

Increasing Rates of Breast Cancer and Cardiac Surveillance Among High-Risk Survivors of Childhood Hodgkin Lymphoma Following a Mailed, One-Page Survivorship Care Plan

Kevin C. Oeffinger, MD,^{1,*} Melissa M. Hudson, MD,² Ann C. Mertens, PhD,³ Stephanie M. Smith, MPH,⁴ Pauline A. Mitby, MPH,⁵ Debra A. Eshelman-Kent, RN, MSN, CPNP,⁶ Jennifer S. Ford, PhD,¹ Judith K. Jones, MD, PhD,⁷ Sharmila Kamani, BA,⁷ and Leslie L. Robison, PhD²

Background. Hodgkin lymphoma (HL) survivors face substantially elevated risks of breast cancer and cardiovascular disease. They and their physicians are often unaware of these risks and surveillance recommendations. **Procedure.** A prospective one-arm study was conducted among a random sample of 72 HL survivors, ages 27–55 years, participating in the Childhood Cancer Survivor Study (CCSS) who were at increased risk for breast cancer and/or cardiomyopathy and had not had a screening mammogram or echocardiogram, respectively, within the prior 2 years. A one-page survivorship care plan with recommendations for surveillance was mailed to participants. In addition, survivors' primary physicians were contacted and provided patient-specific information and a web-based Virtual Information Center was made available for both survivors and physicians. Outcomes were assessed by telephone 6 months after the intervention.

Results. The survivor participation (62/72; 86%) and 6-month retention (56/61; 92%) rates were high. Tension and anxiety, measured by the Profile of Mood States, did not increase following risk notification; 91% of survivors described their reactions to receiving the information in positive terms. At 6 months, 41% of survivors reported having completed the recommended mammogram; 20% reported having an echocardiogram (females 30%, males 10%). Only 29% of survivors visited the website. Nine physicians enrolled, and none used the study resources. **Conclusion.** A mailed, personalized survivorship care plan was effective in communicating risk and increasing compliance with recommended medical surveillance. Internet- and telephone-based strategies to communicate risk were not utilized by survivors or physicians. *Pediatr Blood Cancer.* 2010;56:818–824. © 2010 Wiley-Liss, Inc.

Key words: cancer survivor; late effects; survivorship care plan

INTRODUCTION

More than 80% of children and adolescents with cancer will become long-term survivors [1], contributing to a growing population of patients with unique health care needs. By 20–30 years after diagnosis, 75% of survivors will develop a chronic health condition and almost half will develop a severe or life-threatening condition or die from a chronic condition [2,3]. Excess risk does not appear to plateau with aging, with many second cancers and serious chronic diseases developing in the mid-adult years. Importantly, morbidity and mortality may be reduced through risk-based surveillance and early detection of late effects [4–6]. Thus, the Institute of Medicine (IOM) recommends lifelong follow-up of all childhood cancer survivors, including periodic surveillance for late effects based upon their risks [4]. Further, the IOM recommends that all cancer survivors receive a “survivorship care plan” or written record of their diagnosis and treatment, risk for late effects, and recommendations for follow-up care and surveillance [4,7]. To standardize and facilitate long-term follow-up care of childhood cancer survivors, the IOM charged the Children's Oncology Group (COG) with the development of comprehensive clinical practice guidelines. In September 2003, the COG released the first version of the *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* [5].

Despite these recommendations, the vast majority of adult survivors of childhood cancer do not receive risk-based follow-up care [8–10]. There are several key barriers to such care. Few cancer centers have a specialized program for survivors over the age of 22–25 years and as a result, <20% of long-term survivors are followed at a cancer center [4,9,11]. Survivors are often unfamiliar with the therapy that they received in their younger years and are generally unaware of their risks [12]. While most survivors are seen intermit-

tently by their primary care physician, this population represents a very small fraction of their practice [13–14]. Not surprisingly, most primary care physicians are unfamiliar with this high-risk group and are not cognizant of the surveillance recommendations [15]. Lastly, cancer centers have generally done a poor job in transitioning survivors back to the primary care physician [4]. Indeed, the IOM considers most cancer survivors “lost in transition” [7]. Importantly, this is a universal problem that is not unique to North America [16,17]. The development and testing of interventions that

Additional Supporting Information may be found in the online version of this article.

¹Departments of Pediatrics and Medicine, Memorial Sloan-Kettering Cancer Center, New York; ²Department of Oncology, St. Jude Children's Research Hospital, Memphis, Tennessee; ³Department of Pediatrics, Emory University, Atlanta, Georgia; ⁴Departments of Oncology and Epidemiology & Cancer Control, Stanford University School of Medicine, Stanford, California; ⁵Department of Hematology/Oncology, Children's Hospitals and Clinics of Minnesota, Minneapolis, Minnesota; ⁶Cincinnati Children's Hospital Medical Center, ATP Five Plus Long Term Cancer Survivor Clinic, Cincinnati, Ohio; ⁷The Degge Group, Ltd, Arlington, Virginia

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*Correspondence to: Kevin C. Oeffinger, Departments of Pediatrics and Medicine, Memorial Sloan-Kettering Cancer Center, 1275 York Ave., New York, NY 10065. E-mail: oeffingk@mskcc.org

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educate and inform cancer survivors and their primary physicians and promote recommended surveillance are warranted.

We conducted a study to pilot the usability of a mailed cancer survivorship care plan. We hypothesized that survivors would be very interested in participating in such a study, that a mailed one-page plan would be well received, and that survivors would share this information with their physician. In essence, we theorized that we could positively influence the care of cancer survivors by empowering them with the key information about their health risks. Further, recognizing that most cancer survivors disconnected from their treating institution many years ago, we sought to test whether such an intervention could be delivered across a distance by standard mail. In addition, we were interested in whether clinicians, with their busy schedules, would be interested in communicating directly with our virtual clinical team. Lastly, realizing that a one-page summary and new knowledge of risks for serious diseases may engender a need for additional information, we wanted to test the usability of a web-based virtual information center designed for both survivors and clinicians. For this study, we targeted a particularly high-risk population, Hodgkin lymphoma (HL) survivors who had been treated with chest radiation and/or anthracycline chemotherapy who were not receiving recommended breast cancer or cardiac surveillance.

METHODS

Study Population

All participants were enrolled in the CCSS, a multi-institutional, longitudinal cohort of more than 14,000 ≥ 5 -year survivors of childhood cancer who were diagnosed before age 21, from 1970 to 1986, at one of 26 institutions in the United States and Canada. The CCSS cohort characteristics and study methodology have been described in detail [18–20].

Eligibility for this feasibility study was restricted to HL survivors who had been treated with mantle or modified mantle (chest) radiation and/or anthracycline chemotherapy, with a substantially elevated risk of breast cancer or cardiomyopathy, and who had not had a recommended screening mammogram or echocardiogram, respectively, within the past 2 years. Thus, women were eligible for the breast cancer risk group if they were treated with chest radiation (≥ 20 Gy), were at least 25 years of age at the time of the study and 8 years or more from their radiation, and had never had breast cancer. Women and men were eligible for the cardiac risk group if they were treated with anthracycline chemotherapy (cumulative dose ≥ 200 mg/m²), chest radiation (≥ 30 Gy), or anthracyclines of any dose plus chest radiation, and had never had congestive heart failure. The risk groups were not mutually exclusive; some women were overdue for both screening tests.

Study Design and Procedure

An invitation to participate in the study and a pre-intervention baseline survey was mailed to eligible HL survivors randomly sampled from eight CCSS institutions. Participants were asked to provide the name and contact information for the main physician that they were followed by (primary physician) or usual source of medical care, if applicable. These physicians were mailed an introductory letter and invitation to participate in the study. Survivor and physician participants were compensated \$20 for each completed assessment. The Institutional Review Board at each site approved the protocol.

Intervention Components

Participants were mailed a personalized one-page survivorship care plan (example provided in Supplemental Fig. 1) with key information about their cancer therapy, potential late effects, and risk-based screening recommendations based on the COG Guidelines at the time of the study. A cover letter highlighted the primary study recommendation (mammogram and/or echocardiogram) and encouraged survivors to discuss this information with their physician. Recognizing that such a letter could cause a survivor to experience a sense of fear or uncertainty, we provided a toll-free telephone number to contact the CCSS Coordinating Center or the principal investigator (KCO) with any questions or comments.

Physicians were mailed a letter notifying them of their patient's participation in the study, briefly describing the risks of this population, and inviting them to participate in the 6-month study. In the cover letter, physicians were encouraged to contact the principal investigator (KCO), the study team, or the CCSS with any questions regarding their patient or the screening recommendations, regardless of whether or not the physician enrolled in the study.

All survivor and physician participants were provided access to an educational website designed specifically for HL survivors and their physicians. The website included information about HL, potential problems following therapy, the concept of risk, ways to lower risk, links to other resources, and answers to frequently asked questions. Participants were able to communicate with the research team by submitting a question through the website or calling the CCSS toll free hotline. Each participant was given a unique login ID and password for the website and could choose to view the information in lay terms (survivor portal) or medical terms (health care professional portal). A non-active post-study version of this website is available for viewing at www.nete.com/ccssvc.

Outcomes

To measure the immediate (6-month) effectiveness of the intervention, participants were asked at the 6-month interview whether they had obtained a screening mammogram or echocardiogram since receiving the survivorship care plan, and whether/when they planned to do so. Participants were also asked whether they remembered receiving, reading, and understanding the mailed survivorship care plan, if they wanted more information about risks, whether they had seen a physician since receiving the summary, and if they shared the plan with their physician or planned to do so. Open-ended questions solicited additional feedback regarding survivors' reactions to receiving the survivorship care plan. Website use was tracked electronically and those who used the website were asked if they recalled anything they had learned. To evaluate possible psychological effects of the intervention, the Profile of Mood States (POMS) was administered at baseline and 6 months. The 65-item POMS instrument measures self-reported feelings during the past week to assess six-mood states (tension/anxiety, depression, anger, vigor, fatigue, confusion) and yields a summary score (total mood disturbance) [21]. This validated instrument has been used in a variety of populations, including cancer survivors [22–24].

Statistical Analysis

Descriptive statistics were used to summarize participants' sociodemographics (age, race/ethnicity, education, health

TABLE I. Characteristics of Participants

Characteristics	Females (N = 40)		Males (N = 22)		Total (N = 62)	
	N	%	N	%	N	%
Age at study, years						
Median (range)		39.0 (29.6–55.5)		35.5 (30.8–42.7)		37.3 (29.6–55.5)
Race/ethnicity						
White, non-Hispanic	37	93%	21	100%	58	95%
Minorities	3	7%	0	0%	3	5%
Education						
High school or some college	14	36%	10	45%	24	39%
College graduate	25	64%	12	55%	37	61%
Health insurance						
Yes	38	97%	20	91%	58	95%
No	1	3%	2	9%	3	5%
Primary physician ^a						
Yes	34	85%	14	64%	48	77%
No	6	15%	8	36%	14	23%
Age at diagnosis, years						
Median (range)		14.6(4.2–20.9)		14.7(5.8–20.1)		14.6(4.2–20.9)
Years since diagnosis						
Median (range)		23.9(17.7–34.7)		21.0(17.5–28.4)		22.4(17.5–34.7)

^aOr usual source of medical care.

insurance, and interval since cancer diagnosis), which were obtained from CCSS records. Frequencies and percentages were used to describe the feasibility outcomes. To measure mood changes over the course of the study, paired *t*-tests were used to assess the difference between POMS scores at baseline and 6 months. All analyses were done in SAS version 9.1 (SAS Institute, Inc., Cary, NC) with a two-sided significance level of $P \leq 0.05$.

RESULTS

Study Population

Of 72 HL survivors invited to participate, 1 was unavailable, 4 were lost to follow-up, 5 did not respond, and 62 (86%) participated (Supplemental Fig. II). Table I presents characteristics of participants. Participants tended to be older than non-participants, more likely to be female (65% of participants vs. 50% of non-participants), non-Hispanic white (95% vs. 80%), college graduates (61% vs. 30%), and have health insurance (95% vs. 70%). Participants ranged in age from 29 to 55 years at study (median, 37 years), with about one-third surviving ≥ 25 years since diagnosis.

At the 6-month follow-up, four survivors did not respond, one actively refused, and one died before 6 months. Fifty-six survivors completed the 6-month follow-up interview for a retention rate of alive, eligible participants of 93% (56/60). One participant was diagnosed with breast cancer prior to receiving the information and so was excluded from the analysis. The remaining results pertain to the 55 survivors with baseline and follow-up data.

Survivorship Care Plan

Table II summarizes participants' use of the intervention materials. Six months after the intervention, 78% (43/55) survivors remembered receiving the survivorship care plan in the mail. Of these, nearly all had read and understood it, and 39% said that it made them want more information about their risks. Twenty-nine

survivors had seen a physician since receiving the survivorship care plan, and nearly half shared the plan with the physician (females, 44%; males, 45%). Of those who had not seen a physician or had seen a physician but had not shared the plan, most planned to do so (females, 75%; males, 70%).

Screening Practices

Mammogram recommendations were issued to 34 women, 20 of whom were also advised to have an echocardiogram. Echocardiography was recommended for all 20 men. Table III presents screening outcomes according to the type of test. Before the study, few survivors were aware of recommendations for mammography (32%) or echocardiography (12%). Six months after the intervention, 41% of survivors reported having a recommended mammogram and 20% reported having an echocardiogram (females, 30%; males, 10%). An additional one-third of survivors in both groups said they planned to have the recommended test within the next 6 months.

Physician Outreach

Although 48 (77%) survivors provided contact information for a primary physician, only 9 (19%) physicians agreed to participate in the study. None of these doctors visited the website or contacted the study team or CCSS 1-800 hotline. Since, so few physicians participated, follow-up interviews were not conducted.

Virtual Information Center Website

During the study period, 29% of survivor participants visited the website (females, 37%; males, 15%; Table II). Three women used the website to submit a question to the study team, and none called the CCSS 1-800 hotline. When asked during the 6-month interview, only four survivors could recall anything they learned from the website. Those who did not visit the website said they were too busy (42%), did not remember to visit it

TABLE II. Survivors^{Q4}, Use of Survivorship Care Plan and Website at 6-Month Interview

	Females (N = 35)		Males (N = 20)	
	N	%	N	%
Feasibility outcomes				
Survivorship care plan				
Remembered receiving in mail	28	80	15	75
Read and understood information ^a	28	100	13	87
Wanted more information about risks ^a	12	43	5	33
Since receiving plan ^a				
Have seen physician	18	64	11	73
Shared summary with physician ^b	8	44	5	45
Plan to share plan with physician ^c	15	75	7	70
Virtual information center website				
Visited website during study	13	37	3	15
Recalled anything learned from website ^d	4	31	0	0
Submitted a question through website ^d	3	23	0	0

^aOf those who remembered receiving the survivorship care plan in the mail; ^bOf those who have seen a physician; ^cOf those who have not seen a physician or have not shared the plan with a physician; ^dOf those who visited the website.

TABLE III. Survivors' Self-Reported Screening Knowledge and Practices at 6-Month Interview According to Recommended Screening Test*

	Mammogram (N = 34)		Echocardiogram (N = 40)	
	N	%	N	%
Intervention outcomes				
Screening knowledge and practices				
Aware of recommendations prior to study	11	32	5	12
Recent screening and future intentions				
Completed during study	14	41	8	20
Plan within next 6 months	12	35	14	35
Plan within next 1–2 years	6	18	13	33
Plan ≥2 years or do not plan	2	6	5	12

*Twenty females were at risk of both breast cancer and cardiomyopathy: 19 are included in both screening groups; 1 had breast cancer before the study and is included only in the echocardiogram group.

TABLE IV. Survivors' Mood and Anxiety at Baseline and 6-Month Follow-Up

Mean scores (SD) ^b	Females (N = 35)			Males (N = 19) ^a		
	Baseline	Follow-up	<i>P</i> ^c	Baseline	Follow-up	<i>P</i> [*]
Profile of mood states (POMS)						
Tension/anxiety	8.7 (6.7)	8.7 (5.4)	0.95	7.6 (4.3)	8.5 (6.8)	0.52
Depression	5.6 (5.7)	5.9 (7.3)	0.86	8.5 (9.5)	7.9 (11.8)	0.74
Anger	6.5 (5.0)	8.0 (6.7)	0.22	7.3 (6.4)	8.2 (9.9)	0.61
Vigor	16.6 (6.2)	18.3 (6.3)	0.12	16.6 (6.9)	17.2 (5.7)	0.66
Fatigue	9.6 (5.9)	9.5 (6.1)	0.96	8.2 (5.7)	10.4 (6.1)	0.02
Confusion	6.2 (4.0)	5.6 (4.0)	0.38	5.9 (3.0)	6.7 (4.8)	0.39
Total mood disturbance	20.1 (26.2)	19.3 (28.0)	0.88	20.8 (27.0)	24.5 (40.4)	0.54
Anxiety related to intervention						
Felt anxious after reading/using						
Survivorship care plan		4 of 28 (14%)			6 of 15 (40%)	
Website		5 of 13 (38%)			0 of 3 (0%)	

^aExcludes one male who did not answer POMS questions at 6-month follow-up; ^bHigher scores indicate greater disturbance for all moods except vigor; ^c*P*-value for difference in means from baseline to 6-month follow-up.

(42%), were not interested (24%), and/or had computer or internet problems (15%).

Participants' Reactions to Intervention Materials

On average, participants' mood and anxiety level did not change over the course of the intervention (Table IV). At baseline and follow-up, survivors' POMS scores were similar to those seen in the general population [25]. Males reported greater fatigue after the study than before ($P = 0.02$). During the 6-month interview, 13 survivors said they felt anxious after reading the survivorship care plan or using the website (two reported anxiety from both components). For these survivors, POMS scores did not differ from baseline to follow-up, and tension/anxiety decreased slightly ($P = 0.096$). However, compared to the other survivors, this subset reported greater tension/anxiety at baseline ($P = 0.01$).

Importantly, 91% of participants reacted favorably to the survivorship care plan, reporting positive feelings about receiving the information. Even among the 10 survivors who felt anxious after reading the plan, 9 described their reactions to it in positive terms.

DISCUSSION

This study demonstrates the feasibility of a mailed one-page survivorship care plan to promote risk-based screening among high-risk cancer survivors who are no longer followed at a cancer center. The participation and retention rates were high, and an increase in self-reported mammogram and echocardiogram screening rates 6 months after the intervention was suggestive of the intended effect. Importantly, the survivorship care plan was favorably received by participants. The other two components, direct contact with physicians and an educational website, did not add value to the mailed materials.

While some studies have used a cancer treatment summary to counsel patients in a one-on-one setting [26–28], this is the first study that we are aware of where survivorship care plans were mailed to survivors. Notably, most participants in our study had completed their therapy over 20 years ago. Not surprisingly, prior to the study, few of the participants were aware of the surveillance recommendations. What was surprising, though, was how well this

information was received, particularly recognizing that the survivors were informed of their risk for two very serious health problems. We anticipated that receiving this information would engender an increased level of anxiety, leading to telephone calls or email questions. However, we did not see an increase in anxiety, fears or sense of uncertainty by either standardized measures or open-ended questions. The most impressive change in behavior occurred among women where 41% and 30% reported having a mammogram or echocardiogram, respectively, within 6 months of receiving the survivorship care plan. The difference in uptake between the two tests is consistent with prior reports of screening among long-term cancer survivors in the CCSS, where mammogram rates typically exceed echocardiogram rates by 10–20% [9,29–30].

Primary care physicians express interest in caring for cancer survivors [15,31–32]. In a recent study of adult survivors of childhood cancer, Blaauwbroek et al. [26] demonstrated the feasibility of shared care between cancer specialists and family physicians. The researchers succeeded in showing three points: patients would see their family doctor for a survivor-focused visit; the family doctors were interested in sharing survivor care; and the family doctors returned the necessary medical information needed for continued follow-up. In our study, there was a very low enrollment rate of primary care physicians and no telephone calls or emailed questions about their participating patient. However, when the survivors presented the information to the primary care physician, the requested surveillance test was ordered. Indeed, none of the survivor participants felt that their primary care physician was a barrier to getting the test. These results suggest that while primary care physicians are busy, they appear to be responsive to the needs or requests of high-risk cancer survivors. Perhaps, appropriately trained nurses within the primary care practices would also improve the delivery of health care for these high-risk cancer survivors.

Surprisingly, few survivor and no physician participants visited the web-based information center. The cover letter to both groups provided a one-page description of the content and intent of the "Cancer Survivor Virtual Information Center" and encouraged the submission of questions and feedback through this avenue. Instead, participants said that they were "too busy," "did not remember," or "were not interested." Importantly, almost 40% of the women who

visited the website said that it made them feel more anxious. The cost and resources needed to develop and maintain an information website and the negative impression by users suggests that this may not be a helpful way to inform cancer survivors about their health risks.

Reflecting the primary objective of this study to assess feasibility, the sample size was small, and there was no comparison group. The relatively homogeneous sample of HL survivors may not be representative of the larger population of childhood cancer survivors. Thus, even though participants came from multiple geographically diverse institutions, the generalizability of the findings is limited. The 86% participation rate was high, but the study population was derived from survivors who were already participating in the CCSS cohort. Although it is possible that participants were more interested in health promotion than non-participants, this was unlikely to have a substantial effect since none of the survivors had been following screening recommendations prior to the study. Post-intervention mammogram and echocardiogram rates must be interpreted with caution since 95% of the study population reported having insurance and screening tests were not verified by medical records. Moreover, the 6-month follow-up interval may have been too short to capture the full effect of the intervention or to assess sustainability over time.

In summary, this study demonstrates the feasibility of providing personalized risk information through a one-page survivorship care plan to long-term survivors of childhood cancer to encourage risk-based surveillance for late effects. Importantly, the survivorship care plan was mailed and delivered from a distance, making it well suited for dissemination on a large scale. Moreover, survivors' favorable reactions to the personalized cancer treatment summary and screening recommendations support the feasibility of implementing survivorship care plans, and in so doing, lay the groundwork for future randomized interventions to promote risk-based follow-up care in high-risk cancer survivors.

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