

Response to a Treatment Summary and Care Plan Among Adult Survivors of Pediatric and Young Adult Cancer

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Abstract

Purpose: Survivors of pediatric and young adult cancer are at increased risk for treatment-related problems. Yet, few survivors receive risk-based care. The treatment summary and care plan are recommended to improve understanding of cancer treatment, potential late effects, and recommended screening. It is unknown whether survivors retain, understand, value, and disseminate the document, and whether it causes worry.

Methods: We surveyed 111 adult survivors of pediatric and young adult cancer 1 to 6 weeks after receipt of a one-page treatment summary and care plan (response rate, 96%). Participants answered questions regarding retention, understanding, value, dissemination, concern, and preferences.

Results: Participants were majority female (58%), college-educated (60%), diagnosed with cancer before age 21 (76%), on

average 18 years from diagnosis (range, 2 to 50 years), and treated with radiation and chemotherapy (61%). Median age was 30 years (range, 18 to 65 years). A majority of participants stated that they understood the treatment summary (95%), retained the document (95%), and valued it (92%). A minority reported that the document caused concern (14%) or wanted more information than the form provided (20%). Although the time between receipt of the document and survey was brief, many described dissemination of the document to their personal circle (44%) or an outside provider (10 [33%] of 30 who saw an outside doctor).

Conclusion: A one-page treatment summary and care plan was well-received and did not cause report of undue concern. Additional health-related information was requested by some, and dissemination to outside providers could be improved.

Introduction

As a result of remarkable improvements in cancer detection and therapy, the number of pediatric and young adult cancer survivors in the United States is rapidly rising.¹ Nonetheless, survivors of pediatric and young adult cancer face a substantial risk of late effects and early mortality²⁻⁸; by 30 years from their initial diagnosis, 73% of pediatric cancer survivors will develop at least one chronic physical health condition, whereas in 42% the condition will be severe, life-threatening, disabling, or result in death.² Many late effects can be prevented through early diagnosis and treatment if survivors and their caregivers are adequately informed.⁹⁻¹¹

Treatment summaries and survivorship care plans have been proposed as one method to improve communication and risk-based care. Pediatric oncologists have been creating cancer treatment summaries at the end of therapy for many decades,^{12,13} but these documents were often independent of a plan for follow-up care.⁹ The Institute of Medicine, the Children's Oncology Group, the National Institute for Health and Clinical Excellence, and others have endorsed a combined cancer treatment summary and care plan.^{9,14-18} Many long-term follow-up programs now include a document with both elements; individual components include cancer diagnosis, treatment, potential late effects, and recommendations for follow-up care and surveillance.

Prior studies suggest that patients and primary care physicians are receptive to the concept of a treatment summary and

care plan.^{11,19-23} A recent study²⁴ found that a mailed personalized treatment summary and care plan resulted in improved adherence to recommended screening. Nonetheless, it is not known how these documents might be received in a real-world clinical setting. We distributed a comprehensive, individualized treatment summary and care plan to patients as part of their routine long-term follow-up care (Figure 1). One to 6 weeks later, we questioned patients regarding whether the document raised worry and concern and whether they retained, understood, valued, and disseminated the treatment summary and care plan.

Methods

Patients

We conducted a cross-sectional telephone survey of consecutive patients seen in the Memorial Sloan-Kettering Cancer Center (MSKCC) Adult Long-Term Follow-Up Program for a medical visit between May and August 2010. Eligible participants were cancer survivors 18 years or older; fluent in English; currently cancer free; and without significant neurocognitive, visual, or hearing deficits. During the study period, 148 patients were seen in the clinic. There were 24 ineligible survivors (non-English speaking, n = 3; severe neurocognitive deficit, n = 5; blind, n = 2; deaf, n = 2; interim visit for new acute problem, n = 12). There were eight eligible survivors who were not notified of the study (and thus not contacted) because of high clinic volume on the day that they were seen; the providers did

SUMMARY OF CANCER TREATMENT

Date of preparation: February 2011

Name: John Doe		Date of Birth: 1/1/86	
Cancer Diagnosis: Acute Myelocytic Leukemia (AML)			
Treatment centers: Children's Cancer Hospital, University of California Irvine Medical Center, Children's Hospital of Orange County			
Date of diagnosis: 1/1/2005; age at diagnosis; 19 years old			
Relapse: 7/1/2005 CNS disease, 5/7/2006 bone marrow			
Date of completion of therapy: 7/19/2006			
Radiation Therapy			
Date start	Date Stop	Field	Dose (cGy)
7/11/2006	7/18/2006	Total body irradiation (TBI)	1,200
		Whole brain, retro-orbital and brainstem	600
Chemotherapy			
Drug Name		Dose (units or mg/m ²)	
Cytarabine (IT/IV)			
L-asparaginase			
Mitoxantrone		48 mg/m ² (equivalent to 192 mg/m ² doxorubicin)	
Etoposide			
Daunorubicin		300 mg/m ² (equivalent to 250 mg/m ² doxorubicin)	
Fludarabine			
Idarubicin		48 gm/m ² (equivalent to 240 mg/m ² doxorubicin)	
Methotrexate (IT)			
DepoCyt (IT)			
Cumulative anthracycline dose		682 gm/m ²	
Immunotherapy			
Gemtuzumab (AAML03P1)			
Alemtuzumab (BMT preconditioning)			
Rituximab (GVHD treatment)			
Allogenic, unrelated, 10/10 matched on 7/19/2006			
Preconditioning: Campath, Cyclophosphamide (120 mg/kg) and 1,200 cGy TBI.			
Chronic GVHD of skin and GI tract: treated with Rituximab, Prednisone and Cyclosporine.			
Potential Late Effects		Screening Recommendations**	
<ul style="list-style-type: none"> • Cardiovascular problems • Lung problems • Osteoporosis • Thyroid problems • Fertility problems • Bladder problems • Dental problems • Cataracts • Psychosocial problems including anxiety and depression • Second cancers (rare) 		<ul style="list-style-type: none"> • Annual labs to include: CBC, comp profile, TSH, urinalysis, lipid profile, insulin, CRP, 25-OH vitamin D level, testosterone • Echocardiogram/EKG every year • Pulmonary function test every 1-2 years • Bone density study every 2 years • Dental exam yearly, cleaning every 6 months • Eye exam every year • Counseling and treatment as indicated • Dermatology exam every year 	

Figure 1. Example of the summary of cancer treatment and follow-up care plan. BMT, bone marrow transplantation; CBC, complete blood count; CRP, c-reactive protein; EKG, electrocardiogram; GVHD, graft-versus-host disease; IT, intrathecal; IV, intravenous; TSH, thyroid-stimulating hormone.

not have adequate time to review the study. Of the 116 eligible survivors who were notified of the study and contacted, 111 (96%) completed the telephone survey; one refused to participate when reached by phone, and four could not be reached.

The following data were abstracted from the medical record: age at survey, age at diagnosis, sex, cancer diagnosis, cancer treatment, health insurance status, education level (college graduate or not), and visit status (first-time or return). The MSKCC institutional review board approved all aspects of the study.

Procedures

Telephone survey. Participants were interviewed 1 to 6 weeks after their medical visit, using an internally developed 29-item survey to ascertain retention, understanding, value, dissemination, concern, worry, and preferences for the treatment summary. The survey was rated an 8.2 on the Flesch-Kincaid reading scale.

Retention was defined as having the treatment summary on hand or at home at the time of the survey. Participants were asked by the interviewer to refer to their treatment summary during the survey. Because many participants were at work during the time of the survey, those who indicated having the document at home in a personal file were counted as having retained the form.

To determine value, we asked participants, "How valuable is the treatment summary to you?" Responses were given on a 4-point Likert scale (not at all, a little bit, moderately, or extremely). In addition, participants were asked whether they found the document to be helpful in understanding the plan for their care and whether they considered it a link to their outside providers.

Dissemination was evaluated in two ways. Participants were asked whether they had seen an outside provider or been to an emergency room since receiving the treatment summary, and if so, whether they had shared the document. In addition, participants were asked whether the document had been shared with a spouse, friend, or other person.

In consideration of reported health-related worry among cancer survivors,²⁴⁻²⁷ we included questions regarding general health worry in the past week from the Memorial Symptom Assessment Scale. This instrument was developed to assess a wide variety of psychological and physical symptoms among patients with cancer and has been well validated in this population.²⁸ Our survey asked, "In the past week, did you worry about your health?" followed by questions on the frequency and severity of worry. We also asked whether the treatment summary and care plan caused the participant additional worry. Finally, we asked whether receipt of the document, the "Potential Late Effects" section, or the "Screening Recommendations" section made the participant feel concerned or not concerned.

Finally, patient preferences regarding the current paper form and possible alternatives (eg, wallet card, online, e-mail) were assessed. Participant were also asked whether they had a primary care physician.

Treatment Summary and Care Plan

The MSKCC Adult Long-Term Follow-Up team uses a single-page template to enable efficient documentation of treatment history, potential late effects, and recommended follow-up. It typically takes 1 to 4 hours for the medical team to prepare a treatment summary and care plan for a survivor entering the program, depending on the recency and complexity of the cancer history and the availability of electronic records. Subsequent modification to an existing document as a result of updated guidelines or new diagnoses usually requires 15 to 20 minutes. Typically, the document is reviewed in detail during a new patient visit and briefly during follow-up. Although providers are available after the visit, questions about the document are rare.

Statistical Analyses

Data were analyzed with SAS Version 9.2 (SAS Institute, Cary, NC) and STATA Version 8.0 (Stata, College Station, TX). Bivariate analyses with χ^2 or exact tests, where appropriate, were performed, and odds ratios with 95% CIs were calculated by logistic regression. Multivariate logistic regression was performed to determine factors independently associated with desiring more information on the treatment summary.

Results

Of 116 eligible subjects who agreed to be contacted, 111 (96%) completed the telephone survey. There were no significant differences between the participants and nonparticipants with regards to cancer history and demographics. Participants were majority female (58%), college-educated (60%), diagnosed with primary cancer before age 21 (76%), on average 18 years from diagnosis (range 2 to 50 years), and treated with both radiation and chemotherapy (61%). Subjects ranged in age from 18 to 65 years, with the large majority (74%) between 18 and 39 years old. Nearly one quarter (23%) of participants were new patients who had never received a treatment summary and care plan before. Although all participants had health insurance, just 57% were found to have a primary care physician outside MSKCC (Table 1). Participants who had survived a lymphoma were significantly older than nonlymphoma survivors in the survey, with a median age of 42 years compared with 27 years ($P < .001$).

Retention, Understanding, Value, and Dissemination

Overall response to the treatment summary and care plan was highly positive. One to 6 weeks after receiving a treatment summary and care plan in clinic, 95% of participants had retained the document; 55% had it on hand and 40% had it at home in a personal file.

To the question, "During your visit, did you understand everything on the treatment summary?" 95% subjects responded affirmatively. Of the six individuals who reported not understanding everything, one reported coming to an understanding by calling a nurse practitioner via the phone number

Table 1. Baseline Characteristics of Survivors of Pediatric and Young Adult Cancers (N = 111)

Characteristic	No.	%
Age, years		
Median	30	
Range	18.0-65.0	
Time since cancer diagnosis, years		
Median	18	
Range	2.0-50.0	
Age at cancer diagnosis, years		
Median	16	
Range	0.08-41	
Sex		
Female	64	58
Male	47	42
Completed college*	66	60
First-time visit	25	23
Health insurance (including public insurance)	111	100
Primary care provider	63	57
Cancer diagnosis		
Lymphoma	34	31
Leukemia	26	23
Bone tumor	20	18
Soft tissue sarcoma	15	14
Central nervous system	7	6
Neuroblastoma	4	4
Other	4	4
Wilms' tumor	1	1
Treatment modality		
Chemotherapy plus radiation	68	61
Chemotherapy only	29	26
Stem-cell transplantation	23	21
Radiotherapy only	14	13
Chemotherapy		
Anthracyclines plus alkylating agents	67	60
Alkylating agents only	13	12
Anthracyclines only	10	9
Other chemotherapy only	7	6

* Education status was available for 101 of 110 patients.

on the document. The remaining five reported not understanding part of the cancer history, recommendations, or contact information. Only one, a 37-year-old female survivor, accepted the interviewer's offer for a clinician to call to explain the content in question; the other participants declined, indicating they would wait until their next visit for clarification.

To the question, "How valuable is the treatment summary to you?" 43% of participants selected "moderately" valuable and 50% responded "extremely" valuable. Similarly high proportions found the treatment summary and care plan helpful to them in understanding the plan for their care (95%) and considered it an important link between health care providers (95%).

Of 30 participants who had visited an outside provider since receiving the document, 10 reported giving the provider a copy of the form. No participant had visited the emergency room. Many (44%) had disseminated copies to someone in their personal circle. When compared by retention, understanding, demographics, or cancer history, participants who disseminated a summary were not significantly different from those who did not (results not shown).

A greater proportion of new patients (17 of 25; 68%) indicated learning new information from the treatment summary and care plan compared with returning patients (33 of 86; 39%; $P = .009$); however, new and returning participants did not differ significantly in retention, understanding, or value.

Worry and Concern

We found a small number of patients who reported frequent (15%) or almost constant (2%) general health worry in the past week. Fewer participants (6% of all subjects) rated the worry as "severe" or "very severe." A prior diagnosis of lymphoma (odds ratio [OR] = 2.72; 95% CI, 1.18 to 6.29; $P = .02$) and older age (OR = 1.06; 95% CI, 1.02 to 1.10; $P = .002$) increased the odds of general health worry.

Participants were questioned regarding concern and worry specifically in response to the treatment summary and care plan and its individual components. The document as a whole caused concern for 14% of participants; 86% reported that they were not concerned by the overall form. The "Screening Recommendations" section was troubling for some participants; 14% reported that this section caused concern. The "Potential Late Effects" section caused concern for 28% of participants, although moderate or extreme worry about potential late effects was reported by only 13%.

Participants were asked whether receiving the treatment summary and care plan increased the severity of health worry. Few reported moderate or extreme worry about "cancer" (4%), "coping with survivorship" (3%), or "sexual and/or reproductive issues" (6%). The seven participants who reported sexual or reproductive worry were overwhelmingly male (6 of 7 [86%], $P = .02$) and significantly younger compared with the other 104 participants (median age, 24 to 32 years, $P = .02$).

Overall, 31% of participants were found to be concerned in response to the treatment summary and care plan or its individual sections. Neither these participants nor those who reported general health worry in the past week differed significantly from others in terms of retention, understanding, value, or dissemination of the document (data not shown).

Additions to the Treatment Summary and Care Plan

A large majority (95%) of participants expressed interest in an online or wallet-card version of the treatment summary and care plan. When asked about the amount of information on the document, 80% indicated that the form provided sufficient content, 20% indicated "too little," and none indicated "too much." Participants requested the following additions: (1) current medications and allergies, (2) all current health care providers with contact information, (3) all surgeries (cancer related

Table 2. Odds of Seeking More Information on the Summary of Cancer Treatment and Follow-Up Care Plan Among Survivors of Pediatric and Young Adult Cancer (N = 111)

Characteristic	OR	95% CI	P	Multivariate-Adjusted OR*	95% CI	P
Age, years	1.06	1.02 to 1.10	.005	1.03	0.98 to 1.10	.25
Female sex	1.75	0.65 to 4.70	.27	1.35	0.47 to 3.85	.58
Time since diagnosis, years	1.06	1.01 to 1.11	.01	1.03	0.97 to 1.10	.37
Treatment modality	1.28	0.81 to 2.05	.29	1.43	0.84 to 2.45	.19
First visit to program	0.29	0.06 to 1.32	.11	0.21	0.04 to 1.07	.06
Reported concern on receipt of summary	2.96	0.94 to 9.32	.06	0.76	0.27 to 2.19	.62
Did not understand treatment summary	19.6	2.06 to 185.4	.01	43.4	3.43 to 548.1	.004

Abbreviation: OR, odds ratio.

* Adjusted for age, sex, and time since diagnosis.

and noncancer related), (4) current late effects status, (5) tests with dates and results, (6) mental health recommendations and resources, (7) all dosages of cancer therapy.

Bivariate analysis (Table 2) found that participants who sought more information on the treatment summary were significantly older (median age in years, 40 *v* 29; OR per year increase in age = 1.06; 95% CI, 1.02 to 1.10; *P* = .005), had more years of survivorship (median time since diagnosis in years, 24 *v* 16; OR per year increase in time since diagnosis = 1.06; 95% CI, 1.01 to 1.11; *P* = .01), and were more likely to have reported not fully understanding the treatment summary (OR 19.6, 95% CI: 2.06, 185.4; *P* = .01), compared with participants who were satisfied with the amount of information. After adjusting for age, sex, and time since diagnosis, not understanding the treatment summary increased the odds of desiring more information on the document (OR = 43.4, 95% CI, 3.43 to 548.1; *P* = .004) (Table 2).

Discussion

In this cross-sectional study of adult survivors of pediatric and young adult cancer, most participants retained, understood, and valued the one-page treatment summary and follow-up care plan. In addition, the majority reported that the treatment summary and care plan did not cause them undue concern or worry. Many participants shared the form within their personal circle and with outside providers, although overall dissemination was modest. Importantly, only 57% of participants had a primary care physician outside MSKCC, which may help to explain this finding. Our findings should lend confidence to providers creating treatment summaries and care plans for their patients.

Approximately one in five participants wanted more information on the document, with much of the desired content falling beyond the scope of the typical treatment summary and care plan. Not surprisingly, we found that older participants and those who did not understand the document were more likely to want more information. Providers could identify these survivors by eliciting a patient's level of comprehension during the visit, and could consider revising individual treatment summaries and care plans as feasible.

Importantly, we found that a small group of patients reported frequent or constant general health worry in the past

week. This finding is consistent with prior work in cancer survivors.²⁵⁻²⁷ A small but significant minority of participants reported that the treatment summary and care plan itself triggered concern and worry. Of note, a recent study of Hodgkin's lymphoma survivors found that a mailed one-page survivorship care plan did not worsen tension and anxiety.²⁴ Nonetheless, providers should be alert to the risk of health-related anxiety in this population and to the possible psychological effects of the follow-up care plan. Our program offers counseling and psychological support to every patient. Notably, worried participants in our study did not differ in their retention or dissemination of the treatment summary.

This study is the first, to our knowledge, to provide evidence that adult survivors of pediatric and young adult cancer retain, understand, and value the treatment summary and care plan in a real-world clinic setting. Only a small number of prior studies have examined patient response to treatment summaries and survivorship care plans. Two prior studies^{29,30} reported on an Internet-based tool to create survivorship care plans. Jacobs et al²⁹ reported that fewer than half of survivors were satisfied with the level of information generated by the Internet tool; in contrast, 80% of participants in our study were satisfied with the level of information provided by the form. Three other studies,³¹⁻³³ including a 2007 report on a series of focus groups offering perspectives on post-treatment cancer care, found enthusiastic interest among adult survivors for the prospective receipt of a survivorship care plan but did not distribute patient-specific survivorship care plans or assess their impact.

A recent Cochrane review³⁴ examined the use of recordings or written summaries of medical consultations for patients with active cancer. Sixteen studies including 2,318 adult participants were included. Between 60% and 100% of participants across 12 studies reported that they read or listened to the summary at least once after the initial visit. Among the 10 studies that examined anxiety and depression, no study found a difference between participants who received the summary and those who did not.

Our study has a few limitations. Because of the clinic-based nature of our study population and the unfunded nature of this study, we limited eligibility to patients who were English speaking and did not have significant neurocognitive deficits. Including multiple survey languages or modalities could strengthen

future studies of the treatment summary and care plan. Patients in this study were insured, educated, and observed as part of a survivorship program, which may limit generalizability. A more marginalized population may be in greater need of the treatment summary and care plan. In addition, our outcomes were self-reported and measured after receipt of the document. Because the study interview was conducted by a study staff member and not a clinician, and in light of the nature of our study population, we expected participants to answer reliably. Future studies could include outside confirmation of study end points and should consider before-and-after measures of concern and worry. Finally, as a result of the brief nature of our study, we could not examine health care practices or compliance with recommended screening in conjunction with feelings towards the document. Oeffinger et al²⁴ recently reported that a one-page mailed survivorship care plan resulted in improved adherence with recommended screening among Hodgkin's lymphoma survivors; future studies of the clinical impact of the treatment summary and care plan in other groups of cancer survivors are warranted.

Importantly, the survey did permit participants to recommend improvements to the treatment summary template. In light of participant feedback received during the survey, the medical team updated the "Potential Late Effects" section of the treatment summary and care plan to include "psychosocial problems including anxiety and depression" and considered further revisions suggested by survey participants. As Edwards³⁵ reported more than a decade ago, patients treated for cancer need different types of information at different times and for different purposes. Participants in our study also suggested providing up-to-date medical information on the back of the treatment summary and care plan or offering an online version of the form.

In conclusion, we found that a one-page treatment summary and care plan was accepted and retained by adult survivors of

pediatric and young adult cancers. Furthermore, although some survivors expressed general health worry, the treatment summary and care plan did not result in undue worry or concern for most participants. Effectiveness of this document may be limited, however, as only half of participants identified a primary care provider and dissemination was modest. Future studies could assess health care practices in light of retention and understanding of the treatment summary.

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Authors' Disclosures of Potential Conflicts of Interest

The author(s) indicated no potential conflicts of interest.

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American Society of Clinical Oncology