

Primary Care Providers' Knowledge of Cancer Survivorship Care Plans

Kayla Hergert

Clarkson College

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The number of cancer survivors in the United States continues to grow as treatment for cancer continues to improve. For example, early stage breast, prostate, and colorectal cancers have 5-year survival rates that are above 90%, and the rates continue to improve (Morey et al., 2009). However, cancer survivors have an increased risk of cancer reoccurrence, cardiovascular disease, decreased quality of life, and other comorbidities (Denmark-Wahnefried et al., 2007). The cancer survivorship period needs to focus on ways to increase health and to prevent cancer reoccurrence. Primary care providers play an important role in providing survivorship education by using a survivorship care plan created by the oncology team (Forsythe et al., 2013). Survivorship education examples include following recommended screening guidelines, maintaining a healthy body weight, physical activity, following a healthy diet, limiting alcohol consumption, and smoking cessation (Ligibel, 2012).

Primary care providers are essential in providing survivorship education. This transition period is a pivotal time to teach cancer survivors healthy lifestyle behaviors and educate them on screening recommendations, as motivation for positive lifestyle changes is increased during this time period (Demark-Wahnefried et al., 2007). As patients transition care from their oncologist to their primary care provider, a cancer survivorship care plan needs to be discussed with them. This care plan summarizes their treatment, provides health promotion strategies, and offers recommendations for adhering to screening guidelines (Morgan, 2009). Cancer survivors are at a greater risk for cancer reoccurrence and mortality, so providing survivorship education is key for them to maintain a healthy lifestyle (Morgan, 2009). Primary care providers value survivorship care plans and use them to coordinate care with patients' oncologists (Shalom, Hahn, Casillas, & Ganz, 2011). Yet, primary care providers' knowledge in using survivorship

care plans remains unsettled. Therefore, the goal of this research study is to explore if having a survivorship care plan increases primary care providers' knowledge in providing survivorship care to cancer survivors.

### **Background of the Problem**

A cancer survivor is a patient who has been diagnosed with cancer and is still alive (Morgan, 2009). The Institute of Medicine discusses four areas that are essential for survivorship care. These include prevention, surveillance, intervention, and coordination (Morgan, 2009). Surviving cancer and cancer treatments can have physical and emotional effects on patients and their families. Transitioning from the role of currently having cancer to surviving cancer can be a difficult time for patients and sometimes stressful not knowing what the next steps are in their healthcare plan. Current research shows that a high percentage of cancer survivors do not follow the recommended national guidelines for physical activity and proper diet, with few differences between lifestyle behaviors compared to the population not diagnosed with cancer (Mosher et al., 2009). Cancer survivors are at a greater risk for early death because of the cancer diagnosis, cancer treatment, or from prior health conditions (McCabe et al., 2013).

The Institute of Medicine Report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommends the need for health care providers to help deliver survivorship care and identify cancer survivors' needs (Rowland, Hewitt, & Ganz, 2006). As patients transition from receiving care from their oncologist back to their primary care provider, the oncologist needs to provide the patient with a summary of the care received and recommended health promotion education, which is known as a cancer survivorship care plan. The cancer survivorship care plan

summarizes the patient's treatment, discusses health promotion, and provides the patient with screening guidelines and recommendations for follow-up.

### **Significance of the Problem**

Health promotion and education for cancer survivors is needed now more than ever. The number of cancer survivors continues to increase, as early identification and treatment of cancer improves. According to the National Cancer Institute (2016), there are 15.5 million cancer survivors in the United States, which is estimated to increase to 20.3 million by year 2026. As the number of cancer survivors continues to grow, the length of survivorship also increases. Over half of the cancer survivors in 2016 had survived at least 5 years after being diagnosed (National Cancer Institute, 2016). Cancer survivors are still at a high risk for reoccurrence of the disease, new cancer diagnoses, and increased risk of mortality from cardiovascular disease (Stricker, 2017), making survivorship care plans integral to their ongoing health and quality of life.

### **Research Purpose**

Cancer survivorship research has shown the need for increased communication between oncologists and PCPs in providing survivorship care (Shalom et al., 2011). PCPs can be informed about their patients' survivorship care through the survivorship care plans that are created by the oncology team. PCPs can play a vital role in screening and educating cancer survivors. However, there is limited research on how PCPs perceive the care plans that they receive. The care plans are intended to increase the PCPs' knowledge in providing survivorship care. Therefore, the purpose of this study is to determine if PCPs' knowledge in providing survivorship care to survivors increases because of the information they receive in the survivorship care plan. The research question for this study: Do primary care providers who

receive survivorship care plans perceive an increase in their knowledge in providing survivorship care to cancer survivors?

### **Literature Review**

CINAHL, MEDLINE, MedlinePlus, Google Scholar, UpToDate, and Clarkson Library Super Search databases were used to gather literature on survivorship care plans and PCPs' knowledge in providing survivorship care. Key terms searched included "survivorship care plan," "primary care provider," "cancer survivors," and "cancer survivorship." Limitations for the search included articles published after 2005 and written in the English language. From the search, 26 relevant articles were synthesized into the literature review.

### **Gaps in Knowledge**

Cancer survivorship care research and implementation has been growing over the past decade, but it is still relatively new (Morgan, 2009). One primary complication is a disconnect between the oncology team and PCPs regarding who is responsible for providing survivorship care and education (Morgan, 2009). The Institute of Medicine recommends the use of survivorship care plans, although in one study, 90% of PCPs were unaware of the Institute of Medicine's report on cancer survivors (Salz, Oeffinger, McCabe, Layne, & Bach, 2012). Cheung, Neville, Cameron, Cook, and Earle (2009) discussed the differences patients expected from survivorship care and the actual care they received. The care was less than expected, because the goals of survivorship care were not clinically understood (Cheung et al., 2009). Survivorship education, specifically survivorship care plans, are not being provided to a high percentage of patients, and few are meeting the requirements for quality care plans (Stricker, 2017). This is related to the long length of time required to provide the information, the complexity of information required in the care plan, and lack of reimbursement for providing the

care plan to patients (Stricker, 2017). Survivorship care could be more efficient if provided to PCPs by using a shared-care model (Shalom et al., 2011). For this to happen, PCPs need guidance and education to provide survivorship care, which can be done by using a survivorship care plan (Forsythe et al., 2013). According to Skolarus et al. (2013) PCPs who cared for prostate cancer survivors were surveyed, and only a minority felt comfortable caring for their patients' side effects from cancer treatment. In short, there is limited evidence regarding whether or not PCPs have knowledge of their patients' cancer diagnosis and treatment, potentially interfering with the care they provide (Salz, Oeffinger, McCabe, et al., 2012).

Barriers to using survivorship care plans need to be identified, but research is limited on perception and use of survivorship care plans (Shalom et al., 2011). Some barriers identified to using care plans are that they take too much time to create and PCPs' inability to implement them due to lack of knowledge on cancer survivor issues (Dulko et al., 2015). More research needs to be done to determine if these care plans serve as an adequate method of communication and coordination of patients' care between PCPs and oncologists (Shalom et al., 2011). According to Forsythe et al. (2013) more research is needed on how to more efficiently develop and deliver survivorship care plans. This could affect the percentage of patients receiving survivorship care plans although there is limited research on percentage of survivorship care plans being shared between oncologists and PCPs (Forsythe et al., 2013).

### **Consequences of the Problem**

Cancer survivors who do not receive education on healthy lifestyle behaviors may be at a greater risk for not following them, which could lead to early mortality and cancer reoccurrence. For instance, obesity has been found to increase the risk of cancer reoccurrence in breast and prostate cancer survivors (Ligibel, 2012). Along with physical side effects, cancer reoccurrence

can have financial and psychological effects on patients and their families. High unmet needs of cancer survivors included emotional support, smoking cessation, increasing physical activity, and information on how to handle fear of cancer reoccurrence (Willems et al., 2015). Without proper cancer survivorship education, patients lose out on knowledge about healthy lifestyle choices, screening guidelines, and which providers to notify when symptoms occur. This may lead to confusion for cancer survivors and an increase in emergency department visits, which is not cost effective for the patient or hospital (Stricker, 2017).

Furthermore, Blanchard, Courneya, and Stein (2008) identified that up to 12.5% of cancer survivors were not meeting the recommended physical activity, nutrition, and smoking cessation recommendations, and fewer than 10% actually met two or more of the recommendations. In other words, PCPs not addressing cancer survivorship education could lead to worsening statistics of cancer survivors not following healthy lifestyle behaviors.

### **Proposed Solutions**

The Institute of Medicine recommends that cancer survivors receive a survivorship care plan, which provides a summary of the patient's cancer treatment, follow-up recommendations, and education for healthy lifestyle choices (Morgan, 2009). It is recommended that a multidisciplinary team implement cancer survivorship care plans, which includes the importance of using oncology nurses and nurse practitioners (Morgan, 2009). Having a designated health care provider assigned to discuss survivorship care and to review the survivorship care plan is essential to help cancer survivors maintain healthy lifestyle choices and follow screening guidelines. Weaver et al. (2013) discussed the need for coordination between PCPs and oncologists to provide health promotion strategies and education on cardiovascular risk factors and disease in cancer survivors. PCPs can be used to provide survivorship care education and

can build on their prior relationship with their patients to make them feel comfortable and confident in the care they receive. Mayer, Gropper, et al. (2012) surveyed breast cancer survivors, and 70.2% identified their PCP as having responsibility for monitoring cancer reoccurrence, with the majority of the patients feeling comfortable receiving survivorship care from PCPs and survivorship NPs.

Survivorship care plans need to be understood easily by the PCP. According to Donohue et al. (2015), PCPs surveyed reported the need for shorter, clinician-oriented care plans that were standardized and accessible in an electronic health record. Having a standardized method to delivering care plans will make the process of using them easier and more consistent for PCPs. Originally, survivorship care plans were designed to be given directly to the patient by their oncologist. The patient was responsible for delivering the care plans to their PCP. However, Salz, Oeffinger, McCabe, et al. (2012) discussed that 92% of PCPs preferred the care plan come directly from the oncologist, rather than the patient.

### **Summary of Literature Review**

Survivorship care is an important aspect of cancer survivors' treatment plan. PCPs can play a vital role in providing this care, as long as they have adequate knowledge and information of their patients' treatment plan. This information can be found in the survivorship care plan, if used correctly. The care plans need to be easily accessible and understood by the PCP. Cancer survivors are at an increased risk for cancer reoccurrence and mortality, so proper survivorship education, such as healthy lifestyle choices, screening recommendations, and follow-up care are essential for survivors.

### **Theoretical Framework**



The theoretical framework guiding this research study is Andrew Tannahill's (2008) model of health promotion. Tannahill defines health promotion as enforcing positive health and prevention of ill-health through strategies and policies focusing on education, learning, equity, and environmental and cultural factors. This relates to survivorship care because it focuses on maintaining health and preventing mortality and cancer reoccurrence. Tannahill also defines the term health improvement in his model as sustaining positive health and reducing ill-health through policies and strategies in education and learning. Health improvement can be applied to survivorship care because these patients have overcome a cancer diagnosis and want to continue to strive for improved health.

Concepts defined in Tannahill's (2008) model relate to the proposed research question. The three main concepts guiding Tannahill's model of health promotion are health protection, health education, and prevention (Queen's University Belfast, 2009). Prevention is defined as minimizing or avoiding the risk of diseases and ill health (Queen's University Belfast, 2009). The prevention concept relates to PCPs providing survivorship education to prevent the reoccurrence of cancer in patients by following recommendations and screening guidelines in the survivorship care plan. Health education is defined as communication to increase health and prevent ill-health by improving knowledge (Queen's University Belfast, 2009). Survivorship care plans increase communication between the oncology team and PCPs to improve the health of cancer survivors, making Tannahill's model a solid foundation for exploring survivorship care plans.

### **Methodology**

To accomplish this, I performed a quantitative descriptive study with non-probability, convenience sampling. A descriptive study was used to help describe and synthesize the ordinal-

level quantitative data gathered using a Likert scale (Polit & Beck, 2017). The subjects of the study were Internal Medicine and Family Medicine PCPs at Nebraska Medicine. Data collection began after obtaining approval from the Nebraska Medicine Survivorship Clinic's APRN, Internal Medicine and Family Medicine leaders at Nebraska Medicine, Nebraska Medicine's Clinical Research, Inquiry and Scholarship Committee (CRISC), Clarkson College Institutional Review Board (IRB), and University of Nebraska Medical Center's IRB. The survey used in the study was from SurveyMonkey and consisted of a 5-point Likert scale ranging from 1, strongly disagree, to 5, strongly agree, and two open-ended questions. I distributed the survey link to leadership at Internal Medicine and Family Medicine who then distributed the survey link to all PCPs working in Internal Medicine and Family Medicine at Nebraska Medicine. The survey remained open for 2 weeks with no reminder emails sent.

The email sent to PCPs contained an invitation letter, describing the purpose and nature of the survey. A website link at the bottom of the letter then opened the link to the survey. Participants first viewed the rights of research participants letter. Then, a sample survivorship care plan template was provided to give the participants a visual idea and reminder of a survivorship care plan. After viewing this, the participants were then prompted to the first question, which asked if they had ever received a survivorship care plan. If participants answered "no" to this question, the survey ended. If participants answered "yes" to this question, 10 questions using a Likert scale populated. The Likert scale was used so the researcher could ask questions specific to the survivorship care plan, and if providers perceived an increase in their knowledge in providing survivorship care when using the care plan. The Likert scale provided ordinal-level data. At the end of the survey, two open-ended questions asked for additional feedback for improving the survivorship care plan, as well as how the Survivorship

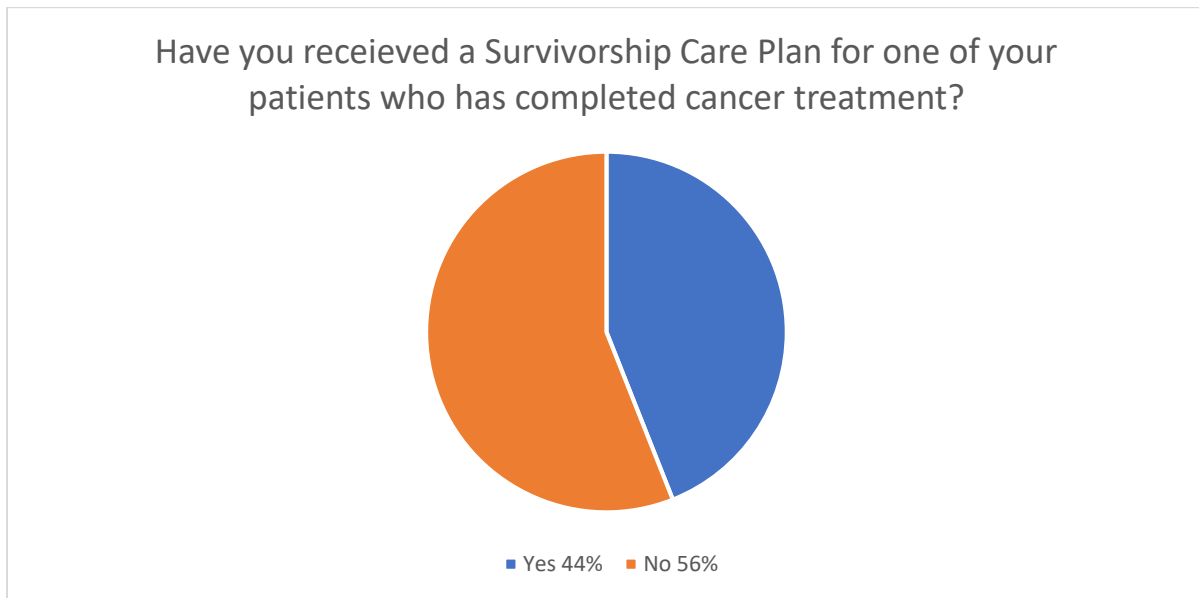
Clinic could be of greater assistance. These open-ended questions provided specific feedback for the Survivorship APRN at Nebraska Medicine and helped create open dialogue between the oncology survivorship providers and PCPs, as well as information to help the PCPs use the survivorship care plan in the future.

After the survey closed, the co-investigator received de-identified, anonymous descriptive data from SurveyMonkey. The results from SurveyMonkey were then analyzed and interpreted, looking for trends in responses and feedback from the two-open ended questions.

### **Summary of Findings**

Nine providers completed the survey out of 87 recipients. This yields a low response rate of 10.3%. Of the 25 providers who started the survey, 11, or 44%, had received a survivorship care plan for at least one of their patients (Figure 1). Fourteen, or 56% of participants, had never received a survivorship care plan for one of their patients. The findings indicated that 77.78% of participants agreed or strongly agreed that the survivorship care plan confirms or increases their knowledge of survivorship care of cancer survivors (Figure 2). Also of note, 77.77% of participants agreed or strongly agreed that the survivorship care plan confirms or increases their knowledge on which surveillance testing is needed for their patients to detect recurrent cancer (Figure 2). Also, another 77.77% of participants agreed or strongly agreed that the survivorship care plan confirms or increases their knowledge of the cancer treatment their patients received (Figure 2). On the other hand, the results showed that 44.44% of participants were neutral, and 11.11% disagreed that the survivorship care plan confirms or increases their knowledge of healthy lifestyle behaviors recommended for cancer survivors (Figure 2). Moreover, while 55.55% agreed or strongly agreed that the care plan confirms or increases their knowledge of

long-term physical side effects of cancer treatment, 44.44% of participants responded they felt neutral to this statement (Figure 2).



*Figure 1.* Results of how many primary care providers have received a Survivorship Care Plan

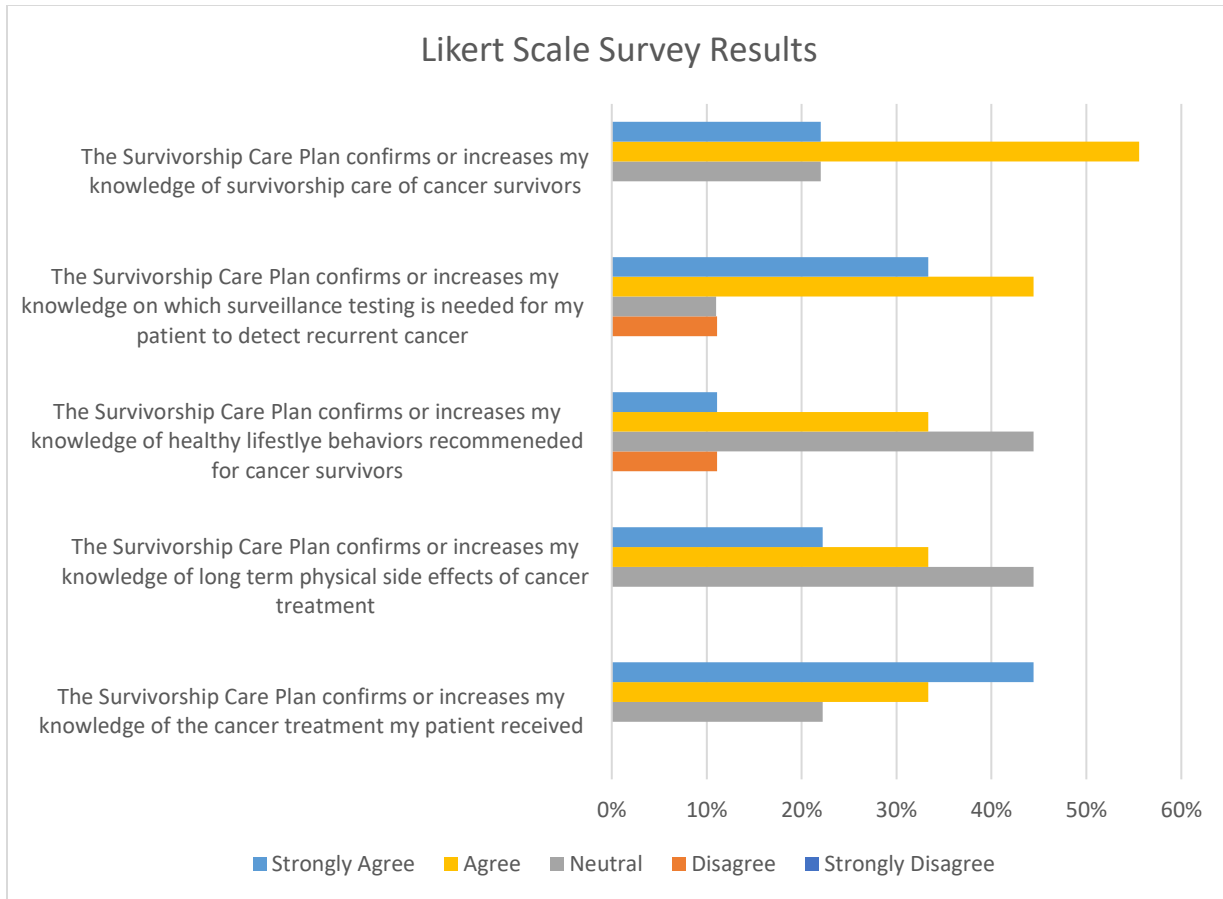
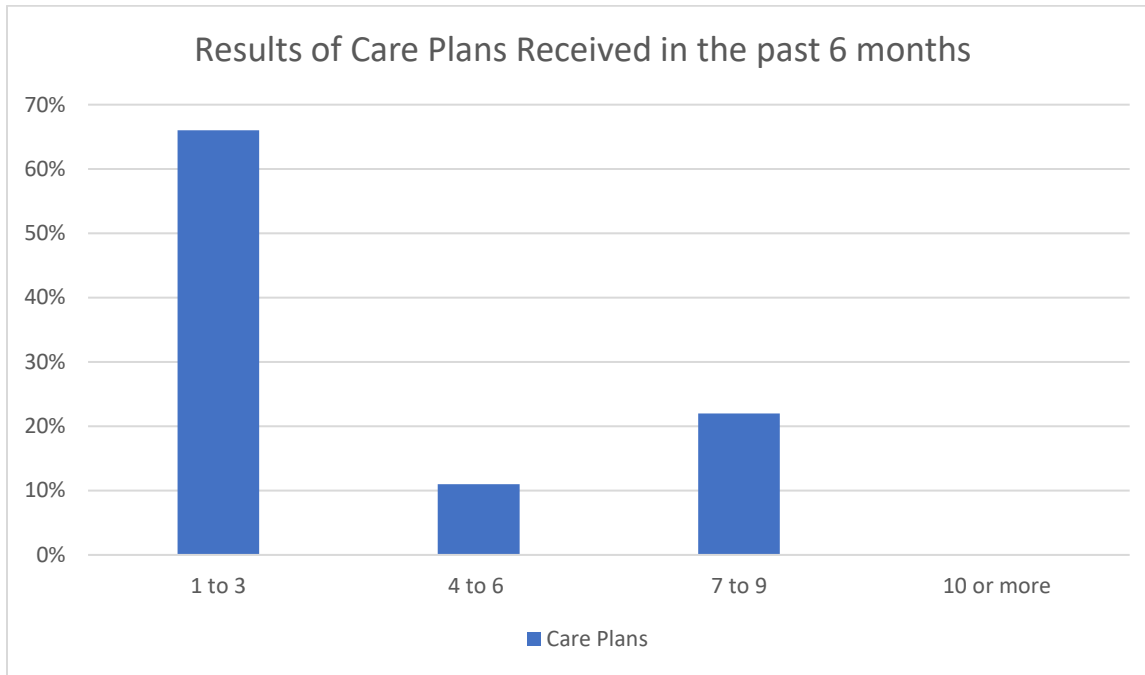


Figure 2. Likert Scale Survey Results

The survey asked how many survivorship care plans the providers had received in the past six months: 66.67% of participants had received one to three care plans, 11.11% had received four to six care plans, 22.22% had received seven to nine care plans, and 0.00% had received 10 or more care plans (Figure 3). Five participants responded to the open-ended question that asked what changes to the survivorship care plan would improve their practice in caring for cancer survivors. The responses included easier ways to reference the document in the chart, making the document shorter with most relevant information at the beginning, and adding a to do list or action items at the beginning of the care plan. The participants were also asked how Nebraska Medicine’s Survivorship Clinic can help improve their care for cancer survivors.

Four participants responded with the following statements: stay the course, reminders within the electronic charting system, education on survivorship care, and patient friendly print outs.



*Figure 3.* How many Survivorship Care Plans has the provider received within the past six months?

Limitations to the study included a low response rate. Along with a low response rate, 56% of participants had never received a survivorship care plan, so they did not go on to complete the rest of the survey. The Internal Medicine leader confirmed that the survey was sent to Internal Medicine providers, but the Family Medicine leader did not respond to the survey email. This limited the number of participants who could have received and completed the survey. Therefore, the response rate was only based on Internal Medicine providers. Another limitation to the survey is that it did not address if the respondents were family medicine providers or internal medicine providers.

### **Conclusion and Recommendations**

In conclusion, participants who responded to the survey described their perceptions of the survivorship care plan. The majority of participants agreed that the survivorship care plan confirms or increases their knowledge of survivorship care for cancer survivors, confirms or increases their knowledge on appropriate surveillance testing needed for their patients, and confirms or increases their knowledge of the cancer treatment their patient received. According to the National Cancer Institute (2016), the number of cancer survivors continues to increase with longer survival rates. Cancer survivors are at greater risk for mortality and cancer reoccurrence, which is why survivorship care is an important aspect to their ongoing care and health (Stricker, 2017). Survivorship care plans aim to help educate and increase providers' knowledge of survivorship care.

It is recommended for more research to be completed to help determine how the survivorship care plan confirms or increases primary care providers' knowledge of survivorship care and how to improve the care plan to make it easier to use. The participants also recommended that the survivorship care plan should be shorter in length, with a to do list highlighted at the beginning of the document. It would be beneficial to have more primary care providers respond to the survey as the response rate was low. Another recommendation is to include a question on the survey to distinguish between internal medicine and family medicine providers. Finally, a majority of participants felt neutral or disagreed that the care plan confirms or increases their knowledge of healthy lifestyle behaviors for cancer survivors, so this topic should be explored further to improve how this information is listed on the care plan.

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