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# Hodgkin's Lymphoma survivors' intentions to follow survivorship care plans

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Hodgkin's Lymphoma Survivors' Intentions to Follow Survivorship Care Plans

by

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Thesis

Submitted to the School of Health Promotion and Human Performance

Eastern Michigan University

in partial fulfillment of the requirements

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### **Abstract**

The purpose of this study was to determine the attitudes, perceived subjective norms, and perceived behavioral control that Hodgkin's Lymphoma (HL) survivors had towards survivorship care plans (SCPs) and how those factors impact their intentions to follow a care plan. Participants were HL survivors who had completed treatment. An online self-reporting questionnaire was used to assess demographics and questions related to HL survivor's attitudes, behavioral intention, perceived subjective norms, and perceived behavioral control. Frequency analysis and correlations were used to describe the participants and their attitudes, perceived subjective norms, and behavioral control in relation to participants' intentions to follow a SCP. Significant correlations were noted between HL survivors' intentions to follow a SCP for five years and the attitudes helpful and easy. Perceived behavioral control was noted to be a predictor of intention to follow a SCP. Cancer doctors recommended 32.7 percent of participants to follow a SCP for HL. Almost 60 percent of participants were not currently following a SCP at the time of completing the online questionnaire. Although participants had positive attitudes toward SCPs, attitudes were not found as a predictor of intention. Future research should focus on survivors' intentions to follow a SCP before, during, and after the survivors follow a SCP to better understand how intentions change.

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## Chapter I: Introduction

It is estimated that by January 2024, the number of cancer survivors in the United States is expected to grow to almost 19 million people (DeSantis et al., 2014). That is 19 million Americans who will face specialized health concerns, including long-term or late effects of cancer and its treatment. The transition from treatment to survivorship can be a difficult journey. It has been recommended by the Institute of Medicine (IOM), American Society for Clinical Oncology (ASCO), and LiveStrong Foundation that patients completing treatment be provided with a multi-component survivorship care plan (SCP) to help with their survivorship transition (Hewitt, Greenfield, & Stoval, 2005; Oeffinger et al., 2014; Rehis, Beckjord, Arvey & McGoldrick, 2011).

Thanks to the publication of the IOM's 2005 report, "From Cancer Patient to Cancer Survivor: Lost in Transition," more research is beginning to focus on the needs of cancer patients who are entering survivorship (Hewitt et al., 2005). However, much of the research has failed to focus on survivors of Hodgkin's Lymphoma (HL), a cancer of the immune system. As of January 1, 2014, it was estimated that there were 197,850 HL survivors (American Cancer Society [ACS], 2014). HL is considered a rare cancer because annually it affects about 9,000 people in the U.S (ACS, 2014). However, HL has a high cure rate, with a five-year survival of 85% (ACS, 2014). Because of HL's cure rate, it has been improperly labeled as a "good cancer" or "easy cancer." This can cause survivors to overlook the severity of their treatment and the impact that it may have on their future health.

Research of HL survivors' needs for SCPs is important because it can help to create new plans and improve upon old plans. The notion of HL being a "good cancer" also creates greater concern to determine whether survivors are being offered SCPs by health care providers or if

they have the intention to follow a SCP. A review of research on other cancers has found that some providers report not offering a SCP. Birken, Mayer, and Weiner (2013) identified that less than 25% of cancer providers reported ever using a SCP. Much of the research has focused on breast cancer and other cancer survivors' attitudes towards SCPs and their reported needs once they finish treatment, but few have determined whether attitudes or the reported needs actually lead to the survivors having intentions to follow the plans.

### **Purpose of the Study**

The purpose of this study was to utilize the Theory of Planned Behavior (TPB) to determine the attitudes, perceived subjective norms, and perceived behavioral control that HL survivors had toward SCPs and how these impacted their intentions to follow a care plan.

### **Significance**

The IOM recommends that all cancer patients should be provided with a SCP once they complete treatment and transition to survivorship. Current research has focused primarily on breast cancer survivors' views on what components are needed for SCPs. Further, research has found that some survivors aren't being offered SCPs (Barton, 2014; Birken et al., 2013; Keesing, McNamara, & Rosenwax, 2014).

### **Hypotheses**

Alternative Hypotheses:

- Survivors with positive attitudes toward SCPs will be more likely to have the intention to follow a SCP.
- Survivors who believe that key people in their lives approve of them following a SCP will be more likely to have the intention to follow a SCP.

- Survivors who believe they have control over their following a SCP will be more likely to have the intention to follow a SCP.

#### Null Hypotheses:

- There is no relationship between HL survivors' attitudes toward SCPs and their intentions to follow a SCP.
- There is no relationship between survivors who believe that key people in their lives approve of them following a SCP will have and their intention to follow a SCP.
- There is no relationship between survivors' belief of control over their following a SCP and their intentions to follow a SCP.

#### **Additional Research Questions**

1. Are HL survivors being offered SCP for HL?
2. Are HL survivors currently following any SCP for HL?

#### **Definitions**

ACS—American Cancer Society

ASCO—American Society of Clinical Oncology

BCS—Breast Cancer Survivor

HL—Hodgkin's Lymphoma, also known as Hodgkin's Disease, is a cancer of the immune system that starts as an abnormal lymphocyte that divides into more abnormal cells and collects in a lymph node to create a mass. If not treated, the abnormal cells can break off and travel to other parts of the body.

IOM—Institute of Medicine

PCP—Primary Care Physician

SCP—Survivorship Care Plan, a record of a cancer patient's cancer history and recommendations for after treatment care. This survivorship care plan assists with the monitoring and managing of long-term and late effects, as well as health promotion.

## **Chapter II: Review of the Literature**

### **Cancer Survivorship**

It is estimated that as of January 1, 2014, there were nearly 14.5 million cancer survivors in the United States (ACS, 2014). This number is expected to increase to 19 million by January 1, 2024, due to improvements in early detection and treatment. The transition from treatment to survivorship can be difficult to navigate. Many survivors face challenges during this transition, including, returning to their former roles as parents or employees, paying medical bills, or deciding what health care provider to see for follow up care. Survivors also face the threat of long-term or late effects of cancer treatment. Chemotherapy, radiation, surgeries, and other treatments can affect the health of cardiac, pulmonary, genitourinary, endocrine, and neurologic systems (Schultz, Stava, Habra, & Vassilopoulou-Sellin, 2011). Additional concern to survivors is the threat of recurrence of cancer or developing a new primary cancer (Schultz et al., 2011). To address these health concerns, it has been recommended that survivors be provided with a SCP (Hewitt et al., 2005; Rechis et al., 2011; Oeffinger et al., 2014).

### **Survivorship Care Plans**

The importance of SCPs was realized thanks to the IOM 2005 report, "From Cancer Patient to Cancer Survivor: Lost in Transition." In the IOM report, it was recommended that all cancer patients ending treatment should be provided with a SCP (Hewitt et al., 2005). Thanks to this recommendation, the concept of SCPs has emerged as the standard of care for cancer patients who have completed treatment and are transitioning to their new status as cancer survivors (Goeren, 2013). In recent years the number of studies examining SCPs has increased, looking at various health care providers, cancer survivors, and other shareholders opinions,

attitudes, and beliefs about SCPs. However, many of these studies only focus on a disease specific SCP or generalized SCP for all cancer types.

The transition from treatment to survivorship can be difficult and confusing for survivors. The SCP is supposed to help smooth the transition from patient to survivor. Mayer, Birken, Check, and Chen (2014) found that many providers preferred a streamlined approach to SCP, whereas survivors preferred flexibility and tailoring. With more than 100 different cancer types with specific treatments, it is important that survivors of each cancer type be examined for SCPs. Currently, many of evaluations of SCPs are for breast cancer survivors (BCSs) (Downs-Holmes, Dracon, Svarovsky, & Sustin, 2014; Sprague et al., 2013; Wiljer et al., 2013; Smith, Singh-Carlson, Downie, Payeur, & Wai, 2011). One cancer type that has little evaluation in cancer SCPs is HL. SCPs need to be addressed by content that is relevant to the cancer type and survivor. Depending on the cancer type and treatment given, survivors will have different levels of risk for long-term and late effects. By tailoring to each cancer type, survivors can have the appropriate information and skills taught to them to help manage their follow-up care.

Evaluations of SCPs help to improve existing plans and create updated guidelines for future plans. The evaluation of a SCP can be over the program components, health care provider's view of the plans, or survivor's opinions, attitudes, and beliefs about the plans. It is important that evaluations be conducted, as it gives researchers and health care provider's insight into what SCPs are currently doing well and what needs improvement according to the various stakeholders. Cancer survivors' preferences and attitudes should be explored and shared to ensure that SCPs are directed appropriately, as survivors are the key stakeholders in SCPs (Keesing, McNamara, & Rosenwax, 2014). Also lacking in research is if the cancer survivors have the intention to follow a survivorship care plan if one is offered.

### **Survivorship Care Plan Usage**

Birken et al. (2013) surveyed employees of organizations that were a part of the South Atlantic Division of the American Cancer Society and who had knowledge of their organizations' SCP use. These organizations included teaching hospital cancer programs, community hospital comprehensive cancer programs, and NCI-designated comprehensive cancer programs. The employees that responded to the survey included nurses, administrators, nurse practitioners, physicians, and social workers. Less than 25% of those surveyed had reported ever using a survivorship cancer plan, although most of the organizations reported use (Birken et al., 2013).

Only 1 of 36 US cancer organizations surveyed provided a SCP to at least 75% of all survivors and their primary care physicians (PCPs) (Birken et al., 2013). Having the oncologist or treating cancer doctor providing a SCP to a PCP is recommended by Hewitt et al. (2005). A SCP can improve communication between a PCP and the oncologist or other cancer team members, helping to improve a survivor's follow-up care (Ezendam et al., 2014). A SCP is also beneficial when a survivor is transitioning from follow-up care with their oncologist to receiving their care only from their PCP. Only 20.2% of a nationally representative sample of providers reported always/almost always providing a SCP (Forsythe et al., 2013). A study conducted of Massachusetts practices found that only 16% of PCP reported having ever received a SCP (Merport, Lemon, Nyambose, & Prout, 2012).

A study by Campbell, Massey, and Myers (2012) found that 2 out of 20 head and neck cancer survivors surveyed were provided with a SCP. Furthermore, only twenty-four percent of the 9,530 respondents who stated they had been diagnosed with cancer on the 2009–2010

Missouri Behavioral Risk Factor Surveillance System reported receiving a SCP (Schootman, Homan, Weaver, Jeffe, & Yun, 2013).

### **Current SCP Evaluations and Studies**

**Breast cancer.** The focus of many studies has been primarily on SCPs for BCSs. Downs-Holmes et al. (2014) completed the Breast Cancer Survivorship Quality Measures Set pilot study (a tool for measuring the quality of post-treatment care created by the Oncology Nursing Society) on their Breast Cancer SCP and found that interventions for psychosocial distress, sleep, bone health, fatigue, lymphedema, menopausal symptoms, and neuropathy were lacking. Additionally, the researchers found that the BCSs were not educated on community resources, diet, exercise, or recurrence (Downs-Holmes et al., 2014). These findings allowed for the institution to improve their breast cancer survivorship care program. The researchers were also able to provide guidelines for other facilities looking to create or improve their programs. Survivor attitudes toward SCPs and beliefs on what their outcomes should be when following a care plan should be taken into consideration when developing a plan (Downs-Homes et al., 2014).

In three focus groups with 25 African American BCSs and 3 advocates, Ashing-Giwa et al. (2013) found that participants supported a SCP that documented all possible long-term and late effects of treatment and medications. The researchers found that the SCPs offered to the BCSs in the focus group lacked adequate content of health history and health promotion. Additionally, participants of the focus group expressed the need for cultural responsiveness and patient centeredness. Smith et al. (2011) also found similar results with their focus groups of 26 BCSs, with participants expressing the need for individualized content. Another study conducted four focus groups with 6 to 12 BCSs (total of 32 participants), who were provided the American

Society of Clinical Oncology (ASCO) SCP template, found that the survivors were dissatisfied with race-specific information and self-care approaches (Burg, Lopez, Dailey, Keller, & Prendergast, 2009). Ashing-Giwa et al. (2013) suggested that BCSs should be included in the development of their SCPs to improve cultural sensitivity and making sure that each individual BCS needs were met. Wiljer et al. (2013) also found that by including BCSs in developing their SCPs it helped to empower survivors to take charge of their health care.

An interesting and helpful approach to gaining more insight in BCSs needs for SCPs was completed by Haq et al. (2013), who created a pilot SCP based on a needs assessment of 19 BCSs, 6 PCPs, and 5 oncology specialist health care providers. Using focus groups and individual interviews, the needs of both BCSs and PCPs were determined and a SCP was designed. The needs assessment found that survivors wanted a SCP with information that was tailored toward their particular life stage and breast cancer diagnosis, addressing both medical and psychosocial concerns, and the need for an SCP throughout treatment was also expressed. Whereas, PCPs preferred that the SCP provide basic information concerning follow-up care and that it be in a user-friendly format. Once the SCP was implemented it was evaluated by BCSs and PCPs with additional focus groups and interviews. The BCSs believed that the information was better structured and more tailored toward their specific needs. Survivors also suggested that there be more focus on health and wellness, including nutrition, exercise advice, breast reconstruction, and a supportive approach to addressing symptoms of recurrence (Haq et al., 2013).

**Other cancer types.** In 2006, Hewitt, Bamundo, Day, and Harvey (2007) conducted focus groups to review survivors' opinions of a SCP that they were provided. The survivors had completed treatment for a different cancer types. The survivors reported that their psychosocial

needs were not met, as many found their cancer specialist to be uncommunicative and lacking compassion once treatment was done. Survivors also found that they were presented with a lot of information orally and preferred a written plan (Hewitt et al., 2007).

Similar studies using focus groups in 2011 found results similar to Hewitt et al. (2007). Marbach and Griffie (2011) and Mayer, Gerstel, Leak, and Smith (2011) both conducted additional focus groups of survivors of different cancer types and found that lack of psychosocial support was a common view of survivors. Both studies also found that survivors wanted an easy to follow plan that was written, or could be printed offline. Marbach and Griffie (2011) also found that survivors wanted more information on late effects so that they could monitor themselves for unusual or abnormal side effects. The focus groups of Marbach and Griffie (2011) also expressed the need for support groups that were cancer specific, massage therapy, yoga, and other health resources. Mayer et al. (2011) reported that survivors requested needing nutrition and health promotion information, information for family members to obtain genetic counseling, and they wanted this information before treatment was finished, rather than receiving it right after completion of treatment.

### **Recommendations**

The guidelines by the IOM, ASCO, and LiveStrong Foundation have been created to help improve the quality of care and quality of life of cancer survivors in the United States. Because of these agencies' efforts, the special needs of survivors are being recognized and addressed. A cancer SCP allows for enhanced follow up care that makes past diagnosis, treatment history, surveillance guidelines, and possible long-term effects readily available for cancer survivors, enabling them to receive better care (Morgan, 2009).

**Institute of Medicine.** Cancer survivorship care is an important part of cancer treatment (Hewitt et al., 2005). In 2005, the IOM published "From Cancer Patient to Cancer Survivor: Lost in Transition" (Hewitt et al., 2005). In this report it was recommended that a SCP be developed by the cancer patient's primary provider(s) of their oncology treatment (Hewitt et al., 2005). The SCP should be given to all patients completing treatment to provide them with a summary of their care and a follow-up care plan (Hewitt et al., 2005). The 2005 recommendations of the IOM are still widely used today as a baseline for many health professionals and organizations developing their own SCPs.

According to the IOM, there are 4 main elements of cancer care that need to be focused on (Hewitt et al., 2005). These areas include prevention, surveillance, intervention, and coordination (Rechis et al., 2011). Efforts should be made to prevent and detect cancer recurrence or new cancers (Oeffinger et al., 2014). Surveillance for new primary cancers or recurrence of cancer should be established (Oeffinger et al., 2014). Because of the possibility of long-term or late effects of cancer or cancer treatment, interventions should be in place to address these issues. Lastly, to guarantee that all needs of a cancer survivor are met, coordination between treating specialist and PCP should occur.

Following treatment, every cancer patient should receive survivorship care (Hewitt et al., 2005). Cancer survivorship care will vary between individual cancer patients, depending on their cancer type, stage of diagnoses, treatment, and any complications related to their cancer diagnoses or treatment (Hewitt et al., 2005). Survivorship care should continue unless the individual has a recurrence, second cancer, or death, and should be resumed again with direction from his or her oncologist or treating team (Hewitt et al., 2005). Survivorship care should also be provided to individuals with chronic or intermittent disease, who may be receiving ongoing

treatment, as these individuals may benefit from survivorship care while living with their diseases (Hewitt et al., 2005).

**American Society of Clinical Oncology.** In addition to the 2005 IOM report, the American Society of Clinical Oncology (ASCO) expanded upon these elements in their 2014 “Providing High Quality Survivorship Care: An ASCO Guide” (Oeffinger et al., 2014). This guide lists more specific components of survivorship care that ensure high quality cancer survivorship care. The ASCO guide states that cancer survivorship care should also include psychosocial monitoring and management, secondary cancer screening recommendations, health education specific to cancer survivors’ diagnoses and treatments, referrals to specialist and other resources, genetic risk assessment if necessary, support of healthy diets and exercise or other health promotion activities, financial or insurance resources, and empower survivors to be advocates for their own healthcare needs (Oeffinger et al., 2014).

**LiveStrong Foundation.** In 2011, the LiveStrong Foundation organized the “Essential Elements of Survivorship Care Meeting” (Rechis et al., 2011). In this meeting key stakeholders in survivorship care came together to build agreement on what elements a SCP must provide to cancer survivors to be effective (Rechis et al., 2011).

The Essential Elements meeting resulted in five tier 1-must have elements, ten tier 2-should have elements, and five tier 3-strive to have elements. Tier 1 elements of survivorship care include developing and providing survivors with a SCP, a psychosocial plan, and a treatment summary, these three items were combined into one element (Rechis et al., 2011). Other tier 1 elements were screening for cancer recurrence and new cancers, care coordination between oncologist and PCP, health promotion education, and symptom management (Rechis et al., 2011). Tier 2 elements included providing education for late effects of cancer and treatment,

psychosocial assessment and care, comprehensive medical examination, nutrition, physical activity and weight management services, a transition (from cancer patient to survivor) visit, late effects rehabilitation, family and caregiver support, patient navigation, and other information on survivorship programs (Rechis et al., 2011). Lastly, the five tier 3 elements were increasing survivor self-efficacy, counseling, quality improvement activities, referrals for special care, and provider continuing education (Rechis et al., 2011). These resulting elements identified by the Essential Elements Meeting contribute to other recommendations made by health agencies and organizations and help to ensure that cancer survivorship care continues to grow. With this growth survivorship care will help to improve the quality of care provided to cancer survivors.

### **Current SCPs Components**

A review of survivorship care plans in Canada, the United States, Europe, the United Kingdom, Australia, and New Zealand was conducted to determine which survivorship care plans follow the recommendations from the IOM (Daudt et al., 2014). The review looked at 16 different studies of SCPs that were conducted in face-to-face settings with a nurse or nurse practitioner. It was found that many of the studies had feedback stating that the SCP information would also be useful throughout their treatment. One of the SCP studies was a randomized control trial that found that the only difference between the control group and intervention group was that those in the intervention group were more likely to correctly identify that their primary care provider was responsible for their follow-up care. Two survivorship care plans with extensive evaluations and with many positive reviews from patients and health care providers included the LiveStrong Foundation care plan (United States) and from the NCSI (United Kingdom).

The NCSI approach is called a “risk stratified pathway” because as treatment nears completion, patients’ follow up is determined by the level of support they need and their ability to self-manage their own follow up care (Daudt et al., 2014). This approach allowed for services to be offered based on each individual’s needs, rather than a standardized approach that may not be effective for everyone. The NCSI SCP begins at a cancer patient’s diagnosis and engages the patient in self-management while offering other services when necessary, continuing up to five years past treatment and taking into consideration a person’s physical, social, psychological, and spiritual health. Additionally, the NCSI assigns a clinical nurse specialist to each new patient, who remains as a point of contact, and conducts assessments throughout and after treatment. A treatment summary and a care plan are completed for each patient at the end of treatment by a multidisciplinary team and are provided to both the patient and PCP. The NCSI’s approach is more a supportive care than survivorship care because the follow up plan allows the survivors to be in control of their plans, allowing survivors to feel more empowered. Evaluations of the risk stratified pathway used by the NCSI has shown improved patient satisfaction, patient confidence in self-managing their own health, cost effectiveness, and reduced demand for acute care and outpatient resources (Davies & Batehup, 2011).

Daudt et al. (2014) identified that a common lacking component of many of the plans was psychosocial services, even though this is included in the IOM’s recommendations. It was also found that only 50% of SCPs provide a list of additional cancer-related information or resources, while less than 50% of the plans addressed genetic testing or financial concerns (Daudt et al., 2014). Many of the organizations that provided SCPs that offered this service at the end of treatment did not follow all of the current IOM recommendations (Daudt et al., 2014).

A possible explanation for these deficient components may be that the IOM framework lacks clarity of what content needs to be included in SCPs (Salz, Oeffinger, McCabe, Layne, & Bach, 2012). A possible solution to overcoming the lack of clarity for SCPs would be to use the LiveStrong Foundations findings from their Essential Elements Meeting (Rechis et al., 2011). It is also recommended that each SCP should be evaluated for effectiveness to make sure that no key components are missing and evaluation should be completed using reliable instruments (Daudt et al., 2014).

Overall, cancer SCPs should be ever evolving, and research and evaluations of current and past program can assist with this. Additionally, recommendations and guidelines should be updated as research and evaluations are conducted. The study by Daudt et al. (2014) suggested that cancer SCPs should be updated into more of a supportive care program, with focus on physical, psychological, social, and spiritual care for all cancer patients, and offered before treatment ends.

### **Hodgkin's Lymphoma**

Hodgkin's lymphoma (HL) is a cancer of the immune system. It is most common in early adulthood, especially in a person's twenties. As of January 1, 2014, it was estimated that there were 197,850 HL survivors in the U.S. (ACS, 2014). HL is considered a rare cancer because annually it affects about 9,000 people in the U.S. HL has a high cure rate, and because of this, it has been improperly labeled as a "good cancer." This can cause a misconception that HL patients do not go through life saving treatments, such as chemotherapy, radiation, stem cell transplants, and other treatments. This misconception can carry over into a HL patient's survivorship as well. HL patients have risks of long-term or late effects just like other cancer

patients do. To address long-term and late effects, it has been recommended that survivorship care plans (SCPs) be provided to all cancer patients who have completed treatment.

### **Theory of Planned Behavior**

The various studies on cancer survivors and cancer survivorship SCPs have utilized different models and theories to analyze survivors' attitudes toward SCPs after the survivors have followed a SCP; however, there are very few studies that analyze survivors' intentions to follow a SCP. The theoretical framework that was used in this study was the Theory of Planned Behavior (TPB). The TPB explores the relationship between behavior and beliefs, attitudes, and intentions (National Cancer Institute [NCI], 2005). The most important determinant of behavior assumed by the TPB is behavioral intention (NCI, 2005). Behavioral intention is determined by the person's attitude toward the behavior, beliefs about whether individuals who are important to the person approve or disapprove of the behavior (also called perceived subjective norms) and perceived behavioral control (Bensley & Brookins-Fisher, 2009).

Although there have not been other studies using the TPB to determine cancer survivors intentions to follow survivorship care plans, similar studies have been conducted that have used the TPB. In a study by Zembre and Ajzen (2013), intentions of individuals to complete a substance abuse program were examined. In this study participants were first interviewed one-on-one using questions based on the TPB, along with the stages of change, treatment motivation, severity, social desirability, and perceived coercion. After two weeks participants were followed up with an additional telephone interviews based on TPB. Zembre and Ajzen (2013) found that the results of this study support using the TPB to understand treatment participation. The study also found that intentions to complete treatment could be explained using attitudes and perceived behavioral control.

Husebo, Dyrstad, Soreide, and Bru (2012) conducted a meta-analysis of studies that used the TPB to predict exercise adherence in cancer patients and survivors. They found that the TPB constructs of intention and perceived behavioral control were strong predictors of exercise adherence (Husebo et al., 2012). The meta-analysis found that attitude, perceived subjective norms, and self-efficacy were nonsignificant in predicting exercise adherence (Husebo et al., 2012). Courneya et al. (2010) completed a similar study that used the TPB to determine exercise adherence in lymphoma patients. Courneya et al. (2010) found that intention and perceived behavioral control did predict exercise adherence. The study did find that those lymphoma patients less than 40 years of age struggled with exercise adherence. HL patients were more likely to have lower adherence to exercise than non-HL patients, which researchers believe is because of disease type, disease stage, and type of treatments (Courneya et al., 2010). Exercise adherence was especially lower in those HL patients that were treated with radiation therapy. Additionally, the study found that motivational variables from the TPB did not predict adherence to exercise in lymphoma patients.

### **Summary and Conclusion**

**Implications and suggested direction.** Breast cancer survivors and their views of survivorship care plans have been well researched and documented. However, cancer is not a one size fits all disease. Each cancer type has different treatment options with after treatment risks for long-term or late effects. Because of these differences, it is important that survivors of every cancer type be researched in regards to their survivorship care, as there may be unique needs for each individual group.

**Rationale for proposed research.** HL is considered to be a rare but highly curable cancer because it has a five year survival rate of about 85% (ACS, 2014). This can sometimes lead to the notion that the patients who are being treated for HL are not receiving treatments that could impact the individual's health in the present or future. The rationale for this proposed research is that other studies and research will choose to focus on more common cancer types that affect a greater number of individuals. This study also will review attitudes, perceived subjective norms, and perceived behavioral control to determine survivors' intentions to follow a SCP, rather than on just survivors' attitudes and beliefs on what components should make up a care plan. The purpose of this study is to determine the attitudes, perceived subjective norms, and perceived behavioral control that HL survivors have toward survivorship care plans and how these impact their intentions to follow a care plan.

### **Chapter III: Methodology**

This study analyzed HL survivors' intentions to follow a SCP. The dependent variable was the intention to participate in a SCP. The independent variables were the constructs of the TPB.

#### **Theoretical Framework**

All of the constructs of the TPB were addressed in this study, including behavioral intention, attitude, subjective norm, and perceived behavioral control. Related to cancer SCPs, behavioral intention evaluated whether an individual would follow a SCP. Cancer survivors' attitudes toward SCPs were determined. To measure subjective norm, cancer survivors' beliefs about whether key people approve or disapprove of them following a SCP was evaluated. Lastly, perceived behavioral control was evaluated by whether survivors felt they could successfully follow the SCP.

#### **Methods and Procedures**

The research protocol was reviewed and approved by the University Human Subjects Review Committee at Eastern Michigan University.

#### **Instrumentation**

An online survey instrument was developed and used to address the research questions guiding this study (Appendix A). The TPB questionnaire developed by Courneya et al. (2010) was modified for HL survivors' intentions to follow SCPs and HL survivor demographics. The questionnaire was entered into *SurveyMonkey* and pilot tested to five HL survivors to test face validity and to make sure that there were no technical issues with the online survey.

The following survey item measured survivors' attitudes toward SCPs:

- Following a SCP for HL for the next five years would be:

- Extremely unhelpful to extremely helpful
  1. Extremely harmful to extremely beneficial
  2. Extremely difficult to extremely easy
  3. Extremely foolish to extremely wise
  4. Extremely unpleasant to extremely pleasant
  5. Extremely bad to extremely good

The following three survey items measured survivors' perceived subjective norms towards SCPs:

- Most people who are important to me think I should follow a SCP for HL.
  1. Strongly disagree to strongly agree
- Most people who are important to me would encourage me to follow a SCP for HL.
  1. Strongly disagree to strongly agree
- Most people who are important to me would support me to follow a SCP for HL.
  1. Strongly disagree to strongly agree

The following 3 items measured survivors' perceived behavioral control towards SCPs:

- If you were really motivated, following a SCP for HL would be:
  1. Extremely hard to extremely easy
- If you were really motivated, how confident are you that you could follow a SCP for HL?
  1. Not confident at all to extremely confident
- If you were really motivated, how much control do you feel you would have in following a SCP for HL?
  1. Very little control to complete control

Finally, the last survey items measured survivors' intentions to follow a SCP.

- I intend to follow a SCP for HL for up to 1 year.
  1. Strongly disagree to strongly agree
- I intend to follow a SCP for HL for 2 years.
  1. Strongly disagree to strongly agree
- I intend to follow a SCP for HL for 3 years.
  1. Strongly disagree to strongly agree
- I intend to follow a SCP for HL for 4 years.
  1. Strongly disagree to strongly agree
- I intend to follow a SCP for HL for 5 years or more.
  1. Strongly disagree to strongly agree

Every question on the survey used a 7 point Likert scale. Spearman Rho correlations were conducted by creating dichotomous categorical variables.

### **Demographics**

In a self-report online questionnaire, age, cancer diagnosis background, and SCP participation were assessed. These items included, gender, the age range the survivor fell into, the age range of their first HL diagnosis, if their HL had ever returned or relapsed, if the survivor had ever followed a SCP for HL in the past, if they were currently follow a SCP for HL, and if following a SCP for HL was ever recommended and by whom.

### **Sample and Sample Recruitment**

The population of interest for this research study was HL cancer survivors. HL survivors were recruited from the Facebook support group for Hodgkin's Lymphoma to take an online questionnaire on *SurveyMonkey*. The Hodgkin's Lymphoma Facebook support group had over 3,700 members, which was made up of survivors, patients, caregivers, and supporters.

### **Data Collection Procedure**

The link to the questionnaire was shared on the Facebook page and also sent via Facebook message to the administrators to encourage group members to participate. Descriptions of the study and eligibility requirements were included when the link to the questionnaire was posted on the Facebook page. When first starting the questionnaire, participants were provided with the informed consent document (See Appendix B). Participants clicked “next” if they agreed to participate and were then taken to the questionnaire.

The questionnaire was administered through the online survey creation tool, *SurveyMonkey*. To provide participant confidentiality, participants were not asked personally identifiable information. The questionnaire was available to those wishing to participate for two weeks. A minimum of 100 participants was expected. If 100 participants were not reached within the two weeks, the survey would remain open until that number was obtained. If 100 participants were reached before the two week closure, the survey would stay open for the remainder of the two weeks. *SurveyMonkey* does not allow the survey to be taken from the same computer more than once. This helped prevent participants from taking the survey more than once. However, there was not a way to prevent a participant from using another computer to retake the questionnaire. The questionnaire took 15 to 30 minutes to complete.

### **Design and Data Analysis**

This study used a cross sectional design. This study sought to answer two key questions: 1.) Are HL survivors being offered SCP for HL? 2.) Are HL survivors currently following any SCP for HL? The data analysis tested the following Alternative hypotheses:

- Survivors with positive attitudes toward SCPs will be more likely to have the intention to follow a SCP.

- Survivors who believe that key people in their lives approve of them following a SCP will be more likely to have the intention to follow a SCP.
- Survivors who believe they have control over their SCP will be more likely to follow a SCP.

Null Hypotheses:

- There is no relationship between HL survivors' attitudes toward SCPs and their intentions to follow a SCP.
- There is no relationship between survivors who believe that key people in their lives approve of them following a SCP will have and their intention to follow a SCP.
- There is no relationship between survivors' belief of control over their following a SCP and their intentions to follow a SCP.

The Statistical Package for the Social Sciences (SPSS) was used to generate descriptive statistics and to determine the frequency of responses and correlations using Spearman's rho.

## Chapter IV: Results

A modified TPB self-reporting, online questionnaire was used to assess the intentions of HL survivors and their intentions to follow a SCP. This chapter will describe the sample, which includes background demographic characteristics and TPB constructs including behavioral intention, attitude, subjective norm, and perceived behavioral control. Additionally, the statistical analyses used to answer the hypotheses and research questions will be presented.

### Description of the Sample

The online *SurveyMonkey* questionnaire was submitted by 110 HL survivors. Of the 110 submitted questionnaires, 99 participants answered all questions. All questionnaires submitted were used when analyzing data, regardless of if all questions on the survey were answered.

In general, the respondents were female (88%), between the ages of 30 to 39 (36%), and had never followed a SCP for HL (49%). Most of the respondents (40%) were first diagnosed with HL between the ages of 21–29. Seventy eight percent of respondents had never had their HL relapse or return. Almost half of respondents (49%) had never followed a SCP for HL in the past and 59 percent were not currently following a SCP. About 33 percent of respondents were recommended by their cancer doctor to follow a SCP. Table 1 provides frequencies for the demographic characteristics of respondents.

Table 1

*Demographic Characteristics of Study Respondents*

Characteristics	Number	Percent
Gender	(n=100)	
Female	88	88.0
Male	12	12.0
Age (years)	(n=100)	
18-20	0	0
21-29	17	17.0
30-39	36	36.0
40-49	25	25.0
50-59	18	18.0
60 or older	4	4.0
Age (years) of 1 <sup>st</sup> diagnoses	(n=100)	
17 or younger	10	10.0
18-20	11	11.0
21-29	40	40.0
30-39	28	28.0
40-49	9	9.0
50-59	1	1.0
60 or older	1	1.0
HL ever relapsed	(n=100)	
Yes	18	18.0
No	78	78.0
Unsure	4	4.0
Followed SCP in past	(n=100)	
Never	49	49.0
>1 year	8	8.0
1-2 years	12	12.0
2-3 years	7	7.0
3>years	24	24.0
Currently following SCP	(n=100)	
Yes	33	33.0
No	59	59.0
Other	8	8.0
Following SCP Recommended by	(n=110)	
Cancer Doctor	36	32.7
Family Doctor	10	9.1
Other Cancer team member	5	4.5
Family member	13	11.8
Cancer patient/survivor	10	9.1
Other (please specify)	23	20.9

\*Percentages based on completed questions.

**Attitude**

Participants were given six different attitudes towards following a SCP for five years and asked to select the number that best fit their response for that attitude. For the first attitude, helpful, the majority of the participants (50.9%) felt that following a SCP for five years would be extremely helpful, and 19.1 percent thought it would be helpful. Most of the participants (48.1%) felt that following a SCP for five years would be extremely beneficial and another 19.8 percent agreed it would be beneficial. About 33 percent were neutral on how easy it would be to follow a SCP for five years, but 27.1 percent felt it would be somewhat easy and 15.9 percent thought it would be easy. The majority of respondents (57.9%) thought that it would be extremely wise to follow a SCP for five years and another 21.5 percent felt it would be wise. Thirty five percent were neutral about how pleasant it would be to follow a SCP for five years, while 34.6 percent thought it would be somewhat pleasant. Most of the participants (43%) thought it would be extremely good to follow a SCP for five years and 22.4 percent felt it would be good. Table 2 provides a profile of HL survivors' attitudes toward following a SCP for five years.

Table 2

*Profile of Participant Attitudes Toward Following a SCP*

Items	Responses	(n)	%
Following a SCP for HL for the next 5 years would be: (attitude 1)	Extremely unhelpful	2	1.8
	Unhelpful	2	1.8
	Somewhat unhelpful	3	2.7
	Neutral	10	9.1
	Somewhat helpful	16	14.5
	Helpful	21	19.1
	Extremely helpful	56	50.9
Following a SCP for HL for the next 5 years would be: (attitude 2)	Extremely harmful	0	0
	Harmful	2	1.9
	Somewhat harmful	0	0
	Neutral	9	8.5
	Somewhat beneficial	23	21.7
	Beneficial	21	19.8
	Extremely beneficial	51	48.1
Following a SCP for HL for the next 5 years would be: (attitude 3)	Extremely difficult	2	1.9
	Difficult	4	3.7
	Somewhat difficult	9	8.4
	Neutral	35	32.7
	Somewhat easy	29	27.1
	Easy	17	15.9
	Extremely easy	11	10.3
Following a SCP for HL for the next 5 years would be: (attitude 4)	Extremely foolish	0	0
	Foolish	0	0
	Somewhat foolish	1	.9
	Neutral	10	9.3
	Somewhat wise	11	10.3
	Wise	23	21.5
	Extremely wise	62	57.9
Following a SCP for HL for the next 5 years would be: (attitude 5)	Extremely unpleasant	1	.9
	Unpleasant	1	.9
	Somewhat unpleasant	8	7.5
	Neutral	38	35.5
	Somewhat pleasant	37	34.6
	Pleasant	15	14.0
	Extremely pleasant	7	6.5
Following a SCP for HL for the next 5 years would be: (attitude 6)	Extremely bad	0	0
	Bad	0	0
	Somewhat bad	1	.9
	Neutral	13	12.1
	Somewhat good	23	21.5
	Good	24	22.4
	Extremely good	46	43.0

\*Percentages based on completed questions.

**Perceived Subjective Norm**

Participants were asked to indicate the degree to which they agreed or disagreed with statements related to subjective norm of following a SCP for HL. The majority of respondents agreed to some extent with all of the statements for subjective norm. Thirty-three percent strongly agreed that people who were important to them thought they should follow a SCP, and 22.4 percent felt that they somewhat agreed with that statement. The majority of respondents (37.7%) strongly agreed that people who were important to them would encourage them to follow a SCP. Another 30.2 percent agreed that those important to them would encourage their following a SCP. Forty-three percent of respondents strongly agreed that those important to them would support them in following a SCP and 30.8 percent agreed. Table 3 provides a profile of perceived subjective norms.

Table 3

*Participant Profile of Perceived Subjective Norms*

Items	Responses	(n)	%
Most people who are important to me think I should follow a SCP for HL.	Strongly disagree	(n=107) 4	3.7
	Disagree	3	2.8
	Somewhat disagree	6	5.6
	Neutral	19	17.8
	Somewhat agree	24	22.4
	Agree	16	15.0
	Strongly agree	35	32.7
Most people who are important to me would encourage me to follow a SCP for HL.	Strongly disagree	(n=106) 1	.9
	Disagree	1	.9
	Somewhat disagree	3	2.8
	Neutral	9	8.5
	Somewhat agree	20	18.9
	Agree	32	30.2
	Strongly agree	40	37.7
Most people who are important to me would support me to follow a SCP for HL.	Strongly disagree	(n=107) 1	.9
	Disagree	0	0
	Somewhat disagree	3	2.8
	Neutral	8	7.5
	Somewhat agree	16	15.0
	Agree	33	30.8
	Strongly agree	46	43.0

\*Percentages based on completed questions.

### Perceived Behavioral Control

Participants were asked to indicate the number that best fit their response for statements related to their perceived behavioral control towards following SCPs for HL. If respondents were really motivated, 32.4 percent thought that following a SCP for HL would be easy. Another 25.5 percent thought it would be extremely easy to follow a SCP for HL if they were really motivated and 25.5 percent also thought it would be somewhat easy to follow a SCP. Many respondents (34.4%) were extremely confident that they could follow a SCP if they were really motivated. If motivated, 27.5 percent of respondents thought they would be somewhat

confident that they could follow a SCP and 25.5 percent were confident they could follow a SCP. When asked how much control they felt they would have in following a SCP, 30.4 percent felt they would have moderate control, 28.4 percent thought they would have near complete control, and 24.5 percent thought they would have complete control. Table 4 provides a profile of perceived behavioral control.

Table 4

*Participant Profile of Perceived Behavioral Control*

Items	Responses	(n)	%
If you were really motivated, following a SCP for HL would be:	Extremely hard	0	0
	Hard	1	1
	Somewhat hard	4	3.9
	Neutral	12	11.8
	Somewhat easy	26	25.5
	Easy	33	32.4
	Extremely Easy	26	25.5
If you were really motivated, how confident are you that you could follow a SCP for HL?	Not at all confident	0	0
	Unconfident	2	2.0
	Somewhat unconfident	0	0
	Neutral	11	10.8
	Somewhat confident	28	27.5
	Confident	26	25.5
	Extremely confident	35	34.3
If you were really motivated, how much control do you feel you would have in following a SCP for HL?	Very little control	0	0
	Little control	0	0
	Some control	7	6.9
	Neutral	10	9.8
	Moderate control	31	30.4
	Near complete control	29	28.4
	Complete control	25	24.5

\*Percentages based on completed questions.

**Intention**

Participants were asked to indicate the degree to which they agreed or disagreed with statements related to intention to follow SCPs for HL. Nearly half of the respondents (52.5%)

strongly agreed that they intended to follow a SCP for HL for up to one year. Almost 50 percent of respondents strongly agreed that they intended to follow a SCP for HL for two years. Many respondents (42.4%) strongly agreed that they intended to follow a SCP for HL for three years. A similar number of respondents (41.4%) strongly agreed that they intended to follow a SCP for HL for both four years and five years or more. Table 5 provides a profile of participants' intention to follow a SCP.

Table 5

*Participants Profile of Intention to Follow a SCP*

Items	Responses	(n)	%
I intend to follow a SCP for HL for up to 1 year.		(n=99)	
	Strongly disagree	5	5.1
	Disagree	2	2.0
	Somewhat disagree	2	2.0
	Neutral	9	9.1
	Somewhat agree	12	12.1
	Agree	17	17.2
	Strongly agree	52	52.5
I intend to follow a SCP for HL for 2 years.		(n=99)	
	Strongly disagree	5	5.1
	Disagree	1	1.0
	Somewhat disagree	4	4.0
	Neutral	12	12.1
	Somewhat agree	15	15.2
	Agree	13	13.1
	Strongly agree	49	49.5
I intend to follow a SCP for HL for 3 years.		(n=99)	
	Strongly disagree	6	6.1
	Disagree	1	1.0
	Somewhat disagree	3	3.0
	Neutral	14	14.1
	Somewhat agree	16	16.2
	Agree	17	17.2
	Strongly agree	42	42.4
I intend to follow a SCP for HL for 4 years.		(n=99)	
	Strongly disagree	6	6.1
	Disagree	1	1.0
	Somewhat disagree	3	3.0
	Neutral	16	16.2
	Somewhat agree	19	19.2
	Agree	13	13.1
	Strongly agree	41	41.4
I intend to follow a SCP for HL for 5 years or more.		(n=99)	
	Strongly disagree	7	7.1
	Disagree	1	1.0
	Somewhat disagree	3	3.0
	Neutral	18	18.2
	Somewhat agree	16	16.2
	Agree	13	13.1
	Strongly agree	41	41.4

\*Percentages based on completed questions.

## Hypotheses

This study was guided by three alternative hypotheses and two key questions.

Alternative hypotheses:

- Survivors with positive attitudes toward SCPs will be more likely to have the intention to follow a SCP.
- Survivors who believe that key people in their lives approve of them following a SCP will be more likely to have the intention to follow a SCP.
- Survivors who believe they have control over their SCP will be more likely to follow a SCP.

Null Hypotheses:

- There is no relationship between HL survivors' attitudes toward SCPs and their intentions to follow a SCP.
- There is no relationship between survivors who believe that key people in their lives approve of them following a SCP and their intention to follow a SCP.
- There is no relationship between survivors' belief of control over their following a SCP and their intentions to follow a SCP.

Key Questions:

1. Are HL survivors being offered SCPs for HL?
2. Are HL survivors currently following any SCPs for HL?

### Recoded Data

The attitude, perceived subjective norm, perceived behavioral control, and five year intention to follow a SCP were recoded so that Spearman's rho correlations could be used to analyze the data. For the first attitude, *following a SCP for HL for the next 5 years would be*, answers were recoded to *unhelpful* if participants answered *extremely unhelpful, unhelpful, or somewhat unhelpful*. If participants answered *extremely helpful, helpful, somewhat helpful*, the data was recoded to be *helpful*. If participants answered *neutral*, these responses were dropped. The remaining attitudes were recoded in the same manner, but each used their own specific attitude. The second attitude had answers recoded to *harmful* or *beneficial*. The third attitude responses became *difficult* or *easy*. The fourth attitude responses were *foolish* or *wise*. The fifth attitude responses became *unpleasant* or *pleasant*. The last attitude responses were recoded to *bad* and *good*.

The responses for those survey items that addressed perceived subjective norm were recoded. If the participants answered *Strongly disagree, Disagree, or Somewhat disagree*, the response was recoded as *Disagree*. If participants answered *Strongly Agree, Agree, Somewhat Agree* the responses were recoded as *Agree*.

The responses for those survey items that addressed perceived behavioral control were recoded. For the question, *if you were really motivated, following a SCP for HL would be*, if participants answered *extremely hard, hard, or somewhat hard* the answer was recoded to *hard*. If participants answered *extremely easy, easy, or somewhat easy* the answer was recoded to *easy*. For the question, *if you were really motivated, how confident are you that you could follow a SCP for HL*, if respondents answered *not at all confident, unconfident, or somewhat unconfident* the answer was recoded to *not at all confident*. If respondents answered *extremely confident*,

*confident, or somewhat confident* the answer was recoded to *confident*. For the question, *if you were really motivated, how much control do you feel you would have in following a SCP for HL*, if respondents answered *very little control, little control, or some control* answers were recoded as *very little control*. If respondents answered *moderate control, near complete control, or complete control* answers were recoded as *complete control*.

Lastly, the question, *I intend to follow a SCP for HL for 5 years or more*, was recoded. If a participant answered *strongly disagree, disagree, or somewhat disagree* answers were recoded to *disagree*. If participant answered *strongly agree, agree, or somewhat agree* the answers were recoded to *agree*.

**Research Question #1:** Are HL survivors being offered SCPs for HL?

A frequency analysis was performed using the survey question, *was following a SCP for HL ever recommended to you by your*, survivors had 6 different options and could choose more than one answer. A total of 70 participants responded to this question, but the frequency analysis was run for the 110 submitted questionnaires. Following a SCP for HL was recommended to 32.7 percent of respondents by a cancer doctor. Family doctors recommended 9.1 percent of respondents to follow a SCP for HL. Other cancer team members recommending survivors accounted for 7.14 percent. Following a SCP for HL was recommended to 11.8 percent of respondents by their family members. There were 9.1 percent of respondents that were recommended to follow a SCP by another cancer patient/survivor.

There was an option for participants to choose other on this survey item and to specify their answer. About 21 percent of participants provided an "other" response. The majority of responses were *none, never recommended, or not offered*. There were a few responses that were similar in terms, stating that participants had done their own research to find out about SCPs.

One person found out about SCPs by a Facebook support group. Table 6 provides a profile of who recommended participants to follow a SCP.

Table 6

*Profile of Participants Recommended Following a SCP*

Item	Responses	(n)	%
Was following a SCP for HL ever recommended to you by your:	Cancer Doctor	36	32.7
	Family Doctor	10	9.1
	Other Cancer team member	5	4.5
	Family Member	13	11.8
	Cancer Patient/Survivor	10	9.1
	Other	23	20.9
			(n=110)

\*Percentages based on number of submitted questionnaires.

**Research Question #2:** Are HL survivors currently following any SCPs for HL?

A frequency analysis was performed using the survey question, *are you currently following a survivorship care plan for Hodgkin's Lymphoma?* Thirty three percent of participants responded *yes* to currently following a SCP for HL. Fifty-nine percent of participants responded *no* to following a SCP for HL. Another 8.0 percent of participants responded *other*. Those that responded *other* generally had followed a plan previously but had stopped, had not been offered a plan, or were following up with a doctor but had not received a written plan. Table 7 provides a profile of participants currently following a SCP for HL.

Table 7

*Profile of Participants Currently Following SCPs for HL*

Item	Responses	(n)	%
Are you currently following a survivorship care plan for Hodgkin's Lymphoma?		(n=100)	
	Yes	33	33.0
	No	59	59.0
	Other	8	8.0

\*Percentages based on completed questions.

**Hypothesis #1:** Survivors with positive attitudes toward SCPs will be more likely to have the intention to follow a SCP.

Spearman's Rho correlations were used to examine the relationship between attitudes and intention to follow a SCP for five years or more. The recoded data was used for attitudes and the intention to follow a SCP for five years or more.

No significant correlations were noted between *foolish-wise* (.) as there was not enough variance between variables to run a correlation for this attitude and intention to follow a SCP for five years or more. No significant correlations were noted between the attitudes *bad-good* (-.038), *harmful-beneficial* (.211) or *unpleasant-pleasant* (.163) and the intention to follow a SCP for five years or more. There was a significant correlation noted between *unhelpful-helpful* (.396), and the five year intention to follow a SCP. There was a significant correlation between the attitude *difficult-easy* (.409) and intention to follow a SCP for five years. See Table 8 for details about the correlations between attitude and five year SCP intention.

Table 8

*Correlation Between Attitude and 5-Year SCP Intention*

	I intend to follow a SCP for HL for 5 years or more.
Following a SCP for HL for the next 5 years would be: (Extremely unhelpful–Extremely helpful) Spearman's rho Correlation Significance (2-tailed) N	.396* .000 76
Following a SCP for HL for the next 5 years would be: (Extremely harmful–Extremely beneficial) Spearman's rho Correlation Significance (2-tailed) N	.211 .067 76
Following a SCP for HL for the next 5 years would be: (Extremely difficult–Extremely easy) Spearman's rho Correlation Significance (2-tailed) N	.409* .002 56
Following a SCP for HL for the next 5 years would be: (Extremely foolish–Extremely wise) Spearman's rho Correlation Significance (2-tailed) N	. .75
Following a SCP for HL for the next 5 years would be: (Extremely unpleasant–Extremely pleasant) Spearman's rho Correlation Significance (2-tailed) N	.163 .231 56
Following a SCP for HL for the next 5 years would be: (Extremely bad–Extremely good) Spearman's rho Correlation Significance (2-tailed) N	-.038 .749 74

\*Significance base on .05

**Hypothesis #2:** Survivors who believe that key people in their lives approve of them following a SCP will be more likely to have the intention to follow a SCP.

Spearman's Rho correlations were used to identify a significant relationship between perceived subjective norms and intention to follow a SCP for five years or more. The recorded

data was used for perceived subjective norms and the intention to follow a SCP for five years or more.

Significant correlations were noted between the perceived subjective norms that those who are important to participants think they should follow a SCP (.364) and would encourage participants to follow a SCP (.301). No significant correlations were noted between the perceived subjective norms that those who are important to participants would support them following a SCP and intention to follow a SCP for five years or more. See Table 9 for details about correlation between perceived subjective norms and intention to follow a SCP for five years or more.

Table 9

*Correlation Between Perceived Subjective Norms and 5-Year SCP Intention*

	I intend to follow a SCP for HL for 5 years or more.
Most people who are important to me think I should follow a SCP for HL. Spearman's rho Correlation Significance (2-tailed) N	.364* .002 68
Most people who are important to me would encourage me to follow a SCP for HL. Spearman's rho Correlation Significance (2-tailed) N	.301* .010 73
Most people who are important to me would support me to follow a SCP for HL. Spearman's rho Correlation Significance (2-tailed) N	.097 .401 77

\*Significance base on .05

**Hypothesis #3:** Survivors who believe they have control over their SCP will be more likely to follow a SCP.

Spearman's Rho correlations were used to identify a significant relationship between perceived behavioral control and intention to follow a SCP for five years or more. The recoded data was used for perceived behavioral control and the intention to follow a SCP for five years or more.

Significant correlation was noted between participants who believe that if they are really motivated following a SCP for HL would be easy (.229) and five year intention. A significant correlation was noted between participants who were confident they could follow a SCP for HL (.479) and their intention to follow a plan for five years. A significant correlation was noted between participants who believed they had control (.493) of the SCP for HL and their intention to follow a plan for five years. See Table 10 for details about correlation between perceived behavioral control and intention to follow a SCP for five years or more.

Table 10

*Correlation Between Perceived Behavioral Control and 5-Year SCP Intention*

	I intend to follow a SCP for HL for 5 years or more.
If you were really motivated, following a SCP for HL would be: (Extremely hard-Extremely easy) Spearman's rho Correlation Significance (2-tailed) N	.229* .049 74
If you were really motivated, how confident are you that you could follow a SCP for HL? (Not at all confident-Extremely confident) Spearman's rho Correlation Significance (2-tailed) N	.479* .000 74
If you were really motivated, how much control do you feel you would have in following a SCP for HL? (Very little control-Complete control) Spearman's rho Correlation Significance (2-tailed) N	.493* .000 74

\*Significance base on .05

## **Chapter V: Summary, Conclusions, and Recommendations**

The hypotheses and research questions in this study were directed by intentions to follow SCPs for HL survivors who participated in Facebook support groups. The following summary discusses the important findings for each of the hypotheses and research questions.

### **Positive Attitudes Toward SCPs**

Significant correlations were noted between HL survivors' intentions to follow SCPs for five years or more and the two attitudes, helpful and easy. The majority of respondents agreed that following a SCP for HL would be helpful rather than unhelpful and good rather than bad. Most respondents also agreed that following a SCP for HL would be wise rather than foolish and beneficial rather than harmful. Most respondents had positive attitudes toward following SCPs.

Similar to the findings of the meta-analysis of exercise adherence in cancer patients and survivors conducted by Husebo et al. (2012), it was found that attitudes did not predict intention to follow a SCP for five years or more. Courneya et al. (2010) also found that attitude did not predict exercise adherence in lymphoma patients. In contrast, Zemore and Ajzen (2013) found that attitudes could predict intentions to complete a substance abuse program.

Unlike other studies that have been completed in the past, this study looked at survivors' intentions to follow a SCP. Most studies focus on survivors who are currently follow a SCP and their attitudes towards the different components that make up the SCP that they are following (Ashing-Giwa et al., 2013; Burg et al., 2009; Downs-Holmes et al., 2014; Hewitt et al., 2007; Mayer et al., 2011; Smith et al., 2011). Findings from previous studies found that survivors felt that their SCPs were lacking additional nutrition, exercise, community resources, and cancer recurrence information (Downs-Holmes et al., 2014; Haq et al., 2013). Other studies found that survivors thought that SCPs lacked psychosocial support and individualized content (Hewit et

al., 2007; Marback & Griffie, 2011; Mayer et al., 2011; Smith et al., 2011). Determining survivors' attitudes toward their current SCPs is important, but so is determining their attitudes towards following a SCP. It gives programs a better understanding on how survivors perceive SCPs. For example, in this research it was found that there was a significant correlation between how easy a SCP would be to follow and the intention to follow a SCP for five years or more. If cancer survivorship programs, oncologist, or other cancer doctors were to offer a SCP to a cancer survivor, the findings from this research help them to know that if the survivors are to have the intention to follow a SCP the survivors need to know that following a SCP would be helpful to their after-cancer follow up and easy to follow.

### **Perceived Subjective Norms Toward SCPs**

Significant correlations were noted between HL survivors' intentions to follow SCPs for five years or more and the perceived subjective norm that those important to survivors think they should follow a SCP and that they would encourage survivors to follow a SCP. Most survivors agreed that those important to them think they should follow a SCP, that those important to them would encourage them to follow a SCP, and that those important to them would support them to follow a SCP.

It was determined that perceived subjective norm was a predictor of intention to follow a SCP for five years or more. This was again similar to the meta-analysis conducted by Husebo et al. (2010), which found that subjective norm was a predictor of exercise adherence. However, Courneya et al. (2010) did not find that perceived subjective norms predicted lymphoma patients' adherence to exercise. Perceived subjective norms were also found to not be a predictor of substance abuse treatment completion in the study conducted by Zembre & Ajzen (2013).

Perceived subjective norms were not measured by other studies. However, some studies did determine oncologist and other cancer team members' beliefs and attitudes toward current SCPs and their usage (Haq et al., 2013; Mayer et al., 2014). Haq et al. (2013), found that PCPs preferred that the SCP provide basic information concerning follow-up care and that it be in a user friendly format. Mayer et al. (2014) found that oncologist and other cancer providers preferred a streamlined approach to SCPs. This information is important as oncologists, PCPs, and other cancer providers utilize SCPs when planning a survivor's follow-up care. Perceived subjective norm is also useful because it helps to determine if survivors believe they have the necessary support and encouragement to follow a SCP. It would be helpful to know who survivors view as important in their lives and influence survivors the most when making health decisions, such as following a SCP.

### **Perceived Behavioral Control Toward SCPs**

Significant correlations were noted between survivors' intentions to follow a SCP and how easy it would be to follow, how confident they were that they could follow one, and how much control they felt they would have. The majority of respondents agreed that following a SCP would be easy, that they would be confident following a SCP, and that they would have some level of control.

It was determined that perceived behavioral control was a predictor of intention to follow a SCP for five years or more. Perceived behavioral control was a predictor of substance abuse treatment completion (Zemore & Ajzen, 2013). Courneya et al. (2010) also found that perceived behavioral control was a predictor of exercise adherence. Additionally, Husebo et al. (2010) found that perceived behavioral control was a predictor of exercise adherence in cancer patients and survivors.

Prior research has not focused on perceived behavioral control of survivors following a SCP. Most respondents in this research felt that if they were really motivated, following a SCP for HL would be easy. Mayer et al. (2014) found that survivors preferred SCPs that were tailored toward their needs and offered flexibility, which could help to make following a SCP easy. The need for individualized content, found by Smith et al. (2011) may also help survivors to feel they have more control over the SCP and more confident in following the SCP since their needs will be better met.

### **Survivors Offered SCPs**

Cancer doctors were found to have recommended survivors to follow a SCP more than a family doctor, other cancer team member, family member, or other cancer patient/survivor. The number of survivors that responded that they were recommended by a cancer doctor was 32.7 percent, which was slightly higher than previous studies. The 2009–2010 Missouri Behavioral Risk Factor Surveillance System found that only 24 percent of the 9530 respondents who were diagnosed with cancer had received a SCP (Schootman et al., 2013). Birken et al., (2013) found that less than 25 percent of the cancer programs that were part of the South Atlantic Division of the American Cancer Society reported ever using a SCP.

### **Survivors Following SCPs**

More than half of respondents were not currently following a SCP for HL (59%). However, 51% of respondents had at some point in their survivorship followed a SCP. Most studies on SCPs focus on survivors who are currently following a SCP. These studies assess attitudes toward the SCPs that are being followed, rather than determining attitudes toward SCPs in general. Downs-Holmes et al. (2014) completed a pilot study using BCSs and their post-treatment follow up using a SCP. They reviewed the BCSs attitudes towards the different

components that made up the SCP they were following and received feedback on what BCs wanted to improve on the SCP. Similarly, Ashing-Giwa et al. (2013) used focus groups of BCSs to determine how well the SCP that was offered to the BCSs met their needs. Hewitt et al. (2007) also conducted focus groups to review survivors' opinions of a SCP that they were provided.

### **Limitations**

The issue of generalizability must be identified as a limitation of this study. Criteria for participation required that they were HL survivors who had completed treatment and were 18 years or older. The questionnaire was only shared on the Facebook support group for HL. These criteria limit generalizing results only to survivors who have completed treatment, are 18 or older, and use online Facebook support groups.

This was a self-reporting study which is limited by the self-evaluation type of assessment. Participants may present themselves intentionally or unintentionally in a more desirable fashion.

### **Conclusions**

The following are major findings of this study:

1. Participants had positive attitudes towards following a SCP.
2. Participants had positive views of their perceived behavioral control towards following a SCP.
3. Participants had positive views of perceived subjective norms towards following a SCP.
4. Participants were more likely to be recommended to follow a SCP for HL by their cancer doctor than by their family doctor, other cancer team member, family member, or cancer

patient/survivor. However, the number of participants recommended by a cancer doctor was still relatively low.

5. The null hypothesis, "There is no relationship between HL survivors' attitudes toward SCPs and their intentions to follow a SCP," was not rejected.
6. The null hypothesis, "There is no relationship between survivors who believe that key people in their lives approve of them following a SCP and their intentions to follow a SCP," was rejected.
7. The null hypothesis, "There is no relationship between survivors' belief of control over their following a SCP and their intentions to follow a SCP," was rejected.

### **Recommendations for Future Research**

Further research into HL survivors' intentions to follow SCPs should focus on survivors' intentions to follow a SCP before, during, and even after following a SCP. This will help to better understand how intentions change over time and may impact future use of SCPs by survivors. Additionally, future research should determine who the important people are in survivors' lives that affect their perceived subjective norms. This is important as it could help to identify others that need to be educated about SCPs.

### **Impact on the Health Education Profession**

There are seven areas of responsibility for health educators: assess individual and community needs for health education; plan health education strategies, interventions, and programs; implement health education strategies, interventions and, programs; conduct evaluation and research related to health education; administer health education strategies, interventions, and programs; serve as a health education resource person; and communicate and advocate for health and health education. The present study assessed the intentions of HL

survivors to follow a SCP. Research should continue to assess intention to follow a SCP and continue determining attitudes, beliefs, and behavior toward following SCPs to improve understanding of why survivors chose to follow or not follow a SCP. Health educators have the opportunity to improve SCP usage by planning and implementing programs for survivors to follow SCPs and for medical professionals to encourage issuing SCPs to survivors. Health educators also have the opportunity to serve as a resource person for SCPs in relation to health promotion and prevention for survivors.

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## Appendix A

### Survivorship Care Plans for Hodgkin's Lymphoma Survey

What is a survivorship care plan?

A survivorship care plan is a personalized plan given to cancer survivors by their doctors, which includes guidelines for monitoring and maintaining their health.

Survivorship care plans can include:

- A treatment summary and details of cancer diagnosis
- Follow-up recommendations for ongoing care
- Health Promotion ideas and suggestions, such as stress reduction, exercise, etc.

For this survey there will be items that use the term "SCP for HL" which stands for Survivorship Care Plan for Hodgkin's Lymphoma.

This first survey item lists 6 different attitudes towards following a SCP for HL for the next 5 years. For each of these 6 different attitudes select the number that best fits your response for that attitude.

1. Following a SCP for HL for the next 5 years would be:

- |    |                        |   |   |   |   |   |                         |
|----|------------------------|---|---|---|---|---|-------------------------|
| a. | 1                      | 2 | 3 | 4 | 5 | 6 | 7                       |
|    | extremely<br>unhelpful |   |   |   |   |   | extremely<br>helpful    |
| b. | 1                      | 2 | 3 | 4 | 5 | 6 | 7                       |
|    | extremely<br>harmful   |   |   |   |   |   | extremely<br>beneficial |
| c. | 1                      | 2 | 3 | 4 | 5 | 6 | 7                       |
|    | extremely              |   |   |   |   |   | extremely               |

	difficult							easy
d.	1	2	3	4	5	6	7	
	extremely foolish							extremely wise
e.	1	2	3	4	5	6	7	
	extremely unpleasant							extremely pleasant
f.	1	2	3	4	5	6	7	
	extremely bad							extremely good

The next three items are about how much support and approval you feel you will receive to follow a Survivorship Care Plan for Hodgkin's Lymphoma (SCP for HL).

2. Most people who are important to me think I should follow a SCP for HL. (Indicate the number that best fits your response.)

1	2	3	4	5	6	7
strongly disagree						strongly agree

3. Most people who are important to me would encourage me to follow a SCP for HL. (Indicate the number that best fits your response.)

1	2	3	4	5	6	7
strongly disagree						strongly agree

4. Most people who are important to me would support me to follow a SCP for HL.  
(Indicate the number that best fits your response.)

1	2	3	4	5	6	7
strongly disagree						strongly agree

The next three items are about how easy or difficult it will be for you to follow a Survivorship Care Plan for Hodgkin's Lymphoma (SCP for HL) if you were really motivated.

5. If you were really motivated, following a SCP for HL would be: (Indicate the number that best fits your response.)

1	2	3	4	5	6	7
extremely hard						extremely easy

6. If you were really motivated, how confident are you that you could follow a SCP for HL?  
(Indicate the number that best fits your response.)

1	2	3	4	5	6	7
not at all confident						extremely confident

7. If you were really motivated, how much control do you feel you would have in following a SCP for HL? (Indicate the number that best fits your response.)

1	2	3	4	5	6	7
very little control						complete control

The next 5 items are about how you plan to follow a Survivorship Care Plan for Hodgkin's Lymphoma (SCP for HL) for different periods of time. For each item select the number that best fits your response for that time period.

8. I intend to follow a SCP for HL for up to 1 year.

1	2	3	4	5	6	7
strongly disagree						strongly agree

9. I intend to follow a SCP for HL for 2 years.

1	2	3	4	5	6	7
strongly disagree						strongly agree

10. I intend to follow a SCP for HL for 3 years.

1	2	3	4	5	6	7
strongly disagree						strongly agree

11. I intend to follow a SCP for HL for 4 years.

1	2	3	4	5	6	7
strongly disagree						strongly agree

12. I intend to follow a SCP for HL for 5 years or more.

1	2	3	4	5	6	7
strongly disagree						strongly agree

## Demographics

Please select the answer that best describes you:

13. I identify my gender as (Select only one response.):

- a. Female
- b. Male
- c. Other (Please specify)

14. Please select the range that your age falls into (Select only one response.):

- a. 18-20
- b. 21-29
- c. 30-39
- d. 40-49
- e. 50-59
- f. 60 or older

15. Please select the range your age at first Hodgkin's Lymphoma diagnosis (Select only one response.):

- a. 17 or younger
- b. 18-20
- c. 21-29
- d. 30-39
- e. 40-49
- f. 50-59
- g. 60 or older

16. Has your Hodgkin's Lymphoma ever relapsed/returned? (Select only one response.)

- a. Yes
- b. No

- c. Unsure
17. This item is to find out if you have ever followed a Survivorship Care Plan for Hodgkin's Lymphoma (SCP for HL) in the past. (Select only one response.)
- a. I have never followed a survivorship care plan for HL.
  - b. I have followed a SCP for HL for less than 1 year.
  - c. I have followed a SCP for HL for 1 to 2 years .
  - d. I have followed a SCP for HL for 2 to 3 years.
  - e. I have followed a SCP for HL for 3 or more years.
18. Are you currently following a survivorship care plan for Hodgkin's Lymphoma? (Select only one response.)
- a. Yes
  - b. No
  - c. Other (Please specify)
19. Was following a survivorship care plan for Hodgkin's Lymphoma ever recommended to you by your (Please indicate **ALL RESPONSES** that apply):
- a. Cancer doctor
  - b. Family doctor
  - c. Other cancer team member
  - d. Family member
  - e. Other cancer patient/survivor
  - f. Other (Please specify)

Thank you for your participation in this survey.

For more information about survivorship care plans or to begin creating your own, you can visit the following websites:

- [http://mncanceralliance.org/wp-content/uploads/2013/07/SurvivorCarePlan3202012\\_Final.pdf](http://mncanceralliance.org/wp-content/uploads/2013/07/SurvivorCarePlan3202012_Final.pdf)

- <http://www.journeyforward.org/>
- <http://www.nursingcenter.com/lnc/static?pageid=721732>
- <http://www.cancer.net/survivorship>
- <http://www.livestrongcareplan.org/>

## Appendix B

# RESEARCH @ EMU

## Consent Form

**Purpose:** The purpose of this research study is to explore the intention of Hodgkin's Lymphoma survivors to follow survivorship care plans.

**Study Procedures:** Participation in this study involves completing an online survey. It should take between 15 and 30 minutes to complete the survey.

**Risks:** The primary risk of participation in this study is a potential loss of confidentiality. No personally identifiable information will be collected in order to minimize this risk. Some of the survey questions are personal in nature and may make you feel uncomfortable. You do not have to answer any questions that make you uncomfortable or that you do not want to answer.

**Benefits:** You will not directly benefit from participating in this research. Benefits to society include understanding factors that may help influence Hodgkin Lymphoma survivors' intentions to follow survivorship care plans.

**Confidentiality:** Confidentiality will be maintained to the degree permitted by the technology used. Your participation in this online survey involves risks similar to a person's everyday use of the Internet. Your information will be stored in a password-protected computer file.

We may share your information with other researchers outside of Eastern Michigan University. If we share your information, we will remove any and all identifiable information so that you cannot reasonably be identified.

This study is being completed to partially fulfill the requirements for a Master of Science in Health Education at EMU. The results of this research may be published or used for teaching. Identifiable information will not be used for these purposes.

**Contact Information:** If you have any questions about the research, you can contact the Principal Investigator, Kortni Evans at [kevans22@emich.edu](mailto:kevans22@emich.edu). You can also contact her adviser, Dr. Joan Cowdery, at [jcowdery@emich.edu](mailto:jcowdery@emich.edu) or by phone at 734-487-2811.

For questions about your rights as a research subject, you can contact the Eastern Michigan University Office of Research Compliance at [human.subjects@emich.edu](mailto:human.subjects@emich.edu) or by phone at 734-487-3090.

### **Voluntary participation**

Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, with no penalty or loss of benefits to which you are otherwise entitled. You may choose to leave the study at any time with no loss of benefits to which you are otherwise entitled. If you leave the study, the information you provided will be kept confidential. You may request, in writing, that your identifiable information be destroyed. However, we cannot destroy any information that has already been published.

### **Statement of Consent**

I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I click "Next" below to indicate my consent to participate in this research study.

## Appendix C

**RESEARCH @ EMU**

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**UHSRC Determination: EXEMPT**

**DATE: August 25, 2015**

**TO: Kortni Evans, BS**  
**Eastern Michigan University**

**Re: UHSRC: # 791159-1**  
**Category: Exempt category 2**  
**Approval Date: August 25, 2015**

**Title: Hodgkin's Lymphoma Survivors' Intentions to Follow Survivorship Care Plans**

Your research project, entitled **Hodgkin's Lymphoma Survivors' Intentions to Follow Survivorship Care Plans**, has been determined **Exempt** in accordance with federal regulation 45 CFR 46.102. UHSRC policy states that you, as the Principal Investigator, are responsible for protecting the rights and welfare of your research subjects and conducting your research as described in your protocol.

**Renewals:** Exempt protocols do not need to be renewed. When the project is completed, please submit the **Human Subjects Study Completion Form** (access through IRBNet on the UHSRC website).

**Modifications:** You may make minor changes (e.g., study staff changes, sample size changes, contact information changes, etc.) without submitting for review. However, if you plan to make changes that alter study design or any study instruments, you must submit a **Human Subjects Approval Request Form** and obtain approval prior to implementation. The form is available through IRBNet on the UHSRC website.

**Problems:** All major deviations from the reviewed protocol, unanticipated problems, adverse events, subject complaints, or other problems that may increase the risk to human subjects **or** change the category of review must be reported to the UHSRC via an **Event Report** form, available through IRBNet on the UHSRC website.

**Follow-up:** If your Exempt project is not completed and closed after **three years**, the UHSRC office will contact you regarding the status of the project.

Please use the UHSRC number listed above on any forms submitted that relate to this project, or on any correspondence with the UHSRC office.

Good luck in your research. If we can be of further assistance, please contact us at 734-487-3090 or via e-mail at [human.subjects@emich.edu](mailto:human.subjects@emich.edu). Thank you for your cooperation.

Sincerely,

April Nelson, MS  
Research Compliance Administrator  
University Human Subjects Review Committee