Patient Reported Outcomes in Cancer Survivorship

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Abstract

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Background: Survivorship services and the use of the treatment summary and survivorship care plan (SCP) have been in place for over ten years. This project evaluates the impact and efficacy of a general survivorship clinic at a comprehensive cancer center by utilizing patient reported outcome data collected pre- and post-clinic combined with medical record derived demographic and treatment data. Methods: The key outcomes measured in this longitudinal study include pre-clinic to one year post-clinic change in knowledge of survivorship information (diagnosis, treatment and long term effects), cancer and treatment related distress (uncertainty, family strain, medical demands, finances, identity, health burden and interference) and health-related quality of life (physical, emotional and social functioning, pain, general health and vitality) as well as the extent to which the clinic visit and SCP met patient needs. The population is described in detail including demographics, diagnosis and treatment history (N=219). Results: Patient knowledge of their own diagnosis and treatment history as well as of the long term effects of their cancer treatment increased after the clinic visit. Overall treatment related distress decreased in addition to distress in the areas of uncertainty and family strain. Over 90% of patients found the SCP useful and reported that the clinic visit met their needs in all areas surveyed including practical, resource, emotional, and symptom-related needs. Conclusions: Although the changes were small, findings from this study support the use of a dedicated, general survivorship clinic model for cancer survivors. This model may be a feasible approach to ensuring our already overtaxed healthcare system can meet the myriad needs of the growing population of cancer survivors.

INTRODUCTION

There are currently 17 million cancer survivors living in the US and this number is expected to reach 22 million in the next 10 years[1]. Survivors represent a unique cohort of the population because of the host of complications they can encounter after treatment ends. Despite this, survivors are often discharged back to their primary care providers and regarded as any other patient by the health system. Research has repeatedly shown that survivors have unique health needs compared to those who have not undergone cancer treatment, such as pain, fatigue, cognitive disturbance, depression, and anxiety. In addition, cancer survivors are at increased risk for major medical complications due to their cancer history or the treatment they received. Some examples include cardiovascular disease, endocrine disorders, and decreased bone health[2,3].

In an effort to meet the needs of survivors, in 2015 the American College of Surgeon's Commission on Cancer implemented a guideline mandating accredited cancer centers to provide a Treatment Summary and Survivorship Care Plan (SCP) to all patients completing cancer treatment[4]. A SCP is a written document summarizing the survivor's diagnosis and treatment history, current health status, and recommendations for ongoing health maintenance and screening. The SCP delineates to the survivor which providers are responsible for specific aspects of their ongoing care[5]. The mandate came nearly 10 years after the first publication highlighting the needs of cancer survivors[6], yet cancer centers across the country continue to struggle with implementing SCPs and other programs for survivors. With mixed evidence on the efficacy of SCPs[7] and in the absence of standardized program models, many centers fail to see the value in dedicating resources to this endeavor. With additional recommendations and guidelines from the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN), managing the growing population of cancer survivors continues to be a challenge.

To lessen the burden on providers with large caseloads of active cancer patients and to focus on survivorship-specific issues, cancer centers across the country have implemented various versions of dedicated survivorship clinics staffed by specialized providers to whom oncologists can refer patients at the end of treatment. Various clinic models exist with most geared toward specific survivor cohorts. Examples include disease specific clinics that serve survivors of a certain type of cancer (i.e. breast cancer), and population specific clinics such as for survivors of childhood cancer or hematopoietic cell transplant. Regardless of the model, most survivorship clinic visits include the creation and dissemination of a SCP to the patient and their providers, though little longitudinal follow-up data exists to assess the impact of these efforts. Furthermore, while published evaluations of disease and population specific cancer survivorship clinics have occurred, an extensive literature search revealed that a broad assessment of pairing a general survivorship clinic visit with the use of SCPs is not available as of this writing.

A limited number of studies have examined the usefulness and impact of SCPs without a visit to a dedicated survivorship clinic. Most of these studies were limited to specific disease groups. One example was a randomized controlled trial of the impact of SCPs on patient-reported outcomes of breast cancer survivors who were randomized to receive or not receive an SCP. The study, conducted by Grunfeld et al, revealed no difference between groups on the patient reported outcomes, including cancer related distress (a focus of the current investigation)[8]. Another study by Bulloch et al provided SCPs to breast cancer survivors. Outcome measures assessed participant knowledge of their cancer diagnosis and treatment as well as long term effects of their disease and treatment prior to and two months after receiving the SCP. The results of this study were mixed but did show limited improvement in knowledge of treatments received, such as correctly identifying chemotherapy agents as well as treatment-related future risks such as secondary malignancies (i.e. leukemia)[9].

Disease-specific survivorship clinics

Gilbert et al conducted an observational study comparing the quality of life and satisfaction with care of prostate cancer survivors who attended a survivorship clinic versus those who received routine follow-up care with no survivorship clinic visit. Results revealed those who attended a dedicated prostate cancer survivorship clinic reported better sexual function, increased overall recovery and more satisfaction with the care they received compared to survivors not seen in the survivorship clinic[10]. In a similar observational study, Dietrich et al found that survivors of early stage breast cancer who attended a survivorship clinic were more likely to be in compliance with NCCN recommendations for surveillance and felt their concerns were more adequately addressed compared to those who did not visit the survivorship clinic[11]. A dedicated lymphoma survivorship clinic in Rochester, MN reported that patients seen at the clinic could better recall receiving information on their long term health risks and were more confident in knowing how to find additional information and resources on cancer survivorship issues compared to survivors who were eligible to attend the clinic but did not[12]. When measured, these programs found no increase in reported distress or poor perceived overall health between patients who did and did not attend a survivorship clinic. This is significant because some opponents to the implementation of survivorship clinics and services posit that merely drawing attention to survivorship issues can cause distress in patients not previously concerned with such matters.

Population-specific survivorship clinics

Adult survivors of childhood cancer have been a focus of recent survivorship research, and initial findings indicate that patients who attend a survivorship clinic can better recall their treatment exposures, such as which chemotherapy drugs they received[13]. These patients could also more readily recite the known risks of those exposures and the late and long term effects to which they are susceptible, and more accurately identified their own cancer diagnosis compared to those who did not

attend[14]. In a similar cohort, Ford et al reported that survivors of childhood cancer attending a survivorship clinic tended to be more compliant with health screenings and surveillance and were less likely to abuse alcohol than non-clinic patients[15]. The Ford study also revealed that both patient groups reported having unmet psychosocial needs and reported their own health as fair or poor, underscoring the need for more attention on survivors following active treatment. Again, these investigations revealed no uptick in distress or decrease in quality of life as a result of utilizing the clinic.

Patient reported outcomes in survivorship

As we shift to a value-based healthcare model, we need more efficient and accurate methods to capture the needs of cancer survivors. Incorporating patient reported outcome (PRO) data into current and emerging clinical workflows can improve survival rates and patient-centered outcomes[13]. As the population of cancer survivors continues to grow, more emphasis on the public and population health impacts of cancer is essential. This growing population will continue to tax our healthcare and public health systems, and metrics are needed to secure resources for addressing their needs. We already use cancer registries to track cancer incidence and survival. Combining PRO data with registry data may be a useful strategy to enhance our understanding of the needs of different classes of survivors and may also aid in monitoring the success of systems as they are implemented. To expand upon the above evidence, this project evaluates the impact and efficacy of a general survivorship clinic at a comprehensive cancer center by utilizing patient reported outcome data collected pre- and post-clinic combined with medical record derived demographic and treatment data.

METHODS

Survivorship Program

The Survivorship Program at Fred Hutchinson Cancer Research Center (Fred Hutch) has three main objectives – clinical care, research and community outreach. Clinical care is provided in the Survivorship Clinic at Seattle Cancer Care Alliance (SCCA). The research team conducts studies involving Survivorship clinic patients as well as studies in other populations. Data for this project was collected as part of a large, multi-site study coordinated by the Survivorship Program and performed at multiple clinical sites throughout the region. This investigation was limited to data collected from patients seen only at the local Survivorship Clinic at SCCA.

Survivorship Clinic visit

The SCCA Survivorship Clinic is open to all adult cancer survivors, regardless of the time since treatment ended or where they received their cancer treatment. Most patients self-refer to the clinic while some are referred by their oncologist or another provider. The visits are covered by Medicare, Medicaid and most commercial insurance plans. The SCP is prepared prior to the visit by a dedicated Survivorship Program registered nurse who reviews the patient's entire cancer and treatment history, including review of outside medical records. The SCP includes a detailed summary of the survivor's diagnosis and treatment and incorporates recommendations for future care tailored specifically to the survivor's disease and treatment exposures. During the visit patients meet with a provider (a nurse practitioner or physician) who assesses their survivorship needs and addresses concerns related to the late and long term effects of their cancer and treatment history. The SCP is jointly reviewed by the provider and patient, and the patient receives a copy of their SCP at the conclusion of the visit.

Medical record data

As part of standard practice for scheduling an appointment in the Survivorship Clinic, patient demographic information is entered into a database, which automatically feeds the patient's information into the Survivorship Information Management System (SIMS). SIMS is a proprietary computer program designed by the Fred Hutch Survivorship Program and is used to generate the SCP. After the visit is scheduled, the Survivorship nurse conducts a thorough review of the patient's medical record, including records obtained from outside facilities. Every effort is made to collect records that give the full picture of the patient's medical history and all cancer treatments received. Because patients can come to Survivorship Clinic at any time after treatment is complete, the medical history reviewed sometimes includes decades worth of records from multiple institutions.

The nurse enters the diagnosis and treatment data abstracted from the medical records directly into SIMS. Diagnosis data entered includes all cancer diagnoses the patient has received prior to their clinic visit. Treatment data includes surgeries, chemotherapy, radiation, and hematopoietic cell transplant. Treatment data entered is extremely detailed and includes drug names, doses and regimens, radiation dose and the body area irradiated, surgery site, and transplant type (allogeneic or autologous). This data comprises the treatment summary portion of the SCP. Based on the information entered in the treatment summary, SIMS generates the care plan portion of the SCP. The care plan includes disease- and treatment-specific risk-based recommendations carefully procured from national guidelines or developed by the expert consensus of physicians and scientists at Fred Hutch and SCCA.

Patient reported data

All patients who schedule an appointment in the Survivorship Clinic are asked to complete a comprehensive pre-clinic questionnaire covering topics such as health care utilization, physical and mental health, lifestyle (including exercise habits, tobacco use, alcohol consumption, etc.), and quality of

life. Patients can choose to complete an online or paper-based questionnaire. The information from the survey is fed into SIMS, compiled into a user-friendly report and made available to the clinic provider to reference during the problem-focused Survivorship Clinic visit. This allows the clinician to provide survivors with customized general medical and cancer recurrence screening recommendations, and health and wellness guidelines tailored to their unique situation. During the clinic intake process, patients are given the option to consent to the use of this data and their treatment data for research purposes.

Online survey. For those who choose the web-based survey, an email invitation is automatically generated and sent to the patient, which includes their unique access code and a link to the survey. Once the patient logs in, they are taken to a welcome screen that explains the purpose of the study and the steps to access the survey. They are then asked to consent to have their data used for research purposes. Patients must consent or decline consent for research before proceeding to the survey. The survey responses from patients who did not consent to research remain in the SIMS application but are not included in this investigation. Patients can quit the survey at any time and come back later to finish where they left off.

Paper-based. Patients who elect to fill out a paper-based version of the survey are mailed an introduction cover letter, consent form, survey with an access code for anonymity when returning the completed survey, and two pre-paid envelopes (one to return the signed consent form and a second to return the de-identified survey). These documents are mailed to patients prior to their initial survivorship-focused clinic visit. They also have the option to bring the survey and consent form to their clinic appointment rather than return them by mail.

Patients who complete and return their survey but do not return their signed consent form are re-approached about study participation at their clinic visit. Patients who provide consent have their data

used for both clinical and research purposes. Patients who do not provide consent have their data used for clinical purposes only and that data is not included in this investigation.

Approximately one year after completing the pre-clinic survey, survivors are asked to complete a follow-up survey. Respondents who completed the web-based survey at baseline received an email with a link to the follow-up survey followed by up to 5 reminder emails. Those that chose the paper option at baseline but had an email address on file also received the follow-up survey via email, however paper follow-up surveys were not distributed. The follow-up survey contains similar questions as the initial survey; however, the follow-up survey also contains questions about patient satisfaction with the survivorship-focused clinic visit and utilization of the SCP.

Case selection

All cancer survivors seen at the Survivorship Clinic were eligible to participate in the study and have their treatment and survey data used for research purposes. There were no exclusion criteria.

We received pre-clinic (baseline) surveys from 426 survivorship clinic patients between September 2012 (start of the study) and February 2019. We chose the cut-off of February 2019 to allow one year prior to the start of data analysis to collect the one year follow-up surveys. Of the 426 patients who completed the pre-clinic survey, 219 (51.4%) also completed the one year follow-up survey. Our primary analyses were conducted using the 219 cases with both baseline and follow-up data. Baseline differences between those who did and did not complete follow-up were analyzed and reported.

Outcome measures

Knowledge of survivorship information. The Confidence in Survivor Information (CSI)[16,17] survey includes questions related to the patient's own knowledge of their diagnosis and treatment history, risks and long term effects of treatment, and related follow-up care. Thirteen items are measured on a 3-point

Likert scale with answer choices of “not at all”, “somewhat”, or “very” confident. The first three items measure confidence in knowledge of past cancer diagnostic and treatment details. The remaining 10 items measure confidence in knowledge about prevention and treatment of long term effects of disease and treatment, prevention of future disease, access to resources, and familial risk of cancer. Total mean score of all items and subscale mean scores are calculated on a scale of 0 to 2 with higher scores indicating more confidence.

Treatment related distress. The Cancer and Treatment Distress Questionnaire (CTXD)[18] is used to measure distress related to cancer and its treatment. This is a 22-item measure with six subscales (uncertainty, health burden, family strain, identity, finances, and medical demands). Responses are on a four-point scale and range from “none” to “severe”. Respondents are asked to answer according to their experience in the past month. Total mean score of all items and subscale mean scores are calculated on a scale of 0 to 3 with lower scores indicating less distress.

Quality of life. The Medical Outcomes Study Short Form-36 Health Survey (SF-36)[19] has two main component scores - mental and physical. Results are further broken down into eight subscales (physical functioning, social functioning, vitality, role physical, role emotional, mental health, bodily pain, and general health). The SF-36 is a widely used measure of health-related quality of life and can be compared to standardized norms by generating t-scores after transforming raw scores into a 0-100 point scale. T-scores for the mental and physical components and all subscales are reported.

Demographic and treatment data. Descriptive characteristics were collected from the electronic medical record by the Survivorship RN and entered manually into SIMS. Data include standard demographics, such as age, sex and race, as well as diagnostic and treatment information. Diagnosis includes the type and location of cancer. Treatment information consists of whether the patient was treated with any of the following: surgery, systemic chemotherapy, radiation, and/or hematopoietic cell transplant.

Additional characteristics were obtained from the survey and included more detailed demographics such as household income, employment status, and insurance.

Analysis

This was an exploratory analysis with no pre-defined hypotheses. Sample size and power analyses were not performed. Characteristics are summarized as frequencies and percentages for categorical variables and mean and standard deviation or median and interquartile range for quantitative variables. For diagnosis, categories representing less than 3% of the sample were grouped in an 'other' category. The 'other' category includes cancers of the respiratory system, soft tissue and skin, bones and joints, and endocrine system. Treatment modalities were grouped in various combinations typically used in cancer treatment.

Analysis of patient reported outcomes included a comparison of responses on the three outcome measures pre- and post-clinic visit. Changes between pre-clinic and one year follow-up in knowledge of survivorship information, treatment-related distress, and quality of life were assessed using paired t-tests. Two-sample t- tests were used to compare changes between various subgroups based on patient characteristics. All data analysis was conducted with R statistical software version 3.6 (R Foundation for Statistical Computing, Vienna, Austria, 2019).

RESULTS

Patient characteristics are reported in Table 1. A total of 219 patients completed the baseline and one year follow-up survey. Mean patient age was 48 years (SD = 16, range = 18-79) and 73% were female. Median time since diagnosis was 3 years (IQR = 1-8). The majority of patients were white (90%), non-Hispanic (95%) and reported having health insurance (95%). About 16% of patients were survivors of childhood cancer (diagnosed under the age of 18).

Responders versus non-responders

Participants who completed both baseline and follow-up tended to be older at diagnosis (mean age = 42, SD = 19 vs mean = 34, SD = 21 for non-responders), older at their clinic visit (mean age = 48, SD = 16 vs mean = 44, SD = 16 for non-responders) and were also closer to the time of diagnosis (median years since diagnosis = 3, IQR = 1-8 vs median = 5, IQR = 2-16 for non-responders). There were no baseline differences between the two groups based on other demographic characteristics including race, ethnicity, sex, marital status, income, education, or insurance. There were no differences in baseline PRO scores between responders and non-responders. A small number of participants (N=12) did not have the opportunity to complete the follow-up survey because they did not have an email address on file to receive the survey link. Paper follow-up surveys were not distributed.

Confidence in Survivorship Information (CSI)

Of the 219 patients surveyed, 201 (92%) responded to every item on the CSI. Confidence in knowledge of survivorship information increased from prior to the clinic visit to one year after the clinic visit (Table 2). This increase was observed in the total score (mean change = 0.29; 95% CI, 0.23 to 0.34; $p < .001$) as well as in the two subscales. Mean change in confidence in knowledge of diagnosis and treatment was 0.12 (95% CI, 0.06 to 0.19; $p < .001$) and mean change in confidence in knowledge of long term effects was 0.34 (95% CI, 0.27 to 0.40; $p < .001$).

The change in CSI total score was compared for various patient characteristics. There was no difference based on sex, age at diagnosis, age at clinic visit, race or transplant vs. non-transplant recipients ($p > .05$; results not shown).

Cancer and Treatment Related Distress (CTXD)

A total of 208 (95%) patients responded to every item on the CTXD. Distress scores decreased for two subscales as well as the total score from pre-clinic to one year post-clinic (Table 2). The mean decrease in total score was 0.08 (95% CI, 0.013 to 013; p = .003). The Uncertainty Subscale asks about uncertainty related to medical problems, late and long term effects, as well as possibility of recurrence of cancer or dying. The mean decrease was 0.13 (95% CI, 0.05 to 0.21; p = .001). The Family Strain subscale includes questions about distress caused by the emotional toll placed on family members and being a burden to other people. It decreased on average by 0.16 (95% CI, 0.08 to 0.24; p < .001). The average decreases in the subscales assessing health burden, identity, finances, medical demands, and interference were smaller and not statistically significant (p > .05).

Subgroups of patients based on various characteristics were compared for the change in total CTXD score. There were no significant differences in the amount of change in distress from pre- to post-clinic based on sex, age at diagnosis, age at clinic visit, years since diagnosis, race, or transplant vs. non-transplant recipients (p > .05; results not shown).

Quality of Life (SF-36)

The average change in quality life (SF-36 t-scores) ranged from an increase of 0.13 to a decrease of 0.27. None of the scales showed significant change from pre-clinic to post-clinic (p > .05; Table 2).

Clinic visit and Treatment Summary and Survivorship Care Plan (SCP)

To assess patients' perceptions of the clinic visit and SCP, the one year follow-up survey included questions about how well the visit met their needs and the usefulness of the SCP. Over 90% of patients reported the clinic visit met their needs to some extent with over half indicating their needs were met "quite a bit" or "very much" in all areas measured (Figures 1 and 2). The highest rating was for resources

and referrals (66% reported “quite a bit” or “very much”) followed by symptom needs (63%), emotional needs (61%) and practical needs (58%). Less than 10% of patients indicated the visit did not meet their needs at all.

Most patients found the SCP helpful in all areas queried. More than 90% indicated the SCP was at least somewhat helpful in making it easier to discuss survivorship issues with their healthcare team (very helpful = 52%, somewhat helpful = 40%) and knowing what recommended screening and tests they should receive (very helpful = 53%, somewhat helpful = 41%). The majority of patients indicated the SCP was somewhat helpful in assisting them with making healthy lifestyle choices (52%) while 42% found it very helpful in this area. Less than 10% found it not at all helpful. About 60% of patients reported having shared their SCP with another provider.

DISCUSSION

Findings from this study generally support the use of a dedicated general survivorship clinic model to serve the needs of cancer survivors. This is evidenced by the post-clinic survey where most patients reported their needs were met by the survivorship clinic visit. The decrease in treatment related distress and increase in the patient’s own knowledge of their treatment history and long term risks also supports the positive impact of this patient care model. Furthermore, we have demonstrated not only the feasibility of collecting patient reported outcome data on a clinic-wide scale, but also the ability to apply that information to the immediate care of the patient. The study also demonstrates the usefulness of the SCP to cancer survivors, validating the time, effort and dedication of nurses and other providers in creating this tool.

We compared our findings to prior work including a recent randomized controlled trial carried out by many of the same researchers involved in this project. That study, completed in 2017, enrolled survivors of hematopoietic cell transplantation and did not involve a survivorship clinic visit[7]. Participants were

randomly assigned to receive or not receive a mailed SCP. The study measured cancer and treatment related distress (CTXD[18]) as well as confidence in knowledge of survivorship information (CSI[16]) at study entry and 6 months later. The study revealed no difference at 6 months between the SCP and non-SCP group in respondents' knowledge of survivorship information but did demonstrate improvement in cancer and treatment related distress. Although the patient population did differ from this investigation, the contrast in the results on these measures may point to the clinic visit component serving as a facilitating factor in improving patient knowledge of their own treatment, late effects and long term risks.

There were several limitations to this study. Not all patients who came to clinic and completed a pre-clinic survey also completed the one year follow-up survey. Since patients who completed the follow-up survey tended to be older and also diagnosed more recently, a different approach may be needed to better engage with younger survivors and those further out from diagnosis. In addition, participants in the study represent a very homogenous group: most were white, insured, highly educated, and reported relatively high income. This could make it difficult to generalize the results to a more diverse population including members of demographic groups known to be at higher risk of not receiving adequate healthcare due to socio-economic factors. We do not have access to similar self-report demographic data for patients who visited the Survivorship Clinic but did not complete the survey. Therefore, we are unable to determine if the sample included in the study is similar to the overall population of patients served by the clinic. It may be useful for future investigations to include an analysis of the demographic make-up of the population served by the clinic in order to inform efforts to ensure inclusivity in access to this phase of cancer care.

The improvements seen in patient outcomes for the clinic studied are encouraging, although the changes seen were small. Additional studies across multiple general survivorship clinics are needed in

order to assess the true impact of this model. The availability of survivorship services and the use of SCPs is largely driven by national accreditation requirements that are limited to treatment centers accredited by the Commission on Cancer. The list of accredited cancer centers comprises only a fraction of the institutions serving cancer patients nationwide and those centers are typically situated within large metropolitan areas[20]. This investigation may serve as a catalyst for other institutions to implement survivorship programs and the use of SCPs in the care of cancer survivors, thereby making comprehensive cancer treatment more equitably available to all who need it.

As our public and private health systems continue to be limited by capacity and administrative barriers, the dynamic and specialized care offered by survivorship clinics serves as a beacon in the overwhelming experience of living through cancer. The availability and continued improvement of the delivery of survivorship services will be a vital component of our health system's ability to adequately and efficiently serve the growing number of people who will survive their cancer thanks to current and future advances in early detection and treatment.

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Table 1. Patient characteristics, N=219

Characteristic	N (%)
Age at clinic visit, years	
Mean = 48, SD = 16	
18-29	37 (17)
30-39	32 (15)
40-49	39 (18)
50-59	43 (19)
60-69	55 (25)
70+	13 (6)
Years since diagnosis	
Median = 3, IQR = 1-8	
0-5	133 (61)
>5-10	44 (20)
>10	42 (19)
Age at Diagnosis, years	
Mean = 42, SD = 19	
0-17	35 (16)
18-39	50 (23)
40+	134 (61)
Gender	
Female	159 (73)
Race	
American Indian or Alaska Native	3 (1)
Asian	9 (4)
Multiple or other	10 (5)
White	196 (90)
Ethnicity	
Hispanic/Latino	10 (5)
Not Hispanic/Latino	208 (95)
Unknown	1
Diagnosis*	
Breast	54 (25)
Lymphoma	51 (23)
Leukemia & Bone Marrow Diseases	32 (15)
Digestive system	30 (14)
Genitourinary	18 (8)
Myeloma	8 (4)
Brain & nervous system	6 (3)
Oral cavity & pharynx	6 (3)
Other	14 (6)
Treatment history	
Surgery only	9 (4)
Chemotherapy +/- radiation	58 (26)
Chemotherapy + surgery	41 (19)
Chemotherapy + surgery + radiation	69 (32)
Radiation +/- surgery	10 (5)
Transplant**	32 (15)

Table 1 (continued)

	N	%
Highest level of school completed		
High school or GED	16	7
Some vocational or college	23	11
2-year college or trade degree	22	10
4-year degree	72	33
Post-graduate degree	76	35
Unknown	10	5
Marital status		
Single	55	25
Married	111	51
Living with partner	15	7
Separated	2	1
Widowed	5	2
Divorced	21	10
Unknown	10	5
Household income		
≤$20,000	25	11
$21,000-$40,000	22	10
$41,000-$60,000	19	9
$61,000-$80,000	26	12
$81,000-$100,000	20	9
$101,000-$120,000	21	10
≥$121,000	65	30
Unknown	21	10
Employment status		
Working full or part time	115	53
In school	15	7
Not employed	21	10
Retired	34	16
On disability	13	6
Other	11	5
Unknown	10	5
Has health insurance		
Yes	207	95
No	2	1
Unknown	10	5

*16 participants had two or more cancer diagnoses, only the first diagnosis is included here

**All participants who had a transplant received chemotherapy, some also received radiation

Table 2. Patient reported outcomes pre- and post-clinic visit

		Baseline	1-year follow-up	Change		
	N	Mean (SD, range)	Mean (SD, range)	Mean (SD, range)	95% CI	P-value*
Knowledge of survivorship information, CSI[†]						
Total	201	0.97 (0.44, 0-2)	1.26 (0.46, 0-2)	0.29 (0.40, -1.08-1.54)	0.23 to 0.34	**<.001**
Confidence in knowledge of diagnosis and treatment	204	1.62 (0.49, 0-2)	1.74 (0.39, 0-2)	0.12 (0.46, -1.33-0.33)	0.06 to 0.19	**<.001**
Confidence in knowledge of long term effects	201	0.78 (0.51, 0-2)	1.11 (0.54, 0-2)	0.34 (0.47, -1.1-1.8)	0.27 to 0.40	**<.001**
Treatment-related distress, CTXD[‡]						
Total	209	0.81 (0.65, 0-2.62)	0.73 (0.58, 0-2.57)	-0.08 (0.39, -1.24-1.06)	-0.13 to -0.03	**.003**
Uncertainty	209	1.11 (0.82, 0-3)	0.99 (0.79, 0-3)	-0.13 (0.57, -1.75-1.8)	-0.21 to -0.05	**.001**
Family strain	208	0.74 (0.81, 0-3)	0.58 (0.74, 0-3)	-0.16 (0.60, -2-1.67)	-0.24 to -0.08	**<.001**
Health burden	208	0.98 (0.90, 0-3)	0.94 (0.80, 0-3)	-0.04 (0.66, -2.17-2)	-0.13 to 0.05	.335
Identity	208	0.66 (0.73, 0-3)	0.61 (0.63, 0-2.75)	-0.04 (0.54, -2-1.5)	-0.12 to 0.03	.233
Finances	209	0.63 (0.74, 0-3)	0.61 (0.75, 0-3)	-0.02 (0.60, -2-2)	-0.10 to 0.07	.714
Medical demands	209	0.63 (0.74, 0-3)	0.57 (0.72, 0-3)	-0.06 (0.59, -2-2)	-0.14 to 0.02	.168
Interference	208	0.79 (0.74, 0-3)	0.73 (0.69, 0-3)	-0.06 (.59, -2-1.6)	-0.14 to 0.02	.328
Quality of life, SF-36[β]						
Physical component	204	18.79 (1.39, 13.95-21.91)	18.88 (1.40, 15.31-22.09)	0.08 (1.17, -3.33-4.88)	-0.08 to 0.24	.323
Mental component	204	11.39 (1.48, 5.95-15.32)	11.24 (1.50, 6.44-14.31)	-0.14 (1.41, -4.37-3.67)	-0.34 to 0.05	.147
Physical Functioning	206	-0.61 (0.86, -4-0.21)	-0.58 (0.87, -4-0.21)	0.03 (0.63, -3.16-2.53)	-0.06 to 0.12	.563
Vitality	205	18.54 (1.07, 15.41-21.65)	18.45 (1.12, 14.63-22.43)	-0.09 (1.18, -4.68-2.34)	-0.25 to 0.07	.287
Social functioning	204	20.89 (2.69, 10.49-26.85)	20.62 (2.69, 10.49-26.85)	-0.27 (2.99, -8.18-5.45)	-0.68 to 0.15	.203
Role physical	205	17.20 (2.75, 10.32-20.12)	17.30 (2.78, 10.32-20.12)	0.11 (2.18, -7.96-8.57)	-0.19 to 0.41	.481
Mental health	205	2.23 (1.40, -2.93-5.52)	2.19 (1.41, -1.24-5.52)	-0.04 (1.25, -3.94-3.38)	-0.21 to 0.13	.638
Bodily pain	204	27.78 (2.32, 20.28-33.38)	27.91 (2.56, 20.07-36.76)	0.13 (2.50, -5.49-12.47)	-0.21 to 0.48	.449
General health	204	12.19 (2.11, 6.70-16.23)	12.10 (2.06, 6.70-16.23)	-0.09 (1.54, -4.29-3.81)	-0.31 to 0.12	.381
Role emotional	206	7.10 (2.21, -0.10-9.23)	7.12 (2.08, -0.10-9.23)	0.02 (2.07, -6.22-7)	0.27 to 0.30	.917

N: number who completed both baseline and 1-year assessments; *paired t-test; †higher score better, ‡lower score better; [β]t-scores

Figure 1a. Treatment summary and survivorship care plan

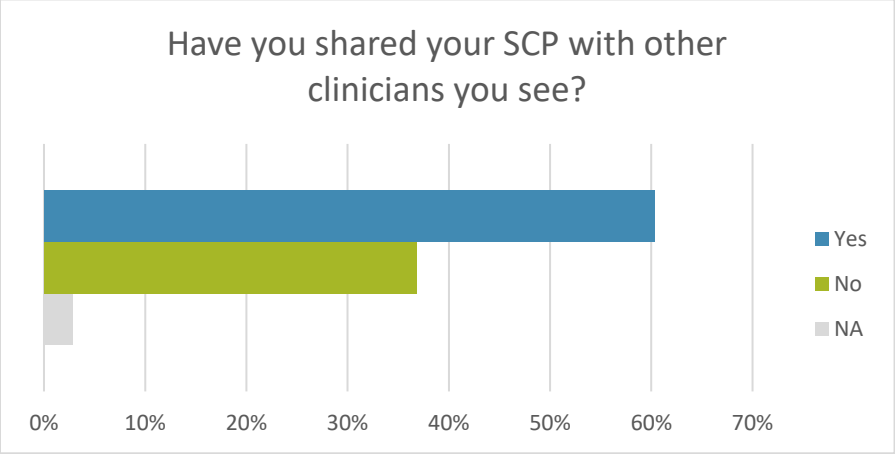

Figure 1b. Treatment summary and survivorship care plan, continued

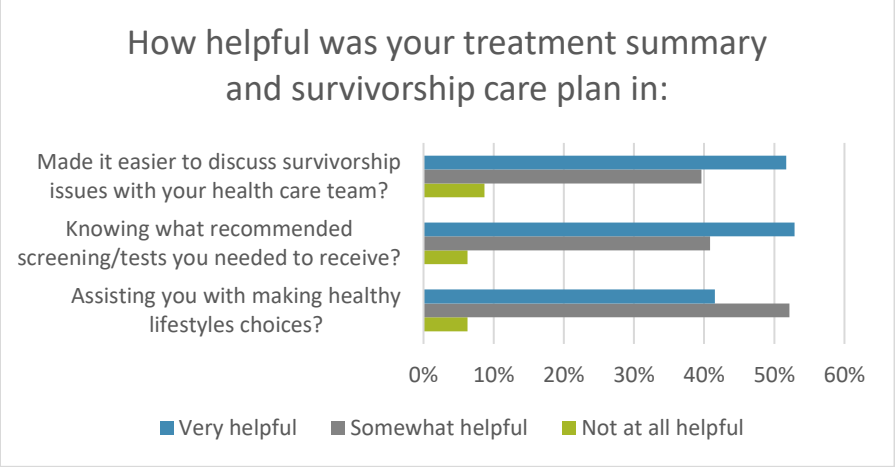

Figure 2. Survivorship clinic visit