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ORIGINAL ARTICLE

A cross-sectional population-based survey looking at the impact of cancer survivorship care plans on meeting the needs of cancer survivors in the posttreatment stage

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Abstract

Purpose The purpose of this study was to determine the impact of receiving a survivorship care plan (SCP) on meeting cancer survivors' overall, informational, physical, emotional, and practical needs. Since the recommendation for implementation of SCPs, there have been numerous studies on their effectiveness with mostly inconclusive results.

Methods All Nova Scotia survivors meeting specific inclusion and exclusion criteria were identified from the Nova Scotia Cancer Registry and sent the 83-item survey to assess experiences and needs across five domains (overall, informational, physical, emotional, and practical). Descriptive statistics (frequencies, percentages) and chi-square analyses were used to examine and report survey findings.

Results The response rate was 44.6%, with 1514 respondents. SCPs were significantly associated ($p < 0.00001$) with receiving timely help and support to meet survivors' overall, informational, physical, emotional, and practical needs posttreatment. For the most part, survivors' clinical characteristics, such as cancer type, time since treatment, chronic comorbidities, and metastases, did not result in differences among the five outcomes.

Conclusions Those who received a SCP reported higher agreement on all five outcomes in comparison to those who did not receive a SCP. Further work should evaluate the delivery of SCPs and the components of SCPs that are most likely to contribute to positive survivor outcomes.

Keywords Survivorship · Survivorship care plan · Needs · Survey · Cancer

Introduction

In 2016, an estimated 15.5 million people with a history of cancer were alive in the USA, and this number is projected to reach 20.3 million in 2026 [1]. Similar figures are seen in Canada, where an estimated 60% of people diagnosed with cancer in 2017 will be alive 5 years after diagnosis [2]. Cancer survivors face unique physical, emotional, and practical needs after diagnosis and treatment, and there is a demand for specific resources to help counsel and support this growing population. Some current models of survivorship care include multidisciplinary clinics, disease-specific clinics, survivorship clinics, and integrated clinics [3]. One tool that may be used to enhance care in these models is a survivorship care plan (SCP). In 2005, the Institute of Medicine recognized both the high unmet needs of cancer survivors and the lack of coordinated survivorship care, and recommended the provision of a SCP after treatment to address these issues [4]. The SCP would include information needed for long-term follow-up care, such as the following: diagnosis, treatments received, possible side effects, recommended follow-up schedule, preventative practices, support services, and contact information for providers and services [4]. At the time, there was insufficient evidence to support the use of SCPs, but it was reasonably assumed that SCPs would improve care [4].

Since the initial recommendation, there have been numerous trials of SCP effectiveness in different settings, and recent reviews have summarized the current state of knowledge [5–8]. One review reported negative findings in the literature, such as the ROGY trial that showed increased anxiety, higher symptom burden, and more contact with a provider in the

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group that received an automated SCP [5, 9]. Poll-franse et al. concluded that SCPs should not be widely used due to lack of efficacy, the range of effects on different patient groups, high costs, potential negative consequences, and practical challenges associated with implementation [5]. In another review, LaGrandeur et al. reported an absence of statistically significant differences in health care delivery outcomes such as frequency of follow-up and adherence to surveillance; however, they reported a positive associated between SCPs and psychosocial and quality of life outcomes [6]. A recent review of 13 randomized controlled trials (RCTs) yielded generally non-significant findings with a limited number of findings that were confined to single studies. Subsequently, Jacobsen et al. concluded that the lack of convergent findings limits the extent to which conclusions can be drawn on SCPs [7]. Klemanski et al. reported that there is inconclusive evidence on the needs of survivors regarding SCPs [8]. The recent POSTCARE trial on the outcomes of SCPs that were created with the patient using motivational interviewing showed positive impact on self-efficacy and self-reported health [10]. A review of qualitative studies found that stakeholders agree that SCPs should be used, but there is a lack of consensus on what SCPs should contain and who should manage creation and delivery. Keesing et al. reported a range of mixed results in support of and against the implementation of SCPs and concluded that more evidence is needed before widespread implementation [11].

In addition to these findings, a recent study highlighted that the outcomes typically assessed in RCTs are often not the outcomes that stakeholders expect from SCP use [12]. Thus, a lack of appropriate or relevant outcomes likely influences our understanding of SCP's effectiveness. The objective of this study was to evaluate the impact of receiving an SCP on meeting the overall, informational, physical, emotional, and practical needs of survivors' posttreatment. We hypothesized that survivors who received a SCP would have greater met needs than those who did not receive a SCP. The intended outcome of this research is to help identify potential gaps in survivor care and to inform strategies for treating the growing population of cancer survivors.

Methods

The Experiences of Cancer Patients in Transition Study was initiated by the Canadian Partnership Against Cancer (Partnership) in collaboration with the provincial cancer agencies across Canada. It was a population-based study to examine cancer survivors' experiences with transitioning from active treatment to well follow-up care, including their needs posttreatment. All ten provinces participated in the study; however, this study examined outcomes in one province (Nova Scotia) only.

Survey

The 83-item survey included items related to the overall, informational, physical, practical, and emotional needs of survivors, barriers to receiving care, administration of care, and demographics. It was based on the LiveStrong and the Cancer Survivors Unmet Needs Measure (CaSUN) surveys, both of which have been validated [13, 14]. The Partnership's study team and key stakeholders ensured that the developed survey reflected the input from Canadian experts in cancer survivorship care. Given the pan-Canadian design of the study, the translation process ensured content equivalence, was reviewed for semantic equivalence and included pilot testing of the French version of the survey with French-Canadian native respondents.

Study respondents

All eligible cancer survivors in Nova Scotia were identified from the Nova Scotia Cancer Registry. The specific inclusion and exclusion criteria for the adult cohort (30+ years) are shown in Table 1. In the adult cohort, the study focused on patients diagnosed with breast, prostate, colorectal, hematologic, and melanoma cancers. The adolescent and young adult (AYA) cohort included survivors diagnosed from May 2, 2012 to May 2, 2014 who received a primary diagnosis of any invasive cancer between the ages of 18 to 29 years (inclusive). The following exclusion criteria were applied to the AYA cohort: stage IV at diagnosis (except for testicular cancer), non-melanoma skin cancer, Kaposi's sarcoma; and cases recorded as having died (at time of extraction).

Survey administration

Authorized personnel at the Nova Scotia Cancer Registry sent the survey directly to survivors who met the eligibility criteria using the survivor's mailing address at diagnosis. Each survivor was sent a survey package by mail that included an invitation letter, an information sheet, instructions for survey completion, the survey with a pre-printed barcode and associated pin, and envelopes with pre-paid postage for return of the survey. To increase response rates, the respondents were given the choice to answer in paper or web format; therefore, instructions were provided to complete the online survey or the paper version. The survey was estimated to take 30 to 45 min to complete and could be completed with assistance of another person. All documentation provided to respondents clearly stated that participation is voluntary.

Data variables

The following self-reported demographics were extracted from the full survey dataset for this study: age, sex, marital

Table 1 Adult cohort: inclusion and exclusion criteria by disease site

Disease site	Timeframe[a]	Inclusions	Exclusions
Breast	May 2, 2012 to May 2, 2014	• ICD-O-3[b] topography code C50.0 to C50.9 (inclusive) • Behaviour code = 3[c] • Female breast cancer cases only	• Stage IV at diagnosis • Lymphoma M95 to M98 (inclusive) • Sarcoma • Cases recorded as having died (at time of extraction)
Colorectal	May 2, 2012 to May 2, 2014	• ICD-O-3 topography codes: C18.0, C18.2 to C18.9, C19.9, C20.9, and C26.0 • Behaviour code = 3	• Stage IV at diagnosis • Lymphoma codes M-95 to M-98 (inclusive) • Sarcomas (see Appendix 2-Sarcoma Codes) • Cases recorded as having died (at time of extraction)
Prostate	May 2, 2012 to May 2, 2014	• ICD-O-3 topography code C61.9 • Behavior code = 3	• Stage IV at diagnosis • Cases recorded as having died (at time of extraction) • ICD-O-3 histology codes: 9050–9055, 9140, and 9590–9992
Melanoma	Nov 2, 2012 to Nov 2, 2014	• ICD-O-3 topography code C44 • ICD-O-3 histology codes 8720 to 8790 (inclusive) • Behaviour code = 3	• Stage IV at diagnosis • Cases recorded as having died (at time of extraction)
Hodgkin lymphoma	Aug 2, 2012 to Aug 2, 2014	• ICD-O-3 histology codes: 9650–9655, 9659, 9661–9665, 9667	• Hodgkin lymphoma and diffuse large B cell lymphoma: stage IV (Cotswold staging system), Stage IV (Ann Arbor staging system) or collaborative stage IV at diagnosis[d] • Cases recorded as having died (at time of extraction)
Diffuse B cell lymphoma	Aug 2, 2012 to Aug 2, 2014	• ICD-O-3 histology codes: 9680	
Acute myelogenous leukemia	Aug 2, 2012 to Aug 2, 2014	• ICD-O-3 histology codes: 9840, 9861, 9865–9867, 9869, 9871–9874, 9895–9897, 9898, 9910–9911, 9920	
Acute lymphocytic leukemia	May 2, 2010 to May 2, 2012	• ICD-O-3 histology codes: 9826, 9835–9836 • For the following histology codes: 9811–9818 and 9837, apply these topography codes C420, C421, and C424	

[a] The timeframe pertains to the time period in which persons were diagnosed

[b] ICD-O-3 is the abbreviation for International Classification of Diseases for Oncology, 3rd edition

[c] Behavior code 3 stands for malignant, primary site

[d] Despite some patients having a reasonable prognosis, these patients likely have more severe disease and more intensive follow-up and surveillance posttreatment than survivors of lower stages

status, education level, employment status, and income. The following self-reported clinical and treatment characteristics were extracted for this study: cancer type, time since treatment, metastases, presence of chronic comorbidities, and receipt of a care plan. In Nova Scotia, SCPs are written documents that contain (1) recommended follow-up schedules and (2) information on possible long-term and late effects, preventative care, and support services and resources. The plans have been developed for each disease site (e.g., breast cancer, colorectal cancer, prostate cancer), but may be further tailored for a survivor by the provision of individualized treatment information and contact information for providers and services.

Study outcomes were based on five survey items related to needs met. Specifically, data from the five following survey items were extracted: (1) overall receiving follow-up cancer care that met my needs, (2) information was available to me when I needed it, (3) I received the care and support for my physical concerns when I needed it, (4) I received the care and support for my emotional concerns when I needed it, and (5) I received the care and support for my practical challenges when I needed it. In the survey, physical concerns were defined as "a variety of things such as swelling, fatigue, hormonal changes, chronic pain, incontinence, nerve problems, sexual health and functioning, and changes to concentration, etc." Emotional concerns were defined as including a variety of things such as depression, anxiety, altered body image, and changes in relationships. Practical challenges were defined as "things like returning to work or school, getting to and from appointments, financial issues, and childcare or eldercare." Respondents answered these statements using a 5-point Likert scale. Their responses were dichotomized into agreement (Strongly agree, Somewhat agree) or not (Neither agree nor disagree, Somewhat disagree, Strongly disagree).

Analysis

The survey was open for a 6-week data collection period. Paper surveys were electronically scanned into a secure and

encrypted web application. The paper survey data files were then merged with the data from online surveys into a secure and encrypted web application called FluidSurveys. All data were analyzed in aggregate. Descriptive statistics (frequencies, percentages) were used to report survey findings. Cross tabulations and chi-square analyses were used to identify differences between the survivor demographics and clinical characteristics. Chi-square analyses were also used to compare the two groups (receipt of SCP: yes/no) on each of the five needs outcomes. We performed all analyses on only valid (non-missing) values. All analyses were completed using Microsoft Excel (Microsoft Corporation, Redmond WA), and verified using SAS (SAS Institute, Cary, NC). Statistical significance was set at $p < 0.05$.

Ethical approval for this study was obtained from Nova Scotia Health Authority Research Ethics Board.

Results

Survivor population

In Nova Scotia, the survey was sent to 3492 cancer survivors who met the inclusion criteria and unmet the exclusion criteria outlined in Table 1. After accounting for those who were deceased or who had undeliverable addresses, the response rate was 44.6% ($n = 1514$). 78.7% of these respondents opted to complete the paper survey, while 21.3% completed the online survey. In Tables 2, 3, and 4, the missing values for each variable were not reflected in the tables, which is why the totals per variable may not equal the total number of respondents (1514). Table 2 presents the sociodemographic characteristics of respondents. The majority of survivors were between the ages of 65 to 84 (60.6%), and most respondents were retired or unemployed at the time of the survey (69.2%). 9.6% of respondents reported having received treatment in the past year, and 5.3% reported metastatic malignancy. The majority of survivors had at least one chronic comorbidity (69.7%). Almost half had received a care plan after their

Table 2 Sociodemographic characteristics of survey respondents (missing values are not reflected in the table, which is why the totals per variable may not equal to the total number of respondents (1514)

Characteristic	Value [*n* (%)]
Age	
< 34	23 (1.5)
35–64	499 (33.2)
65–84	911 (60.6)
> 85	70 (4.7)
Sex	
Male	718 (47.8)
Female	785 (52.2)
Marital status	
Single	83 (5.5)
Partnered	87 (5.8)
Married	1053 (70.3)
Separated, divorced, widowed	275 (18.4)
Education	
High school or less	592 (40.9)
University undergraduate	309 (21.3)
University graduate	135 (9.3)
College or technical school	412 (28.5)
Employment	
Working full-time	246 (17.0)
Working part-time	107 (7.4)
Retired, unemployed	1002 (69.2)
Other	93 (6.4)
Income	
< $25,000	187 (16.2)
$25,000–$50,000	399 (34.6)
$50,000–$75,000	257 (22.3)
$75,000–$125,000	202 (17.5)
$125,000	107 (9.3)
Cancer type	
Breast	473 (31.2)
Colorectal	332 (21.9)
Melanoma	148 (9.8)
Prostate	384 (25.4)
Other[a]	176 (11.6)
Time since treatment	
< 1 year ago	141 (9.6)
1–2 years ago	208 (14.2)
2–3 years ago	455 (31.1)
> 3 years ago	354 (24.2)
No treatment	305 (20.9)
Metastases	
Yes	75 (5.3)
No	1209 (84.6)
Unsure	145 (10.2)
Chronic comorbidities	
1–2	818 (55.9)
> 3	202 (13.8)
None	444 (30.3)
Received a care plan	
Yes	534 (49.3)
No	549 (50.7)

[a] Other included hematological malignancy, bladder, brain/central nervous system, gynecological, sarcoma, stomach/esophagus, testicular, thyroid, and specified option for respondents to fill in another cancer type not listed

diagnosis and/or treatment (49.3%), while the remaining respondents (50.7%) did not receive a SCP.

Needs outcomes based on characteristics

Table 3 presents needs outcomes by characteristic. Most respondents agreed that overall, they received follow-up care that met their needs (87.4%). The majority of respondents agreed they received support for their physical (82.2%), emotional (64.8%), and practical (72.3%) concerns when they needed it. The statement on emotional concerns resulted in the lowest agreement among respondents. Most respondents also agreed that information was available when needed (86.1%). When comparing outcomes for different demographics, there were statistically significant differences among age and sex. With respect to overall needs met, information available, support for physical concerns, and practical challenges, differences were found depending on the respondent's age. For instance, survivors below the age of 34 were more likely to disagree with overall needs met, information availability, support for physical concerns, and practical challenges than those of other age groups. When comparing males and females, there were differences for receiving support for physical concerns. In this case, males were more likely to agree with receiving support for physical concerns (84.8%) than females (79.9%).

Table 3 Demographics and clinical characteristics versus outcomes (all significant differences ($p < 0.05$) are italicized; missing values are not reflected in the table, which is why the totals per variable may not equal to the total number of respondents (1514))

Characteristic	Overall receiving follow-up cancer care that met my needs		Information was available to me when I needed it		I received the care and support for my physical concerns when I needed it		I received the care and support for my emotional concerns when I needed it		I received the care and support for my practical challenges when I needed it	
	Agree	Disagree	Agree	Disagree	Agree	Disagree	Agree	Disagree	Agree	Disagree
Age										
< 34	*17 (73.9)*	*6 (26.1)*	*16 (69.6)*	*7 (30.4)*	*12 (60.0)*	*8 (40.0)*	14 (73.7)	5 (26.3)	*6 (37.5)*	*10 (62.5)*
35–64	*383 (84.2)*	*72 (15.8)*	*402 (84.3)*	*75 (15.7)*	*293 (80.1)*	*73 (19.9)*	183 (62.5)	110 (37.5)	*180 (68.7)*	*82 (31.3)*
65–84	*696 (89.7)*	*80 (10.3)*	*675 (87.9)*	*93 (12.1)*	*449 (84.4)*	*83 (15.6)*	219 (65.2)	117 (34.8)	*231 (76.0)*	*73 (24.0)*
> 85	*46 (88.5)*	*6 (11.5)*	*44 (91.7)*	*4 (8.3)*	*27 (87.1)*	*4 (12.9)*	17 (89.5)	2 (10.5)	*22 (88.0)*	*3 (12.0)*
Sex										
Male	536 (88.9)	67 (11.1)	539 (87.9)	74 (12.1)	*374 (84.8)*	*67 (15.2)*	192 (66.2)	98 (33.8)	186 (72.7)	70 (27.3)
Female	607 (86.1)	98 (13.9)	596 (84.8)	107 (15.2)	*406 (79.9)*	*102 (20.1)*	241 (63.9)	136 (36.1)	255 (72.0)	99 (28.0)
Cancer type										
Breast	377 (84.7)	68 (15.3)	370 (84.5)	68 (15.5)	256 (78.3)	71 (21.7)	158 (64.0)	89 (36.0)	160 (69.6)	70 (30.4)
Colorectal	246 (88.8)	31 (11.2)	243 (86.5)	38 (13.5)	163 (84.0)	31 (16.0)	78 (63.4)	45 (36.6)	99 (75.6)	32 (24.4)
Melanoma	114 (88.4)	15 (11.6)	115 (88.5)	15 (11.5)	55 (82.1)	12 (17.9)	38 (69.1)	17 (30.9)	33 (76.7)	10 (23.3)
Prostate	378 (90.9)	38 (9.1)	289 (88.6)	37 (11.4)	223 (85.4)	38 (14.6)	116 (66.7)	58 (33.3)	106 (75.2)	35 (24.8)
Other	136 (90.7)	14 (9.3)	125 (83.9)	24 (16.1)	88 (83.0)	18 (17.0)	45 (62.5)	27 (37.5)	46 (66.7)	23 (33.3)
Time since treatment										
< 1 year ago	114 (91.2)	11 (8.8)	109 (87.2)	16 (12.8)	76 (83.5)	15 (16.5)	44 (67.7)	21 (32.3)	*53 (75.7)*	*17 (24.3)*
1–2 years ago	169 (84.9)	30 (15.1)	167 (83.5)	33 (16.5)	115 (77.2)	34 (22.8)	75 (63.0)	44 (37.0)	*66 (67.3)*	*32 (32.7)*
2–3 years ago	364 (86.1)	59 (13.9)	374 (87.4)	54 (12.6)	257 (80.1)	64 (19.9)	148 (64.9)	80 (35.1)	*138 (67.0)*	*68 (33.0)*
> 3 years ago	302 (89.6)	35 (10.4)	291 (86.9)	44 (13.1)	200 (85.1)	35 (14.9)	99 (60.7)	64 (39.3)	*110 (74.8)*	*37 (25.2)*
No treatment	171 (86.4)	27 (13.6)	169 (83.7)	33 (16.3)	120 (87.0)	18 (13.0)	62 (72.9)	23 (27.1)	*69 (84.1)*	*13 (15.9)*
Metastases										
Yes	*55 (79.7)*	*14 (20.3)*	*60 (85.7)*	*10 (14.3)*	48 (81.4)	11 (18.6)	26 (61.9)	16 (38.1)	32 (76.2)	10 (23.8)
No	*941 (88.6)*	*121 (11.4)*	*932 (86.9)*	*141 (13.1)*	636 (82.8)	132 (17.2)	359 (65.8)	187 (34.2)	346 (71.9)	135 (28.1)
Unsure	*99 (79.8)*	*25 (20.2)*	*92 (77.3)*	*27 (22.7)*	72 (75.0)	24 (25.0)	35 (53.0)	31 (47.0)	49 (69.0)	22 (31.0)
Chronic comorbidities										
1–2	624 (87.4)	90 (12.6)	623 (87.1)	92 (12.9)	428 (82.2)	93 (17.8)	236 (66.3)	120 (33.7)	235 (72.3)	90 (27.7)
> 3	145 (85.3)	25 (14.7)	137 (81.1)	32 (18.9)	104 (81.9)	23 (18.1)	58 (62.4)	35 (37.6)	61 (67.8)	29 (32.2)
None	344 (87.5)	49 (12.5)	351 (87.1)	52 (12.9)	229 (82.3)	49 (17.7)	126 (62.7)	75 (37.3)	128 (73.6)	46 (26.4)
Overall	1151 (87.4)	166 (12.6)	1142 (86.1)	183 (13.9)	785 (82.2)	170 (17.8)	435 (64.8)	236 (35.2)	444 (72.3)	170 (27.7)

Table 4 Care plans vs. outcomes (all outcomes were statistically significant ($p < 0.00001$); Missing values are not reflected in the table, which is why the totals per variable may not equal to the total number of respondents (1514))

Received a care plan	Overall receiving follow-up cancer care that met my needs		Information was available to me when I needed it		I received the care and support for my physical concerns when I needed it		I received the care and support for my emotional concerns when I needed it		I received the care and support for my practical challenges when I needed it	
	Agree	Disagree	Agree	Disagree	Agree	Disagree	Agree	Disagree	Agree	Disagree
Yes	480 (94.5)	28 (5.5)	484 (94.3)	29 (5.7)	335 (90.1)	37 (9.9)	188 (72.9)	70 (27.1)	182 (80.2)	45 (19.8)
No	394 (76.8)	119 (23.2)	374 (73.8)	133 (26.2)	284 (71.0)	116 (29.0)	164 (53.9)	140 (46.1)	161 (59.2)	111 (40.8)

When comparing the outcomes for different characteristics, there were no statistically significant differences among cancer type or chronic comorbidities for any outcomes. With respect to receiving support for practical challenges, statistically significant differences were found depending on the respondents' treatment status. For instance, those who received no treatment were more likely to state they received care for their practical challenges when needed (84.1%) versus those who received treatment between 1 and 2 and 2–3 years ago (67.3% and 67.0%, respectively) ($p = 0.0298$). There were also differences for two outcomes (overall needs met and information availability) by the self-reported metastases variable. For instance, respondents who reported metastases or were unsure whether they had metastases reported lower levels of agreement (79.7% and 79.8%, respectively) in regard to having their overall needs met than respondents who reported no metastases (88.6%) ($p = 0.0033$).

Needs outcomes based on receipt of care plan

When comparing needs outcomes based on receipt of a SCP, those who received a care plan reported higher agreement with having needs met in all domains (overall, information, physical, emotional, and practical) than those who did not receive a care plan ($p < 0.00001$ for all; see Table 4). For example, 94.5% of those who received a SCP agreed with overall needs being met, while 76.8% of those who did not receive a SCP agreed with overall needs being met.

Discussion

This study examined the impact of SCP receipt on survivor outcomes related to having one's needs met posttreatment. Our findings demonstrate that SCPs have a positive impact on the five outcomes that were assessed: receiving follow-up cancer care that meets overall needs, availability of information when needed, receiving care and support for physical concerns when needed, receiving care and support for emotional concerns when needed, and receiving care and support for practical challenges when needed. These findings are important in that they demonstrate the benefit of SCPs toward addressing both medical and non-medical needs in a diverse cancer survivor population. Survivor demographics resulted in differences among the five outcomes, with a younger age appearing to have a lesser degree of met needs. For the most part, survivor characteristics, such as cancer type, time since treatment, chronic comorbidities and metastases, did not result in differences among the five outcomes.

To date, there has been mixed results on the efficacy of SCPs [5–8]. When it comes to commonly used measures such as quality of life, for example, RCTs have generally found no effect of SCPs on outcomes [15–17]. This study assessed needs that are more proximal to SCP receipt and arguably more likely to be impacted by SCP use than a complex construct such as quality of life. Given the high level of unmet needs in the cancer survivor population, these findings are highly relevant to survivors and their providers. In fact, the differences in the proportions of respondents reporting their needs were met were quite substantial between those who received a SCP and those who did not (see Table 4). For example, 94.5% of respondents who received a care plan reported they were receiving follow-up care that met their needs versus 76.8% who did not receive a care plan.

The outcomes in our study are consistent with outcomes that stakeholders expect from SCP use. A recent study comparing the outcomes assessed in RCTs to outcomes that stakeholders expect from SCPs found that stakeholders (survivors, caregivers, cancer care providers, primary care providers, and organizational/system-level decision-makers) expected SCPs to both meet informational and emotional (e.g., anxiety and worry about recurrence) needs [12], both outcomes evaluated in our study. In our study, 94.3% of those who received a SCP agreed they had information available to them, while only 73.8% of those without receipt of a SCP perceived this to be true. In addition, our findings are consistent with another recent study: a recent survey of breast cancer survivors showed that 98% of those who received a SCP believed it was important to receive it and 84% planned to use it to plan follow-up management [18]. Consistent with these studies, our findings suggest a clearer picture of the effectiveness of SCPs will only occur when researchers assess outcomes that are stakeholder-centered and more proximal to SCP use.

There are a number of strengths of this study. First, this study employed a population-based survey whereby all survivors who were diagnosed with the selected cancers were contacted for participation. Most surveys are administered to survivors attending certain clinics or services only and therefore do not capture the experiences of the entire population. Thus, our approach makes it especially unique in the literature. Second, this study had a high response rate at 44.6% and sample size ($n = 1514$). One limitation of this study, however, is response bias from respondents, which may include social desirability bias as well as recall bias. A second limitation is the representativeness of the sample. Upon testing the representativeness of the respondents on several demographics (sex, age, and cancer type), we found no statistically significant difference between respondents and non-respondents for sex. However, age group and cancer type showed differences: those at both ends of the age spectrum were less likely to participate than those in other age groups, and those with melanoma and Hodgkin's disease were less likely to participate compared to those with other cancer types. Another limitation is that the delivery of SCPs was not standardized, which has been shown to affect a survivor's reception of a SCP [19]. Nevertheless, the fact that we observed such large effects demonstrates utility of an SCP in the absence of a standardized approach for delivery/implementation.

In conclusion, this study demonstrated that SCPs have a positive impact on overall, informational, physical, emotional, and practical needs in the posttreatment period of cancer care. Those who received a SCP reported a higher level of needs met in all five domains in comparison to those who did not receive a SCP. This study has implications for cancer survivors, in that it shows that SCPs enhance the level of met needs among survivors. Future work should evaluate not only the effectiveness of SCPs on more appropriate outcomes, but also the delivery of SCPs and the components that are most likely to contribute to positive survivor outcomes.

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Data availability The principal investigator (Robin Urquhart) has full ownership of the primary data. Access may be allowed, if requested, depending on the parameters of the request. Due to privacy restrictions, the data cannot be placed in a public repository at this time.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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