

# Health information needs and preferences in relation to survivorship care plans of long-term cancer survivors in the American Cancer Society's Study of Cancer Survivors-I

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## Abstract

**Purpose** Survivorship care plans (SCPs) provide cancer patients and health care providers with a treatment summary and outline of recommended medical follow-up. Few studies have investigated the information needs and preferred sources among long-term cancer survivors.

**Methods** Cancer survivors of the ten most common cancers enrolled in the longitudinal Study of Cancer Survivors-I (SCS-I) completed a survey 9 years post-diagnosis ( $n=3138$ ); at time of diagnosis of the SCS-I cohort, SCs were not considered usual care. We assessed participants' current desire and preferred sources for information across ten SCP items and evaluated factors associated with information need 9 years after diagnosis.

**Results** The proportion of long-term cancer survivors endorsing a need for cancer and health information 9 years post-diagnosis ranged from 43 % (cancer screening) to 9 % (consequences of cancer on ability to work). Print media and personalized reading materials were the most preferred information sources. Younger age, higher education, race other than non-Hispanic white, later cancer stage, having breast cancer, having  $\geq 2$  comorbidities, and self-reporting poor

health were associated with greater informational need ( $p<0.05$ ).

**Conclusions/Implications for Cancer Survivors** Long-term cancer survivors continue to report health information needs for most SCP items and would prefer a print format; however, level of need differs by socio-demographic and cancer characteristics. Cancer survivors who did not previously receive a SCP may still benefit from receiving SCP content, and strategies for enabling dissemination to long-term survivors warrant further investigation.

**Keywords** Long-term · Cancer survivor · Health information need · Information delivery source

## Introduction

Although incidence rates are declining for many cancers, an aging population, earlier diagnosis, and better treatment have led to a rapidly increasing number of long-term cancer survivors in the USA and worldwide [1–3]. The majority of people diagnosed with cancer now survive 5 years or more [4]. Long-term cancer survivors, most of whom will be aged >65 years in the next decade, continue to encounter physical, emotional, social, and financial challenges as they transition through the cancer survivorship trajectory, yet little is known about the health information needs of this population from the patients' perspective [5]. In the past, cancer survivors have not systematically received written information regarding recommendations for long-term follow-up that address these challenges. However, accreditation standards from the Commission on Cancer (CoC) of the American College of Surgeons require that by 2015, all cancer centers seeking CoC accreditation must provide a survivorship care plan (SCP) or treatment summary and follow-up plan after

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completion of primary treatment [6, 7]. SCPs summarize multiple health information domains, including describing cancer diagnosis and treatment and their potential long-term side effects, providing a cancer surveillance plan and advice on health promotion, and highlighting supportive community resources [8]. As the content and format of SCPs continue to evolve and their use becomes more widespread, an accurate representation of information needs from the patients' perspective is critical.

Providing cancer and health-related information that is understandable from the patient's perspective improves patient involvement in health care decision-making, satisfaction with health care, coping skills, and communication with family and caregivers and reduces anxiety and mood disturbance [9]. Satisfaction with cancer-related information provision is associated with better overall health-related quality of life and psychosocial health outcomes including depression [10–12]. In contrast, cancer survivors with unmet information needs are more likely to experience psychological distress [13] and lower emotional, functional, social or family well-being, and perception of health competence [10]. Consequently, understanding and meeting the informational needs of cancer survivors is of high public health importance.

Health information needs of cancer survivors may change following active treatment [14–16]. However, the majority of the literature on this topic has focused on information needs and sources in short-term cancer survivors at diagnosis and treatment; few studies have assessed if SCP domains align with the information needs and preferences of long-term cancer survivors in the post-recovery and remission phases of the cancer trajectory [9]. Additionally, the preferred mode of delivery for this information is unclear, yet some research suggests that both needs and preferred information sources shortly after cancer diagnosis and treatment differ by socio-demographic groups and cancer type [13, 17–28]. Characterization of the factors associated with long-term cancer survivors' information needs and preferred sources would support a better understanding of the suitability of SCPs for the most diverse group of cancer survivors. This information would support future investigations of the impact of SCPs on outcome measures that are consistent with SCP content, such as uptake of cancer screening and cancer-related comorbidity, which have been limited to date [29]. Improving understanding of patient preferences for content and dissemination methods may also advance implementation and acceptability of SCPs in practice [30].

We assessed health information needs specific to SCP domains and preferences for various information sources among a nationwide, population-based sample of cancer survivors 9 years post-diagnosis who participated in the longitudinal American Cancer Society Study of Cancer Survivors-I

(SCS-I). This group of cancer survivors, who did not receive SCPs at the time of their primary cancer since SCPs were not considered usual care, was asked to assess their current cancer information needs. Specifically, we asked them what type (content) of cancer information and delivery modalities would be most helpful 9 years after diagnosis. We also examined variation in the above needs and preferences by socio-demographic, clinical, and lifestyle characteristics.

## Methods

### Study population

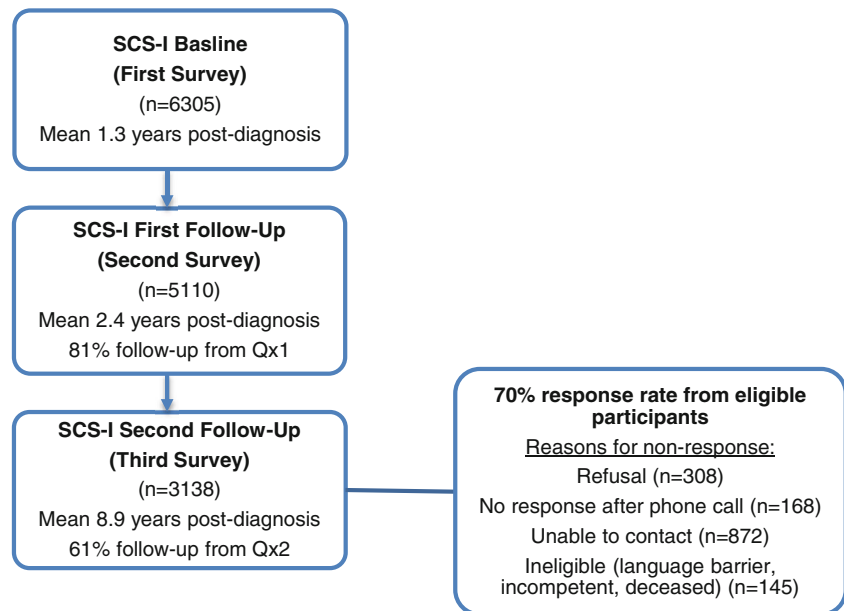
We utilized data from the full national sample of the American Cancer Society's longitudinal SCS-I to evaluate health information-seeking behaviors of a population-based sample of cancer survivors, described in detail previously [31]. A total of 6305 adult (>18 years) cancer survivors with the ten most common cancers (breast, prostate, colorectal, lung, ovarian, melanoma, uterine, non-Hodgkin's lymphoma, kidney, and bladder) were identified and enrolled from central cancer registries in 11 states. Samples were age-stratified (<55 and over 55 at diagnosis), and racial/ethnic minorities, those under 55 years old, and certain cancers were over-sampled [31]. At baseline, participants who were approximately 1 year post-diagnosis completed a mailed, self-administered questionnaire on a wide range of characteristics, including socio-demographic factors, medical history, cancer treatment, lifestyle factors, and psychosocial measures. Clinical characteristics, such as cancer stage and date of diagnosis, were obtained from the state cancer registries. Institutional review board (IRB) approval was obtained from Emory University. Additional IRB approvals were obtained from each state's cancer registry [32].

The study has administered three surveys in total: the baseline (individuals enrolled at approximately 1 year post-diagnosis) and two follow-up surveys (approximately 2 and 9 years post-diagnosis) (Fig. 1). The majority of the three surveys were completed by mail, with a small number administered via telephone. The current analysis focuses on data gathered from the third survey completed by 3138 survivors in the national sample (70 % response rate for eligible participants) approximately 9 years post-diagnosis.

### Assessment of health information needs and preferences

The outcomes of interest were level (% responding yes) of need for ten health information domains. All participants were asked about their current information needs at 9 years post-diagnosis for topics derived from the recommended components of a SCP and its method of development (response options: yes, no-receive adequate information, no-do not need

**Fig. 1** Survey response rates for the Study of Cancer Survivors-1 (SCS-I): baseline to survey 3



information). The topics were (1) possible long-term side effects of the treatment you received, (2) tests and examinations you should have following completion of treatment, (3) cancer screening tests you should have for other types of cancer, (4) behaviors you should adopt to be more healthy (e.g., diet, exercise), (5) possible consequences of having had cancer on your health insurance or finances, (6) possible consequences of having had cancer on your ability to continue to work in your job, (7) cancer-related resources and information, (8) impact of the psychological burden of cancer on yourself and your family, (9) information on the skills family and caregivers can use to support you, and (10) a cancer survivorship care plan you and your doctor would create together. Preferences for health and cancer-related information sources/format were assessed in the national sample using survey questions based on the Health Information National Trends Survey (HINTS) [33].

### Statistical analysis

Selected participant characteristics, current information needs, and preferred information sources were evaluated using basic descriptive statistics. We assessed unadjusted associations with the number of informational needs ( $\geq 2$  vs  $< 2$  needs—dichotomized at the mean) identified at 9 years post-diagnosis and (1) demographic characteristics [age ( $< 55/\geq 55$  years at diagnosis; this age cut point was selected as those  $< 55$  were oversampled in the original design), sex, race/ethnicity (non-Hispanic white/other), education (high school or less/some college/college/graduate degree), employment (employed/unemployed/retired), income ( $< \$40,000/\$40,000\text{--}\$75,000/> \$75,000$  per year), marital status (married/

separated or divorced/single/widowed), health insurance (yes/no)] and medical care provision within the previous 2 years (both primary and specialist care/primary care only/specialist care only/neither primary nor specialist care/missing or unsure); (2) clinical characteristics [cancer type (breast/prostate/colorectal/lung/ovarian/melanoma/uterine/non-Hodgkin's lymphoma/kidney/bladder), primary cancer stage (in situ or local/regional/distant), cancer status (cancer-free/cancer), cancer diagnosis or treatment past 5 years (yes/no), number of chronic conditions (0/1/ $\geq 2$ ), and self-reported health (excellent/very good/good/fair or poor)]; and (3) lifestyle characteristics [(alcohol intake (none/up to one drink per week/up to five drinks per week/up to three drinks per day), body mass index ( $< 18.5/18.5\text{--}< 25/25\text{--}< 30/30\text{--}< 35/35\text{--}< 40/\geq 40$  kg/m<sup>2</sup>), physical activity level (none/ $< 150$  min per week/ $\geq 150$  min per week), smoking (never/former/current), fruit and vegetable intake ( $\leq 1$  day per week/2–3 days per week/4–5 days per week/6–7 days per week)] using  $\chi^2$  tests. Demographic and cancer characteristics were derived from the baseline questionnaire. Income in the previous year, health insurance coverage, time since cancer diagnosis and current cancer status, comorbidities, self-reported health, diet, exercise, alcohol, body mass index, and smoking status were derived from the third survey at 9 years post-diagnosis. Multivariate logistic regression analyses were conducted to determine the independent effects of any characteristics that were significantly associated with level of need ( $< 2$  needs vs  $\geq 2$  needs) in univariate analyses with  $\alpha < 0.05$ . We derived the most parsimonious multivariate model using backwards elimination, and we retained only those variables that were associated with level of need with an  $\alpha < 0.05$ . All analyses were conducted using SAS (version 9.2, Cary, NC).

**Results**

The mean age of the 3138 long-term cancer survivors in the current analysis was 65.8±11.6 years (Table 1), and they were an average of 8.9±0.7 years since diagnosis. The majority was female (59.7 %) and non-Hispanic white (88 % non-Hispanic white, 6 % non-Hispanic black, 3 % Hispanic, 2 % other). Over half of participants had at least some college education (60.5 %) and an annual income >\$40,000 (53.3 %). Almost all participants had health insurance (97 %). The majority of participants were treated by both primary and specialist care providers within the previous 2 years (50 %); overall, 86 % had seen a primary care provider (PCP) within this period. Approximately one fifth (22.2 %) of survivors had a cancer recurrence or received further treatment during the 5-year period prior to completing the follow-up questionnaire. Two thirds of long-term cancer survivors had ≥2 chronic conditions (68.9 %), although most (80 %) self-reported that they were in good to excellent health.

Approximately 9 years post-diagnosis, 42.5 % cancer survivors reported that they would currently like to have more information on cancer screening tests for other types of cancers; 33.1 % would like more information on long-term cancer side effects, while 31.9 % would currently like more information on healthy lifestyle behaviors (Table 2). A similar proportion would like more information on possible consequences of having had cancer on health insurance or finances (28.2 %) and tests and examinations they should receive following cancer treatment (27.0 %).

Participants reported on how they would like to receive cancer information (Table 3). Reading a book, magazine, or other printed publication was most popular (60.9 %), followed by personalized reading materials (57.6 %). Meeting in person with a health care professional was the third preferred source of cancer information (44.4 %), and receiving information by email or internet was ranked lower (40.1 %). Overall, 84 % of responders were internet users (of these, 55 % were aged <55 years, and 45 % were aged ≥55 years at diagnosis). Preference for each type of information source differed by age and education level (*p*<0.05). Those aged <55 years at diagnosis and those with higher educational attainment were more likely to indicate a preference for each source in comparison with those aged >55 years at diagnosis (data not shown).

We evaluated factors associated with greater informational need (≥2 vs <2 needs) 9 years post-diagnosis (Table 4). In multivariate analyses, age, race/ethnicity, education level, cancer type and stage, number of chronic conditions, and self-reported health were significantly associated with number of information needs. Those aged <55 at diagnosis were twice as likely to have a greater number of information needs compared with the older age group (≥55 years at diagnosis) (OR 0.45, 95 % CI 0.38, 0.54). Participants of race/ethnicity other

**Table 1** Characteristics of American Cancer Society Study of Cancer Survivors-I participants who completed the third survey (N=3138)

Characteristic	N (%) <sup>a</sup>
Time since diagnosis (years), mean ± SD	8.9 ± 0.7
Age (years), mean ± SD	65.8 ± 11.6
Age (years) at diagnosis, mean ± SD <sup>b</sup>	56.9 ± 11.7
Sex <sup>b</sup>	
Female	1873 (59.7)
Male	1265 (40.3)
Race/ethnicity <sup>b</sup>	
Non-Hispanic white	2775 (88.4)
Other	342 (10.9)
Education level <sup>b</sup>	
High school or less	1004 (32.0)
Some college	742 (23.7)
College	622 (19.8)
Graduate degree	534 (17.0)
Employment status	
Employed	231 (7.4)
Unemployed	617 (19.7)
Retired	647 (20.6)
Income	
<\$40,000	952 (30.3)
\$40,000–\$75,000	878 (28.0)
>\$75,000	807 (25.7)
Marital status	
Married/marriage-like relationship	1066 (34.0)
Separated or divorced	144 (4.6)
Single	83 (2.6)
Widowed	206 (6.6)
Medical care provision (within 2 years)	
Both primary and specialist care	1567 (49.9)
Primary care only	1106 (35.3)
Specialist care only	50 (1.6)
Neither primary nor specialist care	110 (3.5)
Missing/not sure	305 (9.7)
Health insurance status	
Yes	3045 (97.0)
No	85 (2.7)
Cancer type <sup>b</sup>	
Breast	870 (27.7)
Prostate	654 (20.8)
Colorectal	441 (14.1)
Non-Hodgkin’s lymphoma	213 (6.8)
Uterine	195 (6.2)
Melanoma of the skin	192 (6.1)
Kidney	178 (5.7)
Lung	146 (4.7)
Ovarian	127 (4.1)
Bladder	122 (3.9)

**Table 1** (continued)

Characteristic	N (%) <sup>a</sup>
Primary cancer stage <sup>b</sup>	
In situ or local	2208 (70.4)
Regional	361 (11.5)
Distant	185 (5.9)
Current cancer status	
Cancer-free	2871 (91.5)
Cancer	238 (7.6)
Cancer diagnosis or treatment past 5 years	
Yes	697 (22.2)
No	2261 (72.1)

<sup>a</sup>Numbers may not sum to 100 % due to rounding or missing values

<sup>b</sup>Data from the first (baseline) survey. All other data is from the third (9 years) survey

than non-Hispanic white were 79 % more likely to have greater information needs compared with non-Hispanic whites (OR 1.79, 95 % CI 1.36, 2.36). Education level was also associated with greater information need. Participants with some college (OR 1.55, 95 % CI 1.25, 1.93), who completed college (OR 1.55, 95 % CI 1.23, 1.96), or a graduate degree (OR 1.62, 95 % CI 1.27, 2.06) reported greater informational needs compared with those that completed high school or less. Prostate (OR 0.61, 95 % CI 0.48, 0.77) and colorectal cancer survivors (OR 0.56, 95 % CI 0.42, 0.75) and survivors of uterine (OR 0.62, 95 % CI 0.44, 0.89), melanoma (OR 0.50, 95 % CI 0.35,

**Table 2** Proportion answering “yes” to “what topics would you currently like to have more information about?” in the American Cancer Society Study of Cancer Survivors-I third survey (*N*=3138)

Information	Yes (%)
Cancer screening tests you should have for other types of cancer	1335 (42.5)
Possible long-term side effects of treatment	1039 (33.1)
Behaviors you should adopt to be more healthy (diet, exercise)	1000 (31.9)
Possible consequences of having had cancer on your health insurance or finances	884 (28.2)
Tests and examinations you should have following completion of treatment	848 (27.0)
A cancer survivorship care plan that you and your doctor would create together	562 (17.9)
Impact of the psychological burden of cancer on yourself and your family	538 (17.1)
Cancer-related resources and information (e.g., internet-based sources or telephone numbers of support organizations)	486 (15.5)
Information on the skills families and caregivers can use to support you	403 (12.8)
Possible consequences of having had cancer on your ability to continue work at your job	281 (9.0)

**Table 3** Proportion answering “yes” to “would you like to get information about cancer from the following information sources?” in the American Cancer Society Study of Cancer Survivors-I third survey (*N*=3138)

Information source	Yes (%)
Reading a book, magazine, or other printed publication	1911 (60.9)
Reading materials created for you based on your personal lifestyle/family history	1807 (57.6)
Meeting in person with a health care professional	1392 (44.4)
By email or the internet	1259 (40.1)
Watching a DVD or video	810 (25.8)
Receiving a telephone call from a health care professional	743 (23.7)
Using an interactive CD-ROM that lets you select information you want	705 (22.5)
Attending a public cancer lecture	696 (22.2)
Participating in an online cancer survivorship educational course	567 (18.1)
Participating in an in-person support group	543 (17.3)
Listening to a CD or tape	499 (15.9)
Participating in an online cancer community website	345 (11.0)
Participating in an online (internet) support group	273 (8.7)

0.73), kidney (OR 0.59, 95 % CI 0.41, 0.84), and lung cancer (OR 0.46, 95 % CI 0.29, 0.72) were less likely to report more long-term information needs compared with breast cancer survivors. Participants diagnosed with regional and distant cancer stage were 67 % (95 % CI 1.30, 2.14) and 81 % (95 % CI 1.28, 2.55) more likely, respectively, to identify  $\geq 2$  long-term information needs compared with those diagnosed with in situ or local disease. Participants that self-reported worse health also had greater informational needs long term. Those with fair/poor self-reported health were more than twice as likely to report greater need compared with those reporting excellent health (OR 2.37, 95 % CI 1.66, 3.36).

## Discussion

The results of this study suggest that long-term cancer survivors in the USA who were diagnosed prior to the development of and thus never received SCPs have substantial unmet health information needs that could be addressed through topics covered in SCPs. Greatest interest was for information on cancer screening tests, followed by long-term treatment side effects, recommended healthy behaviors, tests and examinations post-cancer treatment, and possible consequences of having had cancer on health insurance or finances, respectively. A number of socio-demographic and clinical characteristics

**Table 4** Factors associated with informational needs ( $\geq 2$  vs  $< 2$  needs) in the American Cancer Society Study of Cancer Survivors-I third survey ( $N=3138$ )

	Univariate OR (95 % CI) <sup>a</sup>	Multivariate-adjusted OR (95 % CI) <sup>a</sup>
Age at diagnosis (years)		
<55	1.00 (ref)	1.00 (ref)
$\geq 55$	0.43 (0.37, 0.50)	0.46 (0.38, 0.54)
Race/ethnicity		
Non-Hispanic white	1.00 (ref)	1.00 (ref)
Other	1.85 (1.47, 2.32)	1.79 (1.36, 2.36)
Education level		
High school or less	1.00 (ref)	1.00 (ref)
Some college	1.57 (1.29, 1.90)	1.55 (1.25, 1.93)
College	1.53 (1.25, 1.87)	1.55 (1.23, 1.96)
Graduate degree	1.39 (1.12, 1.71)	1.62 (1.27, 2.06)
Cancer type		
Breast	1.00 (ref)	1.00 (ref)
Prostate	0.60 (0.49, 0.73)	0.61 (0.48, 0.77)
Colorectal	0.63 (0.50, 0.79)	0.57 (0.43, 0.76)
Bladder	0.78 (0.54, 1.14)	0.68 (0.45, 1.05)
Uterine	0.78 (0.57, 1.06)	0.62 (0.44, 0.89)
Melanoma	0.48 (0.35, 0.66)	0.50 (0.35, 0.73)
Non-Hodgkin's lymphoma	1.10 (0.81, 1.49)	1.03 (0.66, 1.60)
Kidney	0.67 (0.48, 0.92)	0.59 (0.41, 0.84)
Lung	0.55 (0.39, 0.79)	0.46 (0.29, 0.72)
Ovarian	1.38 (0.94, 2.02)	1.18 (0.76, 1.82)
Primary cancer stage		
In situ or local	1.00 (ref)	1.00 (ref)
Regional	1.58 (1.27, 1.98)	1.63 (1.27, 2.10)
Distant	1.69 (1.25, 2.29)	1.27 (0.84, 1.93)
Number of comorbid conditions		
0	1.00 (ref)	1.00 (ref)
1	1.16 (0.90, 1.49)	1.22 (0.90, 1.65)
$\geq 2$	1.40 (1.15, 1.71)	1.58 (1.24, 2.01)
Self-reported health		
Excellent	1.00 (ref)	1.00 (ref)
Very good	1.38 (1.06, 1.79)	1.39 (1.03, 1.86)
Good	1.71 (1.31, 2.23)	1.75 (1.30, 2.37)
Fair or poor	2.33 (1.71, 3.16)	2.37 (1.66, 3.38)

OR odds ratio

<sup>a</sup> Logistic regression

were associated with level of informational need 9-years post-diagnosis, including age, race/ethnicity, education level, cancer type and stage, number of comorbid conditions, and self-reported health. The two most preferred sources for obtaining cancer information were print media and personalized reading materials, such as a SCP, whereas email/internet was ranked fourth after meeting in person with a health care professional to receive cancer information.

### Comparing long-term versus short-term need for information contained in SCPs

SCPs are intended for dissemination upon completion of active treatment or early in the cancer trajectory; however, our study suggests that long-term cancer survivors who did not receive SCPs after diagnosis may also benefit from this information. The information needs of cancer survivors at various stages in their cancer trajectory have been investigated in a

number of studies. Information-seeking behavior of cancer survivors at all stages of the cancer trajectory were assessed in a population-based telephone survey of 411 participants, post-cancer diagnosis. Prevalence of health/cancer information-seeking was highest for those  $\geq 11$  years post-diagnosis compared with earlier in the trajectory [34]. Conversely, colon, breast, and prostate cancer survivors participating in a longitudinal cohort ( $n=2013$ ) reported highest levels of need at 1 year post-diagnosis, with decreasing need over the subsequent 2 years, although level of need differed by cancer type and information topic [35]. Another cross-sectional survey among 187 cancer survivors found that trend scores for information need decreased with time since diagnosis [36]. In an analysis of cross-sectional data from the Study of Cancer Survivors-II, overall information need was less for those with a longer time since diagnosis for women (11 vs 3 years) but need did not differ for men based on time since diagnosis [37].

The 9-year cancer survivors in this study who were diagnosed prior to routine use of SCPs identified current unmet need for the information that is provided in a SCP. Overall, our results were comparable to the few studies that have assessed health information needs  $\geq 9$  years post-cancer diagnosis that indicated a need for information regarding late cancer/treatment effects, health promotion, ongoing tests and treatments, interpersonal/emotional support, financial issues, and screening/surveillance [11, 18, 34, 37–39]. Those at least 5 years post-diagnosis have indicated similar needs [24, 27, 40], although recently treated cancer patients have also indicated a desire for information on lifestyle and long-term treatment and disease effects in some studies [41]. Our findings are consistent with those reported in another large long-term (up to 14 years post-diagnosis) study of 1197 cancer survivors in California where participants reported a high prevalence of unmet health information need, particularly those that had not previously received a written treatment summary [11]. The ACS Study of Cancer Survivors II ( $n=1514$ ; 25 % were 10-year survivors) identified 16 themes of unmet needs based on open-ended responses. The top ranked themes encompassed needs identified in our analysis, including physical problems (symptoms, diet, and exercise) and education/information needs (follow-up care, self-care, cancer/health research, cancer risks, causes, and prevention) [38].

A previous systematic review of the literature on health informational needs and sources of cancer survivors up through 2003 found that the majority of studies assessed needs during or shortly post-treatment; thus, highly ranked needs included treatment-related, prognosis, and rehabilitation information [9]. In this group of studies, only 3.4 % of participants indicated a need for cancer surveillance or health information, which contrasts our findings for longer term cancer survivors. A more recent systematic review up through February 2012 assessed informational need and priorities among primarily

newly diagnosed cancer patients or survivors  $< 5$  years post-treatment. The 30 studies in this review similarly highlighted that patients prioritized information on prognosis, diagnosis, and treatment information [42].

Some long-term information domains that were assessed may reflect unmet medical needs as opposed to informational needs per se, for example, stress management encompassed within the psychological burden domain, which is difficult to address in a general clinical setting and may require referral for psychological services [39]. However, disentangling how access to medical care influences informational need was beyond the scope of the data collected in our population.

With widespread encouragement of adoption of SCPs in 2015 as recommended by the Institute of Medicine (IOM) [2, 7, 43], the Cancer Survivorship Committee within the American Society of Clinical Oncology (ASCO) [7], and the Commission on Cancer [6], the informational needs of newly diagnosed patients are more likely to be met. The SCP was designed to be an evolving document [30]. Our data suggests a need to provide SCPs for all cancer survivors, which would give individuals who did not previously receive a SCP access to a document that may be able to address some of their unmet informational needs.

### Current specific health information needs

Screening information was identified as the top unmet health information need of long-term cancer survivors in the SCS-I cohort. While long-term cancer survivors are more likely to receive ongoing surveillance of their primary cancer type, a recent prospective study found that people diagnosed with cancer were less likely to receive ongoing screening for other types of cancer compared with those without a cancer diagnosis, despite higher risk for second primary cancers [44]. Other data support the lack of enhanced screening for certain cancer types in this higher risk population compared with the general population [45]. A population-based, retrospective study of 21,111 cancer survivors found that two thirds of breast cancer survivors had never been screened for colorectal cancer, while half of female colorectal cancer survivors had never been screened for breast or cervical cancer [46]. Greater dissemination of long-term screening and surveillance recommendations or national screening guidelines specific to long-term cancer survivors may be warranted to enhance uptake of screening services for early detection of recurrent and second cancers.

We also found that long-term cancer survivors want more information on long-term side effects of cancer treatment. A third of all cancer survivors report ongoing side effects after treatment completion [47]. That proportion is higher for some leading cancers, for example, up to two thirds of breast cancer survivors report ongoing treatment-related effects such as

osteopenia and osteoporosis, twice the proportion of the general population [48].

Information on recommended healthy behaviors ranked highly as an unmet area of need. Cancer survivors' dissatisfaction with available health promotion resources has been reported elsewhere [49, 50]. A national survey found close to a third of cancer survivors were obese and had conducted no leisure time physical activity during the previous 30 days [51]. The increasing evidence that energy balance and related comorbidities play a role in cancer recurrence and survival merits greater emphasis on healthy lifestyle behaviors through SCP content [51–54].

Participants also expressed a need for information on tests and examinations they should have following cancer treatment. Previous surveys have highlighted a desire by cancer survivors for clinical support with respect to prevention and early detection of cancer recurrence [55] and tests for cancer and treatment-related comorbidity. In a British study of 26,213 long-term cancer survivors matched 1:4 to non-cancer controls, breast cancer survivors had a higher risk of heart failure, coronary artery disease, hypothyroidism, and osteoporosis compared with controls [56]. Colorectal cancer survivors were at increased risk for dementia, diabetes, and osteoporosis, while prostate cancer survivors had higher risk of osteoporosis compared with controls [56]. Receipt of follow-up care instructions was associated with better medical follow-up attendance, cancer surveillance, and preventive cancer screening, as well as fewer late/long-term side effects in a 2010 survey of 3541 cancer survivors post-treatment [57].

Many of the information needs reported by participants could be provided by a PCP, including information on cancer screening and healthy behaviors. Long-term survivors in remission are more likely to receive care from a PCP [58], unlike those with recurrence and receiving treatment. The level of resources for cancer survivors in primary care is unclear, although the ACS and ASCO continue to develop consensus guidelines [59–61]. We found that half of long-term cancer survivors recently utilized both primary and specialist care and most had recent access to a PCP. However, utilizing primary versus specialist care was not associated with level of informational need in our analysis. Data on visits to care providers was based on self-report, as was information on whether participants were currently cancer free, which could have influenced our findings. Additionally, reasons for visiting an oncologist as opposed to a PCP may vary widely.

### Preferred delivery format for health information

With widespread adoption of SCPs, the dissemination method may begin to encompass modalities beyond an in-person meeting between patients and their health care providers. Our findings suggest that overall, the highest proportion of cancer survivors rated reading a book, magazine, or other

printed material as a preferred source for cancer information, followed by personalized reading materials, although participants identified multiple preferences that may differ depending on circumstance. The Cancer Information Service Research Consortium recently presented data from three randomized controlled trials of web-based multi-media programs to support cancer treatment and post-treatment decisions. While 50–67 % of participants reported using multimedia, up to 90 % reported using print materials [62]. In the Michigan Prostate Cancer Survivor Study, the top five sources of information were health care provider, someone with prostate cancer, brochures/pamphlets, National Cancer Institute/American Cancer Society, and the internet. Half of prostate cancer survivors visited their primary care provider first for information; 18 % searched on the internet [63]. Another cross-sectional survey of 411 patients (from those undergoing treatment to  $\geq 5$  years post-treatment) attending cancer clinic post-treatment follow-up found that the most preferred source of health information was the internet, followed by health provider [64]; the opposite was true for 865 cancer survivors up to  $\geq 11$  years post-diagnosis that completed a population-based telephone survey [34]. However, those at least 1 year post-treatment have reported seeking cancer-related information from an average of five sources, suggesting that offering a variety of sources may be preferable [65]. Although many organizations are moving towards digital-only content, our data supports the print format currently adopted for SCP dissemination, particularly for this older population of longer term cancer survivors. The fact that print material was ranked more highly than in-person information exchange warrants further investigation, as well as preferred information sources specific to each identified health information need.

The internet was the fourth preferred information source in the current analysis. Confusion with regards to the information available via the internet [34, 66, 67] and skepticism of unknown internet sources could be a barrier to this mode of delivery [68]. The HINTS survey highlighted that cancer survivors used the internet at a lower rate than the general population [69]. Frameworks that use patient-level data to personalize electronic communication between practitioners and cancer patients are currently under development [70] and may offer new avenues for delivering SCP-related information in the future, yet more work is needed to understand if these technology-driven formats will be acceptable.

### Demographic and clinical factors associated with health information need

We observed differences in number of informational needs by socio-demographic characteristics (age, race/ethnicity, education), cancer characteristics (type, stage), and health status (number of comorbid conditions, self-reported health),



underscoring the need to individualize the information provided in SCPs. Information needs of cancer survivors earlier in the cancer trajectory have been shown to differ significantly by demographic, psychosocial, clinical, and cancer characteristics in a number of studies [11, 50, 71–73]. We found that younger people were more likely to indicate informational needs 9 years post-diagnosis. Earlier in the cancer trajectory, younger age has previously been shown to predict greater informational needs [40]. However, level of need may also differ by informational topic, such as sexuality or social life, for younger compared with older cancer survivors [42]. In a large cluster analysis of cancer patients 2 years post-diagnosis, high information seekers were highly educated, whereas constrained information seekers were of lower socio-economic status [74]. Our analysis similarly highlighted that highly educated long-term cancer survivors were more likely to report greater information needs compared with those less educated. Other studies have reported discordant findings, where low educational attainment, but not health literacy, was associated with greater cancer informational need [75]. We also found that minority participants reported greater informational need, but we did not identify differences by income status. Minority ethnic groups that do search for health information are more likely to specifically seek support service information and psychosocial support compared with non-Hispanic whites [37, 71]. A recent cross-sectional survey of breast and prostate cancer survivors (>2 years post-treatment) showed that African Americans reported greater informational needs compared with other races [76]. The National Cancer Institute's 2003 HINTS Survey similarly found that cancer information seekers were younger, female, had higher income, and a regular health care provider [73]. Among men in the Michigan Prostate Cancer Survivor Study, whether informational needs were addressed also differed by age and race; older men and white survivors were more likely to report receiving adequate information from a health care provider [63]. Needs may also differ by level of health insurance [77], although we could not evaluate this association since the majority of the study population had health insurance coverage [40].

Longer term informational needs differed by cancer type as addressed in previous studies [78, 79]. Compared with breast cancer survivors, prostate, colorectal, uterine, melanoma, kidney, and lung cancer survivors identified fewer informational needs. A cross-sectional analysis of informational needs of 2010 cancer survivors in Pennsylvania also found that information-seeking behavior differed by cancer type, although differences were reduced at later cancer stages [79]. We observed that those diagnosed at the regional cancer stage and those with worse self-reported health were more likely to have a higher number of health informational needs 9 years post-diagnosis; few previous

studies have examined differences in health information needs of cancer survivors by cancer stage.

### Strengths and limitations

Strengths of this study include the large number of long-term cancer survivors and population-based sampling. Our current cohort was largely composed of breast, prostate, and colorectal cancer survivors, which is representative of the broader population of cancer survivors in the USA [80]. However, a few limitations should be noted. Although demographic and clinical data were collected longitudinally, questions about specific informational needs and preferred sources of information were developed after the baseline questionnaire, and therefore, analysis was cross-sectional. A further consideration is the fact that one fifth of participants had a cancer recurrence or required further cancer treatment during the follow-up period. This population may have different information needs to the broader population of long-term cancer survivors, and it is unclear whether they received a SCP following completion of treatment for their recurrence or second cancer. Although minorities were oversampled in the original design, the sample was still predominantly non-Hispanic white, with similar representation of minorities in the third survey compared with the first (baseline) survey. Therefore, our results may not generalize to cancer survivors of other race/ethnicity. While we explored the number of informational needs by demographic and cancer characteristics separately, we did not assess how different combinations of these characteristics influenced number of information needs, for example, for individuals of certain race/ethnicity and education level. The drivers of differences in level of need for these subgroups are an interesting potential area of future research. Future large, observational, longitudinal studies that assess the changing needs of cancer survivors across the cancer survivorship continuum are warranted.

### Conclusion

Long-term cancer survivors in our population had unmet informational needs, particularly with regards to screening, long-term cancer and treatment effects, and healthy lifestyle behaviors. Number of informational needs differed by socio-demographic, clinical, and cancer characteristics. Long-term cancer survivors preferred a print format for health information dissemination. Our findings indicate that cancer survivors who did not previously receive a SCP reported a desire for its contents 9 years post-diagnosis, supporting delivery of SCP content to this population. As the unmet needs evaluated in our study reflect the current content of survivorship care plans, our findings support the plan for their wider

implementation and suggest that dissemination should also be expanded to long-term cancer survivors.

### Compliance with ethical standards

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### Conflicts of interest

None  
The authors assume full responsibility for analyses and interpretation of these data.

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