IMPROVING SURVIVORSHIP CARE AT A COMMUNITY CANCER CENTER: A PROGRAM EVALUATION

by

Melissa Raelene Bowen

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DEDICATION

Dedicated to my family, near and far. This would not have been possible without your daily sacrifices, encouragement, and support. It really does take a team. To my children, Leopold and Ophelia, may you one day realize the inspiration you have provided me on this journey. To my husband Bradley, this would not have been possible without you by my side. Your belief in me instilled confidence when it was lacking, your motivation kept me pushing when things were difficult, and your support was unwavering, which helped me continue this project to completion.

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ABSTRACT

Survivorship care is an opportunity to prepare cancer survivors for living a life impacted by cancer. The physical, psychological, and spiritual effects of cancer goes beyond the days or hours patients have spent receiving treatment. Over a decade ago, the Institute of Medicine created the survivorship care plan (SCP) as a solution for improving care for cancer survivors. The Commission on Cancer (CoC) since adopted the SCP as an accreditation standard which requires SCP delivery to at least 50% of eligible survivors. However, the implementation of SCPs has been challenging as the evidence supporting its use is mixed. There is minimal evidence to support SCPs positively impact patient outcomes, yet, patients report higher satisfaction with survivorship knowledge, find the SCP helpful, and recommend its use. As a result, organizations are confronted with meeting a CoC standard that is difficult to implement and has discordant evidence to support its use. The purpose of this project was to provide a program evaluation for a CoC accredited community cancer center that is committed to improving survivorship care for adult oncology patients. Three objectives were assessed; percentage of SCP delivery completions, evaluation of the SCP and visit with a pre and post survey, and assessment of survivors ongoing needs with a Cancer Impairment Screening Tool. A small case study was also conducted. Between February 1st and July 31st fifty-seven SCP visits were completed, however, only 36 survivorship visits met eligibility criteria making the completion rate 35.6%. The pre and post survey revealed patients had an increase in; knowledge of the SCP visit purpose, available resources, familiarity with treatment side effects, and importance of the visit. There were no reports of unmet needs on the post survey. Survivors most common treatment concerns were numbness in extremities, muscle weakness, fatigue, physical limitations, and sleep difficulties. In conclusion patients find value in the SCP and visit and its use should not be abandoned. It is well understood that survivorship care can be complex. Advancing survivorship care from the sole provision of the SCP to a more individualized process may better address the specific needs of individual cancer survivors.

CHAPTER ONE

INTRODUCTION

Background and Significance

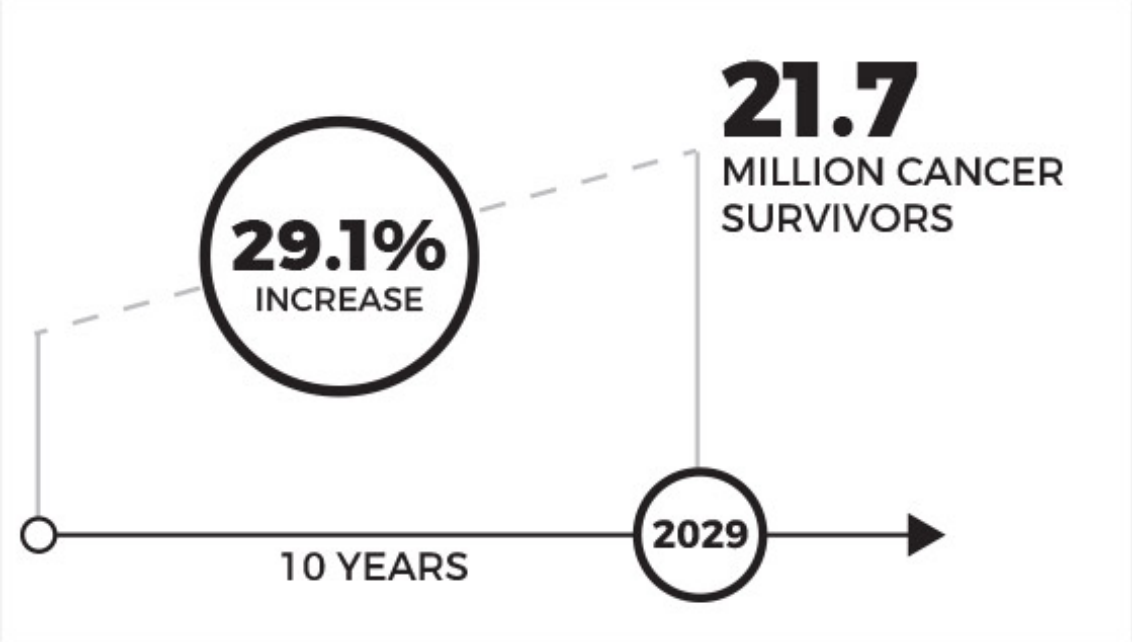
Many cancer survivors continue to experience the side effects of their cancer and treatment for years after treatment completion (Playdon et al., 2016). The physical, psychological, and spiritual impact of cancer go beyond the days or hours patients spend receiving treatment (Denlinger et al., 2014; Goetz & Klemp, 2018). Survivorship care is an opportunity to prepare cancer survivors for living a life impacted by cancer. Today, addressing the unique needs of cancer survivors is an expectation of survivorship care (Commission on Cancer [CoC], 2014). However, this has not always been the case. For many years, the challenges facing cancer survivors after treatment went unnoticed. An impetus for change came in 2005, when the Institute of Medicine (IOM) released "From Cancer Patient to Cancer Survivor: Lost in Transition". This report brought awareness to the inadequate care that cancer survivors were being provided and identified the unmet needs cancer survivors were facing as a result of their treatments (Hewitt, Greenfield, & Stovall, 2006). The IOM's recommendation for addressing the gap in care was a survivorship care plan (SCP) (Hewitt et al., 2006). Requirements of the care plan included guidance on prevention and detection for recurrence or new cancers, surveillance recommendations for recurrence or new primaries, interventions for long term effects from treatment, and care coordination (Hewitt et al., 2006).

In 2012, the Commission on Cancer (CoC) of the American College of Surgeons demonstrated their commitment to prioritizing the care of cancer survivors by advancing the IOM's report through their creation of accreditation Standard 3.3 (See Appendix A). This standard requires organizations seeking accreditation to incorporate the delivery of a SCP to every eligible cancer survivor (CoC, 2014). The SCP is to include: a personalized treatment summary, communication about the potential short- and long-term effects of treatment, possible signs of recurrence, recommendations for follow up and surveillance, identification of patient's care team, available supportive resources, and information on healthy living (CoC, 2014; Denlinger et al., 2014). The implementation of Standard 3.3 was phased into routine care in 2015. Originally, by 2019, organizations were expected to deliver survivorship care plans to 100% of eligible patients, but the requirement for SCP delivery currently is being maintained at only 50% for eligible patients. This discrepancy highlights the complexity and challenges surrounding SCP implementation (CoC, 2014; Deline, 2018; Denlinger et al., 2014).

With advancements in medicine and treatments, patients diagnosed with cancer are living longer, thereby making survivorship care essential to preparing survivors for life after treatment. According to the National Cancer Institute, as of January 2019, there were an estimated 16.9 million cancer survivors in the United States. By 2029, this number is expected to increase to 21.7 million (National Cancer Institute [NCI], 2019) (Figure 1). Among the current cancer survivors, 67% (10.3 million) are 5 or more years from diagnosis and 45% are 10 or more years from diagnosis. An estimated 18% of cancer survivors are 20 or more years from diagnosis (NCI, 2019). Encouragingly, the

estimated number of cancer survivors living 5 more years from their diagnosis is expected to increase by 33% over the next decade. This increase would result in approximately 15.1 million cancer survivors by 2029 (NCI, 2019). The most common cancer sites among cancer survivors include: female breast (23%), prostate (21%), colorectal (9%), gynecologic (8%), and melanoma (8%). The majority of cancer survivors are 65 years of age or older (64%) (NCI, 2019).

Figure 1: Projected increase in number of cancer survivors (NCI, Statistics, 2019).



The SCP has been put forth as the solution for addressing cancer survivors' needs. However, the delivery of the SCP has been a challenge logistically (Birken et al., 2015). Common reported barriers include reimbursement concerns, cost-effectiveness, time, lack of institutional resources, and complexity of Standard 3.3 (Stricker & O'Brien, 2014;

Brennan, Gormally, Butow, Boyle, & Spillane, 2014). Many institutions are uncertain how to resolve the barriers preventing the consistent delivery of SCPs (Deline, 2018).

The lack of clear guidelines also contribute to the inconsistency of SCP use (Birken et al., 2015). In 2014, the CoC issued a clarification to its survivorship standards, acknowledged that health care delivery models for survivorship care vary among organizations, and confirmed that there is no single evidence-based best practice for survivorship care (CoC, 2014). As a solution, in 2016 organizations were granted more flexibility in determining the healthcare member responsible for survivorship care delivery, which now includes nurses and credentialed clinical navigators in addition to physicians and advanced practitioners (CoC, 2016). While broadening the responsibility for survivorship care plan delivery was intended to assist organizations in meeting Standard 3.3, a "Trending Now in Cancer Survey" released in 2017 revealed that Standard 3.3 was still reported as the most difficult standard to achieve. Eighty percent of respondents reported that meeting this standard is "somewhat challenging" or "very challenging" (Deline, 2018). This survey shows that the challenges organizations face in the implementation of survivorship care are ongoing and that the model of care is not the only factor contributing to the complexity of survivorship care delivery.

Definitions

Survivorship care refers to comprehensive care provided to cancer survivors. Specifically, it includes addressing the needs cancer survivors face after treatment and assisting in long term management of their care (American Society of Clinical Oncology, n.d.). While there are various definitions of a cancer survivor, the CoC defines cancer

survivors based on the eligibility criteria outlined in Standard 3.3, which requires a diagnosis of a stage I-III cancer and completion of treatment for curative intent (CoC, 2016). There is recognition that patients with metastatic disease may be considered survivors, but they are not the target of Standard 3.3 and the delivery of the SCP (CoC, 2016). The National Coalition Cancer Network (NCCN) provides a more broad definition and believes an individual becomes a cancer survivor from the time of diagnosis, through the balance of his or her life. The NCCN's definition also includes family members, friends, and caregivers, as they are also affected by cancer (National Comprehensive Cancer Network [NCCN], 2018). National survivorship statistics reflects the NCCN definition. While the CoC supports the NCCN definition, the intended target of Standard 3.3 is patients without metastatic disease (CoC, 2016). In this paper, the CoC definition of a cancer survivor will be used for the discussion of survivorship care.

Problem Summary

It has been over a decade since the use of the SCP was identified as a necessary component of care for cancer survivors (Nekhlyudov, Ganz, Arora, & Rowland, 2017). The essence of the SCP creation by the IOM was to improve the care for cancer survivors by summarizing care received, providing a communication tool for future health coordination, and preparing for living a life after cancer treatment (Hewitt et al., 2006). However, evidence supporting the use of survivorship care plans is mixed (de Rooij et al., 2018b; Jacobsen et al., 2018)

To date, little evidence exists to demonstrate survivorship care plans have a positive impact on patient-reported outcomes (Brothers, Easley, Salani, & Andersen,

2013; Jefford et al., 2016; Klemanski, Browning, Kue, Klemanski, & Browning, 2016). Cancer survivors, however, report increased satisfaction with provided information in survivorship care plans and increased confidence in survivorship knowledge (Brennan et al., 2014; Mayer et al., 2016; Mayer et al., 2014). Additionally, cancer survivors believe the survivorship care plan is helpful and recommend its use (Brant et al., 2016; Klemanski et al., 2016; Post et al., 2017). While other evidence supporting SCP use currently may be insufficient, cancer survivors' own reports of positive experiences provide support for their continued use. As a result, organizations are facing the challenge of implementing a CoC standard requirement that has mixed evidence to support its use and a lack of evidence based guidelines to provide structure for the delivery of survivorship care (Birken et al., 2015; Brothers et al., 2013; Klemanski et al., 2016; Mayer et al., 2016). The recommendation for bridging the gap of evidence is advancing survivorship care from the sole provision of the SCP document to a more individualized process that is considering the specific needs of cancer survivors and stakeholders expectations (Birken et al., 2018b; de Rooij et al., 2018b; Jacobsen et al., 2018; Nekhlyudov et al., 2017).

Purpose

The purpose of this clinical project was to provide a program evaluation for a community cancer center that is committed to improving survivorship care for adult oncology patients. According to Stricker and O'Brien (2014), implementing the CoC's Standard 3.3 in a community setting is a "particularly challenging environment for implementing survivorship care because of limited resources and high practice volume"

(p.19). Organizations have flexibility in determining how they want to provide care for their cancer survivors and adapt Standard 3.3 into their health care system. Using a systematic framework for program evaluations, outlined by the Centers for Disease Control and Prevention (CDC), an assessment of the program's effectiveness in meeting their identified outcomes was conducted. A case study was also utilized to understand the survivors' perspective of the SCP and their use of the SCP.

CHAPTER TWO

REVIEW OF THE LITERATURE

Review of Literature

With the CoC's creation of Standard 3.3 organizations were required to deliver SCPs to all eligible patients (CoC, 2014). Incorporating this standard into routine care has proven to be complex and challenging (Birken, Deal, Mayer, & Weiner, 2014). A review of the literature was completed to provide understanding of the factors that are contributing to the varied support for SCP use and the recommendations for improving survivorship care. Research databases included in the search were CINAHL, Web of Science, COCHRANE, Joanna Briggs, and Google Scholar. Searches were limited to articles published between 2005–2019, about adult patients, and in the English language. Key search terms included survivorship, survivorship care plans, cancer survivors, implementation, patient reported outcomes, survivorship care, models of care, and barriers.

Barriers to Implementation

The implementation of survivorship care plans into routine care of cancer survivors has been a complicated process. Researchers have identified a number of barriers preventing organizations from consistently incorporating SCPs into practice, including lack of staff, financial reimbursement, institutional resources, stakeholder support, and time (Irwin, Klemp, Glennon, & Frazier, 2011; Klemanski et al., 2016; Salz et al., 2014; Stricker & O'Brien, 2014). In a cross-sectional survey by Birken et al.

(2014), a lack of resources was identified as the most commonly reported barrier (76%) to survivorship care plan use among the 1,850 programs surveyed. Difficulty with SCP use and the lack of internal support for SCP use were also reported at 29% and 24% respectively (Birken et al., 2014). Similar findings were observed by Irwin et al. (2011) from a survey of 399 oncology nurses. Funding concerns and lack of time were reported by 46% as barriers for SCP implementation. Additionally, their survey also identified a lack of organizational interest and a lack of physician support were preventing SCP development (Irwin et al., 2011).

The development of a SCP can be a time-consuming process that requires dedicated personnel. According to Stricker and O'Brien (2014), the creation of a SCP can take on average between 60 and 90 minutes. Another study by Dulko et al. (2013) found the average time to be 53.9 minutes. Much of the time is spent reviewing medical records, creating the treatment plans, and manually entering the information, which can be challenging when patients have been treated at multiple facilities (Dulko et al., 2013). Technology advancements could improve this process if SCP templates were able to automatically extract pertinent data into the SCP. A program evaluation by Isaacson, Hulme, Cowan, and Kerkvliet (2018) pursued this solution but found the technology unavailable, and as a result the time for SCP creation took between 30 and 60 minutes.

Contributing to the time and personnel barriers of SCP implementation is the lack of reimbursement. According to Birken (2018), very few organizations have been able to attain reimbursement for SCP development. While a Medicare code exists for SCP creation, funding is not available to reimburse the fulfillment of this service (Birken et

al., 2018a). Without reimbursement opportunity, an economic incentive is lacking, which further contributes to the challenges of including SCPs in routine survivorship care. A lack of financial motivation may affect community organizations the most as they often function with limited resources while balancing high patient volumes (Stricker & O'Brien, 2014). One solution for attaining some revenue for survivorship care is adopting the advanced practitioner model for the delivery of the SCP. This allows the delivery of the SCP to be a billable service as there are existing codes for this visit. However, the time invested in the SCP creation is still not billable and is an expense organizations must absorb (Mayer et al., 2014; Rosales et al., 2014).

Another significant barrier contributing to the inconsistency of survivorship care plans is the lack of evidence based guidelines. A quality appraisal of the guidelines for survivorship care by Birken et al. (2015) resulted in none of the proposed 16 guidelines being strongly recommended. Most of the guidelines encouraged survivorship care plan use but Birken and colleagues concluded the plan was not supported by sufficient evidence. Ultimately, the authors recommended only five guidelines, concluding there is a need to improve guideline quality, hypothesizing that consistency in SCP delivery will likely improve with more defined guidelines (Birken et al., 2015).

Survivorship Care Plan Delivery

Many studies identify survivorship care as a feasible component of care for cancer survivors (Mayer et al., 2016; Mayer et al., 2014; McCollum, Wood, & Auriemma, 2014; Post et al., 2017). However, implementation of survivorship care has been challenging and inconsistent. This is in part because the lack of structure and guidance on how to best

incorporate SCPs in to everyday patient care (Birken et al., 2015). Currently, a physician, advanced practice provider (APP), nurse, or certified clinical navigator can deliver the SCP (CoC, 2016), but questions remain regarding who should be responsible for survivorship care. Adoption of the various models is individualized for organizations and evidence is lacking to support a particular model (Hahn et al., 2018). While having flexibility in meeting Standard 3.3 may be beneficial in helping organizations adopt a model that best meets their structure, it may also be contributing to confusion and inconsistencies.

The SCP development and delivery is a time-intensive process which lends itself well to the idea put forth by Klemp (2015) that "one size does not fit all". In analyses of nurse and physician models, comparisons on specific outcomes have been minimal, which offers little support for the adoption for one model over another (Halpern et al., 2015; Klemp, 2015). In a randomized evaluation by Brothers et al. (2013), survivorship care plan delivery by physicians was evaluated for significant outcomes on care. Survivors were randomized to visit with a SCP or a visit without a SCP and usual care. The physicians were provided standardized instructions for SCP delivery. The results demonstrated that patients perceived no significant impact on helpfulness of written materials, quality of care, and health services between the two groups. The physicians were scored high for the care provided (Brothers et al., 2013). According to Yang et al. (2014), the national projected demand for oncologists and radiologists is expected to reach 40%, where the supply in FTEs may only grow by 25% by 2025. The results will be an overall shortage of medical oncologists and radiation oncologists by 2025. The

anticipated shortage of physicians in oncology may encourage organizations to consider other models for SCP delivery. Utilizing advanced practitioners for the SCP visit would create more availability for oncologists to see new patients and patients receiving treatment but would still allow for the SCP to be a billable visit.

Nurse-led models have been put forth as a feasible and reliable structure for survivorship care that addresses the concerns of oncologists' availability and still provides quality care (Monterosso, Platt, Bulsara, & Berg, 2019; Post et al., 2017; Spears, Craft, & White, 2017). In a review of 15 randomized and non-randomized studies from 2007–2017, Monterosso et al. (2019) found the nurse-led model to have significant benefits for survivors' cognitive and social quality of life (QoL) outcomes. When compared to other standard approaches, the nurse-led model had better outcomes on survivorship care (Monterosso et al., 2019). Similarly, Spears and colleagues' assessment of survivorship care provided by advanced practice registered nurses (APRN) found the APRN model improves patient satisfaction, is cost efficient, and improves productivity. Spears et al. also proposed the APRN as suitable for survivorship care delivery because of their education background, clinical expertise, and the ability to generate revenue for this service. While this model of care is feasible, the lack of randomized controlled studies in this systematic review makes it difficult to generalize the findings.

The responsibility for survivorship care is varied among cancer programs but the nurse-led model is frequently utilized (Monterosso et al., 2019). In a large, national observational study, nurse navigators, oncology nurse practitioners, and registered nurses were surveyed about the responsible parties for survivorship care. Nurse navigators were

identified by approximately half of the respondents as the responsible party for SCP implementation (Birken et al., 2018a). The delivery of SCPs by oncology NPs was reported at 31% and oncologists at 24% (Birken et al., 2018a). A surprising finding was that 73% of respondents identify eligible survivors on a case-by-case basis and have no formal process for identifying cancer survivors (Birken et al., 2018a). This finding exposes the difficulty organizations are having in consistently delivering survivorship services and suggests that a lack of structure may be contributing to this challenge.

The previously discussed barriers to survivorship care implementation directly impact an organization's decision for assigning responsibility for SCP delivery. Some oncologists have expressed concerns that the SCPs do not help in the overall management of cancer survivors' care and require excessive time and resources (Klemanski et al., 2016). In a survey study by Salz et al. (2014), 245 oncology providers, including MDs, APPs, and clinical nurse specialists from 14 different organizations, were questioned about their opinions on SCPs. Responses were positive for SCP use, but respondents also expressed concerns about how to integrate them into clinical practice. More than half of the respondents (58% to 65%) believed in the importance of disseminating information contained in an SCP (Salz et al., 2014). Interestingly, oncology providers perceived that primary care providers benefit the most from SCPs (>85%) because the treatment summary the primary care providers receive can contribute to their ongoing management of patients (Salz et al., 2014). In summary, Salz and colleagues expressed concerns that the benefits of SCPs were not overtly recognized by oncology providers. They propose the SCPs should be a priority for oncology providers as they can help prepare survivors

and their primary care providers for the care needed after treatment. With the projected shortage of oncology providers, this after treatment care will likely fall increasingly upon primary care providers (Salz et al., 2014). Organizations may be able to address this potential gap in care by prioritizing survivorship care through the adoption of a nurse-led survivorship model with APPs delivering the SCP.

Survivorship Care Plan Outcomes

Evidence supporting SCPs is mixed which is likely contributing to the difficulty with implementation. The primary goal of the SCP is to address the physical and emotional impact of cancer and cancer treatments on survivors. Unfortunately, despite the optimism surrounding the creation of the SCP, evidence of the benefits for cancer survivors has not materialized in the research. To date, evaluation of SCPs with randomized controlled studies assessing patients receiving an SCP and not receiving an SCP, found no significant differences on quality of care, health service satisfaction, cancer survivor distress, quality of life (QoL), or patient satisfaction (Boekhout et al., 2015; Brothers et al., 2013; Grunfeld et al., 2011; Hershman et al., 2013; Jefford et al., 2016; Mayer et al., 2016; Nicolaije et al., 2015). In a study by Boekhout et al. (2015), 337 women with early stage breast cancer were followed for 24 months after collecting baseline data. The results demonstrated no statistical significance in the outcomes between SCP and non-SCP groups on cancer specific distress (p=0.75), psychological distress (p=0.33), patient satisfaction (p=0.67), adherence to guidelines (p= 0.43), or continuity of care (p=0.78). These results were similar to Grunfeld et al.'s (2011) conclusions from a blinded controlled study with a similar population of breast cancer

survivors. A 12 months post-treatment survey revealed no significant differences between SCP and usual care on cancer related distress, QoL, patient satisfaction, coordination of care, or health services (Grunfeld et al., 2011).

A more recent randomized controlled trial by Jefford et al. (2016) assessed the impact of SCPs for colorectal cancer patients. Data collections at two and six months revealed no significant differences between the survivorship care group plus usual care and usual care on psychological distress, unmet needs, or QoL outcomes. However, cancer survivors receiving survivorship care plus usual care had increased satisfaction with their post-treatment care. The impact of SCPs also does not seem to change with time. In a study by de Rooij et al. (2017), ovarian cancer survivors from the ROGY trial, a cluster, pragmatic randomized controlled Dutch study, were surveyed at six, twelve, and twenty-four months. The results demonstrated patients receiving an SCP reported no significant differences in the information received or the care received. Unfortunately, patients receiving an SCP expressed less confidence in their treatment and its ability to cure.

While randomized controlled studies have not provided the support for SCP use as originally intended, observational studies have put forth a more diversified picture. Survivorship care involving the delivery of the SCP have demonstrated an increase in patients' knowledge, high patient satisfaction, confidence in survivorship knowledge, and improved coping (Johnson, Minchew, Richter, Craft, & Lerner, 2017; Mayer et al., 2016; McCollum et al., 2014; Rosales et al., 2014). Communication and quality of care may also improve with the use of SCPs. According to a survey by Blanch-Hartigan et al.

(2015), the use of SCP resulted in cancer survivor's reporting higher personal communication care scores and were "over three times as likely to report excellent/very good care quality compared to cancer survivors who did not receive and SCP as part of their care" (p.1277).

SCPs additionally may have a number of unintended consequences on cancer survivors' care (de Rooij et al., 2018a; Nicolaije et al., 2015). Patients receiving SCPs have reported more symptoms than patients not receiving a SCP. The reported symptoms include increased emotional concerns, negative illness perceptions, and increased healthcare use (Nicolaije et al., 2015). However, Hershman et al. (2013) found SCPs did significantly reduce health worry among breast cancer patients at the three month mark but the results did not hold at the six month survey. Additionally, Boekhout et al. (2015) hypothesized that an SCP would lead to better adherence to follow-up guidelines and reduce the number of post-treatment visits to the cancer center, however, the twelve and twenty-four month assessment did not support this hypothesis. Cancer survivors who discharged using a standard approach had similar adherence to follow-up recommendations and did not have an increased use of cancer center services. Unlike Nicolaije and colleagues, Boekhout et al. did not find the SCP to have any negative effects on reported outcomes.

Cancer survivors may also have ongoing anxiety and depression related to their cancer journey. The SCP has been hypothesized as a helpful tool to address the ongoing emotional needs of cancer survivors. Providing support for this hypothesis, a survey of 3,191 cancer survivors concluded that adult cancer survivors receiving a SCP may have

short- and long-term benefits on their psychological well-being (Oancea & Cheruvu, 2016). However, a randomized controlled study by de Rooij et al. (2018a) demonstrates the SCP may be insufficient to meet the emotional needs of some cancer survivors. In their study, symptoms of anxiety and depression were assessed at six, twelve, and twenty-four months after diagnosis. Patients were randomized to the SCP care or usual care group and no direct beneficial effects of SCPs on anxiety or depression were observed. Additionally, patients with endometrial cancer who reported more symptoms and expressed a more negative perception of their illness had indirect effects after receiving an SCP. After six months, SCPs indirectly increased fatigue, insomnia, and anxiety (standardized, $\beta = 0.58$, SE=0.09, $p<0.01$; $\beta=0.69$, SE=0.08, $p<0.01$; $\beta=0.58$, SE = 0.09, $p = 0.01$) (de Rooij et al., 2018a).

Similarly, six months post-treatment, ovarian cancer patients who expressed decreased confidence in their treatment's ability to provide a cure and who had received a SCP also reported indirect effects on their emotional well-being ($\beta = 0.27$, $p = 0.02$). The unintended effects of SCPs were only observed in gynecological cancers limiting the generalizability of the findings. However, the researchers recommend more attention be given to the potential negative effects of SCPs as it pertains to quality of life and anxiety (de Rooij et al., 2018a). Survivors with ongoing emotional needs may require other resources to adequately address their concerns.

According to Jacobsen et al. (2018), analyzing the impact of survivorship care plans is challenging because of the variability in the outcomes being evaluated. Furthermore, inconsistencies in studies make it difficult to compare outcomes and draw

conclusions for guidelines. Jacobsen and colleagues concluded in their systematic review of 11 nonrandomized and 13 randomized studies that the SCP alone is not enough to meet the complex needs of cancer survivors. While SCPs should be a necessary component of survivorship care, the lack of evidence discovered in their review demonstrates the need for more efforts directed at improving the health outcomes and delivery of care for cancer survivors (Jacobsen et al., 2018).

Cancer Survivors' Perspective

An important consideration when assessing SCPs and survivorship care is the cancer survivors' perspective. While the strength of randomized controlled trial evidence for SCP use is lacking, cancer survivors have reported a desire for the information (Jefford et al., 2016; Kinnane, Piper, & Jefford, 2017). Cancer survivors also have reported satisfaction with survivorship visits and express that the visits are meeting their needs (Rosales et al., 2014). In a survey by Kinnane et al. (2017), almost 98% of the 219 cancer survivors surveyed wanted an SCP. The reported anticipated uses of the SCP included a record of cancer treatment (61%), a reminder of ongoing care (57%), a better understanding of diagnosis and treatment (56%), and to share with PCP (52%) (Kinnane et al., 2017). The most desired elements cancer survivors wanted included in the SCP were description of symptoms to watch for and report, a summary of their treatment, and a plan for follow up (Kinnane et al., 2017).

Cancer survivors have expressed the need for comprehensive care following the completion of treatment (Jefford et al., 2016). The SCP document is consistent with what cancer survivors prefer; a document without clinical jargon that contains relevant and

easily understood information. Additionally, cancer survivors desire a treatment summary that includes diagnosis and prognosis, signs and symptoms of recurrence, long term effects of treatment, recommendations for health promotion, surveillance plan, and local resources (Jefford et al., 2016; Klemanski et al., 2016; Stricker & O'Brien, 2014). SCP delivery close to end of treatment, within six months following treatment, and delivery of the plan either in person or by phone call is the favored delivery method (Dulko et al., 2013; Stricker & O'Brien, 2014). Interestingly, a national longitudinal study that surveyed 3,138 cancer survivors 9 years post-diagnosis and without receipt of an SCP revealed unmet health informational needs (Playdon et al., 2016). Cancer survivors reported a desire for more information on cancer screenings (42.5%), long-term treatment side effects (33.1%), healthy lifestyle behaviors (31.9%), impact of cancer on finances and insurance (28.2%), and surveillance tests and follow up after cancer treatment (27.0%) (Playdon et al., 2016). The survey also inquired how cancer survivors preferred to receive cancer information. The most popular method was reading a book, magazine, or other printed publication (60.9%) followed by personalized reading materials (57.6%). The third preferred source for cancer specific information was meeting in person with a health care provider (44.4%) which does provide support for the SCP delivery during a visit (Playdon et al., 2016).

Survivorship has potential benefits for survivors but it needs to be a more personalized process (Nekhlyudov et al., 2017). In a cross-sectional survey by de Rooij et al. (2018b), cancer survivors responded to a variety of health specific questions. The results revealed that up to 40% of survivors surveyed had either no or low unmet needs.

Among the respondents who did have unmet needs, four identifiable categories emerged: low needs (42%), mainly physical needs (16%), mainly psychological needs (20%), and both physical and psychological needs (23%) (de Rooij et al., 2018b). The most reported unmet needs were related to side effects, self-care, and emotional coping. Thirty percent of patients reported fatigue was their most troubling side effect from treatment. This was followed by twenty percent identifying continued memory problems and issues with weight gain (de Rooij et al., 2018b). Approximately thirty percent identified nutrition counseling, physical activity, and meditation and relaxation as needs associated with self-care. Among emotional coping needs the highest reported concerns were fear of recurrence (34%), anxiety or worry (28%), and managing stress (22%) (de Rooij et al., 2018b). Health care needs vary among cancer survivors. By recognizing the spectrum of concerns that can exist after treatment, completion of the SCP may encourage practices to identify patient-specific needs and help to cater educational resources appropriately. Time and resources can be invested in meeting the actual needs of individual cancer survivors and bring meaning to a process that has potential for positively impacting survivors' lives.

Summary and Recommendations

The development of the SCP has been a solution for acknowledging and addressing the care needs of cancer survivors beyond treatment completion. The SCP is a communication tool that is a CoC standard requirement which is motivating many organizations to adopt the SCP into standard practice. As previously discussed, implementing survivorship care is challenging. The lack of strong evidence supporting

the use of SCPs brings into question the cost effectiveness for organizations seeking to adopt this service into their practice.

According to Birken et al. (2018a), the barriers surrounding the implementation of SCPs are affecting the ability of organizations to adopt survivorship care in to practice as only an estimated 12-43% of US programs have been able to implement SCP delivery into routine care. The ability to overcome the numerous barriers that are hindering the incorporation of SCPs for everyday survivorship care will heavily influence organizations' capability to meet the needs of cancer survivors. Birken and colleagues hypothesize that the inconsistency in SCP use likely influences the evaluation of SCP effectiveness. Without consistent implementation of SCPs, it will be difficult to accurately assess the impact they are having on cancer survivors' care. The inconclusive results from randomized controlled trials may actually be a result of inconsistent implementation of SCPs rather than the SCPs themselves being ineffective (Birken et al., 2018a). Additionally, many of the randomized controlled studies have assessed breast cancer and gynecological patients which also brings in to question the generalizability of the findings (Brothers et al., 2013; de Rooij et al., 2017; Grunfeld et al., 2011; Hershman et al., 2013; Nicolaije et al., 2015).

The lack of strong randomized controlled evidence for SCP use is offset by stakeholder endorsement, collegial agreement of benefit, cancer survivors' perspectives, and observational studies. This offers support for the continued use of the SCP. At the conclusion of treatment, patients have physical and emotional needs that should be met. The SCP can be a useful in addressing the information and communication preferences of

cancer survivors. Perhaps, the SCP should be considered only as the communication tool it was created to be and the expectation of it solving the needs of cancer survivors abandoned. Alternatively, survivorship programs should focus on implementing a holistic approach to care that is meaningful for survivors. Moving survivorship care beyond a requirement standard and into a spectrum of care may help organizations prioritize survivorship care and move past the expectation that one approach will work for every facility and demographic of patients.

CHAPTER THREE

THEORETICAL UNDERPINNINGS

Conceptual Framework

One purpose of the DNP scholarly project was to "add value to the practice site" (Dunphy, Winland-Brown, Porter, & Thomas, 2019, p. 9). By focusing efforts on the current survivorship program at a cancer center in Montana, the care being provided to cancer survivors can be improved and become a part of routine care. One strategy for improving practice is through the use of program evaluations. Research has demonstrated that program evaluations are an effective method for analyzing survivorship care (Mayer et al., 2014; McCollum et al., 2014; Post et al., 2017).

The Evaluation Framework for program evaluations created by the Centers for Disease and Control (CDC) guided this project. This framework was selected because its fundamental purpose is the application of results into program improvement. Moving beyond a summary of evidence and conclusions to implementing steps will bring positive changes to the program undergoing evaluation (CDC, 2012). While the setting of this project is not a public health program, which the CDC mainly evaluates, the standards and steps of the evaluation are applicable. Currently, organizations are developing survivorship programs with minimal guidance on how to implement survivorship care into their practice. The Evaluation Framework is a step-wise approach for gathering evidence and applying the findings to initiate change.

The Evaluation Framework consists of 4 standards: utility, feasibility, propriety, and accuracy (Figure 2). These standards exist to guide a program evaluation but the specifics of each standard are to be individualized to the unique program undergoing evaluation (CDC, 2012). Six steps are involved with the process of evaluating a program:

- Engage stakeholders
- Describe the program
- Focus the evaluation design
- Gather credible evidence
- Justify conclusions
- Ensure use and share lessons learned

Figure 2*:* Evaluation Framework Steps

Figure 1.1
Evaluation Framework

(CDC, 2012)

These steps will be integrated into this paper and will provide the structure for the program evaluation. Applying this framework to the evaluation of the cancer center

survivorship program will help identify the progress the program is making in meeting its goals, assessing the desired outcomes of the program, assisting in quality improvement needs, and uncovering how to maintain and improve the existing program to ensure continued success (CDC, 2012).

Nursing Theory

After treatment completion, patients begin a transition in their care. They are learning to navigate a new life that is no longer dictated by their next appointment, treatment, or upcoming scan. For many, this adjustment is emotionally difficult and consumed with uncertainty. Cancer survivors are challenged with adjusting back into life before their cancer diagnosis but still carry the uncertainty about the next steps of their care and about their future health outcomes. Survivorship care is a proposed response for helping patients with transitioning from treatment to living a life affected by cancer. As previously discussed, the emotional and physical side effects of cancer and treatment do not just disappear after treatment completion but often continue with the patient.

In 1988, Merle Mishel introduced the middle-range nursing theory Uncertainty in Illness to describe the uncertainty many patients encounter when receiving a diagnosis and facing the complex and unfamiliar experiences of their disease (Zhang, 2017). In 1990 Mishel produced a reconceptualized Uncertainty in Illness theory to "address the experience of living with continuous uncertainty in either a chronic illness requiring ongoing management or an illness with the possibility of recurrence" (Mishel, 2014, p. 53). Mishel's Uncertainty in Illness theory has four components: antecedents generating uncertainty, appraisal of uncertainty, coping with uncertainty, and adaption to the illness.

This theory will provide the theoretical support for the value of survivorship and the importance of evaluating the delivery of this aspect of care. The theory captures the significance of quality of life and caring for the whole person which is important for cancer survivors as they transition into the survivorship aspect of their care and confront the uncertainty of their disease.

Antecedents Generating Uncertainty

Patients can experience uncertainty at any point in their care. In survivorship, patients transition from a familiar treatment plan to a new focus of care that is unknown. This transition creates new illness stimuli that Mishel describes as antecedents that can develop into uncertainty when patients are unfamiliar with the experience or their expectations are not consistent with actual events. Mishel believes a patient's cognitive capacity can directly affect the experience of uncertainty (Mishel, 2014). A stronger cognitive capacity transfers into improved understanding of the new stimuli and less uncertainty. Additionally, support from healthcare providers, education, and social support can assist patients in understanding their experience and reduce the likelihood of uncertainty (Zhang, 2017). Survivorship care is an opportunity to address the new illness stimuli created from the transition of care after treatment. It serves as an occasion to introduce the services and support survivors need to overcome the uncertainty that could accompany this phase in their cancer journey.

Appraising Uncertainty

Mishel presents the appraisal of uncertainty as a strategy for preserving hope by confronting uncertainty as an opportunity and by holding on to the potential for positive

outcomes. When individuals are presented with a stressor they begin appraising the situation to determine whether they are facing a danger (threat) or opportunity (challenge). Additionally, they are assessing whether they can apply the necessary coping resources to respond to the stressor (Zhang, 2017). Individual appraisal of uncertainty is directly related to personality characteristics, attitudes, and beliefs (Mishel, 2014). When situations are interpreted as a threat, individuals who perceive the possibility of a negative outcome may seek to reduce uncertainty by utilizing coping strategies. Alternatively, if situations are appraised as an opportunity and the potential outcomes are assessed as positive, coping strategies will be implemented to maintain uncertainty (Zhang, 2017).

Coping with Uncertainty

The management of uncertainty requires coping with the unknown. The mental and physical coping strategies employed will be directly related to the appraisal of uncertainty. Mishel proposes that situations interpreted as a threat will activate mobilizing and affect control of coping strategies. For example, some patients may seek out more information in an attempt to eliminate the source of uncertainty. Others may emotionally disengage in order to reduce the emotional impact of uncertainty (Zhang, 2017). Alternatively, when patients appraise uncertainty as opportunity, the focus is maintaining the uncertainty. Mishel proposes that buffering strategies are employed to assist in neutralizing any threatening information and avoid exposure to new stimuli that may impact their appraisal of uncertainty (Zhang, 2017). Importantly, Mishel's Uncertainty in Illness theory does not promote one strategy over the other. Rather, it

emphasizes the importance of matching an individual's appraisal of uncertainty with the appropriate coping strategies. The uncertainty of survivorship and treatment completion will be appraised differently by each patient. When delivering survivorship care, assessing how patients interpret their next steps of care will be essential for providing patient-centered care and promoting appropriate coping strategies.

Adaption to Illness

The fourth component of Mishel's theory is the achievement of new balance through adaption. Through the utilization of appropriate coping strategies, patients can adjust to the experiences that created their uncertainty (Mishel, 2014). It is important to have an understanding of the source of patient's uncertainty first in order to effectively assist them through this process. Nurses and healthcare providers are in a position to support patients as they confront their diagnosis and help facilitate a forward-looking approach to their ongoing care (Mishel, 2014).

Theory Application

Survivorship is an opportunity to address the source of patients' uncertainty. After treatment completion, patients often seek a guarantee that their cancer will not return and focus on signs of recurrence. Mishel's uncertainty appraisal proposes that survivors are presented with a choice on how to interpret the next steps of their care. Some may interpret survivorship care as an opportunity to cope with the uncertainty but maintain a positive outlook for their future care. Others may assess the uncertainty that comes with survivorship as a threat and choose to focus on using their coping strategies to face their

worst fears. Cancer survivors are impacted by their diagnosis in many different ways. Survivorship care is a communication strategy that seeks to guide patients during their uncertainty and to provide coping strategies that maintain hope and promote adaption. By emphasizing the aspects of their future healthcare decisions that survivors can control, and by offering guidance on ways to continue recovery from treatment, survivorship care offers a way for survivors to prepare for the next phase of their healing.

CHAPTER FOUR

METHODS

Stakeholders Perspective

The creation of this project was inspired by the need for improvement in survivorship care that was identified after meeting with key stakeholders at the cancer center in Montana, including clinic managers, cancer committee members, cancer support community director, nurses, and social workers. Meetings and discussions with the cancer center manager and director of the cancer center in 2018 revealed minimal oversight of the survivorship process and care being provided to cancer survivors. After learning of the projected deficiency in meeting CoC's Standard 3.3, the need for a survivorship program and standardized process for improving the delivery of SCPs was evident.

Setting

The cancer center is part of a community based health care center located in Bozeman, Montana. It primarily provides oncology care to patients within Gallatin County, but also to patients in surrounding counties including Park County, Madison County, Lewis and Clark County, Jefferson County, Broadwater County, Beaverhead County, and Meagher County. According to the 2018 United States Bureau Report, there were an estimated 111, 876 people living in Gallatin County and an estimated 48,532 people living in Bozeman (United States Census Bureau, 2018).

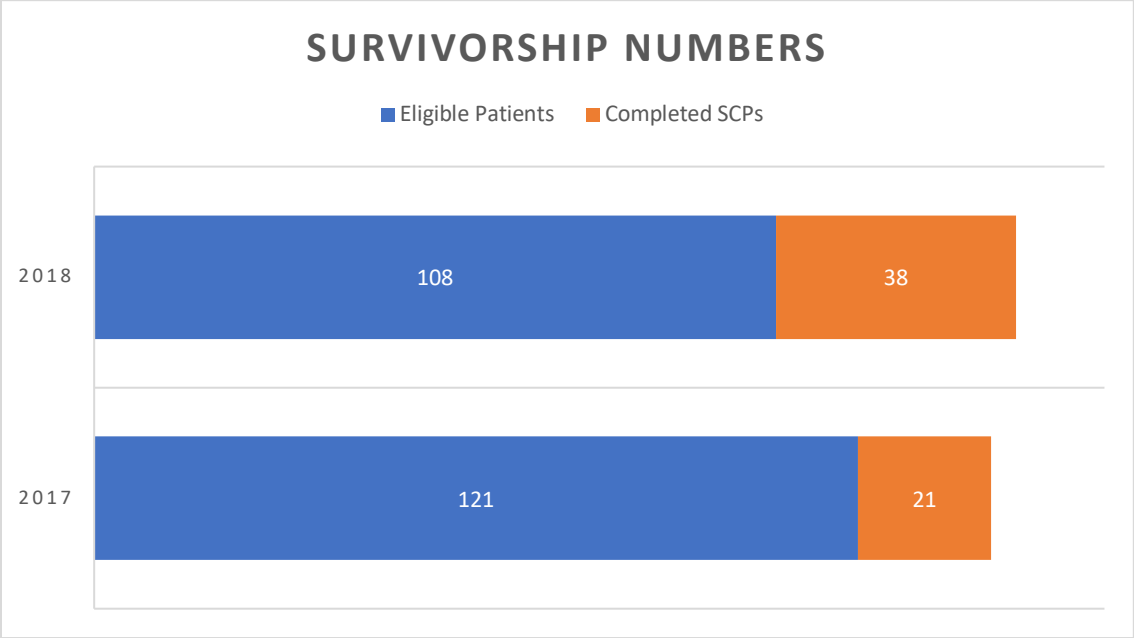
Currently, the cancer center is staffed with five oncologists, one radiation oncologist, seven advanced practitioners and eight oncology nurse navigators. The oncologists see patients with all cancer types and strive to provide the highest quality of care in a community setting. In 2018, approximately 404 new patients were evaluated at the cancer center; 194 were male and 210 were female. The majority of patients were between the ages of 51-70 years (53%) followed by 71 and older at 32%. Fifteen percent were < 30-51 years of age. In 2017, approximately 378 new patients presented to the cancer center for evaluation; 175 were male and 203 were female. Similar to 2018, the majority of patients were between the ages of 51-70 (50%) followed by 130 patients 71 years and older (34%). There were 49 patients between ages 31-50 years and 9 patients under 30, together comprising just over 15% of the new patients seen in 2017.

Survivorship Program Overview

Since 2015, survivorship care at the cancer center has been slowly incorporated into the clinic. A lack of guidance for survivorship care contributed to inconsistency in delivering SCPs and addressing the needs of the cancer survivors at the cancer center. By 2018, programs seeking accreditation with the CoC were to achieve 50% completion of SCP delivery for eligible patients. The cancer center's 2018 CoC review revealed that only 13% of total eligible survivors seen at the cancer center received an SCP in 2017. There were 121 eligible patients and 21 completed survivorship care visits with a care plan. In 2018, 35% of total eligible survivors treated at the cancer center received a SCP and SCP visit. There were a total of 108 eligible patients for survivorship and a delivery of 38 SCPs (Figure 3). The shortcoming in meeting Standard 3.3 highlights the limited

attention being provided to survivorship care. The difficulty in implementing survivorship care was a known challenge at the cancer center that had been left unaddressed.

Figure 3: Comparison of Eligible Patients for Survivorship and Completed SCPs



The deficiency in Standard 3.3 was the impetus for change. In response to the identified shortcomings, the cancer center decided to begin prioritizing survivorship care. A committee was formed to address the deficiency and create a survivorship program. The committee consisted of oncology clinical nurse navigators (including the author), a social worker, a scheduler, a nurse practitioner, a nurse manager, and a cancer center IT representative.

An assessment of the current process was conducted by the committee. This revealed a lack of leadership for survivorship care, limited staff knowledge of

requirements, a need for a process for identifying eligible survivors, and SCP development responsibility to include more than one individual (Figure 4). To address these needs, the committee developed a new work flow, expanded job responsibilities, incorporated the electronic medical records (EMR), and improved education (Figure 5). Ultimately, the priority became not just to make the survivorship program meet a requirement, but to effectively improve the care being provided to cancer survivors.

Figure 4: Fishbone Model of Survivorship Care Process at Cancer Center

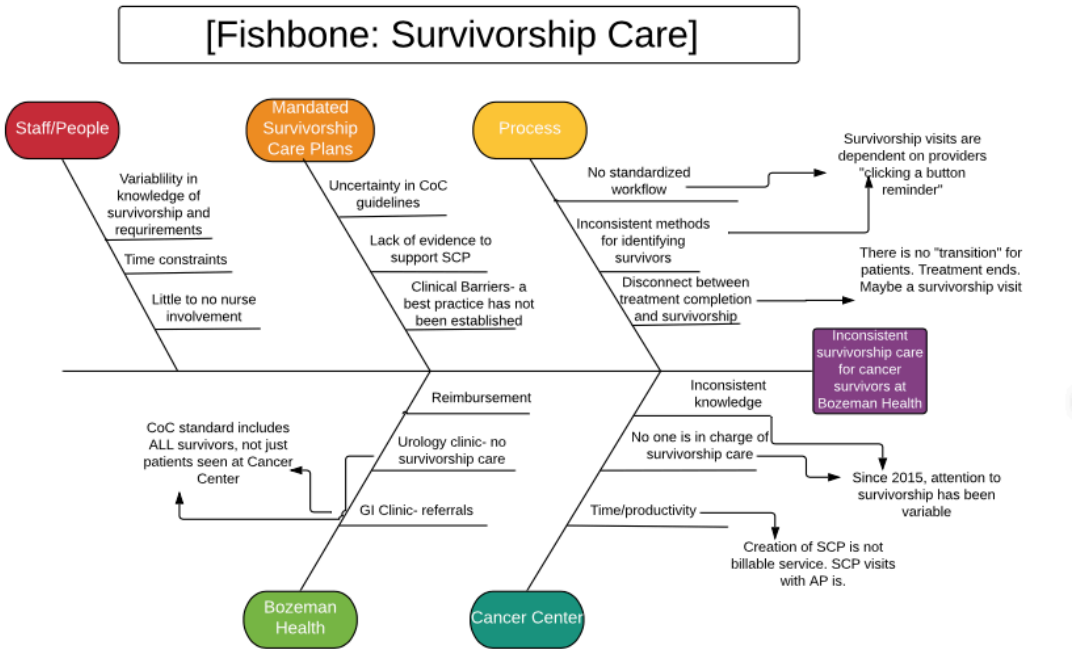
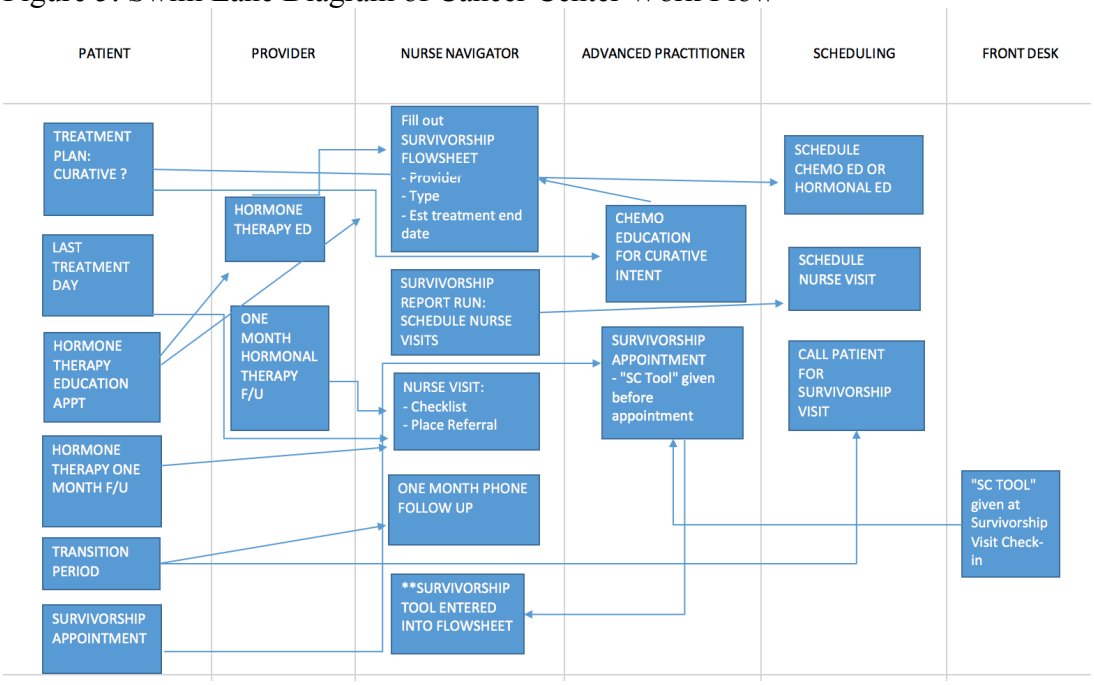


Figure 5: Swim Lane Diagram of Cancer Center Work Flow



Population

Eligibility for participation in the project was based on the CoC definition of cancer survivors. Adults diagnosed with a stage I-III cancer with completion of treatment with curative intent were eligible for this project. Patients with metastatic disease or partial completion of treatment were excluded. While the CoC eligibility standard includes patients that could be treated at other specialty clinics at the hospital, this project is limited to patients treated at the cancer center as this is where the majority of cancer survivors receive care.

Ethical Issues

Prior to the start of the project, an application for exemption status was submitted to the Institutional Review Board (IRB) (See Appendix B) . Upon review by IRB, exception status was granted. The proposed project, including the survey questions to be delivered through Survey Monkey, were reviewed with the cancer center director and risk management personnel. Internal permission was granted to proceed with the program evaluation with an agreement to disclose all finding for review prior to inclusion in this paper (See Appendix C). Consent was implied by agreeing to participate in the survey. A summary of consent and project purpose was available for review by participants (See Appendix D). All participants were aware of the option to decline the survey without consequence on the care they would receive. Both pre-intervention and post-intervention surveys were anonymous. Surveys were administered by employees of the cancer center— either the project lead, medical assistants, or nurse practitioners. Age and sex were the only demographics collected. Patient confidentiality and HIPPA compliance were adhered to at all times.

Cancer survivors' participation in the case study portion of the program evaluation was voluntary and anonymous. A summary explaining the purpose of the case study and the consent were available for review by participants (See Appendix E). Additionally, patients were informed that their decision to participate would have no impact on the care they would receive. Consent was implied by agreeing to answer questions at the visit and at subsequent telephone calls or visits.

Evaluation Design and Intervention

In response to the CoC Standard 3.3 deficiency, a survivorship program was developed at the cancer center. Goals were developed to improve the survivorship care being delivered but staff oversight of the project was still lacking. There was no formal evaluation framework in place to assess whether the newly developed survivorship program and the proposed changes for implementation would improve the identification of survivors for the delivery of SCPs. To assist in this process, the project lead, also a current oncology nurse navigator at the cancer center, welcomed the opportunity to provide a formal evaluation of the survivorship program. Utilizing the steps of the Evaluation Framework, a program assessment for survivorship care was conducted at the cancer center between February 1st, 2019 and July 31st, 2019.

Three project objectives were created to assess the survivorship program and provide feedback for improving survivorship care. The first outcome measure was the determination of the percentage of SCP delivery completions. This number reflects the capability of the newly developed process for identifying eligible survivors and following them until treatment completion when they would be eligible for a SCP. The percentage is formulated based on the number of completed SCP visits divided by the number of eligible patients. To ensure accuracy of percentage calculations, all new patients were screened for eligibility and a chart review was completed for every patient receiving an SCP. A part of the new survivorship program work flow also included the completion of a survivorship flowsheet in the EMR. The flowsheet was a method for tracking patients who were receiving treatment for curative intent and included an estimated completion

date for treatment. The purpose of the flowsheet was to identify eligible patients for survivorship. The number of completed survivorship flowsheets were reviewed to determine whether this was an effective process for identifying eligible survivors (See Appendix F).

The second outcome measure consisted of evaluating the SCP and visit. To assess this aspect of the program, a pre- and post-visit survey was created and administered to patients receiving a survivorship appointment. Questions were developed to assess cancer survivors' knowledge of survivorship, impact of the SCP and visit, and perceived support after treatment completion. Patients were asked to fill out the pre assessment survey on an iPad via Survey Monkey prior to their visit with the APP. At the conclusion of the SCP visit, the patients were provided the post-visit survey on the iPad by either the nurse practitioner, medical assistant, or DNP student.

Third, there was an analysis of the ongoing needs of cancer survivors at the SCP visit. One new implementation for the survivorship program included the delivery of a survivorship assessment tool. At the beginning of the program evaluation, an assessment tool created by the cancer center was being utilized for assessing the concerns of cancer survivors. In March, the form was changed to a validated Cancer Impairment Screening Tool (CIST) developed by Survivorship Solutions (See Appendix G). The decision to change forms was made by the project lead and manager of the cancer center in an effort to provide consistency across disciplines. The rehabilitation team at the hospital had recently contracted with the consultancy firm, Survivorship Solutions, for survivorship resources and it was decided to utilize a tool that could be used by the cancer center and

the rehabilitation team. The CIST consists of 30 questions that ask patients about physical, spiritual, financial, and practical concerns. In addition to the CIST tool, the form includes questions specifically requested by the cancer center; the patient health questionnaire-2 (PHQ-2) to assess depression, the Generalized Anxiety Disorder-2 (GAD-2) to assess anxiety, and questions about advance directives and genetic testing. Prior to the SCP visit, cancer survivors were provided a survivorship tool to complete prior to their SCP visit with the advanced practitioner. The advanced practitioner would review the results of the assessment tool with the patient during the visit, making referral recommendations based on their assessment and the assessment key from the survivorship tool.

An additional aspect of the program evaluation included a small case study. At the SCP visit, four patients were invited to participate in answering additional questions about their survivorship experience. Patients were asked to answer four questions about the survivorship process at the conclusion of the SCP visit. At three and six months post visit, five questions were asked about SCP use, primary care visits, resource utilization, and future coordination of care (See Appendix H). The questions were asked and answers were recorded by the project lead.

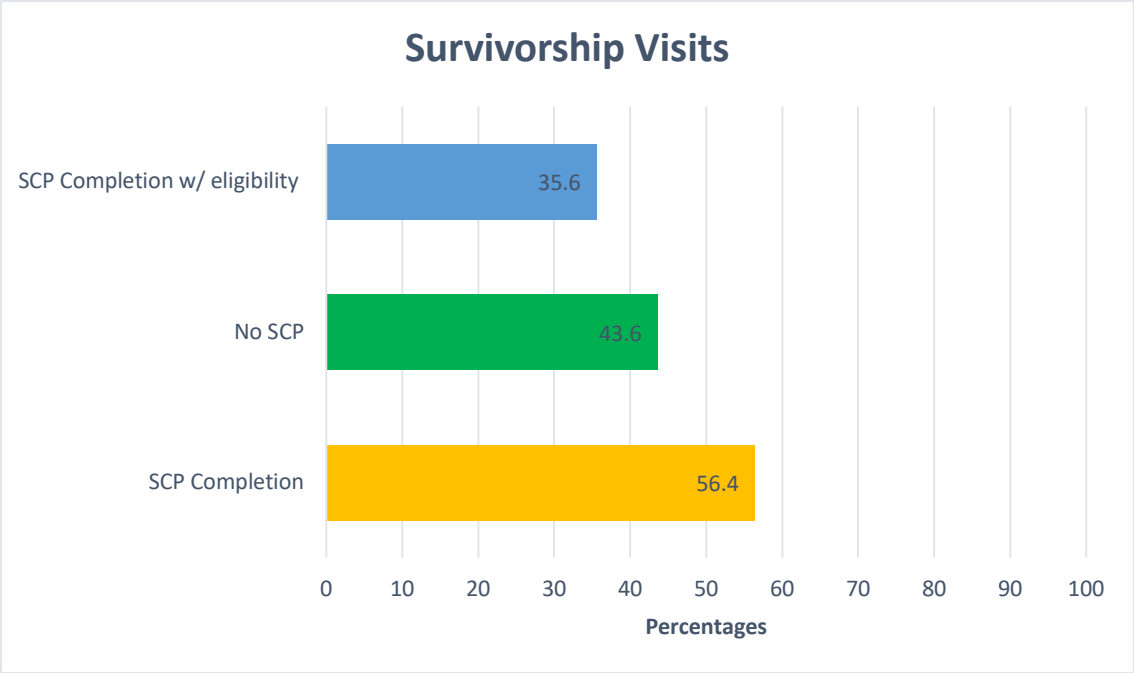
CHAPTER FIVE

OUTCOMES/RESULTS

Survivorship Visits

Between February 1st and July 31st, 2019 there were 101 eligible survivors for SCP visits based on new patient screening. During this time, 57 SCP visits were completed for a completion rate of 56.4%. However, only 36 survivorship visits met the CoC Standard 3.3 eligibility criteria, reducing the percentage to 35.6% for SCP completion (Figure 6). A possible explanation for the discrepancy between completed visits and eligibility is that the program creation increased the awareness of survivorship and, as a result, providers were independently placing referrals for patients that had completed treatment for a curative intent treatment but had not received a SCP. The reason for exclusion was primarily due to the SCP delivery not occurring within a year of diagnosis. A chart review was completed for each patient to ensure an accurate percentage calculation. There were 35 flowsheets completed on eligible new patients during this six month period, indicating that 34.6% of patients were being identified with the flowsheet process.

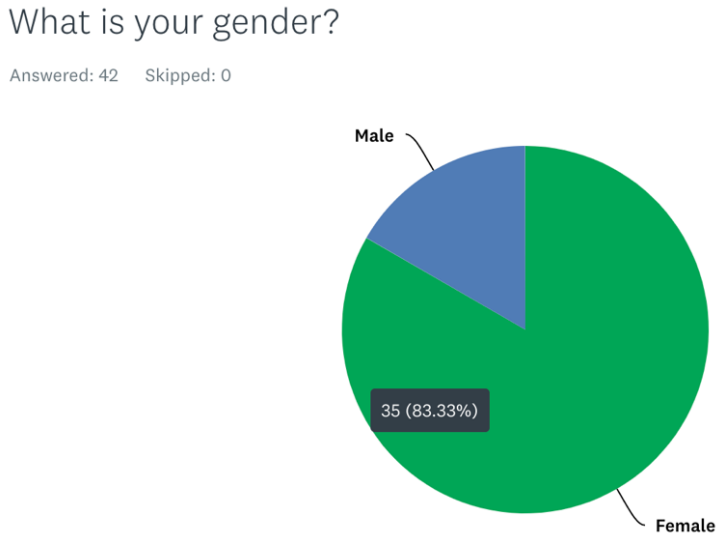
Figure 6: Comparison of Survivorship Visit Completion Outcomes



Demographics

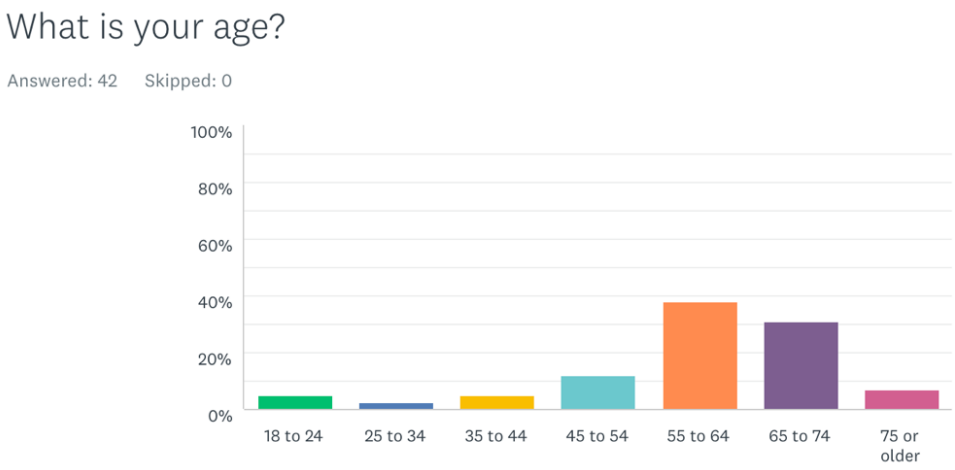
Forty-two cancer survivors completed the pre-intervention and post-intervention survey for a completion rate of 77% (N=57). Of the responses, the majority were female (83.3%) (Figure 7). Most of the patients were between the age of 55 to 64 years (38.1%), followed by ages 65 to 74 (31%), and 45 to 54 (11.9%). There were only five patients who were younger than age 44 (Figure 8).

Figure 7: Gender Distribution



ANSWER CHOICES	RESPONSES	
Female	83.33%	35
Male	16.67%	7
TOTAL		42

Figure 8*:* Age Distribution



ANSWER CHOICES	RESPONSES	
18 to 24	4.76%	2
25 to 34	2.38%	1
35 to 44	4.76%	2
45 to 54	11.90%	5
55 to 64	38.10%	16
65 to 74	30.95%	13
75 or older	7.14%	3
TOTAL		42

Pre-Intervention Survey

Forty-two patients responded to knowing the purpose of the SCP visit. Of the responses, eleven patients (26.2%) identified knowing “a lot” or “very much” about the purpose of the survivorship visit. Fourteen patients (33.3%) identified “somewhat” knowing the purpose of the visit and 17 patients (40.1%) did not know the purpose of the visit or knew “a little”. When asked about unmet needs related to their cancer diagnosis thirty-two patients (78%) indicated they had no unmet needs. Nine patients (22%) indicated having unmet needs related to their cancer. One individual skipped this

question. Most respondents (88%) had some knowledge of available supportive resources with most identifying they were “somewhat” familiar with available resources. Four patients were “a little knowledgeable” and there was only one patient with no knowledge of supportive resources. Evaluation of the knowledge of short- and long-term side effects revealed over half the patients had some degree of familiarity with the potential side effects of their treatment.

All patients reported some level of support in their transition in to survivorship. The majority of patients (74%) reported “a lot to very much” in their feelings of support in their transition into survivorship. There were no patients reporting feelings of no support. When asked about the next steps of their care the responses were mixed. Nineteen patients (45%) knew “a lot to very much” about their future care and another nineteen patients (45%) knew “somewhat to a little” about their future care. Four patients (9.5%) did not know what the next steps of their care would be in the future. Twenty patients (50%) communicated support for the importance of the survivorship visit. Thirteen patients (32.5%) described the visit as “somewhat” important and 7 patients (17.5%) reported the survivorship visit as “a little to not at all” important. Two patients did not respond to this question (See Appendix I).

Post-Intervention Survey

The post-survivorship survey revealed 38 (90%) of responders knew the purpose of the SCP visit. Four patients reported “somewhat” knowing the purpose of the survivorship visit. The majority of patients (87.5%) identified no unmet needs after the survivorship visit and 8 patients (12.5%) indicated there were still unmet needs. Two

patients responded with “very much” for unmet needs related to their cancer diagnosis. There were also two patients that skipped this question. All surveyed patients identified knowledge of supportive resources, with 54.7% indicating they “very much” knew the resources available to them. The majority of patients were familiar with the short- and long-term side effects of treatment (53.6% very much, 41.46% a lot, and 4.8% somewhat).

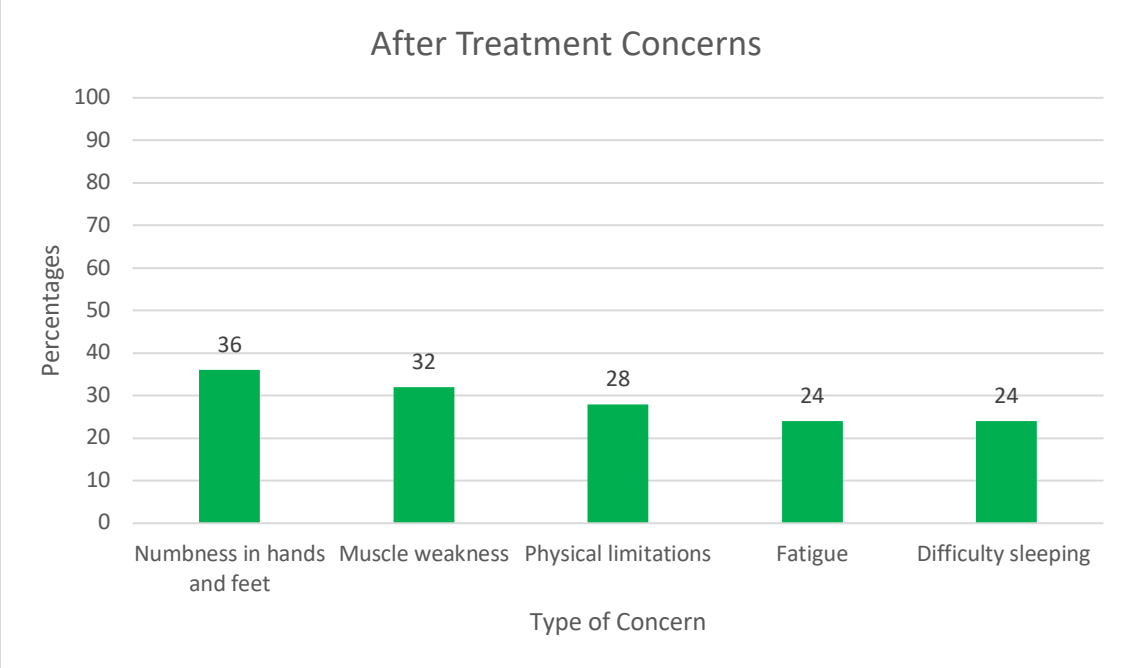
All patients identified some support in their transition into survivorship. The majority (91%) expressed “very much and a lot” in regards to the degree of support they felt in their transition. Most patients also knew the next step of their care (very much 65.8%, a lot 29.27%, and somewhat 2.44%). Of 40 responses, 60% of patients reported the visit was very important. No responses indicated it was not an important visit. Of 41 responses, 95% of patients identified learning something new from the survivorship appointment. Two patients indicated they did not learn anything new from the survivorship visit and one individual did not answer the question (See Appendix J).

Cancer Survivor Screening Tool

Prior to the SCP visit, patients were provided either the Cancer Survivor Assessment Tool created by the cancer center or the CIST tool while they waited in the lobby or the exam room. Which tool patients received depended on when they received their SCP visit. Between February 1st and July 31st, 2019, twenty-five patients completed an assessment tool. The most commonly reported concerns occurring after treatment were: numbness or tingling in hands or feet (36%), muscle weakness (32%), physical limitations (28%), fatigue, and difficulty sleeping or feeling rested upon waking (24%)

(Figure 9). Only twenty-three patients completed the additional questions on the assessment tool and most did not report any emotional concerns on the PHQ-2 or GAD-2. Four patients identified being nervous or on edge, three were unable to control their worrying, four patients had less interest in doing things, and two patients reported feeling down or depressed. Over one-half of the patients have an advance directive. Only 26% reported being involved with supportive services.

Figure 9: Percentage of Most Common Concerns after Treatment



Case Study

A total of four patients were asked to participate in a case study at the conclusion of their SCP visit. All four patients answered all 4 questions at the SCP visit. Only two patients answered the questions again at approximately 3 and 6 months. At the initial interview after the SCP visit, survivors' comments were mixed in regards to their feelings

about survivorship and the SCP. Two survivors expressed uncertainty about the visit. One individual was unfamiliar with survivorship and had never been informed why the visit was being scheduled. The other individual had been informed about the visit but did not know what to expect or what was going to be discussed. The other two survivors expressed appreciation for the visit and were looking forward to the appointment. They both felt they had been prepared for the survivorship visit and knew what to expect.

When the survivors were asked how they anticipated utilizing the SCP, one survivor expressed reassurance in having the knowledge about the long-term side effects of their treatment. Another survivor reported appreciation for an outline of the next steps of their follow-up care. Two survivors expected to use the SCP as a tool for guidance of care and a reference for future health decisions. One survivor decided to complete genetic testing after their SCP visit and learning the benefits of this testing. All the survivors had positive feelings towards the survivorship process. Three survivors were unclear about the terminology "survivor" and had not considered themselves a survivor prior to the visit. One survivor reported conducting a web search prior to the visit in order to be more prepared for the visit. When asked if anything about the survivorship process could have been done differently, three patients reported more information about survivorship would have been helpful. One survivor suggested a pamphlet or handout that described the visit. One survivor would have liked to have known if a physical exam was going to be a part of the visit.

At three months post SCP visit, one survivor reported little thought had been given to the SCP and the visit. The SCP had not been referenced since the appointment.

A primary care visit had not been completed because the survivor is a college student and her primary care provider (PCP) is in another town. She does anticipate sharing the SCP with her PCP in the future. The overall feelings of survivorship were still positive, and the survivor expressed reassurance about the information and resources available. At the time of the interview, supportive resources had not been pursued and she had no intention of seeking out additional support.

The second survivor to complete the 3 month follow-up questions reported she had also not referred back to the SCP since the visit. However, she expressed appreciation for the resource and gratitude for a document that "could keep her on track when her brain cannot remember the next steps". She had not had a visit with her PCP and was unsure whether the PCP had received her SCP. She shared intentions to set up an appointment with her PCP in the next few months. Over all, feelings of survivorship were related to emotional triggers and worry. She had found talking to others about her experience helpful and identified herself as a resource for other patients going through cancer treatment. She is involved with the local Cancer Support Community and participates in their yoga classes.

The 6 month interview revealed similar responses for SCP utilization. Both survivors had not referred back to the SCP but were reassured by the information provided. A visit with a PCP had also not occurred for either survivor and it was still unclear whether the PCPs had received their SCP. One survivor shared she was hesitant to return to her PCP because he was the provider that initiated the work up for her cancer diagnosis. Facing him again would be emotional and bring back memories she is not sure

she is ready to encounter. Feelings of survivorship were also mostly unchanged for both survivors. One survivor shared she had given survivorship little thought. The other survivor felt survivorship was a process she went through and is now on the other side. She feels she has less support from family and friends as she has become farther removed from her treatment. She expresses still needing this support. She is familiar with available resources but has not pursued anything new and declines a need for any referrals.

CHAPTER SIX

DISCUSSION

Pre/Post Comparisons

When comparing the pre- and post-visit survey data, there are some important observations. First, after the SCP visit, patients' overall knowledge of the SCP visit purpose increased (Figure 10), indicating the SCP purpose does become clearer during the visit. Second, although a handful of patients identified unmet needs on the post-survivorship survey they were not disclosed on the pre-survivorship survey. A possible explanation is that the SCP visit uncovered unmet needs that patients were unaware of or failed to disclose on the pre-survey but remembered after the visit. Over all, the majority of patients reported no unmet needs (Figure 11).

Figure 10: Comparison of Knowledge of SCP Visit Purpose between Pre- and Post-Visit Survey

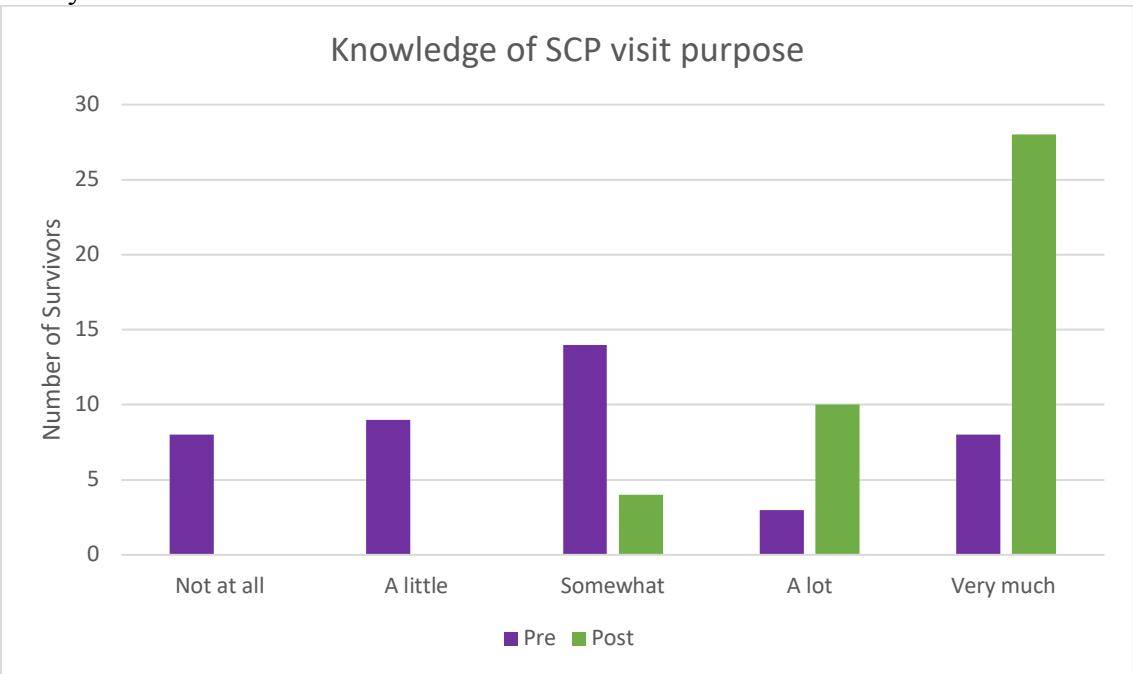
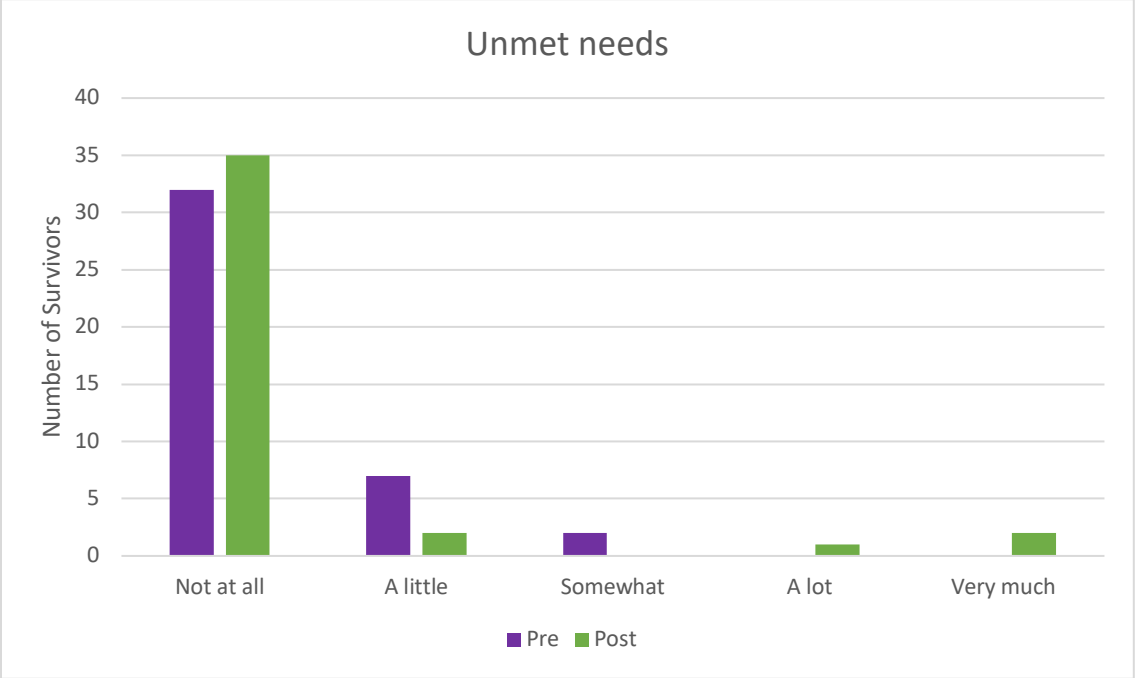


Figure 11: Comparison of Unmet Needs between Pre- and Post-Visit Survey



Third, an increase in knowledge of survivorship resources is observed between the pre- and post-visit survey. After the SCP visit, the majority of patients were very familiar with available resources, but the pre-visit survey demonstrated the majority of patients were only somewhat familiar (Figure 12). Fourth, patients reported an overall increase in familiarity with treatment side effects. The survey comparison reveals the majority of patients familiarity with treatment side effects went from "somewhat" to "very" after the SCP visit (Figure 13). This reinforces the belief that the SCP visit is beneficial in educating patients about the specifics of their treatment plans.

Figure 12: Comparison of Familiarity with Resources between Pre- and Post-Visit Survey

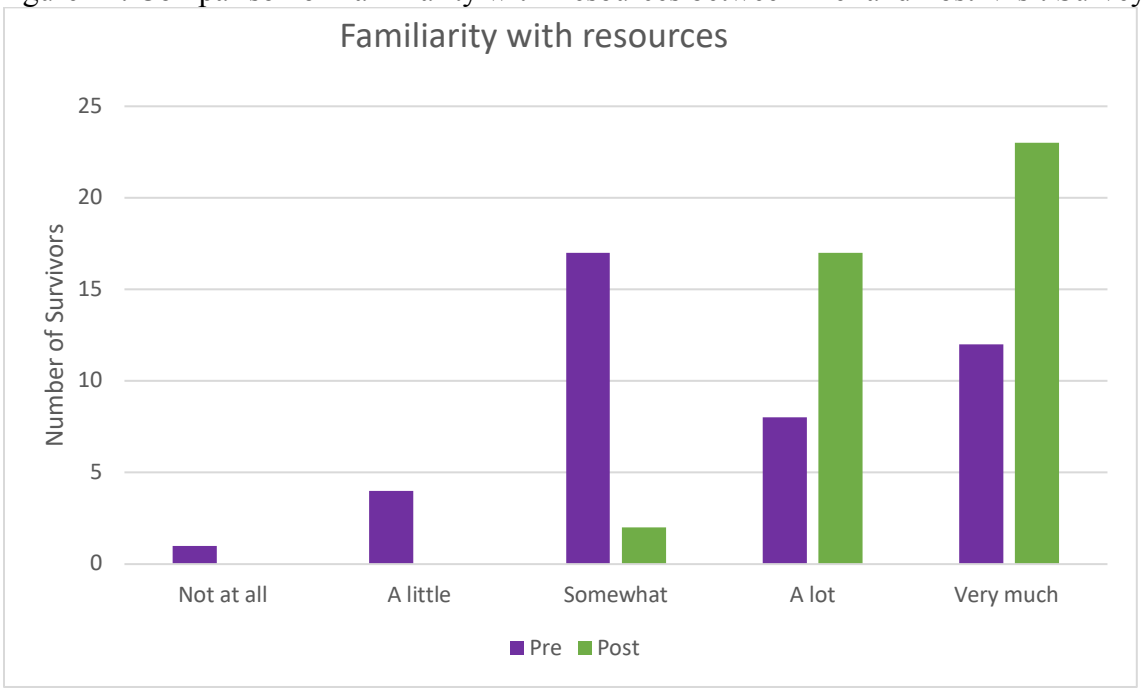
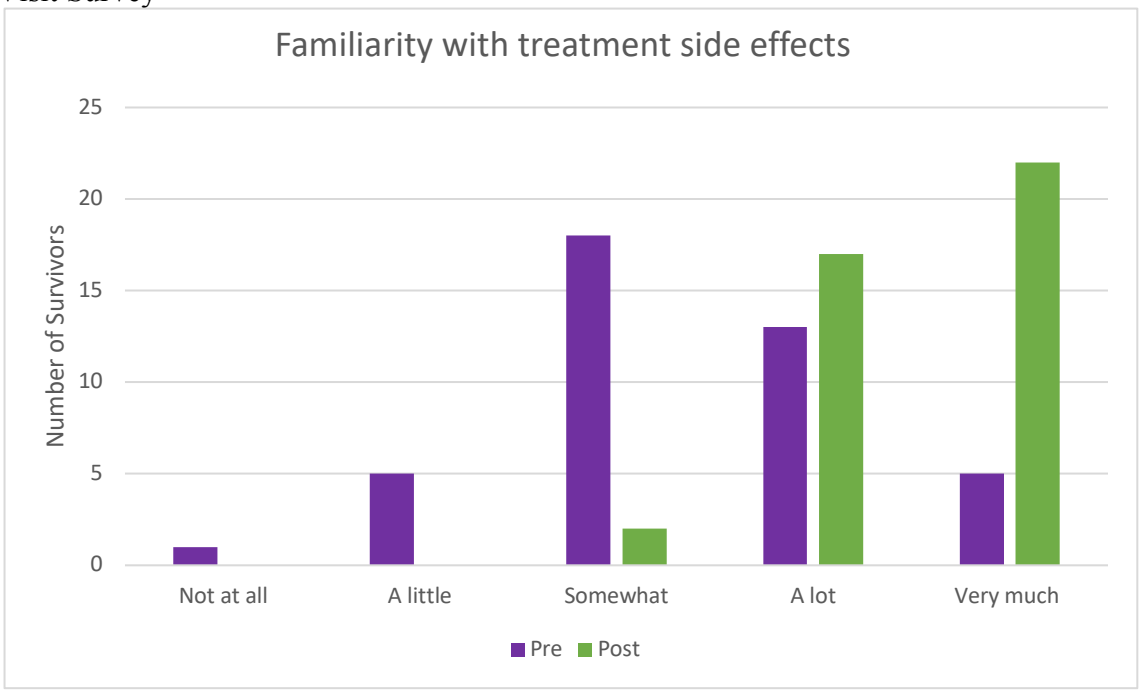


Figure 13: Comparison of Familiarity of Treatment Side Effects between Pre- and Post-Visit Survey



Finally, the post-visit survey data demonstrates that patients were more familiar with the next steps of their care and felt more supported in their transition into survivorship (Figure 14 and Figure 15). Additionally, the assessment of the importance of the SCP visit increased after the visit (Figure 16). This provides support for continuing SCP visits as part of the survivorship care program.

Figure 14: Comparison of Knowledge in Next Steps of Care between Pre- and Post-Visit Survey

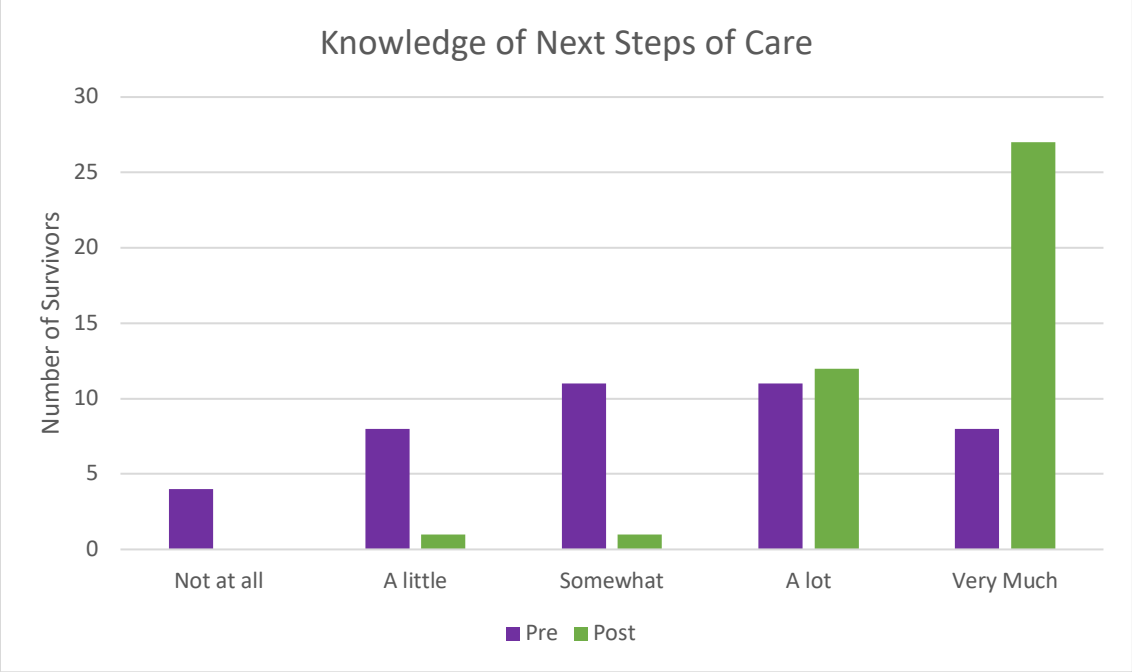


Figure 15: Comparison of Reported Support in Transition into Survivorship between Pre- and Post-Visit Survey

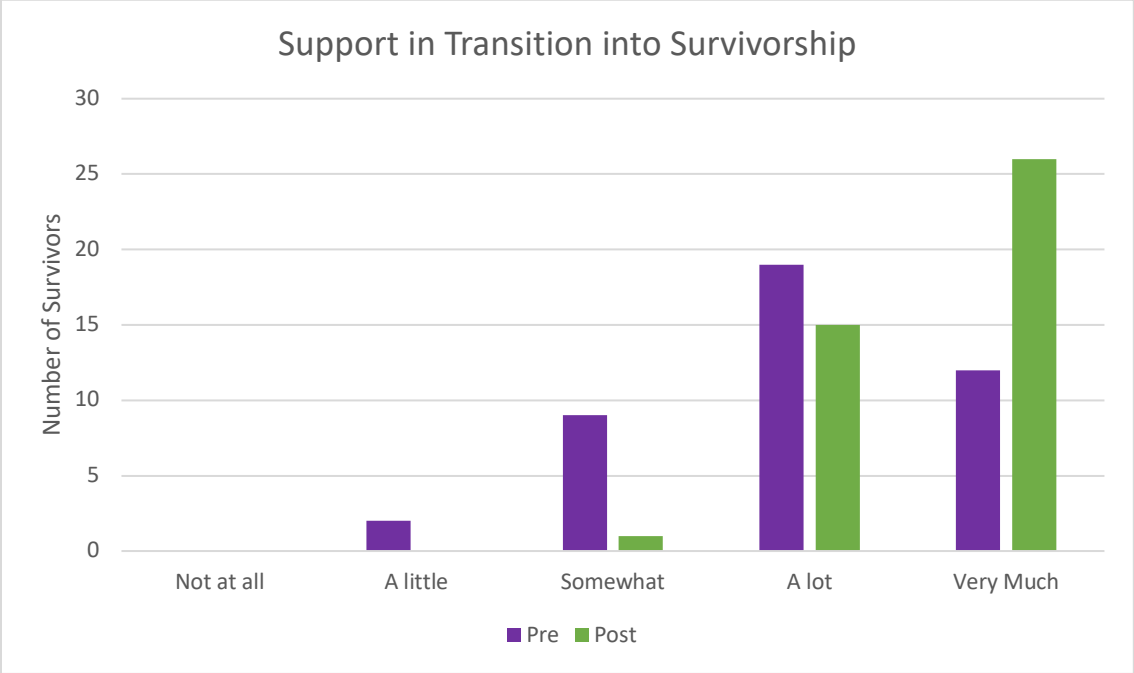
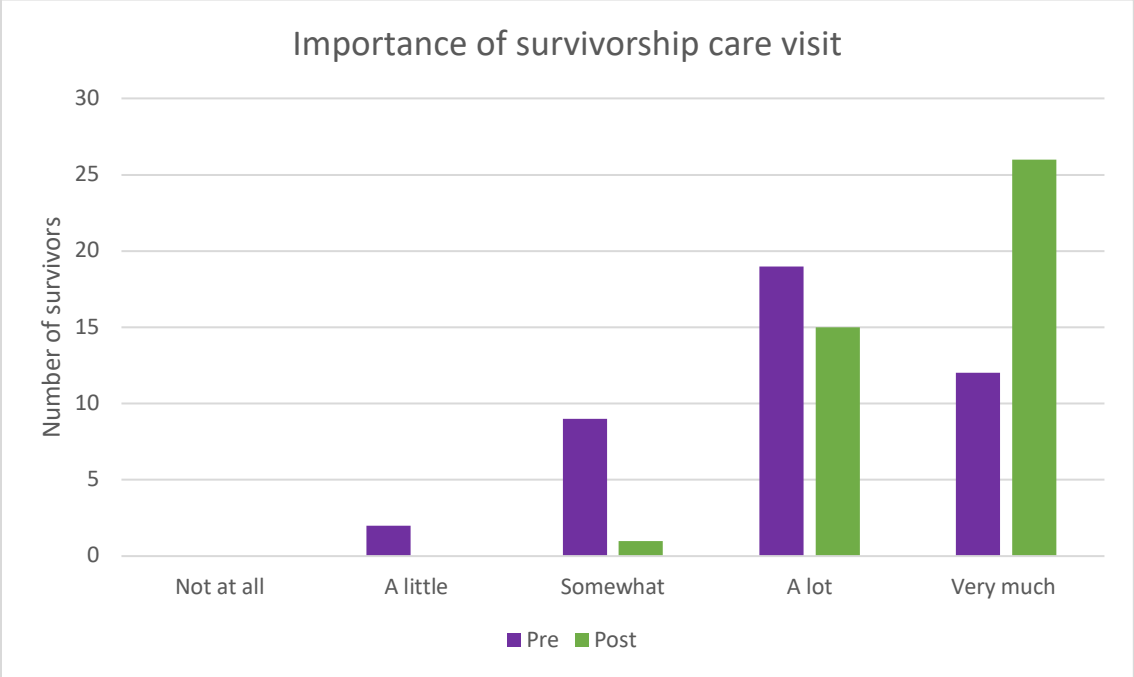


Figure 16: Comparison of Reported Importance of Survivorship Care Visit between Pre- and Post-Visit Survey



The results of the pre- and post-visit survey highlight important aspects of survivorship care and are consistent with the literature. Cancer survivors increased their knowledge regarding their care after the SCP visit and reported the SCP visit is important. These findings are consistent with the conclusions of Brant et al. (2016), Klemanski et al. (2016), and Rosales et al. (2014) as they also discovered that patients report benefits from the SCP and recommend its use.

Case Study Summary

While the case study was small, it highlights the patients' perspective and offers guidance on aspects of survivorship that should be further explored. The initial interview revealed a need for improving communication about survivorship. Creating more awareness about the survivorship visit and SCP could help prepare patients for their appointment and facilitate a more engaged discussion about their care. This may also encourage future utilization of the SCP. There were challenges in reaching patients for the 3 and 6 month post-visit follow-up, which resulted in only two patients participating in these interviews.

The feelings and reflections from these two survivors revealed different perspectives about survivorship. One survivor expressed appreciation for the information but otherwise was disengaged from resources and PCP follow-up. The other survivor shared feelings that revealed the emotional aspect of survivorship and the complexity of this process that others may encounter. The two different perspectives reinforce the idea that survivorship care should be individualized and that each survivor's needs will not be the same. This observation is consistent with the findings from Hahn et al. (2018), which

concluded survivorship care is not a one-size fit all and meeting patients' needs requires a more comprehensive and patient-specific approach. Further exploring different patient perspectives could help the development of a comprehensive program that can meet a variety of needs. Both survivors had also not been evaluated by their PCP at 6 months. Further attention to the barriers preventing this key component of survivorship care should be addressed as it is encouraged in order to help patients begin transitioning care from their oncologist after treatment.

Limitations

The pre/post-visit study design is a limitation to this study as it does not account for changes that can occur over time and changes that could be related to variables for which there is no control. Such variables could include personal factors/experiences, the advanced practitioner delivering the SCP visit, time of day, type of cancer and treatment, and the length of time since treatment completion. Another limitation is the CoC definition of survivor and calculation of eligible patients. Part of the CoC definition includes the delivery of the SCP within 6 months of treatment completion or within a year from diagnosis. This is extended to 18 months for patients treated with hormonal therapy. In an effort to implement the new survivorship process and improve awareness for survivorship, providers and staff at the cancer center were placing survivorship referrals for any patient who had completed treatment with a stage I-III cancer diagnosis. As a result, 11 completed SCP visits were unable to be included in the percentage calculation because the SCP was delivered after the appropriate timeline as designated by the CoC. There were also 33 eligible patients included in percentage calculations that

were diagnosed in 2018 but completed treatment in 2019. The CoC accounts for this carryover in eligible patients with the assumption that every year approximately the same number of patients will be carried over to the following year for treatment completion. However, this number is not precise and variability is inevitable.

Clinical Implications

Since the development and implementation of this project, new CoC accreditation standards have been created which will impact survivorship care delivery requirements. The change has transitioned Standard 3.3 Survivorship Care Plan into Standard 4.8 Survivorship Program (CoC, 2020). The requirement for meeting a designated percentage for SCP delivery has been eliminated and the focus has shifted to developing a survivorship program. The standard emphasis is now on providing services and programs for survivors, specifically, having a designated leader and team to guide these efforts. This change will be phased in over the next year, and organizations seeking accreditation are expected to be in compliance by January 1st, 2021 (CoC, 2020).

Meeting Standard 4.8 will require developing a multidisciplinary team, formally documenting at least three services for cancer survivors, and annually reporting the participation in the defined services and areas for improvement to the organization's cancer committee (CoC, 2020). The SCP is still encouraged and can be a part of the services offered for cancer survivors, but SCPs are no longer a requirement. Individual organizations will determine whether to continue using SCPs and which population of survivors will receive an SCP. The program will require ongoing monitoring and

evaluation. Goals, resources, and services may change or remain the same year to year as long as the requirements are being met (CoC, 2020).

Perhaps the most beneficial change to come of the CoC 2020 standard changes is the recognition that survivorship care requires a multidisciplinary team effort and ongoing monitoring and development. This change is supported by the literature as numerous studies have recommended survivorship become a more individualized process (Birken et al., 2018b; de Rooij et al., 2018b; Hahn et al., 2018; Jacobsen et al., 2018; Nekhlyudov et al., 2017). The proposed CoC survivorship program changes will be able to better address the specific needs of cancer survivors and can involve stakeholders' expectations as the program will have multidisciplinary representation. Organizations are being provided more freedom in developing a program that fits the patients' and organizational needs. While creating a survivorship program is a way to assign responsibility to team members for this aspect of care, the time requirements and financial impact remain to be seen. Additionally, the monitoring of the program, identifying cancer survivors, and developing services may also be challenges of Standard 4.8.

Recommendations

Reflecting on the findings of a program evaluation is essential for promoting continued use and guiding changes for program improvement. The results of this program evaluation offer recommendations for enhancing the successful portions of the program, expanding survivorship services, and progressing towards the new CoC 2020 guidelines.

Based on the survivors' responses to the survey, support for the continued use of the SCP and visit would be encouraged. Patients increased their familiarity with treatment side effects, improved their knowledge of available resources, and all survivors found some benefit to the visit. This finding is consistent with study results of Brant et al. (2016) and Kinnane et al. (2017) as they found patients had high satisfaction with SCPs and recommended their use. Maintaining the SCP as a part of survivorship care will also meet one of the requirements of the new CoC 2020 guidelines. If the cancer center chooses to continue with the SCP, one recommendation would be to focus on improving patients' preparation for the SCP visit. Of the surveyed survivors, 40% had limited knowledge about survivorship prior to their visit. Improving patients understanding of survivorship and the purpose of the SCP will encourage more active participation during the visit and help patients get the most of the services being provided.

Creating a designated team will also be essential to providing consistent and patient-centered survivorship care. The successful implementation of survivorship care has been observed in programs that designate healthcare professionals to leadership roles within survivorship program (Isaacson et al., 2018). Leadership is essential in coordinating and promoting survivorship care. This program evaluation revealed the completion of SCP visits for eligible patients did not meet the 50% requirement but overall SCP delivery almost doubled, which shows the process can work. The program evaluation also revealed the flowsheet process is not being utilized consistently, which will lead to decreased identification of cancer survivors. For continued use of this process, it is recommended a member of the survivorship program team be assigned to

tracking eligible patients with the flowsheets based on the defined criteria or a new work flow should be created. Relying on the nurse navigators to fulfill this aspect of the work flow is not reliable and may add another task to an already overwhelming work load.

The continued use of the CIST tool is strongly recommended. Jacobsen et al. (2018) concluded in their systematic review that the SCP is not enough and recommended survivorship care involve more focus on improving health outcomes. Utilizing the CIST tool is one way to move care beyond one document. It will also assist in the cancer center's transition to implementing the CoC 2020 guidelines. Specifically, the CIST tool provides focus for the SCP visit, opportunity for referrals, and a method for identifying cancer survivors needs. Connecting patients with community resources to address their specific needs may result in better resource utilization. Only 26% of surveyed survivors reported being involved with supportive resources. The number of available resources can be overwhelming and providing survivors with individualized suggestions may offer the encouragement needed to seek out additional support. This may require educating staff about current resources and support services in order to effectively empower survivors to seek out and utilize these resources.

As part of the program evaluation, the project lead worked with the IT department to create a flowsheet in the EMR for entering the results of the CIST tool. This allows report generation through the EMR which will provide specific information regarding the most commonly identified issues facing the cancer survivors at the organization. With the flowsheet data, the cancer center can continue to customize its education and resources to meet the actual needs of their patients and not just the assumed needs of cancer survivors

in general. Further exploring whether cancer survivors with a specific type of cancer find more benefit from the SCP may also help narrowly define which populations to focus on in the SCP delivery. There are also other aspects of survivorship that were not addressed in this evaluation but would be important to assess in the future, including improvement of collaboration with PCPs, ensuring patients are following up with PCPs after treatment, and patients use of their SCP.

Conclusion

The CoC changes to survivorship standards represent an adaption to the approach of survivorship care. Moving away from a mandated SCP, which had mixed reports on survivors' outcomes and difficulty with implementation, towards a more patient-focused program will hopefully benefit cancer survivors. The literature has clearly identified the ongoing needs of cancer survivors and perhaps it was short sighted to expect one document to be the solution for all patients. However, this program evaluation demonstrates that patients find value in the SCP and visit and its use should not be abandoned altogether. It is well understood that survivorship care can be complex. The needs of survivors can vary greatly, depending on the type of cancer and the treatment received. Providing a variety of services and programs may be a way to diversify survivorship care and expand the care being offered in order to meet the needs of more survivors. Improving patients' understanding of survivorship is one way to increase engagement in this aspect of care. Additionally, becoming more familiar with the actual needs of cancer survivors through the CIST tool and referrals will help the development of a program that is evolving with its patients' needs. Ongoing evaluation of the survivor

identification process, program development, and survivorship services will be essential in sustaining a survivorship program that brings value to cancer survivors.

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APPENDICES

APPENDIX A

COC SURVIVORSHIP STANDARD 3.3

STANDARD 3.3
Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a treatment summary and follow-up plan to patients who have completed cancer treatment. The process is monitored and evaluated annually by the cancer committee.

DEFINITION AND REQUIREMENTS

The Institute of Medicine report *From Cancer Patient to Cancer Survivor* outlines the importance of providing cancer survivors with a comprehensive treatment summary and follow-up plan (i.e. survivorship care plan) that reflects the treatment they received, and addresses post-treatment needs and follow-up care to improve health and quality of life.

The Survivorship Care Plan (SCP) is a record that summarizes and communicates what transpired during active cancer treatment, recommendations for follow-up care and surveillance testing/examinations, referrals for support services the patient may need going forward and other information pertinent to the survivor's short- and long-term survivorship care.

The American Society of Clinical Oncology (ASCO) has defined the minimum data elements to be included in a treatment summary and SCP. This core set of data elements and templates are available on the ASCO website. At a minimum, all SCPs must include ASCO's recommended elements describing treatment summary and a follow-up care plan to meet compliance for this standard. Additional resources to assist with the development of SCPs are available through the National Coalition for Cancer Survivorship, Journey Forward, American Cancer Society, and LIVESTRONG Foundation.

PROCESS REQUIREMENTS

Cancer programs must develop and implement processes to monitor the formation and dissemination of a SCP for analytic cases with Stage I, II, or III cancers that are treated with curative intent for initial cancer occurrence and who have completed active therapy.

Within the SCP processes are policies and procedures identifying the appropriate healthcare provider(s) from patients' oncology care team who will be responsible for approving and discussing the SCP. Providers who are part of the patient's care team that are appropriate under the standard to deliver the SCP include:

- Physicians
- Registered Nurses
- Advanced Practice Nurses
- Nurse Practitioners
- Physician Assistants
- Credentialed clinical navigators (does not include lay navigator)

The printed or electronic survivorship care plan must contain input from the principal physician and oncology care team who coordinated the oncology treatment for the patient, as well as input from the patient's other care providers (outside treatment information), if applicable. If two separate facilities are providing treatment, both facilities collaborate to complete and provide the SCP. In all cases, programs, hospitals, and physician offices should work together to provide the information necessary for completion of a SCP that contains all required elements.

The survivorship care plan is given and discussed with the patient upon completion of active, curative treatment and recorded in the patient medical record. The timing of delivery of the SCP is within one year of the diagnosis of cancer and no later than six months after completion of adjuvant therapy (other than long-term hormonal therapy). The 'one-year from diagnosis' requirement to have a SCP delivered is extended to 18-months for patients receiving long-term hormonal therapy. Providing the SCP by mail, electronically, or through a patient portal without discussion with the patient does not meet the standard.

Continued on next page

Patients excluded (ineligible) from Standard 3.3 requirement include:

- Patients with Stage 0 or IV or metastatic disease, though survivors by varying definitions are not required to receive a SCP under Standard 3.3. However, programs may choose to provide SCPs to metastatic patients.
- Patients who are pathologically diagnosed but never treated or seen for follow-up by the accredited program are not required to receive a SCP from the facility providing diagnosis.

Implementation of the standard and required percentage of SCPs provided must follow the schedule as outlined:

- January 1, 2015–December 31, 2015: Implement process to provide SCPs to ≥ 10 percent of eligible patients who have completed treatment.
- End of 2016: Provide SCPs to ≥ 25 percent of eligible patients who have completed treatment.
- End of 2017: Provide SCPs to ≥ 50 percent of eligible patients who have completed treatment.
- End of 2018 and on: Provide SCPs to ≥ 75 percent of eligible patients who have completed treatment.

During the implementation periods, cancer programs may choose to initially concentrate on their most common cancer sites while demonstrating progress on expanding SCP to eligible patients for all disease sites. To calculate the percentage of eligible patients, it is recommended that you begin with your number of analytic cases as the denominator and then subtract ineligible patients.

SPECIFICATIONS BY CATEGORY

All programs fulfill the standard as written.

DOCUMENTATION

The program completes all required standard fields in the SAR.

Each calendar year, the program uploads:

- Policies and procedures to generate and disseminate a comprehensive treatment summary and survivorship care plan to eligible cancer patients who have completed cancer treatment. The documented processes must include, at a minimum:
  - » Defined patient eligibility
  - » Identify appropriate mechanisms for generating the survivorship care plan
  - » Identify the appropriate individual(s) for delivering the survivorship care plan
  - » The method and timing of delivery of the survivorship care plan
  - » Tracking and reporting the number of SCP's provided to patients
- A sample of a treatment summary and survivorship care plan that is used by the cancer program
- Cancer committee minutes that document the annual evaluation of the SCP processes and the outcomes of the evaluation

During the on-site visit, the surveyor will discuss with the cancer committee the process implemented to create and disseminate SCPs for eligible patients.

RATING COMPLIANCE

(1) Compliance: Each calendar year, the program fulfills all of the following compliance criteria:

1. The cancer committee develops a process to generate and disseminate a comprehensive treatment summary and survivorship care plan to eligible cancer patients who have completed cancer treatment.
2. The process is monitored, evaluated, and presented to the cancer committee annually, and documented in the minutes.
3. The number of eligible patients who received a survivorship care plan meets the implementation criteria.

(5) Noncompliance: The program does not fulfill one or more of the compliance criteria each calendar year.

APPENDIX B

INSTITUTIONAL BOARD REVIEW EXEMPTION

MONTANA STATE UNIVERSITY

INSTITUTIONAL REVIEW BOARD

For the Protection of Human Subjects
FWA 00000165

2155 Analysis Drive
c/o Microbiology & Immunology
Montana State University
Bozeman, MT 59718
Telephone: 406-994-4706
FAX: 406-994-4303
E-mail: cherylj@montana.edu

Chair: Mark Quinn
406-994-4707
mquinn@montana.edu
Administrator:
Cheryl Johnson
406-994-4706
cherylj@montana.edu

MEMORANDUM

TO: Melissa Bowen and Jennifer Sofie

FROM: Mark Quinn Mark Quinn CTJ
Chair, Institutional Review Board for the Protection of Human Subjects

DATE: January 8, 2019

RE: *"Improving Survivorship Care at a Community Cancer: A Program Evaluation"* [MB010819-EX]

The above research, described in your submission of January 7, 2019, is exempt from the requirement of review by the Institutional Review Board in accordance with the Code of Federal regulations, Part 46, section 101. The specific paragraph which applies to your research is:

___ (b) (1) Research conducted in established or commonly accepted educational settings, involving normal educational practices such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

__X__ (b) (2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

___ (b) (3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if: (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) federal statute(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

___ (b) (4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available, or if the information is recorded by the investigator in such a manner that the subjects cannot be identified, directly or through identifiers linked to the subjects.

___ (b) (5) Research and demonstration projects, which are conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine: (i) public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; or (iv) possible changes in methods or levels of payment for benefits or services under those programs.

____ (b) (6) Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome foods without additives are consumed, or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA, or approved by the EPA, or the Food Safety and Inspection Service of the USDA.

Although review by the Institutional Review Board is not required for the above research, the Committee will be glad to review it. If you wish a review and committee approval, please submit 3 copies of the usual application form and it will be processed by expedited review.

APPENDIX C

DEIDENTIFICATION ANALYSIS AND PROJECT APPROVAL

Bozeman Health De-Identification Analysis

Identifier Present	Yes	No
Names		X
All geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, & their equivalent geocode, except for the initial 3 digits of a zip code if the unit formed by combining zip codes with the same three initial digits contains more than 20K people and the initial 3 digits of a zip code for all such geographic units containing 20K or fewer people is changed to 000		X
All elements of dates (except year) directly related to an individual, including DOB, ADM Date, DC date, Date of Death, or Age over 89		X
Telephone Number		X
Fax Number		X
E-Mail Address		X
SSN		X
Medical Record Number		X
Health Plan Beneficiary Numbers		X
Account Numbers		X
Certificate/license Numbers		X
Vehicle Identifiers and Serial Numbers, License Plate Numbers		X
Device Identifiers and Serial Numbers		X
Web Universal Resource Locators (URLs)		X
Internet Protocol (IP) address numbers		X
Biometric Identifiers, including finger and voice prints		X
Full face photographic images and any comparable images		X
Any other unique identifying number, characteristic, or code, except as permitted by paragraph (c) of 164.514(b)		X
Does BDHS have actual knowledge that the information could be used alone or in combination with other information to identify an individual who is a subject of the information?		X

Reason for Disclosure/Use: Melissa Bowen is a nurse navigator for the Cancer Center and would like to conduct a study to improve the care plan compliance rate for the survivorship program, which is a component of the accreditation program that the Cancer Center participates in. Currently we are struggling with meeting this goal and she would like to gather data to be utilized to assist in improve our compliance rate. Specific patient information will not be gathered, there will be a focus on diseases and approximately 50-75 patients will be part of the study. Identify the total number of eligible patients and compare to the patients that have a completed care plan. Review that any element of a date service must be removed, it would be appropriate to reference January-June 2018. Also discussed if a certain disease process had 10 or less patients then would need to aggregate this data.

Goal: Utilize data to improve nursing workflow to increase the number of eligible patients who receive a completed plan of care.

Prior to releasing the de-identified information, please review with the Privacy Officer to ensure the data has been de-identified.

APPENDIX D

SURVEY CONSENT

Survey Consent

I am an MSU Doctorate of Nursing student at MSU and I am evaluating survivorship care at Bozeman Health. Meeting the needs of cancer survivors and preparing for the transition in care after treatment is a priority of Bozeman Health Cancer Center. In order to better understand the effectiveness of the current survivorship program and areas for improvement, you are being asked to complete the following survey. If you agree to participate you will be asked to complete a three-minute survey before and after your survivorship appointment today. Participation is voluntary and you can choose to not answer any questions you do not want to answer and/or you can stop at any time. If you choose not to participate, you will still receive the scheduled survivorship care visit as planned with no changes to the care being provided to you. Your answers will not be associated with any personal information. By completing the survey, you are implying consent.

APPENDIX E

CASE STUDY CONSENT

Case Study Consent

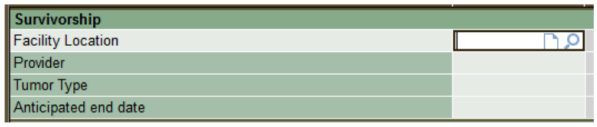
I am an MSU Doctorate of Nursing student at MSU and I am evaluating survivorship care at Bozeman Health. Meeting the needs of cancer survivors and preparing for the transition in care after treatment is a priority of Bozeman Health Cancer Center. In order to better understand the effectiveness of the current survivorship program and areas for improvement, you are being asked to participate in a case study. If you agree to participate you will be asked to answer additional questions after your survivorship appointment today, and again in 3 and 6 months. In 3 and 6 months you will be contacted by telephone or at a future visit. Participation is voluntary. You can choose to not answer any questions you do not want to answer and/or you can stop at any time. If you choose not to participate, you will still receive the scheduled survivorship care visit as planned with no changes to the care being provided to you. Your answers will not be associated with any personal information. By agreeing to answer the questions you are providing consent.

APPENDIX F

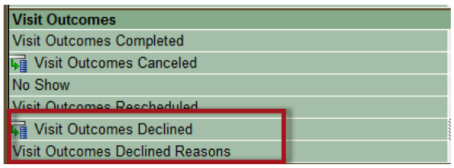
SURVIVORSHIP FLOWSHEET

II. Nurse Navigator Chemo Education Appointment

- During the Chemo education appointment, the Nurse Navigator will initiate the survivorship flowsheet (#1851) for all curative intent treatments and document the facility location, provider, and anticipated end date.



  - » If treatment end date changes, the Nurse Navigator will update survivorship flowsheet.
  - » If patient declines survivorship visit, the Nurse Navigator will document this in the survivorship flowsheet under the Visit Outcomes section.



APPENDIX G

CANCER IMPAIREMENT SCREENING TOOL

BOZEMAN HEALTH
DEACONESS HOSPITAL

Cancer Impairment Screening Tool (CIST)

Objective

The Cancer Impairment Screening Tool (CIST) is a holistic screening tool that is used to identify ***physical, emotional,*** and ***functional impairments*** that are commonly experienced by patients diagnosed with cancer. These side effects or problems may develop as a new onset of symptoms, or they may result from the worsening of pre-existing conditions.

It is important to systematically screen oncology patients multiple times throughout the care continuum because impairments may occur at any time during cancer care and many impairments may not be communicated to or identified by treating providers. Pivotal medical visits, such as *diagnosis, completion of chemotherapy or radiation treatments, discharge,* and *follow-ups* are essential opportunities to screen patients for impairments.

In addition to screening patients at specific medical visits, patients may also be screened as often as necessary to ensure that new impairments are identified acutely or when pre-existing conditions worsen. Impairment screenings are also ideal opportunities to educate patients regarding *potential* impairments that may occur during or after their cancer diagnosis and treatments. Copies of the CIST may be issued to patients as handouts or educational supplements if no patient reference is available.

All members of the cancer care team should be proficient in the purpose, administration, and interpretation of the CIST. When impairments are identified, team members should be knowledgeable regarding referral pathways to appropriate and available cancer support services.

Administering the Tool

Patients should complete the CIST independently if possible. However, if a patient is unable to complete the screen independently, a caregiver or staff member may verbally read the statements to the patient and record patient responses as indicated. The administering staff member should instruct the patient as follows:

"There are well-known physical, emotional, and functional side effects that commonly occur due to your type of cancer and its treatments. Detecting these problems, or "impairments" as soon as possible is important because impairments respond best when caught early. It is also important for us to be aware of any pre-existing problems you have, because they may worsen during this time.

It is important to your cancer care team that you maintain your highest function and quality of life. Our team can address most side effects and problems that you may experience due to your cancer diagnosis and treatments. Cancer support services, such as cancer rehabilitation and counseling, are often covered by insurance and are recommended by your provider to optimize your care.

Please take a couple minutes to review the statements listed on this form. If you are currently experiencing any of the problems listed or have had these problems in the past, please indicate so by marking the appropriate response box. Do not leave any statements without a response.

Keep in mind that side effects may occur at any time, so you may be screened multiple times to ensure that we don't miss anything that comes up.

Please let us know if you have any questions."

BOZEMAN HEALTH
DEACONESS HOSPITAL

Patient label:

Cancer Impairment Screening Tool (CIST)

Date:_____

This screening tool identifies ***impairments,*** which are ***physical, emotional,*** and ***functional*** **problems** that you may be experiencing because of your cancer or cancer treatments. Because impairments may occur *before, during,* or *after* cancer treatments have ended, you may be surveyed multiple times.

Please select the most appropriate response to the following statements:

	NO PROBLEM	PROBLEM: Existed **before** my cancer diagnosis or treatments began.	PROBLEM: Started **after** my cancer diagnosis or treatments began.
1. I feel aches, stiffness, or pain.	☐	☐	☐
2. I don't have full motion in my joints.	☐	☐	☐
3. My muscles feel weak.	☐	☐	☐
4. Parts of my body feel full, heavy, or swollen.	☐	☐	☐
5. I feel numbness or tingling in my hands or feet.	☐	☐	☐
6. I have difficulty handling small objects (*e.g., buttoning, writing, texting, etc.*)	☐	☐	☐
7. I am unusually tired or don't have the energy to perform my daily activities (*e.g., household chores, shopping, errands, child care, elder care, pet care, etc.*)	☐	☐	☐
8. I have difficulty with my ability to work, go to school, care for my home, or care for others.	☐	☐	☐
9. My ability to exercise or be physically active is limited.	☐	☐	☐
10. I have difficulty with driving or transportation.	☐	☐	☐
11. I have concerns about my balance or have fallen.	☐	☐	☐
12. I have difficulty changing position, walking, or climbing stairs (*e.g., getting in or out of bed, sit to stand, speed, distance, etc.*)	☐	☐	☐
13. I feel dizzy at times.	☐	☐	☐
14. I have difficulty with my vision or hearing.	☐	☐	☐
15. I am confused, easily distracted, or forgetful at times.	☐	☐	☐
16. I have difficulty putting words together, understanding, or following directions.	☐	☐	☐
17. I have difficulty with speaking or oral function (*e.g., effort in speaking, forming words, slurred speech, kissing, etc.*)	☐	☐	☐
18. I have difficulty swallowing or eating (*e.g., pain, choking, coughing, food sticking, dental problems, etc.*)	☐	☐	☐
19. My appetite is abnormal (*e.g., increased, decreased, nausea, vomiting, etc.*), or I have lost/gained weight without trying.	☐	☐	☐
20. I have concerns about my appearance or body image.	☐	☐	☐
21. I have difficulty with my sexual function or intimacy.	☐	☐	☐
22. I have problems with my urination or bowel movements (*e.g., incontinence, urgency, frequency, constipation, diarrhea, etc.*)	☐	☐	☐
23. I have difficulty with my self-care or personal hygiene (*e.g., eating, bathing, grooming, dressing, toileting, etc.*)	☐	☐	☐
24. I have difficulty sleeping or do not feel fully rested when I wake up.	☐	☐	☐
25. I have concerns about my emotions (*e.g., sad, nervous, anxious, worried, hopeless, fearful, uninterested, lonely, guilty, etc.*)	☐	☐	☐
26. I struggle with my spirituality (*i.e., religion, meaning of life, purpose, etc.*)	☐	☐	☐
27. I have concerns or difficulties with my finances (*e.g., cost of care, loss of income, housing, transportation, childcare, food, medications, etc.*)	☐	☐	☐
28. I have habits or behaviors that cause me concern (*e.g., smoking, drug use, alcohol abuse, poor eating habits, risk-taking, domestic abuse, etc.*)	☐	☐	☐
29. I am unsatisfied with my quality of life (*e.g., independence, relationships, recreational/social activities, wellness, etc.*)	☐	☐	☐
30. I have another problem not listed.	☐	☐	☐

(Please see reverse side of page.)

BOZEMAN HEALTH
DEACONESS HOSPITAL

CIST Interpretation

Patients assign item responses as "no problem" or "problem". Any item indicated as "problem" should be followed up with additional questions to determine appropriate patient resources or for referral to appropriate interdisciplinary cancer care services to further evaluate the impairment. This CIST *key* may aid in determining appropriate referral pathways.

KEY	PT	OT	ST	DIETARY / NUTRITION	MENTAL HEALTH	SOCIAL WORK	SPIRITUAL CARE	PALLIATIVE CARE	NO PROBLEM	IMPAIRMENT
1.	I feel aches, stiffness, or pain.								No Problem	DISCOMFORT, PAIN
2.	I don't have full motion in my joints.								No Problem	RANGE OF MOTION
3.	My muscles feel weak.								No Problem	STRENGTH
4.	Parts of my body feel full, heavy, or swollen.								No Problem	EDEMA, LYMPHEDEMA
5.	I feel numbness or tingling in my hands or feet.								No Problem	NEUROPATHY
6.	I have difficulty handling small objects (*e.g., buttoning, writing, texting, etc.*)								No Problem	FINE MOTOR, COORDINATION
7.	I am unusually tired or don't have the energy to perform my daily activities (*e.g., household chores, shopping, errands, child care, elder care, pet care, etc.*)								No Problem	ENDURANCE, FATIGUE
8.	I have difficulty with my ability to work, go to school, care for my home, or care for others.								No Problem	ADLs
9.	My ability to exercise or be physically active is limited.								No Problem	PHYSICAL ABILITY
10.	I have difficulty with driving or transportation.								No Problem	DRIVING, TRANSPORTATION
11.	I have concerns about my balance or have fallen.								No Problem	BALANCE
12.	I have difficulty changing position, walking, or climbing stairs (*e.g., getting in or out of bed, sit to stand, speed, distance, etc.*)								No Problem	GROSS MOTOR, COORDINATION
13.	I feel dizzy at times.								No Problem	VESTIBULAR
14.	I have difficulty with my vision or hearing.								No Problem	VISION, HEARING
15.	I am confused, easily distracted, or forgetful at times.								No Problem	MEMORY, CONCENTRATION, COGNITION
16.	I have difficulty putting words together, understanding, or following directions.								No Problem	COGNITION, PROCESSING
17.	I have difficulty with speaking or oral function (*e.g., effort in speaking, forming words, slurred speech, kissing, etc.*)								No Problem	COMMUNICATION, PHONATION
18.	I have difficulty swallowing or eating (*e.g., pain, choking, coughing, food sticking, dental problems, etc.*)								No Problem	SWALLOWING
19.	My appetite is abnormal (*e.g., increased, decreased, nausea, vomiting, etc.*) OR I have lost/gained weight without trying.								No Problem	APPETITE, TASTE, TEXTURE
20.	I have concerns about my appearance or body image.								No Problem	BODY IMAGE, APPEARANCE
21.	I have difficulty with my sexual function or intimacy.								No Problem	SEX, INTIMACY
22.	I have problems with my urination or bowel movements (*e.g., incontinence, urgency, frequency, constipation, diarrhea, etc.*)								No Problem	URINARY/BOWEL CHANGES
23.	I have difficulty with my self-care or personal hygiene (*e.g., eating, bathing, grooming, dressing, toileting, etc.*)								No Problem	SELF-CARE, BATHING,
24.	I have difficulty sleeping or do not feel fully rested when I wake up.								No Problem	SLEEP
25.	I have concerns about my emotions (*e.g., sad, nervous, anxious, worried, hopeless, fearful, uninterested, lonely, guilty, etc.*)								No Problem	EMOTIONAL
26.	I struggle with my spirituality (*i.e., religion, meaning of life, purpose, etc.*)								No Problem	SPIRITUALITY
27.	I have concerns or difficulties with my finances (*e.g., cost of care, loss of income, housing, transportation, childcare, food, medications, etc.*)								No Problem	FINANCES
28.	I have habits or behaviors that cause me concern (*e.g., smoking, drug use, alcohol abuse, poor eating habits, risk-taking, domestic abuse, etc.*)								No Problem	BEHAVIORAL
29.	I am unsatisfied with my quality of life (*e.g., independence, relationships, recreational/social activities, wellness, etc.*)								No Problem	QUALITY OF LIFE
30.	I have another problem not listed.								No Problem	OTHER

BOZEMAN HEALTH
DEACONESS HOSPITAL

Patient label

Patient:_____ Date: _____

Please select the most appropriate response:

Over the last 2 weeks, how often have you been bothered by?	Not at All 0	Several Days 1	More Than Half the Days 2	Nearly Every day 3
1. Feeling nervous, anxious, or on edge				
2. Not being able to stop or control worrying				
3. Little interest or pleasure in doing things				
4. Feeling down, depressed, or hopeless				

Please respond to the following statements:		Yes	No
5. I have an advanced directive.			
6. I am involved with supportive resources.			
7. I have had genetic testing.	Date of testing:		

APPENDIX H

CASE STUDY QUESTIONS

Case Study Questions

Initial Visit:

How did you feel about coming to this appointment today?

How do you see yourself using the survivorship care plan?

What are your over-all feelings of survivorship?

Is there anything that you feel could have been done differently?

3 and 6 month follow up:

How do you see yourself using the survivorship care plan?

Have you used your SCP or referred back to it?

Did your primary care provider receive the SCP? Have you seen your primary care provider since completing treatment and transitioned into survivorship?

Over-all feelings of survivorship

Resources- have you used or looked into any of the resources presented to you or referrals?

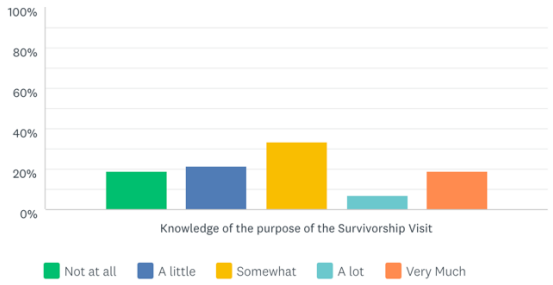
APPENDIX I

PRE-SURVIVORSHIP VISIT SURVEY RESULTS

Pre-Survivorship Questions

I know the purpose of the survivorship visit today

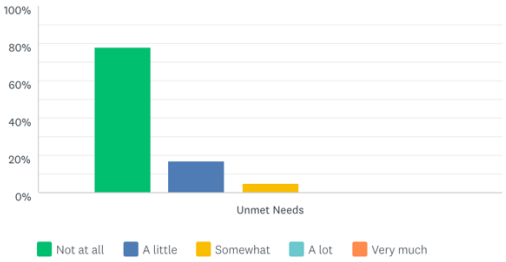
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of the purpose of the Survivorship Visit	19.05% 8	21.43% 9	33.33% 14	7.14% 3	19.05% 8	42	2.86

I have unmet needs related to my cancer diagnosis

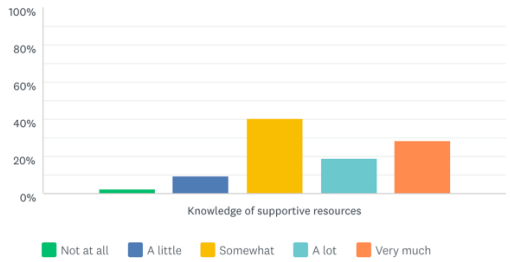
Answered: 41 Skipped: 1



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Unmet Needs	78.05% 32	17.07% 7	4.88% 2	0.00% 0	0.00% 0	41	1.27

I am familiar with available supportive resources

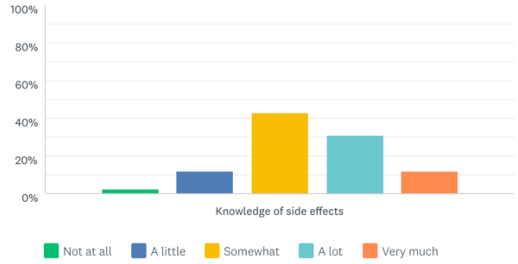
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of supportive resources	2.38% 1	9.52% 4	40.48% 17	19.05% 8	28.57% 12	42	3.62

I am familiar with short and long-term side effects of my treatment

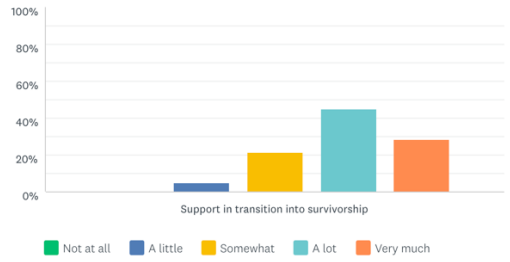
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of side effects	2.38% 1	11.90% 5	42.86% 18	30.95% 13	11.90% 5	42	3.38

I feel supported in my transition into survivorship

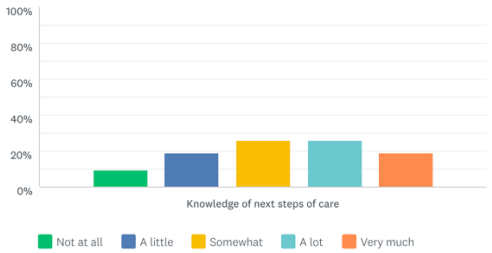
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Support in transition into survivorship	0.00% 0	4.76% 2	21.43% 9	45.24% 19	28.57% 12	42	3.98

I know what the next step of my care will be

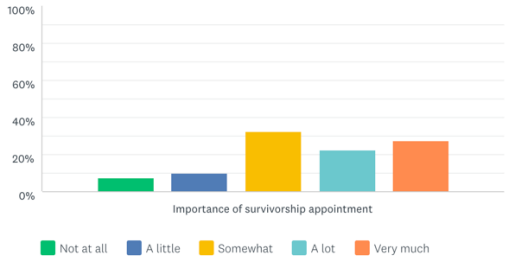
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of next steps of care	9.52% 4	19.05% 8	26.19% 11	26.19% 11	19.05% 8	42	3.26

I feel it is important to have a survivorship appointment

Answered: 40 Skipped: 2



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Importance of survivorship appointment	7.50% 3	10.00% 4	32.50% 13	22.50% 9	27.50% 11	40	3.52

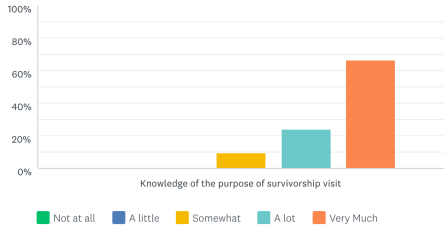
APPENDIX J

POST-SURVIVORSHIP VISIT SURVEY RESULTS

Post-Survivorship Questions

I know the purpose of the survivorship visit today

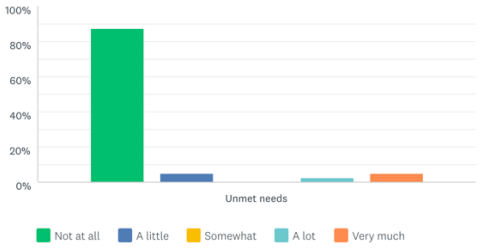
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of the purpose of survivorship visit	0.00% 0	0.00% 0	9.52% 4	23.81% 10	66.67% 28	42	4.57

I have unmet needs related to my cancer diagnosis

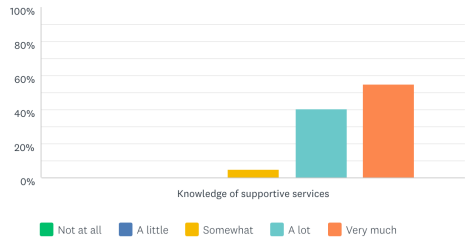
Answered: 40 Skipped: 2



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Unmet needs	87.50% 35	5.00% 2	0.00% 0	2.50% 1	5.00% 2	40	1.32

I am familiar with available supportive resources

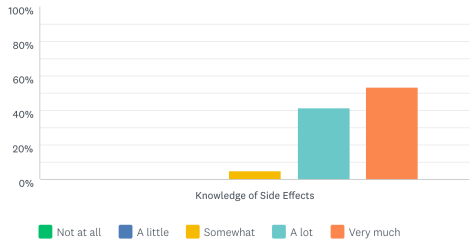
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of supportive services	0.00% 0	0.00% 0	4.76% 2	40.48% 17	54.76% 23	42	4.50

I am familiar with short and long-term side effects of my treatment

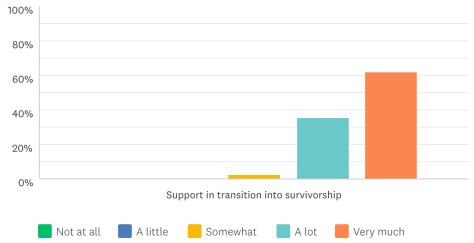
Answered: 41 Skipped: 1



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of Side Effects	0.00% 0	0.00% 0	4.88% 2	41.46% 17	53.66% 22	41	4.49

I feel supported in my transition into survivorship

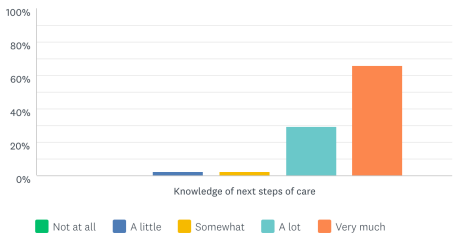
Answered: 42 Skipped: 0



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Support in transition into survivorship	0.00% 0	0.00% 0	2.38% 1	35.71% 15	61.90% 26	42	4.60

I know what the next step of my care will be

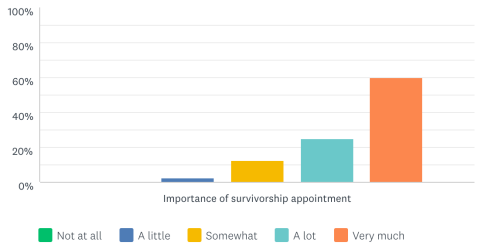
Answered: 41 Skipped: 1



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Knowledge of next steps of care	0.00% 0	2.44% 1	2.44% 1	29.27% 12	65.85% 27	41	4.59

I feel it is important to have a designated survivorship appointment

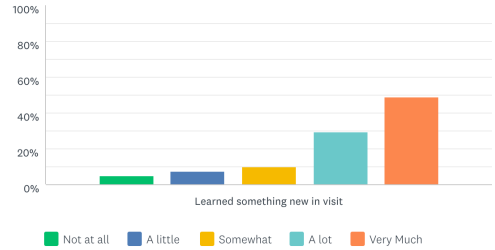
Answered: 40 Skipped: 2



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Importance of survivorship appointment	0.00% 0	2.50% 1	12.50% 5	25.00% 10	60.00% 24	40	4.42

I learned something new in today's survivorship appointment

Answered: 41 Skipped: 1



	NOT AT ALL	A LITTLE	SOMEWHAT	A LOT	VERY MUCH	TOTAL	WEIGHTED AVERAGE
Learned something new in visit	4.88% 2	7.32% 3	9.76% 4	29.27% 12	48.78% 20	41	4.10