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# Age and Cancer Treatment Are Related to Receiving Treatment Summaries and Survivorship Care Plans in Female Young Adult Cancer Survivors

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The study determined factors associated with patient-reported receipt of survivorship care plans and/or treatment summaries (SCP/TS). Two hundred forty female young adult cancer survivors ages 18-44 completed a web-based survey that included self-report on receiving SCP/TS. Mean age was 32.8 (standard deviation 5.8) years; 20% were diagnosed with cancer at age <21. Only 47% reported receipt of SCP/TS. Age <21 at diagnosis (odds ratio [OR] 2.0, 95% confidence interval [CI] 1.0-3.9), chemotherapy (OR 2.3, 95% CI 1.2-4.6), central nervous system radiation (OR 2.5, 95% CI 1.1–5.6), and bone marrow transplantation (OR 7.2, 95% CI 1.5– 33.3) were significantly associated with higher odds of SCP/TS receipt. Improved integration of TS and SCP into cancer survivorship care is needed.

Keywords: survivorship care plan, treatment summary, cancer survivorship

# Introduction

DVANCES IN CANCER treatment have enabled the ma-A jority of young people diagnosed with cancer to become long-term survivors. Nearly 300,000 cancer survivors are diagnosed during childhood, adolescence, and young adulthood in the United States.<sup>1</sup> These individuals frequently experience late effects related to their cancer and cancer treatment, which require follow-up care.

Providing survivorship care plans (SCP) to cancer survivors was recommended by the Institute of Medicine in 2006 to support the transition in care from treatment to survivorship.<sup>2</sup> SCPs are personalized documents that usually include information on cancer diagnosis and treatments, potential adverse consequences of these treatments, recommendations for screening for cancer recurrence, and prevention of other comorbidities. Treatment summaries (TS) provide information limited to cancer diagnosis and treatment exposures and are usually incorporated into SCP. TS and SCP are typically created by the cancer treatment team and provided toward the end of cancer therapy in paper form or as a document accessible online.

Professional and advocacy organizations, including the American Society of Clinical Oncology, American Cancer Society (ACS), and Livestrong Foundation, support providing SCPs. $^{3-5}$  Moreover, the Commission on Cancer mandates its use.<sup>6</sup> However, use of SCPs remains inconsistent, ranging from 14% to 43%.<sup>7–10</sup> To date, studies have been conducted to examine SCP formats, content, means of delivery, provider perception on utility, and implementation, with conflicting results on efficacy.<sup>7,9,11</sup> For example, a one-page SCP focused on breast cancer and cardiovascular risks led to increased postintervention rates of obtaining mammograms and echocardiograms in high-risk survivors of childhood Hodgkin lymphoma, suggesting that SCP influenced early detection.<sup>12</sup> In contrast, a randomized controlled trial in early-stage breast cancer survivors showed that self-reported health outcomes were not affected by receipt of SCP, which included treatment summary, follow-up guidelines, and a summary table.<sup>1</sup>

Little research has been conducted on receipt of SCP or TS in real-life practice from the patient perspective. Rates of survivors reporting receipt of a written treatment summary were similar between adult cancer survivors in Missouri (24%)<sup>14</sup> and AYA-aged survivors (30%).<sup>15</sup> The majority (75%) of survivors at an academic center reported receiving a follow-up care plan, but 40% of this information was provided only verbally.<sup>16</sup> Given limited research on receipt of SCP/TS from the patient perspective and previously reported

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low rates of written TS and care plans, the objectives of this study were to describe patient-reported receipt of SCP/TS in a cohort of female young adult cancer survivors who have completed primary cancer treatment and determine the patient and treatment characteristics associated with receipt of SCP/ TS. We hypothesized that younger age at diagnosis, recent cancer diagnosis, advanced cancer stage, intensive cancer treatment, and comorbid medical conditions would be associated with higher likelihood of reporting receipt of SCP/TS.

### **Materials and Methods**

We conducted a secondary analysis of an ongoing prospective cohort study, Fertility Information Research Study. Female young cancer survivors were recruited through diverse sources: social media outreach by cancer advocacy groups (60%), six university-based fertility preservation programs (26%), FERTLINE, the Oncofertility Consortium's telephone hotline (6%), and community outreach or word of mouth (8%).<sup>17</sup> Eligibility criteria included: female, age 18– 44, and a personal history of cancer and cancer treatment. Participants were consented over the telephone and completed an enrollment questionnaire via the Internet or by telephone interview. Participants then completed annual follow-up questionnaires. The study was approved by the Institutional Review Board at the University of California, San Diego.

These analyses used data from participants who completed the first follow-up questionnaire between April 2013 and June 2015. Participants provided self-reported demographics, cancer diagnosis, treatment characteristics, and receipt of SCP/TS. To assess TS receipt, participants were asked, "Did any doctor, nurse, or other health professional EVER give you a written summary of all the cancer treatments that you received?" To assess SCP receipt, participants were asked, "Did any doctor, nurse, or other health professional EVER give you a survivorship care plan to provide guidelines for monitoring and maintaining your health after completing treatment for cancer?" For both questions, participants were required to select from the following options: no, yes, don't know/not sure, or prefer not to answer. Participants were classified as reporting receipt of SCP/TS if they responded "yes" to both the questions. Participants who responded "no" or "don't know/not sure" to both the questions were classified as not receiving SCP or TS. No participants chose the option of "prefer not to answer."

#### Statistical methods

Descriptive statistics were calculated as frequencies and percentages or means and standard deviations (SD). The primary outcome of interest was receipt of SCP/TS. Exposures of interest were compared by outcome using Student's *t*-test or Fisher's exact test.

Logistic regression models were used to determine the association between participant characteristics and receipt of SCP/TS. In multivariable models, age at cancer diagnosis was dichotomized into <21 and  $\geq$ 21 years, the age cutpoint between pediatric and adult cancer care. Variables associated with receiving SCP/TS in bivariable analyses were included in the multivariable model. Significance was set at *p* < 0.05. Analyses were conducted using SPSS statistical software v23 (IBM Corporation).

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# Results

Among 334 cancer survivors enrolled in the parent cohort between 2011 and 2013, 240 completed the follow-up questionnaire and were eligible for this analysis. Ninety-four participants were excluded for not completing the follow-up questionnaire, resulting in missing data on the outcome (receipt of SCP/TS). Compared with the 240 included participants, the 94 ineligible survivors were similar in demographic and cancer characteristics, with the exception of being diagnosed with cancer at an older age (mean 29.0 [SD 8.4] years in excluded vs. 27.2 [SD 7.1] years in included) (data not shown).

Table 1 depicts demographic characteristics of participants. Mean age (SD) was 32.8 (SD 5.8) years. The majority of participants were white (79%), college graduates (89%), and had health insurance (95%). The two most common cancer types were breast cancer (29%) and lymphoma (26%) (Table 2). Seventy-nine percent of participants reported receiving chemotherapy, 49% radiation, 61% surgery, and 6% bone marrow or stem cell transplant as part of their cancer treatment.

One hundred thirteen participants (47%) reported receiving SCP and/or TS. Among them, 86 (35.8%) reported receiving TS only, 67 (27.9%) reported receiving SCP only, and 40 (16.7%) reported receiving both. Six participants (2.5%) responded "don't know"/"not sure" to SCP and TS receipt questions.

In bivariable analyses, age at cancer diagnosis, current age, education level, receipt of chemotherapy, and bone marrow transplant treatment were significantly associated with receipt of SCP/TS. While any radiation was not associated with receipt of SCP/TS, radiation to the central nervous system was related to higher rates of receipt. Other demographic and cancer characteristics were not significantly associated with receipt of SCP/TS (Tables 1 and 2).

The multivariable model for receipt of SCP/TS included age at diagnosis, chemotherapy, central nervous system (CNS) radiation, and bone marrow transplant treatment (Table 3). Current age and education were not included due to collinearity with age at diagnosis. Participants who were diagnosed younger than 21 years had significantly higher odds of receiving SCP/TS, compared with those who were age 21 or older at diagnosis (OR 2.0, 95% CI 1.0-3.9). In addition, those who received chemotherapy had more than twofold higher odds of receiving SCP/TS than those who did not undergo chemotherapy (OR 2.3, 95% CI 1.2-4.6). Participants exposed to CNS radiation had more than twofold increased odd of reporting receipt of SCP/TS (OR 2.5, 95% CI 1.1–5.6). Finally, participants who underwent bone marrow transplantation had significantly higher odds of receiving SCP/TS than those who did not undergo a bone marrow transplant (OR 7.2, 95% CI 1.5-33.3). Additional analyses using only receipt of SCP or only receipt of TS as the main outcomes, or excluding participants with metastatic disease (7.5%) did not materially change these results (Supplementary Tables S1-S3; Supplementary Data are available online at www.liebertpub.com/jayao).

# Discussion

In this cohort of young female cancer survivors surveyed between 2013 and 2015, almost half reported receiving a written summary of their cancer treatments and/or guidelines for maintaining health in survivorship. Among demographic and cancer characteristics, younger age at diagnosis, receipt

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	Overall, N=240 (%)	Received SCP/TS, n=113 (%)	Did not or unsure about receiving SCP/TS, n=127 (%)	p <sup>a</sup>
Current age, years mean (SD)	32.8 (5.8)	31.9 (6.6)	33.5 (4.9)	0.04
20–24	29 (12.1)	19 (16.8)	10 (7.9)	0.08
25-30	66 (27.5)	37 (32.7)	29 (22.8)	
>30	145 (60.4)	57 (50.5)	88 (69.3)	
Race				
White	190 (79.5)	91 (80.5)	99 (78.6)	0.16
Black	9 (3.8)	7 (6.2)	2 (1.6)	
Asian	13 (5.4)	4 (3.6)	9 (7.1)	
Other	27 (11.3)	11 (9.7)	16 (12.7)	
Ethnicity				
Non-Hispanic	218 (91.2)	103 (91.2)	115 (91.3)	0.52
Hispanic	20 (8.4)	9 (8.0)	11 (8.7)	
Education				
College graduate	209 (88.9)	91 (83.5)	118 (93.7)	0.02
Did not graduate from college	26 (11.1)	18 (16.5)	8 (6.3)	
Income				
≤50,000	76 (31.7)	39 (34.5)	37 (29.1)	0.43
>50,000	144 (60.0)	63 (55.8)	81 (63.8)	
Declined to answer	20 (8.3)	11 (9.7)	9 (7.1)	
Health insurance				0.14
No	12 (5)	3 (2.7)	9 (7.1)	
Yes	228 (95)	110 (97.3)	118 (92.9)	
Comorbid medical conditions <sup>b</sup>				
0	65 (27.1)	35 (31.0)	30 (23.6)	0.24
1 or more	175 (72.9)	78 (69.0)	97 (76.4)	

TABLE 1. PARTICIPANT CHARACTERISTICS BY RECEIPT OF SURVIVORSHIP CARE PLAN/TREATMENT SUMMARY IN A COHORT OF FEMALE ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS (N=240)

Due to missing data, some variables do not add up to 240.

<sup>a</sup>Fisher's exact test or Student's *t*-test.

<sup>b</sup>Comorbid medical conditions included asthma/lung high blood pressure, diabetes/high blood sugar, being overweight (obesity), overactive/underactive thyroid, depression/bipolar disorder, eating disorder, rheumatologic diseases, Crohn's disease/ulcerative colitis, seizures/neurologic disorders, and TIA/stroke.

SCP, survivorship care plan; SD, standard deviation; TS, treatment summaries.

of chemotherapy, history of CNS radiation, and prior bone marrow transplant were significantly associated with selfreport of receiving SCP/TS. The data demonstrate that selfreported receipt of these documents is not uniform across the young adult cancer survivor population. Drawn from survivors treated across the United States, these findings highlight a gap in survivorship care.

The results are consistent with provider- and patientreported data on SCP/TS.<sup>8,9,16,18</sup> A decade after publication of the Institute of Medicine SCP guidelines, use of these documents remains limited and inconsistent.<sup>7,19</sup> In this cohort, the proportion of participants reporting receipt of SCP/ TS did not increase in those diagnosed after 2006. Among National Cancer Institute-designated cancer centers, fewer than half reported delivering SCP to breast and colorectal cancer survivors.<sup>9</sup> In a national sample of medical oncologists, half reported always or almost always providing TS, while 20.2% reported always or almost always providing SCP.<sup>8</sup> From the patient perspective, a limited number of studies suggest patient-reported receipt of SCPs ranging from 24% to 35%.<sup>14,15</sup> It is not surprising that fewer than half of survivors in this cohort reported receiving a SCP/TS.

We found that survivors of pediatric cancers, diagnosed and treated before age 21, were more likely to report SCP/TS receipt than survivors diagnosed as young adults. We speculate that this finding stems from the treatment setting at tertiary pediatric facilities, follow-up care structure, and involvement of caregivers. In pediatrics, long-term follow-up programs began in the 1980s, significantly earlier than for adults.<sup>20</sup> The earlier introduction of these programs into childhood cancer care may explain the higher observed odds of reporting receipt of SCP/TS by younger patients. In addition, healthcare provider–patient interactions almost always include parents/guardians for pediatric patients. Providing information to both patients and their caregivers may support retention of this information. Finally, graduation from pediatric medical care into adult care is a transition point that may emphasize the importance of retaining medical information via TS/SCP.

We found higher odds of reporting SCP/TS receipt by participants exposed to chemotherapy and bone marrow transplantation. This finding may be due to the known higher risks of late effects associated with these treatments. Patients exposed to chemotherapy are at risk for multiple comorbidities such as cardiovascular diseases, secondary malignancies, and reproductive health issues.<sup>21–24</sup> The prevalence of any chronic condition among  $\geq$  5-year childhood cancer survivors ranged from 66% (ages 5–19) to 88% (ages 40–

	Overall, N=240 (%)	<i>Received SCP/TS</i> , n=113 (%)	Did not or unsure about receiving SCP/TS, n=127 (%)	p <sup>a</sup>
Age at diagnosis, years mean (SD) <21 $\ge 21$	27.2 (7.1) 48 (20.0) 192 (80.0)	26.7 (7.8) 29 (25.7) 84 (74.3)	27.7 (6.6) 19 (15.0) 108 (85.0)	0.26 0.05
Cancer diagnosis Breast Lymphoma Gynecologic Blood, Leukemia Thyroid Other <sup>b</sup>	68 (28.5) 62 (25.9) 19 (8.0) 19 (8.0) 14 (5.8) 57 (23.8)	32 (28.3) 31 (27.4) 7 (6.2) 12 (10.6) 3 (2.7) 28 (24.8)	36 (28.6) 31 (24.6) 12 (9.5) 7 (5.6) 11 (8.7) 29 (23.0)	0.25
Cancer stage Stage 1 Stage 2 Stage 3 Stage 4 Other	49 (20.5) 74 (31) 41 (17.2) 18 (7.5) 57 (23.8)	17 (15) 36 (31.9) 23 (20.4) 12 (10.6) 25 (22.1)	32 (25.4) 38 (30.1) 18 (14.3) 6 (4.8) 32 (25.4)	0.12
Diagnosis year <2006 2006–2010 >2010	52 (21.7) 75 (31.3) 112 (46.7)	21 (18.6) 39 (34.4) 53 (46.9)	31 (24.4) 36 (28.3) 59 (46.4)	0.46
Time since cancer diagnosis, years mean (SD) <2 2–5 >5	5.5 (4.7) 35 (14.6) 136 (56.9) 68 (28.5)	5.3 (4.5) 19 (16.8) 65 (57.5) 29 (25.7)	5.7 (4.9) 16 (12.7) 71 (56.3) 39 (31.0)	0.43 0.53
Surgery for cancer Chemotherapy	147 (61.5) 189 (79.1)	65 (57.5) 98 (86.7)	82 (65.1) 91 (72.2)	0.24 0.007
Radiation therapy CNS Chest Pelvis	119 (49.8) 30 (12.5) 72 (30.1) 20 (8.3)	58 (51.3) 20 (17.6) 32 (28.3) 10 (8.8)	61 (48.4) 10 (7.8) 40 (31.4) 10 (7.8)	0.69 0.03 0.76 0.82
Endocrine therapy Bone marrow or stem cell transplant Cancer recurrence Secondary cancer	$\begin{array}{c} 44 \ (18.4) \\ 14 \ (5.9) \\ 12 \ (5.0) \\ 6 \ (2.5) \end{array}$	15 (13.3) 12 (10.6) 7 (6.2) 2 (1.8)	$\begin{array}{c} 29 \ (23.0) \\ 2 \ (1.6) \\ 5 \ (3.9) \\ 4 \ (3.1) \end{array}$	0.07 0.004 0.56 0.69

TABLE 2. CANCER AND TREATMENT CHARACTERISTICS BY RECEIPT OF SURVIVORSHIP CARE PLAN/TREATMENT SUMMARY IN A COHORT OF FEMALE ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS (N=240)

Due to missing data, some variables do not add up to 240.

<sup>a</sup>Fisher's exact test or Student's *t*-test.

<sup>b</sup>Other cancer types included bone, brain, colon, kidney, lung, melanoma, pancreas, rectum, skin (nonmelanoma), soft tissue, throatpharynx, other.

49).<sup>24</sup> While this study cannot determine if higher reporting of SCP/TS receipt resulted from patient versus provider awareness of increased late effects with chemotherapy and transplant, we speculate that awareness of late effects in young survivors by patients and providers alike may improve patients' recognition of SCP/TS receipt. Alternatively, it is possible that participants without SCP/TS underreport treat-

ment exposure because of the lack of this supporting document, a limitation of the cross-sectional design.

Several limitations should be noted. First, we did not have access to medical record data on whether SCP or TS were provided and are therefore unable to differentiate between not receiving SCP/TS or not recalling receipt. However, recent study on providing SCP to breast cancer survivors

TABLE 3. UNADJUSTED AND ADJUSTED MODELS OF RECEIPT OF SURVIVORSHIPCARE PLAN/TREATMENT SUMMARY (N=240)

	Unadjusted OR (95% CI)	р	Adjusted OR (95% CI)	р
Age at diagnosis (<21 vs. $\geq$ 21)	1.9 (1.0–3.7)	0.04	1.9 (1.0–3.8)	$0.05 \\ 0.02 \\ 0.04 \\ 0.04$
Chemotherapy	2.5 (1.3–4.9)	0.007	2.3 (1.2–4.7)	
BMT	7.4 (1.6–33.7)	0.01	6.9 (1.5–32.2)	
CNS radiation	2.5 (1.1–5.6)	0.03	2.4 (1.1–5.6)	

Adjusted model included all variables shown in the table. BMT, bone marrow transplant.

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suggests high rates of recalling receipt.<sup>25</sup> Second, we do not have information on the treatment setting and location, limiting our ability to study these factors. No cognitive testing was performed to assess participant's comprehension of our questions on SCP or TS receipt. However, only six participants answered that they did not know or were unsure about receipt of SCP or TS, suggesting that this population is aware of these types of written information and supports the validity of the questions. In addition, this study was not designed to get detailed information about SCP or TS format, content, and/or mode of delivery. Finally, it is important to emphasize that much of our cohort comprised white, educated survivors, limiting generalizability.

Currently, research is ongoing to determine the type of information, format, and mechanisms for delivery and implementation of SCP that would change patient-important outcomes. As these initiatives are undertaken, our report provides data on which subsets of young survivors may not be receiving or recognize that they have received these survivorship support aids. These data suggest that better integration of SCP is needed in care of young cancer survivors.

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## **Authors Contribution**

K.S.: Conception and design, data analysis and interpretation, article writing, and final approval. S.A.D.R.: Conception and design, data analysis and interpretation, article writing, and final approval. B.W.W.: Data analysis and interpretation, article writing and final approval. J.R.G.: Conception and design, article writing, and final approval. S.R.: Conception and design, data analysis and interpretation, article writing, and interpretation. H.I.S.: Conception and design, data analysis and interpretation, article writing, and final approval.

### **Protection of Human Subjects**

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Declaration of Helsinki 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

# **Author Disclosure Statement**

No competing financial interests exist.

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