



Published in final edited form as:

J Cancer Educ. 2014 December ; 29(4): 720–727. doi:10.1007/s13187-014-0645-7.

Determinants of survivorship care plan use in United States cancer programs

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Abstract

Background—Cancer programs are increasingly required to use survivorship care plans (SCPs). Compliance with SCP use requirements will be evaluated at the cancer program level. Cancer program-level determinants of SCP use may suggest strategies for compliance. The objective of this study was to describe SCP use and identify its cancer program-level determinants.

Methods—We surveyed employees knowledgeable about survivorship practices in cancer programs throughout the United States with a wide range of annual incident cancers, program types, and cancer care quality improvement organization memberships (81/100 response rate). We used descriptive statistics to describe SCP use and bivariate statistics to identify its cancer program-level determinants.

Results—Most respondents (56%) reported that SCPs were not used. In programs reporting use, SCP use is restricted primarily to breast (82%) and colorectal (55%) cancer survivors, and few providers use SCPs. When developed, SCPs seldom reach survivors and their primary care providers. Most respondents (78%) reported beginning to use SCPs because of requirements. Frequently cited barriers included insufficient resources (76%), perceived difficulty using SCPs

Previous presentation:

None

Disclaimers:

None

(29%), and lack of advocacy for SCP use from influential people (24%). SCP use was positively associated with academic program type ($p=.009$) and membership in the National Cancer Institute's Community Cancer Centers Program ($p=.009$) and negatively associated with freestanding program type ($p=.02$).

Conclusion—SCP use in United States cancer programs is highly inconsistent. Many cancer programs plan to implement SCPs to comply with SCP use requirements. Support specifically intended to facilitate SCP use may be more effective than non-specific resources.

Keywords

Survivorship care plan; survey; cancer program; determinants

Introduction

The transition from cancer treatment to follow-up care is often difficult for the nearly 14 million cancer survivors in the United States [31]. Survivors have unique physical, psychological, social, and spiritual health needs that are optimally addressed through (1) the prevention and detection of new cancers, (2) surveillance for cancer spread or recurrence, (3) intervention for consequences of cancer and its treatment, and (4) coordination between oncologists and primary care providers (PCPs) [15]. Optimal care may be compromised by PCPs' and oncologists' conflicting perspectives on their roles in survivorship care; these conflicting perspectives may result in the duplication or omission of services [6]. Survivors often report feeling poorly educated regarding psychological, social, and sexual health issues [26] and their risk for recurrence [18], and they report being dissatisfied with care following cancer treatment [14].

To facilitate cancer survivors' transition to follow-up care, beginning in 2015, cancer programs accredited by the Commission on Cancer (CoC) must demonstrate that they have developed and implemented a process for providing survivorship care plans (SCPs) – written documents that often, but not always, include a summary of cancer treatment and recommendations for surveillance, preventive care, wellness behaviors, and symptoms to report following treatment [15, 8]. Increasing numbers of cancer care quality improvement organizations (e.g., National Coalition for Cancer Survivorship [22]; American Society for Clinical Oncology [2]; National Comprehensive Cancer Network [24]; National Cancer Institute Community Cancer Centers Program [21]) have issued similar recommendations and guidelines.

CoC and other cancer care quality improvement organizations plan to evaluate compliance with SCP use requirements at the cancer program level (e.g., whether or not a process for providing SCPs has been developed and implemented in the cancer program). As such, understanding determinants of SCP use at the cancer program level may facilitate compliance with SCP use requirements. Most existing studies assess determinants of SCP use at the provider or patient level [13, 12, 11, 28]. The little evidence that exists regarding cancer program-level determinants of SCP use is tangential to primary research findings, from a single state [20], or from a very small number of cancer programs [32, 30, 5].

A recently published study analyzes the 36 cancer programs of the 81 cancer programs analyzed in the present study that reported sometimes or regularly using SCPs [4]. The recently published study answered the question, “Among cancer programs reporting at least some SCP use, how consistently are SCPs used (i.e., developed and delivered to all survivors and their PCPs)?” A key implication of the recently published study’s results was that cancer care quality improvement organizations (e.g., Commission on Cancer) should clearly specify how compliance with survivorship care plan use requirements will be assessed. In contrast, the objective of the present study was to answer the question, “What are cancer program-level determinants of whether or not survivorship care plans are used in US cancer programs?” In fulfilling this objective, the present study fills a gap in the literature and suggests strategies for promoting SCP use that will be useful to the practitioners who will be held accountable for ensuring that their cancer programs comply with SCP use requirements.

Methods

Study sample

We conducted a cross-sectional survey of cancer programs throughout the US with a wide range of annual incident cancers, program types, and cancer care quality improvement organization memberships. A sampling frame was created for programs with membership in at least one of the following cancer care quality improvement organizations: CoC [9], the Association of Community Cancer Centers [3], the National Comprehensive Cancer Network [23], and/or the American Society of Clinical Oncology’s Quality Oncology Practice Initiative [1]. We took this approach because CoC programs serve 80 percent of all newly diagnosed US cancer patients [9]; therefore, our sampling frame included programs that serve the majority of US cancer survivors. We improved upon these figures by including programs that were members of cancer care quality improvement organizations other than CoC.

After eliminating programs in the same state with the same name, 1,991 programs were included in the sampling frame. We eliminated another 141 programs that were duplicate listings of programs with different names but the same location and/or staff. The final sampling frame included a total of 1,850 programs. The primary objective of our study was to estimate SCP use in US cancer programs with 95% confidence intervals that were no wider than $\pm 10\%$. The standard error of an estimator depends on sample size; we determined that a sample size of 100 was sufficient to achieve our objective: If 50% of cancer programs were to use SCPs, the half-width of the 95% confidence interval would be $\pm 10.2\%$; smaller or larger estimates would result in an even smaller half-width of the 95% confidence interval. In addition, a sample of 100 cancer programs was sufficient to assess exploratory associations with hypothesized determinants, and a sample of 100 cancer programs was manageable given the time-consuming process of identifying potential survey respondents (see method described below).

Survey development

The survey was based on a review of the Institute of Medicine's report: *From Cancer Patient to Cancer Survivor: Lost in Transition* [15] and scientific literature. A team of experts developed the survey. Survivorship experts, including a practicing provider of breast cancer survivorship care, ensured that the survey reflected relevant clinical and policy issues, such as the importance of developing and delivering SCPs to survivors and their PCPs, and activities of key cancer care quality improvement organizations. Experts in dissemination and implementation of innovations in cancer care ensured that the survey reflected key dimensions of the innovation life cycle, such as dissemination, diffusion, adoption, and implementation. Survey methodologists promoted the likelihood that potential respondents would complete the survey. We also refined the survey based on cognitive interviews with 8 employees who had knowledge of survivorship practices in programs not included in the final study sample. Survey items were phrased to elicit responses regarding SCP use any time in their program's history. The final survey consisted of 15 items (see Table 1).

Survey respondent identification

We acknowledge that SCP use may vary within cancer programs. However, given our objective of identifying organization-level determinants of SCP use consistency, we sought a single respondent per program who could answer questions about their program's characteristics (e.g., annual incident cancers). The following method was used to identify potential respondents. A research assistant used publicly available information to call sampled programs to identify employees with knowledge regarding survivorship practices who could respond to the survey. The research assistant asked for someone in the program who knew about how the program's survivors were transitioned to follow-up care after treatment was complete. This process continued until the research assistant identified an employee in the program who would be able to answer questions regarding (1) whether or not SCPs were used in the program and (2) reasons why SCPs were or were not used in the program. The research assistant collected a specific address, direct phone number, and email address for the employee.

Survey administration

The survey was conducted between January and May 2013 using the standards of Dillman's Total Design Method [10]. Initially, depending on the availability of an email address, we sent an email or a letter to respondents letting them know that they would receive an invitation to complete the survey in a few days. Three days later, we sent an introductory email with a link to an online version of the survey or an envelope containing a cover letter, survey, and return envelope. Emails or postcards were sent to thank respondents who completed the survey and to remind non-respondents to complete the survey. Two weeks after the initial survey mailing, replacement surveys were sent to non-respondents by first class mail or email. Two weeks later, non-respondents were called to request a response. This pattern repeated, allowing two-week intervals between contacts for as many as ten total attempts. Upon completing the survey, respondents had the option of being entered into a raffle to win an iPad. An employee with knowledge of survivorship practices from 81 of the 100 programs contacted completed the survey (81% response rate). The institutional review

board at the University of North Carolina at Chapel Hill exempted the study from human subjects review.

Variable descriptions

SCP use—Survey items and response options are listed in Table 1. The survey included the following definition of an SCP: “a written document that often, but not always, includes the following information regarding care after cancer treatment is complete: treatment summary; surveillance plan; preventive care; and symptoms to report.”

We based our measure of SCP use on the Institute of Medicine’s report [15], the third author’s clinical experience, and feedback from cognitive interview participants. Our primary measure of SCP use was *whether or not SCPs were used* at the time of the survey. We categorized programs as using SCPs if respondents reported using SCPs “regularly” or “sometimes.” We categorized programs as not using SCPs if respondents reported no longer using, not currently using but planning to use, or not currently using and not planning to use SCPs. Secondary measures were used to understand the breadth and depth of SCP use within programs. We operationalized breadth of SCP use – i.e., how widespread SCP use was in the program – as the *percentage of providers who used SCPs* and the *percentage of survivors for whom SCPs were used*. We conceptualized depth of SCP use as the extent to which cancer programs’ SCP use went beyond developing SCPs to delivering SCPs to their intended audience: survivors and their PCPs; we operationalized depth of SCP use as the *percentage of survivors whom SCPs were delivered* and the *percentage of PCPs to whom SCPs were delivered*. To further characterize SCP use, we asked respondents *when SCP use began* and *in which tumor groups SCPs were used*.

Determinants of SCP use—Based on the notion that innovations are used when the motivation, means, and opportunity exists [33], we organized determinants of SCP use at the cancer program level in three categories: To understand the motivation to use SCPs, we asked respondents *why SCPs were used* in their programs (i.e., reasons for SCP use). To assess whether or not cancer programs had the means to use SCPs, we asked respondents about *barriers to SCP use* in their program. We operationalized the opportunity to use SCPs as cancer program characteristics that might influence the likelihood that cancer programs would use SCPs. Studies have shown relationships between health services utilization and geographic location. To assess geographic variation in SCP use, we captured programs’ *location* using ZIP codes. When available, ZIP codes were converted to rural/urban indicators using Rural-Urban Commuting Areas data [27]. ZIP codes were identified as a rural or urban subtype; subtypes were aggregated into dichotomous rural and urban categories. To assess whether SCP use was more likely to be reported in larger programs due to, for example, better infrastructure, we operationalized *annual incident cancers* as a program’s unduplicated number of cancer patients. American College of Surgeons assigns the *program types* listed in Table 1 based on organization type (e.g., academic), services provided, and number of cancer patients served [1]. We assessed differences in SCP use across program types because, for example, National Cancer Institute-designated comprehensive cancer programs engage in research that may assist programs in using SCPs. To assess variation in SCP use associated with *cancer care quality improvement*

organizations' SCP use guidelines and recommendations, we asked respondents whether their program was a member of one of the organizations listed in Table 1. Since program members' professional background may influence their perspective on SCP use, respondents were also asked which *position* they held at their program at the time of the survey.

Analysis

To describe SCP use and hypothesized determinants, we report response frequencies and percentages. To compare (1) respondents to programs in the sampling frame not randomly selected for inclusion in the study sample and (2) programs that used SCPs to those that did not use SCPs, we used Wilcoxon Rank Sum tests for continuous independent variables (e.g., annual incident cancers) and Fisher's exact tests for categorical independent variables (e.g., program type). Unadjusted two-tailed p-values are reported. Relationships between variables were considered significant at the $p < .05$ level. The unit of analysis was the program. Analyses were conducted using SAS statistical software v9.3 (Cary, NC).

Results

Descriptive statistics are reported in Table 1. There were no differences in location, annual incident cancers, or program type between programs that returned surveys and programs that were not included in the sample (all $p > 0.13$).

SCP use

Forty-four percent of respondents reported that SCPs were used in their programs at the time of the survey: Thirty percent reported that SCPs were used sometimes, and 15 percent reported that SCPs were used regularly. Of respondents who reported that their programs did not use SCPs at the time of the survey (56%), most indicated that they planned to use SCPs (93%).

In 58 percent of programs reporting SCP use at the time of the survey, less than a quarter of providers had ever used SCPs. The majority of respondents (69%) indicated that SCPs were used for fewer than half of survivors in their programs. Most respondents reported that SCPs were delivered to half or fewer of survivors for whom SCPs were developed (63%) or their PCPs (61%). Current or planned SCP use was restricted primarily to breast (82%) and colorectal (56%) cancer survivors.

Determinants of SCP use

Barriers to SCP use—The most commonly reported barrier to SCP use was lack of resources (76%). Other commonly cited barriers included the perception that SCPs are difficult to use (29%) and that influential people (e.g., physician champions, managers) had not advocated for SCPs to be used (24%).

Reasons for SCP use—The most commonly cited reason for SCP use was CoC's 2012 program standards (78%). Indeed, in the majority of programs (57%), SCP use began in 2012 or 2013, after CoC issued program standards related to SCP use. Other commonly

cited reasons for SCP use were the belief that SCPs may improve quality of care (75%) and National Comprehensive Cancer Network guidelines (54%).

Cancer Program Characteristics—Of the 77 respondents who reported their position, most were registered nurses (39%), nurse practitioners (19.5%), or other clinical staff (19.5%). Respondents reported an average of 1,280 annual incident cancers (range 1–14,000) in their programs. A third of respondents were employed in community comprehensive cancer programs (33%), a quarter were employed in community hospital cancer programs (24%), 12 percent came from academic cancer programs, and less than 10 percent of sampled programs fell into other program type categories. Most respondents' programs were members of CoC (77%), and more than a third were members of the American Society of Clinical Oncology's Quality Oncology Practice Initiative (37%) and National Comprehensive Cancer Network (36%).

Relationships between SCP use and hypothesized determinants

Neither barriers nor reasons for SCP use were statistically significantly associated with SCP use.

Academic programs (89% v 38%, $p=.009$) and those with NCCCP membership (89% v 38%, $p=.009$) were significantly more likely to indicate current SCP use. Freestanding programs were significantly less likely to report current SCP use (0% v 48%, $p=.02$). Other relationships were not statistically significant.

Discussion

The objective of this study was to describe SCP use and identify its cancer program-level determinants in cancer programs throughout the US with a wide range of annual incident cancers, program types, and cancer care quality improvement organization memberships. Results indicate that, in the majority of US cancer programs, SCPs are not used. This is consistent with other estimates of SCP use in US cancer programs, which range from 14 to 53 percent [20, 7, 5, 30].

Also consistent with previous studies, we found that when SCPs are developed, they are infrequently delivered to survivors or PCPs [20, 17, 28]. Addressing the gap we found between SCP development and delivery to survivors and their PCPs is important given evidence of disparities in the receipt of SCPs across survivor age and gender [16]. There are several possible explanations for the gap that we found between SCP development and delivery to survivors and their PCPs: Cancer programs may not have fully implemented SCPs at the time of the survey – nearly two years before SCP use requirements take effect; programs may lack the resources to deliver SCPs; or they may develop SCPs to meet minimum standards for compliance with cancer care quality improvement organizations' SCP use requirements.

Nevertheless, we found no associations between SCP use and cancer care quality improvement organizations' requirements or guidelines. Instead, we found that membership in the NCCCP was positively associated with SCP use. NCCCP offers member programs

support that is specifically intended to promote SCP use (e.g., SCP templates for breast cancer survivors) [25]. Similarly, we found that academic programs were more likely to use SCP. Academic cancer programs provide postgraduate medical education and participate in cancer-related clinical trials, which may give academic cancer programs access to cutting-edge knowledge regarding best survivorship practices. Taken together, our results suggest that support specifically intended to facilitate SCP use may promote SCP use more effectively than the non-specific resources (e.g., time, staff, training, money) that are commonly cited as determinants of SCP use [20, 7, 11, 5, 13, 19, 29].

Limitations

Our study has several limitations. Survey items were not validated. In addition, we did not assess the reliability of our survey items; only one employee in each cancer program responded to the survey. It is unclear whether another employee would have responded similarly. Social desirability bias may have caused respondents to over-report SCP use. Future research should assess the reliability and validity of survey items intended to measure SCP use at the cancer program level.

Our sampling frame only included cancer care programs that were members of the cancer care quality improvement organizations listed in Table 1; it excluded programs that were not members of any of these cancer care quality improvement organizations. Members may be more likely to use SCPs, so our estimates of SCP use may understate SCP use in US cancer programs. In addition, the final sampling frame may have retained duplicates, despite our efforts to eliminate them. These issues emphasize the need for a comprehensive list of programs that provide cancer treatment as a resource for researchers who study cancer programs.

Our sample size limited our ability to detect small but potentially meaningful differences regarding relationships between SCP use and hypothesized determinants. Further, respondents who agreed to participate in the study may have been more likely to respond if their programs used SCPs; however, the variation in study outcomes suggests otherwise. Finally, we did not distinguish between sporadic use and consistent, proficient SCP use (i.e., effective implementation). Additional research is needed to better understand what distinguishes sporadic use from consistent, proficient SCP use.

Implications

Despite the limitations described above, our findings have implications for cancer care quality improvement organizations that require SCP use, cancer programs that seek compliance with these requirements, and the practitioners who will be held accountable for their programs' compliance with SCP use requirements. Cancer care quality improvement organizations should take into consideration that cancer programs with particular characteristics may struggle to comply with SCP use requirements. In particular, we found that freestanding cancer program type was negatively associated with SCP use. Our results also suggest that, more generally, cancer programs that do not get support specifically intended to facilitate SCP use may struggle to comply with requirements. Cancer care quality improvement organizations may be a resource for this support.

Cancer programs seeking to comply with SCP use requirements may benefit from support that is specifically intended to facilitate SCP use. Non-specific resources (e.g., time, staff, training, money) may be less effective in promoting SCP use. The practitioners who will be held accountable for their programs' compliance with SCP use requirements may assist by identifying the specific support needed for SCP use.

Future research

Future research should examine differences in SCP use among members of cancer care quality improvement organizations and program types in subgroup analyses. Such analyses will require more cancer programs in each subgroup than were necessary for our exploratory analyses. Subgroup analysis would allow for future studies to identify mechanisms underlying relationships between program type and SCP use (e.g., What promotes SCP use in academic programs and deters it in freestanding programs?) and between NCCCP membership and SCP use (e.g., Does the support that NCCCP offers facilitate SCP use?). Understanding the mechanisms underlying these relationships may help to improve practice.

Acknowledgments

Acknowledgement of research support:

Dr. Birken's effort was funded by grant number 5 R25 CA57726 from the National Cancer Institute.

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Table 1

Survey item response options and frequencies (n = 81)

#	Item	Response options	Frequency (%)
1	Which of the following options best describes SCP use in your cancer program? <i>Please check one.</i>	SCPs are used <u>regularly</u> . → Please proceed to Question 3. SCPs are used <u>sometimes</u> . → Please proceed to Question 3. SCPs were <u>previously</u> used, but we <u>no longer</u> use them. → Please proceed to Question 3. SCPs are <u>not</u> used, but we are <u>planning</u> to use them. → Please SKIP to Question 8. SCPs are <u>not</u> used, and we <u>do not plan</u> to use them. → Please SKIP to Question 9.	15.00 30.00 0.00 51.25 3.75
2	Approximately when did SCP use <u>begin</u> in your cancer program? <i>Please enter an approximate start date or check "Don't Know".^a</i>	1995 2006–2009 2010–2013	3.33 13.33 83.32
3	Approximately what percentage of providers in your cancer program has used SCPs? <i>Please check one percentage or "Don't Know."</i>	0–25% 26–50% 51–75% 76–100% Don't know	58.33 2.78 16.67 16.67 5.56
4	For approximately what percentage of all survivors in your cancer center are SCPs developed? <i>Please check one percentage or check "Don't Know."</i>	0–25% 26–50% 51–75% 76–100% Don't know	47.22 22.22 8.33 13.89 8.33
5	Approximately what percentage of SCPs is delivered to survivors? <i>Please check one percentage or check "Don't Know."</i>	0–25% 26–50% 51–75% 76–100% Don't know	45.71 17.14 5.71 22.86 8.57

#	Item	Response options	Frequency (%)
6	Approximately what percentage of SCPs is delivered to survivors' primary care providers? Please circle one percentage or check "Don't Know."	0–25% 26–50% 51–75% 76–100% Don't know	52.78 8.33 2.78 19.44 16.67
7	For survivors in which tumor groups have SCPs been/will SCPs be used? Please check all that apply.	Breast Colorectal Testicular Prostate Other	81.58 55.26 0 38.16 53.95
8	What kinds of SCP templates have been/will be used? Please check all that apply. ^a	LIVESTRONG Care Plan American Society for Clinical Oncology (ASCO) Survivorship Care Plan Journey Forward Other	13.16 32.89 19.74 90.79
9	Why did/will your cancer program begin using SCPs? Please check all that apply. ^a	Desire to comply with American College of Surgeons (ACoS) Commission on Cancer (CoC) cancer program 2012 standards Belief that it may improve quality of care Desire to comply with National Comprehensive Cancer Network (NCCN) guidelines Desire to comply with American Society for Clinical Oncology (ASCO) practice guidelines Other There are not enough resources (e.g., time, staff, training, money) to use SCPs. Perception that SCPs are difficult to use.	77.63 75.00 53.95 43.42 153.94 76.32 28.95
11	Approximately how many new cancer patients are seen in your cancer program per year? Your best guess is fine.	Influential people (e.g., physician champions, managers) have not advocated for SCPs to be used. Other	23.68 48.69
12	Please enter the ZIP code where your cancer program is located. ^c	Urban	1279.63 ^b 88.60

#	Item	Response options	Frequency (%)
		Rural	11.40
13	Please indicate your cancer program type. <i>Please check all that apply.</i> ^a	Community hospital comprehensive cancer program	41.56
		Community hospital cancer program	27.27
		Teaching hospital cancer program	18.18
		Other	53.25
14	Of which professional society/societies is your cancer program a member? <i>Please check all that apply.</i> ^a	American College of Surgeons (ACoS) Commission on Cancer (CoC)	75.95
		Association of Community Cancer Centers (ACCC)	37.97
		American Society for Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI)	36.71
		National Comprehensive Cancer Network (NCCN)	35.44
		Other	26.58
15	What is your current position in the cancer program? <i>Please check all that apply.</i> ^a	Registered nurse	39.00
		Nurse practitioner	19.50
		Other	41.60

^aThe percent of responses to infrequently selected options have been collapsed. Specific response options and frequencies are available upon request from SB.

^b Average number of new cancer patients per year

^c ZIP codes identified as urban or rural using Rural-Urban Commuting Areas data