

Unmet Needs of Oregon Cancer Survivors:  
Are Survivorship Care Plans Addressing Survivor Needs?

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### **Abstract**

**Background:** Despite clinical guidelines supporting the use of survivorship care plans in survivorship visits, multiple meta-analyses have shown survivorship care plans do not have a statistically significant effect on crucial patient outcomes, including satisfaction with information and follow-up care, cancer-related distress, and quality of life measures. Cancer survivors may also have unmet needs not previously known or addressed in their survivorship care. The goals of this program evaluation include: (1) identify unmet needs of Oregon cancer survivors, (2) explore patient-reported use of survivorship care plans in Oregon, and (3) assess patient-perceived survivorship care plan efficacy in addressing unmet needs.

**Intervention:** A 4-part online survey was developed to include a cancer history form, demographics, and the Cancer Survivor Unmet Needs questionnaire (CaSun). A novel, additional section of this survey was developed by the researcher with input from an oncology expert to investigate patient-perceived survivorship care plan use and strength in satisfying unmet needs. No personal health information was collected. The online survey link was included in a letter sent to eligible participants via MyChart. To preserve patient confidentiality, messages were sent by medical assistants during chart scrubs for upcoming telehealth visits.

**Results:** 14 participants were contacted (8 from Gresham and an estimated 6 from East Portland clinics) during a 3-week period. No surveys were returned during this timeframe. Impacts from the COVID-19 pandemic contributed significantly to the limited reach of this project.

**Conclusions:** Replication, expansion, and/or modification of this intervention is needed to achieve the goals of this project. Modifications may include reminder messages and/or use of paper surveys.

*Keywords:* cancer survivorship, survivorship care plans, cancer survivor unmet needs

## Introduction

Cancer afflicts millions of Americans regardless of age, race, ethnicity, gender, socioeconomic status, geographic location, or comorbidities. According to the National Cancer Institute (NCI), 38.4% of Americans will be diagnosed with cancer at some point during their lifetime and a projected 1,735,350 new cancers are expected to be diagnosed in 2018 alone (2018). Though new cancers continue to be found every day, overall death rates from cancer have dropped an average of 1.5% each year from 2007-2016 in the USA (NCI, 2018). The Centers for Disease Control and Prevention (CDC) attributes this drop in cancer deaths to advances in early detection and treatment of cancer (2018). With this decline, the overall number of cancer survivors in America is growing, resulting in an expected 20.3 million survivors by 2026 (NCI, 2018). Cancer survivors have unique health needs and challenges compared to the general population and are, unfortunately, underrepresented in research.

Cancer survivors often face risk of second cancers, prolonged side effects from treatment, poor health status, psychosocial challenges, and financial burdens (CDC, 2018). Nurse practitioners may play a unique role in addressing cancer survivor needs by working with the oncology team to incorporate survivorship care plans into both specialist and primary care visits. Survivorship care plans, in electronic or written format, provide cancer treatment summaries, surveillance and screening recommendations, follow-up timelines, information on treatment-related side effects, psychosocial assessment and interventions, guidelines for primary-care providers, and individually-tailored health promotion strategies (i.e. healthy weight goals, exercise, diet, alcohol and smoking cessation, immunizations, sunscreen use, and sleep hygiene) (National Comprehensive Cancer Network [NCCN], 2019). As such, survivorship care plans

have been routinely recommended by the Institute of Medicine (IOM) since 2006 (Hewitt, Greenfield & Stovall, 2006).

## **Literature Review**

### **Search Strategy**

A literature review was conducted during the months of June 2019-November 2019 with the aim of (1) exploring survivorship care plan use and (2) assessing effectiveness of survivorship care plans in meeting the needs of cancer survivors. The databases PubMed, CINAHL, Cochrane Library, and Ovid in addition to the Oncology Nursing Society and National Comprehensive Cancer Network websites were reviewed for relevant publications. Search terms included “cancer survivors,” “cancer survivorship,” “cancer survivor unmet needs,” “survivor unmet needs,” “survivorship care plan,” and “survivorship care plan and unmet needs.” Results were refined using publications within the last 5 years, with inclusion of older landmark studies identified from bibliographies. 9 high-quality articles were selected for analysis.

### **Survivorship Care Plan Use**

As previously mentioned, survivorship care plans are recommended by the IOM as a cornerstone for survivorship care (Hewitt, Greenfield & Stovall, 2006). Per guidelines, survivorship care plans should contain the following elements: cancer type and treatments received, potential for side effects, information regarding timing of follow-up, recommendations for health promotion, information on legal protections with regard to employment and access to health insurance, and availability of psychosocial services in the community (Hewitt, Greenfield & Stovall, 2006). Additionally, the IOM recommends survivorship care plans be written by the principal provider(s) of oncology treatment and shared with cancer survivors, perhaps at a discharge consultation visit after completion of treatment. Survivorship care

should be shared between oncology teams and primary care providers to address all aspects of patient needs (Hewitt, Greenfield & Stovall, 2006). Despite the lack of evidence to support the routine use of survivorship care plans, the IOM feels survivorship care plans are a “common sense” approach to improving the care of cancer survivors, however, they do recommend additional research in this area (Hewitt, Greenfield & Stovall, 2006).

Since implementation of the IOM’s survivorship care guidelines, limited high-quality research has been performed on survivorship care plan construction, use, and delivery. In a recent study conducted by Birkin, Deal, Mayer, and Weiner (2014), inconsistent use of survivorship care plans across US cancer centers was demonstrated. The authors included 1,850 cancer centers with membership in a cancer care quality improvement organization in their study (2014). A survey inquiring about both survivorship care plan development and delivery to patients and primary care providers was emailed to employees at these cancer centers. Findings from these surveys indicate that most cancer centers are developing and delivering survivorship care plans to less than half of their patients (Birkin et al., 2014). The authors did note regional discrepancies in survivorship care plan use; cancer centers in the Northeast region of the US used survivorship care plans more consistently compared to other regions (Birkin et al., 2014). This variation may be related to socio-demographics and/or payment structures (Birkin et al., 2014).

### **Survivorship Care Plan Efficacy and Feasibility**

Multiple studies on survivorship care plan efficacy have been conducted with mixed results. One systematic review found no significant effect of survivorship care plans on survivor distress, satisfaction with care, cancer-care coordination, or oncological outcomes in randomized controlled trials (Brennan, Gormally, Butow, Boyle & Spillane, 2014). Furthermore, a meta-

analysis conducted by Hill et al. (2019) found no difference between survivorship care plan recipients and controls on patient-reported anxiety, cancer-related distress, depression, perceived cancer and survivorship knowledge, physical functioning, satisfaction with follow-up care, information provision, and self-efficacy. However, the authors reported survivorship care plan use may improve both survivors' self-reported adherence to medical recommendations and healthcare professionals' knowledge of survivorship care and late effects of treatment (Hill et al., 2019). Jacobsen et al. (2018) drew similar conclusions in their systematic review: current research does not provide adequate evidence that survivorship care plans improve health outcomes and health delivery. In the articles reviewed by Jacobsen et al. (2018), single studies found statistically significant improvement in depressive symptoms, health worry, outlook on life, amount of information received, and satisfaction with care when survivorship care plans were used. However, this effect was not seen in other survivorship care plan studies, moreover, suggesting inconclusive findings at best. Similarly, in a review of current literature, Van de Polle-Franse, Nicolaije and Ezendam could not find enough evidence to support or reject large-scale implementation of survivorship care plans (2017).

Despite mixed findings in efficacy, multiple systematic reviews did determine survivorship care plans are feasible, and reported positive provider responses regarding construction and delivery of survivorship care plans (Hill et al., 2019; Jacobsen et al., 2018). Cancer survivors have also demonstrated high levels of acceptability and satisfaction with receiving survivorship care plans (Brennan et al., 2014; Hill et al., 2019; Jacobsen et al., 2018). Barriers to survivorship care plan implementation, despite good feasibility and overall acceptance rates, include: reimbursement issues, provider time, time to develop survivorship care plans (estimated to be at least 1 hour), personnel available to assist with survivorship

care plan production, and communication systems (Brennan et al., 2014).

### **Survivorship Care Plan Use and Unmet Patient Needs**

In a small study of lung and colorectal cancer survivors, researchers implemented a Self-Management Survivorship Care Planning intervention (Reb et al., 2017). This intervention allows for patients to participate in the development of their survivorship care plans and encourages self-management techniques with treatment side effects, lifestyle changes, and seeking out support (Reb et al., 2017). Surveys were conducted pre- and post-intervention. From this data, the authors found the intervention scored high in content, usefulness, and timing of delivery (Reb et al., 2017). Furthermore, qualitative findings of this study indicate patients would like more content to address grief, physical symptoms, nutrition, family issues, and spiritual concerns (Reb et al., 2017). To a certain extent, incorporating self-management techniques in survivorship care planning may improve unmet needs in cancer survivors.

Another small qualitative study conducted by de Rooij et al. (2018) focused on gynecologic cancer survivors' and their oncology providers' perspectives of survivorship care planning. Several themes emerged from these interviews, including concerns for unmet needs and survivorship care plan preferences. In general, survivor unmet needs included pain, neuropathy, fatigue, mood problems (i.e. anxiety, depression), and fear of recurrence in addition to need for contact information and referral for care (de Rooij et al., 2018). Provider unmet needs centered on fear of cancer recurrence or disease progression and wanting to learn more health promotion strategies (de Rooij et al., 2018). Both patients and providers mostly favored written survivorship care plans, however, both groups were amenable to an online care plan (de Rooij et al., 2018). Additionally, survivors preferred ongoing use and update of the survivorship care plan by the oncology team, as opposed to a one-time consultation at the end of treatment (currently suggested by the IOM) (de Rooij et al., 2018).

A large study on adolescent and young adult cancer survivors (those between the ages of 15 and 39-years-old) assessed for a relationship between the use of survivorship care plans and unmet patient needs (Shay, Parsons, & Vernon, 2017). Of the 1,395 participants, 30% reported receiving a survivorship care plan and 86% reported receiving instructions for follow-up care (Shay, Parsons, & Vernon, 2017). Unmet needs in this study were categorized using the 2010 LIVESTRONG Survey for People Affected by Cancer. Needs identified by participants included addressing recurrence concerns, information on late side effects, family risk of cancer, and fertility information (Shay, Parsons, & Vernon, 2017). Further analysis demonstrated that survivors who received a written treatment summary or follow-up instruction had lower odds of recurrence concerns or need for information on fertility and late treatment side effects (Shay, Parsons, & Vernon, 2017). Although this study's population of interest was adolescent and young adult survivors, findings demonstrate the potential for written treatment summaries in meeting the needs of cancer survivors. Future research is needed.

### **Gaps in Knowledge**

Despite strong recommendations from multiple national organizations, limited research is available to support the routine use of survivorship care plans. Given the mixed findings of prior studies, it is unclear if survivorship care plans are effective in meeting cancer survivor needs. Furthermore, little is known regarding survivorship care plan content and delivery in everyday use. Although NCCN and IOM publish guidelines for survivorship care plan composition, it is unclear if all clinicians are including all recommended aspects in survivorship care plans. Variability may exist between oncology providers given the lack of a universal template. Additional research is needed to further delineate the role of primary-care providers in survivorship care plan utilization.



### **Theoretical Framework**

The role of survivorship care plans in addressing patient needs is reflective of Roy's Adaptation Model. A cancer diagnosis and the subsequent changes it brings can affect multiple aspects of life. Roy's Adaptation Model focuses on four biopsychosocial adaptive systems to cope with change: physiologic/physical, self-concept/group identity, role function, and interdependence (Polit & Beck, 2017). The goal of nursing care in this model is to promote adaptation and regulate stimuli affecting adaptation (Polit & Beck, 2017). As such, survivorship care plans may be a useful intervention for meeting the needs of cancer survivors and promoting biopsychosocial adaptation during this transitional period.

### **Purpose of Project**

The purpose of this project is to (1) identify unmet needs of cancer survivors living in Oregon, (2) explore survivorship care plan use in Oregon clinics, and (3) assess the effectiveness of current survivorship care plans in meeting the needs of cancer survivors.

### **Methods**

#### **Setting**

The project will enroll multiple Oregon Health & Science University (OHSU) Community Hematology Oncology clinics, with the pilot clinic being the Gresham location. This clinic in particular has expressed a desire for more research in survivorship care and is actively recruiting for survivorship studies. The Gresham clinic is made up of teams of oncologists, nurse practitioners, registered nurses, medical assistants, and ancillary staff (including front office, schedulers, billing/coding, financial coordinators, and administrative assistants). Social workers and a palliative care nurse practitioner are also available to support patients through their cancer

journeys. A practice manager leads the team in provision of care and hosts morning meetings with staff prior to patient arrival. The Community Hematology Oncology clinics care for patients with both hematologic and solid tumor malignancies, moreover, allowing for broad representation of various cancers in this project. Providers describe the majority of their patients as active and engaged with care. Additionally, many patients are familiar with principles of research and may have experience with clinical trials.

The greatest facilitators for this project are the key stakeholders: clinic staff and the patients. As previously mentioned, oncologists at the Gresham clinic are motivated to engage in survivorship care research. Barriers to this project include the need to recruit and train multiple staff on project details and participant criteria. Working with multiple clinics is inherently challenging, given the range of employees involved, distance between clinics, and need for ongoing feedback and communication throughout the project. To address this obstacle, the researcher will round at clinic staff meetings regularly and assess for challenges to project implementation. A final potential barrier for participants is the need for access to the internet and/or a mobile device capable of utilizing the internet.

### **Population of Interest**

The population of interest for this project is cancer survivors. According to the definition put forth by the NCI and adapted by the NCCN, “an individual is considered a cancer survivor from the time of diagnosis, during and immediately after treatment, and through the balance of his or her life” (2019). Based on this definition, the project will include all patients with a history of cancer diagnosis that have completed treatment for cancer, and are between the ages of 40- and 75-years-old. Furthermore, all patients must be proficient in English, as alternate language materials are not available. The age parameter has been set to focus on adult cancer

survivors (as opposed to pediatric or young adult cancer survivors) and to protect the privacy of patients over the age of 75-years-old. It is difficult to assess a proper sample size for this project, given the nature of cancer care and broad definition of cancer survivor. Therefore, this project will hope to recruit as many eligible participants as possible. To protect the identity of patients from the researcher, clinic staff will distribute flyers to cancer survivors meeting eligibility criteria. Furthermore, recruitment flyers will be placed in areas of high visibility throughout the Community Hematology Oncology clinics. All data collected will not contain personal health information or contact information, so as to maintain patient confidentiality. To ensure ethical treatment of participants, a request for determination was filed with the OHSU Institutional Review Board (IRB). In late February 2020, the IRB deemed this project non-human research.

### **Proposed Implementation**

#### **Intervention**

To address the goals of this project, a survey will be developed to assess for patient-perceived unmet needs in survivorship care and how well oncology teams, with the utilization of a survivorship care plan, are meeting those needs. The survey will be constructed with input from OHSU statisticians and the OHSU REDCap team. Utilizing the online survey platform REDCap, all data collected from the survey will be secure and readily exportable for statistical analysis. A link to the online survey will be printed on recruitment flyers. Flyers will also include information about the project, eligibility criteria, time to complete surveys, and researcher contact information (OHSU email address). Participants will be instructed to complete the survey one time; however, this may be difficult to regulate since the survey will be available via a public link. No incentive or compensation will be offered for completing the survey. As presented earlier, staff (i.e. front office schedulers, medical assistants, registered

nurses, and oncologists) will distribute flyers to eligible participants. Flyers will also be displayed in patient waiting rooms and infusion rooms. Teamwork will be essential in accurately capturing the patient population of interest. To ensure all staff questions and concerns are addressed, the researcher will attempt to attend staff meetings at least once per week to assess for feedback. At the completion of this study, data from the survey will be analyzed by the researcher. Analysis will include descriptive statistics utilizing survey scores, demographics, and cancer history. Furthermore, a two-sample t-test will be performed using SPSS software to compare the means of patient need scores with and without the presence of a survivorship care plan. The null hypothesis is patients with a survivorship care plan and patients without a survivorship care plan will have equal unmet needs scores. Statistical significance will be calculated and based on a p-value of  $<0.05$ . All findings will be presented to participating clinics. With this data, oncology clinics may or may not find areas of improvement in their survivorship care and may or may not choose to use survivorship care plans.

### **Measures**

The electronic survey will consist of four sections: cancer history, demographics, the Cancer Survivors' Unmet Needs questionnaire, and an additional short form inquiring about survivorship care plan use. The cancer history section will double as a screening tool by asking about the presence of a cancer diagnosis, cancer type, age of treatment completion, and current age. Non-identifiable demographics collected will include: gender, race, ethnicity, state of residence, and rurality of residence (i.e. participants will identify if they live in an urban/metro, suburban, or rural region). The Cancer Survivors' Unmet Needs questionnaire (CaSun), developed by Dr. Katherine Hodgkinson and colleagues, was selected for its comprehensive

content, good patient acceptability, and high internal consistency and reliability (Hodgkinson et al., 2007). In this questionnaire, participants will be asked to identify current needs in domains of information and medical care, quality of life, and psychosocial concerns. If an unmet need is present, participants will rank how strong of a need this is for them (weak, moderate, or strong). Scores will be calculated based on domains using the questionnaire manual. This survey is used with permission from the authors. An additional evaluation tool, developed with input from an oncology expert, will ask about the presence of a survivorship care plan and if primary care providers have access to the survivorship care plan. Survey instructions will include the definition of survivorship care plan for universal understanding. If a participant indicates that they do have a survivorship care plan, they will be asked to rate how well their survivorship care plan addresses needs recognized in the CaSun questionnaire (with each question addressing a different domain of need). Finally, participants will be asked to rate how well their survivorship care addresses their needs overall on a scale of 0 to 10. Scores will be calculated using Likert scales combined with overall numerical rating of survivorship care. Surveys are included in the appendix section of this paper.

As previously discussed, the survey will be hosted on OHSU's REDCap website. A public link will be generated from this website and distributed on flyers. To ensure accuracy of data collected, this survey link will not be posted in any forum outside of the flyers distributed at the OHSU Community Hematology Oncology clinics. As with all surveys, the risk of self-report bias exists and will need to be taken into consideration when interpreting the data. Perhaps by ensuring anonymity, patients will answer without fear of repercussion or judgment, moreover, mitigating inherent self-report bias to a certain extent. To ensure the survey is capturing the right population, participants will be required to start with the cancer history screening tool and will not be allowed to proceed with the rest of the survey unless eligibility

criteria is met.

Ethical considerations, such as IRB oversight, are taken into account with this project. There is minimal risk of harm in this study; however, the CaSun questionnaire does contain questions participants may find personal or emotionally-triggering. CaSun survey instructions encourage participants to reach out to their oncology teams or local cancer support networks for guidance with meeting needs. Flyers and survey instructions will reiterate that participants may quit the survey at any time and are under no obligation to partake. Since this project is deemed non-human research, informed consent is not required to complete the survey. Researcher email address will be provided for questions or concerns related to the project.

Projected costs of this study are minimal and related to flyer printing and distribution. Printing will be done through OHSU's Brand Portal. Rates are currently 18 cents per flyer. With an estimated need of approximately 200 flyers, total costs for this project are expected to be \$36.00.

### **Implementation of Project**

#### **Project Modifications Related to COVID-19 Pandemic**

Due to unforeseen circumstances related to the COVID-19 pandemic, modifications were made to this project that ultimately affected survey distribution and timing of project delivery. Originally, the project launch was estimated to be early March 2020 with data collection continuing until May 2020. Unfortunately, due to campus shutdown and cancellation of required in-person REDCap classes, the online survey was not approved for use by REDCap until late April. This ultimately led to a shorter data collection period (over 3 weeks instead of 2-3 months).

Changes to survey recruitment and distribution were also necessary to capture this project's population of interest. With the advent of COVID-19, in-person survivorship visits (with clinicians at recruitment sites) were replaced with telehealth visits. Therefore, flyers posted in highly visible areas and circulated to potential participants were no longer a viable option. In discussion with participating oncology teams and REDCap experts, it was decided to send MyChart messages through Epic's messaging platform to reach eligible participants in lieu of flyers. A letter containing information about the survey and survey link was constructed by the researcher and reproduced as an Epic SmartPhrase. The SmartPhrase was shared with Medical Assistant Leads along with instructions for using the SmartPhrase and sending MyChart messages. Medical assistants at OHSU Community Hematology Clinics in Gresham and East Portland identified potential participants using eligibility criteria while scrubbing charts for upcoming telehealth visits with clinicians. One message was sent per participant during the 3 week data collection period. Overall, the medical assistants identified 14 eligible participants during this timeframe (8 from the Gresham clinic and an estimated 6 from the East Portland clinic). Unfortunately, no completed surveys were returned over the span of 3 weeks.

### **Successes and Challenges**

Successes of this project included effective planning and construction of an online survey. Furthermore, consultation with OHSU's statisticians, research designers, and REDCap specialists contributed to this project's thorough foundation. Clinician buy-in and rapport with oncology team members facilitated project initiation as well as openness to project modifications. Feedback was regularly obtained from medical assistants on a weekly basis. In general, medical assistants found project eligibility criteria simple, the SmartPhrase easy to use, and sending MyChart messages during chart scrubs to be practical. Using this modified study

design, participant confidentiality was preserved throughout the entirety of this project in alignment with IRB protocol for non-human research. Additionally, the changes made to this project resulted in zero cost, moreover, contributing to project feasibility.

Challenges associated with this study included duration of data collection, minimal number of patients using MyChart, and lack of follow-up with eligible participants. Furthermore, it is not known if clinicians or oncology teams discussed the project with participants outside of the single MyChart message. All of these factors contributed significantly to the project's limited recruitment of cancer survivors and absence of findings.

### **Outcomes**

Poor findings in research utilizing online surveys is prevalent. In one large study assessing online survey response rates in primary care, it was discovered online surveys are returned on average 22.6% of the time (Aerny-Perreten, Domínguez-Berjón, Esteban-Vasallo, & García-Riolobos, 2015). This number increased through emailed survey reminders, with survey returns equating to 32.9% after a second reminder and 39.4% with a third reminder (Aerny-Perreten et al., 2015). Factors that decreased likelihood of online survey completion included male gender and those over the age of 60-years-old (Aerny-Perreten et al., 2015). Since this project did not utilize emailed survey reminders, an expected return rate would be around 22.6%. Applying this percentage to contacted participants (14), we would expect 3 completed surveys. Given the target population for this project was cancer survivors between the ages of 40-75-years-old, age may be a contributing factor to unanswered surveys. This is further supported by median age of cancer diagnosis, which is currently 66-years-old in the USA (NCI, 2018). In addition to age, access to internet, internet usage, and familiarity with web platforms likely play a role in poor online survey response in this group.



Less likely factors contributing to low survey return include: time to complete survey and lack of incentive to complete the survey. Aerny-Perreten et al. found most online surveys are returned within 3 days of receiving the electronic questionnaire (2015). The last MyChart messages in this project were sent to participants about 1 week before survey closure, therefore, allowing sufficient time for those who were likely to respond. Increasing the timeframe of data collection may have allowed for more participant recruitment and perhaps more survey returns.

Monetary incentives to complete an online survey may be less effective in this population. Research on questionnaire use in prostate cancer survivors with a median age of 66.8-years-old demonstrated that a \$5.00 incentive did not significantly impact survey return rates (Bakan, Chen, Medeiros-Nancarrow, Hu, Kantoff, & Recklitis, 2014). What was successful in this study was use of Priority mailing and repeat survey mailing, which significantly increased participant response (Bakan et al., 2014). Using a mailed introductory letter followed by a mailed survey resulted in an overall survey completion rate of 71.4% (Bakan et al., 2014). Given this relatively high response rate, it may be fruitful to mail questionnaires to older cancer survivors in the future. However, this may have a significant impact on project costs and require additional funding.

### **Practice-Related Implications**

#### **Limitations**

Inherent to research in patient-perceived outcomes is the risk of self-report bias. This project aimed to mitigate self-report bias by ensuring participant confidentiality, however, self-report bias may persist despite anonymity and affect future findings. Furthermore, in working

with a small sample size at two Portland-area clinics, it may be difficult to apply these findings to a larger population. For these reasons, generalizability should be limited to participating clinics. All eligible cancer survivors at these clinics were contacted, therefore, randomization was not applied. Participants also essentially self-selected to complete the survey (or not). Non-randomization and self-selection of participants may affect both internal and external validity. Confounding variables, such as medical and psychosocial comorbidities, were not accounted for in this project and may threaten internal validity. Instrument selection, as well, may affect internal validity. Though the largest component of this survey included a well-studied questionnaire with high internal consistency and validity, a crucial part of the survey was created by the researcher with input from an experienced oncology clinician. The validity of crafted questionnaires is not known, therefore, it is difficult to assess if this created tool effectively captures survivorship care plan efficacy. At best, findings from this project could establish a correlation between survivorship care plan use and patient-reported unmet needs, as opposed to a cause-and-effect relationship.

### **Conclusions**

This project presents a novel intervention for assessing patient-reported unmet needs, survivorship care plan use, and survivorship care plan efficacy. A 4-part survey was developed to include cancer history, demographics, CaSun questionnaire, and additional survivorship care plan questions. Potential findings from this project could provide evidence for more comprehensive survivorship care and inclusion or rejection of survivorship care plans. Oncology teams may find the results useful for their own practice and incorporate various elements described in patient responses. Since the nature of this project is a program evaluation looking at existing structures and domains within cancer survivorship care, the sustainability of possible

care improvements is likely high and at relatively low cost. Additional clinician time may be needed to integrate broader principles of survivorship care, including but not limited to psychosocial needs, financial concerns, and need for additional information. Extra clinician time may also be required for development and review of survivorship care plans with patients. Allowing for appropriate reimbursement of these activities may increase clinician buy-in and overall sustainability of changes. Evaluation and application of pertinent study findings are likely to improve the care cancer survivors receive and ultimately contribute to higher patient satisfaction with survivorship visits.

### **Next Steps**

Future research is needed to accomplish the goals of this project. Reproduction of this project may yield valuable findings that are applicable to participating oncology clinics. Expansion of this intervention to include all OHSU Community Hematology Oncology clinics may produce larger, more diverse results. Possible modifications to this project to improve survey return rate could include reminder notifications and/or mailed surveys to eligible participants. Mailing surveys does incur higher project costs; but, as demonstrated by relevant literature, this may ultimately lead to significantly higher survey completions. Return to flyer distribution as a recruitment strategy may also improve overall reach of this project and survey response rates. However, a printed website hyperlink or barcode that can be scanned with a smartphone device may present challenges for digital immigrants. Familiarity with and access to internet likely pose a significant challenge for this population of interest. Barriers related to internet use could be mitigated with implementation of paper surveys in the future. Perhaps to maintain patient confidentiality, anonymous paper surveys could be distributed to eligible participants at oncology clinics by staff members. In this model, surveys would either be

collected at subsequent visits, or more realistically, mailed back to staff at oncology offices. The researcher could then collect the paper surveys from the clinics and create an electronic record for each returned survey in REDCap, moreover, allowing for secure data storage and analysis. Replication, expansion, and/or modification of this project may yield meaningful results that address gaps in knowledge and improve survivorship care.

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**Appendix**



# Cancer History

You have been invited to take part in this survey because you have completed treatment for cancer (chemotherapy, immunotherapy, surgery, and/or radiation) and, by definition, are a cancer survivor. Cancer survivors may be cured of their cancer or living with their cancer as a chronic disease. Participants taking hormonal therapies, such as tamoxifen, anastrozole (Arimidex), or letrozole (Femara) are eligible for this survey.

The purpose of this survey is to learn more about patient needs in cancer survivorship care and how our oncology teams are currently addressing your unique needs. Your responses will enable us to make recommendations about what sort of supports and services should be available to survivors of cancer and their families in the future.

Your answers are confidential and no personally identifiable information or contact information will be collected from you.

You will complete a cancer history form, brief demographics survey, the Cancer Survivors' Unmet Needs Survey (CaSUN), and a short additional questionnaire asking you to rate how well your current survivorship care meets your needs.

The estimated time to complete all surveys is about 45 minutes. You will be able to save your answers and return to the survey, if needed (please note: this option is not recommended for those on a shared computer or device). Please only take this survey once. The survey will close on May 29th, 2020 at midnight.

Participation in this survey is optional, and you may quit your survey at any time.

Please contact Alexis Czorny, OHSU study co-investigator, with questions or concerns regarding this survey: [czorny@ohsu.edu](mailto:czorny@ohsu.edu)

---

## Cancer History

Have you EVER been told by a doctor, nurse, or other health professional that you have cancer?

- Yes  
 No  
 Don't know / Not sure

---

At what age did you complete treatment for cancer?

\_\_\_\_\_

---

What age are you currently?

\_\_\_\_\_

---

How many different types of cancer have you had?

- One
- Two
- Three or more
- Don't know / Not sure

---

Please select your cancer type(s):

---

Breast

- Breast cancer

---

Female reproductive (Gynecologic)

- Cervical cancer (cancer of the cervix)
- Endometrial cancer (cancer of the uterus)
- Ovarian cancer (cancer of the ovary)

---

Head/Neck

- Head and neck cancer
- Oral cancer
- Pharyngeal (throat) cancer
- Thyroid

---

Gastrointestinal

- Colon (intestine) cancer
- Esophageal (esophagus)
- Liver cancer
- Pancreatic (pancreas) cancer
- Rectal (rectum) cancer
- Stomach

---

Leukemia/Lymphoma (lymph nodes and bone marrow)

- Hodgkin's Lymphoma (Hodgkin's disease)
- Leukemia (blood) cancer
- Non-Hodgkin's Lymphoma

---

Male reproductive

- Prostate cancer
- Testicular cancer

---

Skin

- Melanoma
- Other skin cancer

---

Thoracic

- Heart
- Lung

---

Urinary cancer

- Bladder cancer  
 Renal (kidney) cancer

---

Others

- Bone  
 Brain  
 Neuroblastoma  
 Other

---

If Other, please list:

---

---

For BRFSS Survey Questions

Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Questionnaire.

Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2009.

<http://www.cdc.gov/brfss/suggestedcitation.htm>

# Demographics

Please contact Alexis Czorny, OHSU study co-investigator, with questions or concerns regarding this survey:  
czorny@ohsu.edu

## Demographic Questionnaire

Gender

- Female
- Male
- Other
- Do not care to respond

If Other, please list:

---

What is your race?

- American Indian/Alaskan Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Black or African American
- White
- Other

If Other, please list:

---

Ethnicity

- Not Hispanic
- Hispanic

In what state do you reside?

- Oregon
- Washington
- Other

If Other, please list:

---

9. What best describes your area of residence?

- City/Urban
- Country/Rural/Small Town
- Suburb

# Cancer Survivors' Unmet Needs Survey

Survivors of cancer sometimes report ongoing issues and the need for various services many years after the completion of treatment. The following statements cover a range of different issues which survivors of cancer may face. The issues include:

information and medical care issues

quality of life

emotional and relationship issues

and the impact of cancer on your life perspective.

We want to learn about your need for services RIGHT NOW. While we recognize that people may have had many needs at diagnosis and during treatment, this study is focusing on your needs AFTER your primary treatment finished. Your responses will enable us to make recommendations about what sort of supports and services should be available to survivors of cancer and their families in the future. We also want to know about any positive changes to your life that you may have experienced as a result of your cancer. Please tick the answer that best describes your experience. There are no right or wrong answers.

Survey used with permission from authors: K. Hodgkinson, P. Butow, G.E. Hunt, S. Pendlebury, K.M. Hobbs, S.K. Lo, & G. Wain (2007)

Please contact Alexis Czorny, OHSU study co-investigator, with questions or concerns regarding this survey: [czorny@ohsu.edu](mailto:czorny@ohsu.edu)

EXAMPLE:

\* This person needs information following the completion of their cancer treatments and this need is moderately strong.

**(A) Information Needs & Medical Care Issues: The first few questions ask about your current need for information and your experience of medical care.**

**In the last month...**

**I need up to date information...**

No need or not applicable

Have need, but need is being met

Need is currently unmet

[reset](#)

**If need is currently unmet, how strong is your need?**

Weak

Moderate

Strong

[reset](#)

---

EXAMPLE:

\* This person's partner/family has a need for information but this need is currently being met.

**2. My family and/or partner needs information relevant to them...**

- No need or not applicable  
 Have need, but need is being met  
 Need is currently unmet

reset

---

**(A) Information Needs & Medical Care Issues: The first few questions ask about your current need for information and your experience of medical care.**

In the last month...

I need up to date information...

- No need or not applicable  
 Have need, but need is being met  
 Need is currently unmet

If need is currently unmet, how strong is your need?

- Weak  
 Moderate  
 Strong

2. My family and/or partner needs information relevant to them...

- No need or not applicable  
 Have need, but need is being met  
 Need is currently unmet

If need is currently unmet, how strong is your need?

- Weak  
 Moderate  
 Strong

3. I need information provided in a way that I can understand...

- No need or not applicable  
 Have need, but need is being met  
 Need is currently unmet

If need is currently unmet, how strong is your need?

- Weak  
 Moderate  
 Strong

---

4. I need the very best medical care...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

5. I need local health care services that are available when I require them...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

6. I need to feel like I am managing my health together with the medical team...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

7. I need to know that all my doctors talk to each other to coordinate my care...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

8. I need any complaints regarding my care to be properly addressed...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

9. I need access to complementary and/or alternative therapy services...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

**(B) Quality of Life: The next few questions ask about the impact that cancer has had on various areas of your life, including your health and daily activities.**

In the last month...

---

10. I need help to reduce stress in my life...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

11. I need help to manage ongoing side effects and/or complications of treatment...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

12. I need help to adjust to changes in my quality of life as a result of my cancer...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet



---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

13. I need help with having a family due to fertility problems...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

14. I need assistance with getting and/or maintaining employment...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

15. I need help to find out about financial support and/or government benefits to which I am entitled...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

16. Due to my cancer, I need help getting life and/or travel insurance...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

17. Due to my cancer, I need help accessing legal services...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

18. I need more accessible hospital parking...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

**(C) Emotional & Relationship Issues: These next few questions ask about your emotional responses to surviving cancer, and the impact that cancer has had on your personal relationships.**

In the last month...

---

19. I need help to manage my concerns about the cancer coming back...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

20. I need emotional support to be provided for me...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

21. I need help to know how to support my partner and/or family...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

22. I need help to deal with the impact that cancer has had on my relationship with my partner...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

23. I need help with developing new relationships after my cancer...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

24. I need to talk to others who have experienced cancer...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

25. I need help to handle the topic of cancer in social and/or work situations...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

26. I need help to adjust to changes to the way I feel about my body...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

27. I need help to address problems with my/our sex life...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

28. I need an ongoing case manager to whom I can go to find out about services whenever they are needed...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

**(D) Life Perspective: Sometimes survivors of cancer report that their cancer experience has changed the way they view their life, their future. These next few questions ask about these issues.**

---

In the last month...

---

29. I need help to move on with my life...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

30. I need help to cope with changes to my belief that nothing bad will ever happen in my life...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

31. I need help to cope with others not acknowledging the impact that cancer has had on my life...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

32. I need help to deal with my own and/or others expectations of me as a "cancer survivor"...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

33. I need help to try to make decisions about my life in the context of uncertainty...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

34. I need help to explore my spiritual beliefs...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

35. I need help to make my life count...

- No need or not applicable
- Have need, but need is being met
- Need is currently unmet

---

If need is currently unmet, how strong is your need?

- Weak
- Moderate
- Strong

---

36. Please list any other needs that you have experienced in the last month:

**(E) Positive Changes: The final few questions ask you about positive changes that you may have experienced as a result of your cancer. Please note that the response options are different to previous questions.**

In the last month...

---

37. I have benefited from contact with other cancer survivors and/or their families...

- Yes, but I have always been like this
- Yes, this has been a positive outcome
- No, and I would like help to achieve this
- No, and this is not important to me

---

38. I focus more on things that are important...

- Yes, but I have always been like this
- Yes, this has been a positive outcome
- No, and I would like help to achieve this
- No, and this is not important to me

---

39. I realize how precious life is...

- Yes, but I have always been like this
- Yes, this has been a positive outcome
- No, and I would like help to achieve this
- No, and this is not important to me

---

40. I have made lots of positive changes in my life...

- Yes, but I have always been like this
- Yes, this has been a positive outcome
- No, and I would like help to achieve this
- No, and this is not important to me

---

41. I have grown as a person...

- Yes, but I have always been like this
- Yes, this has been a positive outcome
- No, and I would like help to achieve this
- No, and this is not important to me

---

42. I appreciate my relationships with others more....

- Yes, but I have always been like this
- Yes, this has been a positive outcome
- No, and I would like help to achieve this
- No, and this is not important to me

---

Comments:

# Survivorship Care Questionnaire

Please contact Alexis Czorny, OHSU study co-investigator, with questions or concerns regarding this survey:  
czorny@ohsu.edu

**A survivorship care plan is a document, either electronic or printed, that provides information specific to your cancer staging, diagnosis, treatment, and scheduled follow-up. There may be additional information included in this document, such as post-treatment needs or side effects, and recommendations for overall health and wellbeing.**

Does your oncology team use a survivorship care plan?

- Yes
- No
- Unsure

Does your primary care provider have access to your survivorship care plan?

- Yes
- No
- Unsure

Please reflect upon your previous answers to the Cancer Survivors Unmet Needs survey and state your level of agreement with these statements.

My survivorship care plan satisfies my need for information regarding my cancer diagnosis, treatment, and follow-up.

- Completely disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Completely agree

My survivorship care plan addresses the impact cancer has had on my quality of life, including the needs I have because of treatment-related side effects.

- Completely disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Completely agree

My survivorship care plan addresses any emotional or relationship needs I have experienced since surviving cancer.

- Completely disagree
- Somewhat disagree
- Neutral
- Somewhat agree
- Completely agree



---

Reflecting upon your previous answers to the Cancer Survivors' Unmet Needs Survey...  
How well does the survivorship care provided by your oncology team meet your needs overall?

Please answer on a scale of 0-10 (0 = my survivorship care does not meet my needs at all, 10 = my survivorship care completely meets my needs).

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10