Provider VV volume‡					
Low (<10 VV)	20	11 (56)	9 (45)	Reference	
High (20-30 VV)	74	70 (95)	4 (5)	14.32	3.76-54.60
Risk for late effects					
Low	29	26 (90)	3 (10)	Reference	
Moderate	29	27 (93)	2 (7)	1.56	0.24-10.09
High	36	28 (78)	8 (22)	0.40	0.10-1.69
Met clinical care objectives ($n = 93$)					
No	51	40 (78)	11 (22)	Reference	
Yes	42	40 (95)	2 (5)	5.55	1.15-26.41

Abbreviation: VV, virtual visit.

OR in bold are significant at p < .05.

3 | RESULTS

3.1 | Provider responses

Most CCS seen for VV identified as male (57%) were between the age of 18 and 29 years (38%) and had been treated for a hematologic malignancy (62%) (Table 1). Similar proportions of CCS were classified by providers as low, moderate, and high risk for treatment-associated complications based on disease, treatment exposures, and co-morbidities (31%, 31%, and 38%, respectively). Number of VV increased over time, with most visits occurring in the last half of the study period, weeks 6–10 (67%).

Providers reported discussion of late-effects and follow-up recommendations, the primary objective of survivorship care, as the most common focus of VVs (82%). Despite occurring during the pandemic,

COVID-19-related symptoms were not a focus of most VV (38%). New symptoms (treatment/nontreatment) were the focus of 36% of VV and concern for cancer recurrence, a focus for only 6%. Although not a common focus (23%), emotional health was discussed in almost every visit (93/94) (Table 1). As screening for cancer recurrence and organ toxicity are components of LTFU, laboratory tests or imaging were recommended after almost all VV with only 4% considered urgent. Providers considered the VV as a substitute for an IPV for most CCS (72%), recommending a nonurgent IPV in addition to VV for 13%, and urgent IPV for only 7%. However, approximately half of VV (51/94; 51%) did not fully meet providers' clinical objectives. Primary reason providers offered for not meeting objectives was not having information from physical examination (47/51 VV; 92%), lack of point-of-care labs/imaging (five VV), limited ability to provide emotional support (two VV), and lack of mental health specialist (one VV) (data not shown).

[†]High satisfaction group includes all visits rated "completely" or "very" satisfied.

 $^{^{\}ddagger}$ Four providers with <10 VV classified as low volume; three providers with >20–30 VV classified as high volume.

TABLE 3 Responses to patient satisfaction surveys

Tresponses to patient satisfaction	Tour veys	
	n	%
Participant characteristics (N = 38)		
Patient gender		
Female	24	63
Male	14	37
Patient age (years)		
<18	11	29
18-29	15	40
30+	12	32
Respondent		
Patient	25	66
Parent/guardian	13	34
Visit content		
Getting list of tests/scans needed		
Very helpful	29	76
Somewhat helpful	3	8
N/A	6	16
Learning about recommended cancer follow-up)	
Very helpful	26	68
Somewhat helpful	3	8
N/A	9	24
Discussing emotional health		
Very helpful	23	61
Somewhat helpful	5	13
N/A	10	26
Asking about worrisome symptom		
Very helpful	18	47
Somewhat helpful	2	5
N/A	18	47
Learning about prior cancer treatment		
Very helpful	10	26
Somewhat helpful	2	5
N/A	26	68
Satisfaction		
Overall satisfaction		
Completely	23	61
Very	12	34
Moderately	2	5
Slightly/not at all	0	0
	U	U
Helpfulness compared to IPV	٥٢	//
	25	66
As/nearly as helpful Madarately helpful but less helpful	0	
As/nearly as helpful Moderately helpful, but less helpful Much/very much less	9	24 11

(Continues)

TABLE 3 (Continued)

	n	%
Future Visit Preference		
All/almost all VV	14	37
Mixed VV and IPV depending on need	17	45
All/almost all IPV	7	18

Abbreviations: IPV, in-person visit; N/A, not applicable; VV, virtual visit.

Despite these limitations, providers were highly satisfied with VV, with 37% reporting they were "completely" satisfied and 49% "very" satisfied. To explore correlates of provider satisfaction, we compared visits rated as "completely" or "very" satisfied (n=81) to all other visits (n=13) using logistic regression (Table 2). Provider satisfaction was not associated with patient variables (age, gender, diagnosis, risk category, all p>.05). Higher levels of provider satisfaction were associated with VV conducted later in the study period, by providers with greater VV volume, and when VV met clinical objectives (Table 2).

3.2 | CCS responses

Most CCS identified as female (63%) and were between the age of 18 and 29 (40%). CCS reported the most helpful content of the VV was getting specific recommendations for follow-up testing and learning about recommendations for cancer-related LTFU (76% and 68%, respectively) (Table 3). Discussions of emotional health were also reported as helpful by most CCS (61%). Satisfaction level with VV was high, with almost all respondents "completely" (61%) or "very" satisfied (34%). Fisher's exact tests comparing "completely" satisfied respondents to all others revealed no significant differences on gender, age category, or respondent type (patient vs. parent/guardian; *p*'s > .05, data not shown). Most CCS rated their VV "as" or "nearly as" helpful as an in-person LTFU visit (66%) and expressed a preference for future VV either in combination with (45%), or as a substitute for all/nearly all IPV (37%).

4 DISCUSSION

Childhood cancer survivors and providers in our survivorship practice were very satisfied with video-conferencing for LTFU during the COVID-19 pandemic, and provider satisfaction increased with experience. Except for physical examination, VV met provider's objectives for LTFU and were often considered a substitute for an IPV. Most CCS considered VV as helpful as IPV and want VV to remain as an option for LTFU care postpandemic.

Similar to other studies of patient satisfaction with telemedicine, CCS were very satisfied with VV for LTFU.^{8,11–13} Although we attempted to identify correlates, satisfaction was not associated with demographic or clinical variables analyzed in our study. Additional studies investigating both patient and system factors are needed to

further explore satisfaction with VV and identify which CCS may be best served by this modality.

Not surprisingly, providers satisfaction was higher as they gained experience with VV. Providers reported that not having information from physical examination and on-site testing were limitations of VV for meeting survivorship care objectives. Alternatives such as coordinating examination and testing with local primary care providers and remote examination tools could be explored to address these limitations of VV.

Generalizability of these findings is limited because this study included a small sample of providers and CCS at a single institution over a study period defined by restrictions on IPV. Furthermore, satisfaction may be overestimated because of biases introduced by providers selecting which CCS were offered VV and limited uptake of the patient survey.

In summary, the COVID-19 pandemic provided the opportunity to assess VV as an option for LTFU care for CCS. Participants in our study expressed a high level of satisfaction with VV and the desire to continue this modality post-pandemic. Despite limitations noted above, results support implementation of VV visits for LTFU care of CCS when IPV are restricted, as well as future research on use of VV as an option for LTFU when barriers to IPV exist. Further studies are needed to explore factors that may enhance the quality of virtual care for survivors and providers, including studies investigating hybrid-care with physical examination and laboratory-testing done by primary care providers and virtual care that incorporates remote examination technology.

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