

TRANSCENDING ILLNESS: POST-TRAUMATIC GROWTH IN LEUKEMIA AND  
LYMPHOMA SURVIVORS

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## Abstract

The years following treatment are often associated with physical and mental health sequelae for cancer survivors and caregivers. They may be more distressing for survivors and caregivers of leukemia and lymphoma than solid tumor survivors. Survivors of life-threatening illnesses have been found to show positive biopsychosocial changes, termed posttraumatic growth. Cancer survivors with more severe diagnoses often display higher levels of posttraumatic growth. Positive and negative biopsychosocial changes may be more pronounced among caregivers and survivors of leukemia and lymphoma than of solid tumors. This is the first study to compare biopsychosocial changes following cancer diagnoses among solid versus non-solid cancer survivors and caregivers.

Fifty-one cancer survivors and their caregivers were recruited online through classified advertisements for research participants and snowball sampling. They completed a demographic questionnaire including questions about their diagnoses, treatments, and perceived cancer severity along with a battery of questionnaires measuring different domains of adjustment to cancer including: posttraumatic growth, negative biopsychosocial changes due to cancer, health-related quality of life, and social support. Chronbach Alphas were conducted to demonstrate the internal consistency for questionnaire data among the caregiver and survivor subgroups of the sample. Correlation matrices were calculated for questionnaire data among caregivers and survivors to demonstrate the relationships between the different outcome variables. Multiple regressions and t-tests were conducted to test the differences in levels of posttraumatic growth, negative biopsychosocial changes attributed to cancer, health-related quality of life, and social support among solid versus non-solid tumor survivors and caregivers.

The results from the hypothesis testing did not suggest that a diagnosis of a solid versus non-solid tumor nor a higher degree of perceived severity of diagnosis predicted significant differences in posttraumatic growth, negative biopsychosocial changes related to cancer, health-related quality of life, or social support. This is likely partially due to the small sample size utilized in this study and the impact of potential moderators including: social economic status, comorbid medical conditions, and time since treatment cessation. Further research into biopsychosocial adjustment to cancer survivorship and care giving could facilitate understanding and provision of services to address the biopsychosocial needs of cancer survivors and caregivers.

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## List of Abbreviations and Symbols

ALL: Acute lymphocytic leukemia

AML: Acute myeloid leukemia

CDC HRQoL: Centers for Disease Control Health Related Quality of Life scale

CLL: Chronic Lymphoblastic leukemia

CML: Chronic Myeloid leukemia

IBM SPSS: International Business Machines Statistical Package for the Social Sciences

IOCv2: Impact of Cancer scale volume 2

LLS: Leukemia and lymphoma survivor

$M$ : arithmetic mean

MCAR: Missing completely at random

OSS-3: Oslo Social Support Scale

$p$ : the statistical significance

PTGI: Posttraumatic Growth Inventory

QOL: Quality of Life

$r$ : the correlation coefficient

SD: the standard deviation of values from the mean

SE: the standard error of the sample

$t$ : the resulting statistic from a t-test, used in hypothesis testing

$\alpha$ : Cronbach's Alpha, a measure of the internal consistency of a questionnaire

$\beta$ : Beta coefficient, a standardized estimate from regression analyses

## Chapter 1. Introduction

Leukemia and lymphoma are classified as non-solid tumors that occur in the hematopoietic stem cells, found in bone marrow, and lymphatic cells, respectively (Jaffe, Harris, Stein, & Vardiman, 2001). The National Cancer Institute estimated the prevalence of leukemia and lymphoma in the United States to be 1,735,350 and the incidence to be 174,250 each year based on data regarding the trends in incidence rates over recent years (Leukemia and Lymphoma Society, 2018). For the purpose of this dissertation, individuals in treatment for cancers, such as leukemia and lymphoma, will be referred to as patients and those who have completed treatment will be referred to as survivors.

### *Common Diagnoses*

There are over 50 identified subtypes of leukemia and lymphoma (see Appendix A for a complete list). In the United States, the most common diagnoses within the categories of leukemia and lymphoma are non-Hodgkin lymphoma, followed by acute myeloid leukemia, chronic lymphocytic leukemia, Hodgkin lymphoma, acute lymphoblastic leukemia, and chronic myeloid leukemia (Leukemia and Lymphoma Society, 2014). Non-Hodgkin lymphoma is the most common class of diagnoses of non-solid tumors and describes a number of B-cell malignancies, which are disordered development of a subclass of white blood cells in the immune system that travel through the lymphoid tissue (Evans & Hancock, 2003). In contrast, Hodgkin lymphoma is characterized by a mutation of lymphatic cells into Reed-Sternberg cells, large cells that typically have more than one nuclei, often associated with the Epstein-Barr virus (Küppers and Rajewsky, 1998). Hodgkin lymphoma can cause lymphocyte depletion, which reduces the effectiveness of the immune system.

Acute Myeloid Leukemia (AML) refers to a sudden proliferation of immature blood cells in the bone marrow due to a mutation (Shipley & Butera, 2009). Chronic Myeloid Leukemia (CML) also refers to a mutation in the stem cells that develop into blood cells in the bone marrow, leading to an increase in immature blood cells but is associated with a slower onset (Hehlmann, Hochhaus, & Baccarani, 2007). Chronic lymphocytic leukemia (CLL) arises due to a mutation in the bone marrow leading to impaired B-cell receptor activity and low production of blood cells, resulting in anemia (Dighiero & Hamblin, 2008). Acute lymphoblastic leukemia (ALL) involves a proliferation in immature blood cells that often block the development of functioning mature cells and typically peaks in early childhood but can affect adults as well (Inaba, Greaves, & Mullighan, 2013).

### *Staging*

Staging refers to the process in which the clinical severity of a cancer, including such factors as the size of a tumor and the degree to which it has spread outside of the original location, is determined through medical assessment, such as biopsy and blood tests (National Cancer Institute, 2018). In cases of non-solid tumors, the categories in which the cancer is staged, the criteria by which the tumors are classified, and the prognostic value provided by the stages vary substantially by diagnostic subtype (e.g. American Cancer Society, 2018; National Cancer Institute, 2018). Understanding of the severity, risk for recurrence, and risk of death from cancer and its treatment often is significantly different between cancer patients/survivors and their medical providers and this difference is particularly pronounced among patients/survivors of non-solid tumors (e.g. El-Jawahri et al., 2017; Shimer et al., 2018). Difficulties in communications between patients and medical providers, as well as the overall complexity of the

staging processes and the results of these processes may contribute to misunderstandings among patients/survivors about the severity of their diagnoses.

### *Treatment*

Like many other types of cancers, leukemia and lymphoma are typically treated with chemotherapy, radiation therapy, biological therapy, and/or bone-marrow transplantation, depending on the diagnosis, stage, and patient characteristics (e.g. general health). Chemotherapy describes medications administered intravenously, directly into the central nervous system fluid, or orally that are formulated to destroy malignant cells (Leonard, 1998). For certain cancers, such as Hodgkin lymphoma, the chemical formulation is able to specifically target the specific genetic makeup of the cancer cells. However, the effectiveness of chemotherapy is more effective for certain types of cancers, such as Hodgkin lymphoma, than for others, such as many forms of non-Hodgkin lymphoma. The degree to which the cancer has progressed also impacts the efficacy of chemotherapy. Chemotherapy can also be toxic to other cells as well, causing different side effects including nausea, intense fatigue, hair loss, changes in smell and taste, neuropathy, anemia, and increased susceptibility to infection (Cherrier-De Wilde, 2013). In certain patients, these side effects can be lethal. Careful monitoring and dosage adjustments are necessary to ensure that these concerns do not outweigh their benefits.

Radiation therapy involves directing a concentrated dose of radiation to the site of a particular tumor (Leonard, 1998). This burns cancer cells, thereby killing them. Although radiation therapy can kill cancer cells, it can also cause mutation in nearby healthy cells that can develop into different tumors, known as secondary malignancies (Travis, Allan, Pui et al., 2011). Radiation therapy can also damage nearby cells, causing a range of problems depending on the location, including cardiovascular disease, which can be fatal.

Treatments that utilize large quantities of substances produced by the human body to counteract malignant cells are known as biological therapies (Leonard, 1998). These include the drug interferon, commonly used to treat leukemia. Interferon is a cytokine; they assist the body's immune response to cancer cells, disrupt cancer cell growth, and assist in the development of normal cells. Side effects and complications of biological treatment vary depending on the type of treatment and dosage and include fatigue, insomnia, depression, thrombocytopenia, anemia, and congestive heart failure (Foon, 2012).

In certain cases, bone marrow can be harvested from donors or the cancer patient while in remission and transplanted into the cancer patient while the disease is active (Leonard, 1998). This is a fairly common treatment in leukemia patients and involves destroying the patient's current bone marrow using high doses of chemotherapy and/or radiation therapy. When the transplanted bone marrow comes from a source other than the patient, there is a risk of a condition called graft-versus host disease in which the T-cells in the donor bone marrow attack tissue or organs in the bone marrow recipient (Blazar, Murphy, & Abedi, 2012). This condition can be fatal if it is resistant to treatment with immunosuppressant drugs.

Evidence based treatment for non-Hodgkin lymphoma varies depending on the exact type of lymphoma but generally includes some form of chemotherapy and radiation therapy (Evans & Hancock, 2003). AML is typically treated with chemotherapy, and/or stem cell transplantation once the patients are in remission, depending on their general health (Shipley & Butera, 2009). Following remission, treatment with an additional regiment of chemotherapy and/or bone marrow transplantation may be implemented to improve survival and cure rates. CML is highly responsive to treatment with a small-molecule pill that when taken daily, suppresses the cell proliferation of the cancer cells (Hehlmann et al., 2007). Chemotherapy, radiation therapy, and

hormone therapy are often utilized with intermediate and advanced staged CLL patients; however, they carry a variety of risks including infection, secondary malignancies, and hematological toxicity (Halleck et al., 2008). In many early-stage CLL cases, the risk of treatment due to side effects and complications often outweighs foreseeable benefits and watchful waiting is the best practice treatment unless the disease progresses. Hodgkin lymphoma often responds well to treatment with chemotherapy and radiotherapy (Girinsky et al., 2006). ALL is typically treated with up to 4 years of chemotherapy (Inaba et al., 2013).

### *Prognosis*

The prognosis of non-Hodgkin lymphoma varies widely depending on the size and location of the tumor(s), the stage, and the general health of the patient (Evans and Hancock, 2003). The particular genetic abnormality associated with the cancer cells is the best predictor of prognosis (Grimwade et al., 1998). Hodgkin lymphoma is often curable with chemotherapy and radiation therapy, however complications and secondary malignancies can occur when radiation therapy is not implemented optimally (Girinsky et al., 2006).

Without treatment, AML is fatal within several weeks to months (Shipley & Butera, 2009). Even with best practice treatment, AML patients often do not survive for more than two years after treatment. With evidence-based treatment, CML has a good prognosis for most patients (Hehlmann et al., 2007). The course and prognosis of CLL varies widely, with patients surviving from several months to multiple decades after diagnosis (Dighiero & Hamblin, 2008). Staging is not always an optimal predictor of prognosis. When diagnosed in early childhood, the prognosis for ALL is optimistic; however, ALL does not respond as well to treatment in adulthood (Inaba et al., 2013). In general, the five-year survival rate estimates are up to 88% for Hodgkin

lymphoma, 79% for non-Hodgkin lymphoma, and 59% for leukemia (Siegel, Ma, Zou, & Jemal, 2014).

As such, the majority of leukemia and lymphoma survivors (LLS) are living well past their original diagnosis. These LLS need to re-adjust to their daily lives with new strengths and limitations following treatment and, in the case of chronic lymphocytic leukemia and chronic myeloid leukemia, over the course of ongoing treatment (Parry, Morningstar, Kendall, & Coleman, 2011).

#### *Cost of Treatment*

The out-of-pocket costs for treatment in the United States is high even with insurance. The National Cancer Institute (2010) estimated that prior to the Affordable Care Act, the average costs for the first year of treatment when patients were insured were as follows: \$33, 167 for female leukemia patients, \$57, 881 for female lymphoma patients, \$36, 036 for male leukemia patients, and \$60, 701 for male lymphoma patients. This can often mean substantial debt for LLS and their families (Parry et al., 2011). The Affordable Care Act has set a maximum per policy period for out-of-pocket health care expenses at \$6,600 for individuals and \$13 200 for families, affecting all enrollees (HealthCare.gov, 2014). It is hoped that this will have a significant impact on the financial situation of LLS.

#### *Health Related Quality of Life in Leukemia and Lymphoma Patients*

Health related quality of life (QOL) measures an individual's functioning across a variety of domains related to disease and disorder, including issues related to finances (Guyatt, Feeny, & Patrick, 1993). Understanding health related QOL is important in determining the impact a disease, disorder, or treatment has on the overall wellbeing of patients and survivors.

While actively in treatment for their cancers, leukemia and lymphoma patients face a variety of concerns related to their QOL. A study from Sweden showed a marked deterioration in multiple areas of QOL over the course of treatment for patients with acute leukemia or advance stage lymphoma (Persson, Larsson, Ohlsson, & Hallberg, 2001). The highest levels of deterioration were in ability to function across the social domain and the various roles required for independent living, such as employment and household duties. Health related QOL was inversely related to psychological distress in leukemia and lymphoma patients in the United Kingdom (Montgomery, Pocock, Titley, & Lloyd, 2002). Concerns about receiving inadequate information on their diagnoses and treatment options were common.

While most studies on health related QOL have focused on the effects of cancer treatments, there is some evidence to indicate that the cancers themselves contribute to changes in functioning. The level of circulating cytokines was associated with various measures of cognitive impairment, fatigue, and overall QOL in a study on patients with AML and myelodysplastic syndrome in the United States (Meyers, Albitar, & Estey, 2005).

#### *Negative Biopsychosocial Changes Following a Cancer Diagnosis/Treatment*

Multi-disciplinary health care providers and researchers have become increasingly aware of the psychosocial distress cancer survivors suffer from following treatment (e.g. Parry et al., 2011). This is typically conceptualized as decreases in health related QOL following the cessation of cancer treatment (e.g. Holland and Rexnik, 2005; Bishop et al., 2007). Information on specific psychosocial challenges faced by LLS survivors is limited; however, there is a growing body of evidence on such challenges across a variety of groups of cancer survivors (e.g. Connerty & Knott, 2013; Stanton et al., 2005), much of which might be relevant to LLS. In 2008, the Institute on Medicine published a report urging cancer care providers to arrange for cancer



survivors to receive assistance in a variety of psychosocial domains following treatment cessation. These recommendations include adequate provision of information about diagnoses and available services, financial assistance, and support for associated distress.

The months and years following treatment can often be more psychologically challenging for cancer survivors than diagnosis and treatment (Holland and Rexnik, 2005). While actively in treatment, many cancer patients do not have the time or energy to adequately process their experience with cancer (Stanton et al., 2005). This processing typically happens following treatment. Studies on cancer survivorship have found that survivors often are preoccupied with anxiety and hypervigilance about potential signs of cancer recurrence (e.g. frequently checking for swollen lymph nodes), feel abandoned by their health care providers when visits become less frequent, and do not think that the health care system adequately addressed their needs (e.g. Deimling, Kahana, Bowman, & Schaefer, 2002; Parry et al., 2011). Fear of recurrence was correlated with additional health problems and family stressors among cancer survivors in the United States (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007). Cancer survivors have also reported that their loved ones often do not understand the extent to which cancer has changed their lives (Connerty & Knott, 2013).

#### *Survivorship Challenges among Caregivers of Cancer Survivors*

Caregivers of cancer survivors often face similar challenges once their loved ones complete treatment. One domain in which such difficulties emerge is health related QOL. Bishop and colleagues (2007) conducted a study on American cancer survivors who had received hematopoietic stem-cell transplantation, their spouses, and healthy controls. They found that the spouses of survivors endorsed sleep difficulties, sexual problems, and depressive symptoms at rates greater than among healthy controls.

Fear of recurrence is a common concern among both cancer survivors and their loved ones. Mellon and colleagues (2007) found that families of cancer survivors in the United States endorsed a greater level of fear of recurrence than the survivors themselves. Correlates of fear of recurrence among family members of cancer survivors included additional family stressors and the meaning that caregivers attached to the cancer in relation to the family's identity and functioning. In an American study on cancer-related distress in cancer survivors and their caregivers, Matthews (2003) found that caregivers endorsed higher levels of overall distress and fear of recurrence than the cancer survivors.

There is some evidence that diagnoses and demographic variables impact caregiver challenges in different ways. Kim, Wellisch, Spillers, and Crammer (2007) found that American female caregivers of breast cancer and ovarian cancer survivors reported lower levels of distress than survivors of cancer types experienced by both sexes, such as lung cancer, leukemia, and lymphoma. Age was inversely related to the level of unmet psychosocial, medical, and financial needs endorsed by American cancer caregivers (Kim, Kashy, Spillers, & Evans, 2010). At two years following the diagnosis, female caregivers reported greater unmet psychosocial needs than their male counterparts. Greater unmet needs were associated with more mental health concerns for survivors (Kim et al., 2010). Kim and colleagues (2008) found that the level of dissimilarity in distress experienced between prostate cancer survivors and their wives predicted increased mental health concerns for the spouses. Dissimilarity in distress levels conversely predicted better physical health in husbands of breast cancer survivors.

#### *LLS-Specific Biopsychosocial Changes Following Diagnosis/Treatment*

Lingering physical effects, such as fatigue and neuropathy, are also often a concern for LLS in the months and years following treatment cessation (Parry et al., 2011; Jones, Parry,

Devine, Main, & Okuyama, 2015). The large variability amongst diagnoses, prognoses, and age of onset in LLS can often lead to fewer commonalities in the biological and psychosocial impacts of cancer in individuals with LLS as compared to those of more common and/or heterogeneous cancers (Jones et al., 2015). This can cause feelings of isolation for survivors whom often have difficulty finding support from fellow survivors whom experience the same types of psychosocial concerns following treatment. These factors also may lead to difficulties finding information that fully addresses survivors' concerns in a manner that is easy to comprehend and readily available (Parry et al., 2011). The financial burden of treatment is also a concern amongst many cancer survivors in the United States and particularly when there are limited sources of financial support for the particular diagnoses, such as leukemia and lymphoma. The costs of after care, such as follow-up visits, scans, and blood tests, are often cost-prohibitive to survivors already financially strained and can lead to insufficient monitoring for recurrence (Parry et al., 2011). In addition, many LLS find that they cannot continue to satisfy occupational requirements due to the physical sequelae of their cancer and treatment, further limiting their financial resources following treatment.

#### *Course of Negative Biopsychosocial Changes among LLS*

These concerns can last for years following the cessation of cancer treatment. Syrjala and colleagues (2003) followed a cohort of LLS who had received hematopoietic stem cell transplantation in the United States for five years post-treatment. By the five-year follow-up assessment, only 63% of participants who had not experienced recurrence were functioning without major physical, psychological, or occupational concerns. Poorer psychological functioning at five years post-treatment was associated with a higher risk for recurrence and/or complications following treatment (Syrjala et al., 2004). At a 10-year follow-up assessment of

quality life among LLS in the United States, Lim and Zebrack (2006) found that QOL was related to the size and strength of survivors' social networks. This relationship was mediated via use of supportive services (e.g. support groups and psychotherapy).

While much of the work on health related QOL in patients with leukemia and lymphoma focuses on the side effects of treatment, there is some evidence that the cancers might impact QOL independently of the treatments. A study from the United States investigated the levels of QOL, fatigue, cognitive impairment, and cytokine levels in patients prior to treatment for AML or myelodysplastic syndrome (Meyers, et al., 2005). Although overall QOL did not appear to be impaired prior to treatment initiation, significant cognitive impairment and fatigue were found.

#### *Correlates of Negative Biopsychosocial Changes Following a Leukemia or Lymphoma*

##### *Diagnosis*

Specific treatments might also play a role in influencing survivorship concerns among LLS. A study from the Netherlands investigated the health related QOL among non-Hodgkin lymphoma survivors 5-15 years following diagnosis (Mols et al., 2007). Survivors who received chemotherapy were found to experience more health related QOL problems than survivors who received watchful waiting or radiation therapy alone. Financial concerns were prominent among this group, including difficulty obtaining a home mortgage and fulfilling job responsibilities due to their cancer diagnosis and treatment (Mols et al., 2007). A study from Norway examined changes in QOL following stem cell transplantation from a donor and chemotherapy compared to those who received stem cell transplantation from their own tissue one to three years following treatment (Hjermstad et al., 2004). They found improvements in health related QOL among all groups with greater improvements found among the group receiving stem cell transplantation from a donor and chemotherapy.

### *Posttraumatic Growth*

Posttraumatic growth refers to positive biopsychosocial changes that occur to individuals following the experience of traumatic events (Tedeschi & Calhoun, 1995). These changes vary from individual to individual in patterns that are similar among survivors of similar crises (Park, 2004). Positive changes following traumatic events allow individuals to not only survive their stressful situation, but to rise above it to a greater level of personal development than they were at prior to their crisis (Zoellner & Maercker, 2006). This growth often occurs through changes in self-perception, such as recognizing one's own strength in overcoming a crisis, outlook on life, social support, and spirituality (Tedeschi & Calhoun, 1995). There is some evidence suggesting a positive correlation between experiencing posttraumatic growth and adjusting to new life circumstances as a result of the trauma (Zoellner & Maercker, 2006). It has also been proposed that posttraumatic growth can serve as a form of avoidance of the negative emotions associated with trauma (Zoellner & Maercker, 2006).

Posttraumatic growth has been found in a variety of populations of trauma survivors including refugees displaced due to combat (Powell, Rosner, Butollo, Tedeschi, & Calhoun, 2003), survivors of natural disasters (Cryder, Kilmer, Tedeschi, & Calhoun, 2006), and survivors of terrorist attacks (Laufer & Solomon, 2006). Although the specific patterns of posttraumatic growth appear to differ among these heterogeneous groups of trauma survivors, common themes appear across groups (e.g. Park, 2004; Zoellner & Maercker, 2006). Schema changes to accommodate the experience of surviving the trauma have been proposed as a potential explanation for posttraumatic growth (Janoff-Bulman, 2004). Research suggests that there appears to be a positive relationship between the severity of the trauma experienced and the

degree of growth, with participants who experienced a greater severity of trauma showing more posttraumatic growth (e.g. Tedeschi & Calhoun, 1995; Tedeschi & Calhoun, 2004).

#### *Posttraumatic Growth in Cancer Patients and Survivors*

Posttraumatic growth has been found in a number of groups of cancer survivors. It has been investigated in survivors of breast cancer (Sears, Stanton, & Danoff-Burg, 2003; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Bellizzi & Blank, 2006), cancer treated with bone-marrow transplantation (Widows, Jacobsen, Booth-Jones, & Fields, 2005), gynecological cancer (Simonelli, Fowler, Maxwell, & Andersen, 2008; Ponto, Ellington, Mellon, & Beck, 2010), childhood cancer (Yi & Kim, 2014), and adolescent cancer (Barakat, Alderfer, & Kazak, 2005). The majority of these studies measured posttraumatic growth using the Posttraumatic Growth Inventory (PTGI) by Tedeschi and Calhoun (1995). The PTGI conceptualizes posttraumatic growth as positive change in the following domains: relationships with others, new opportunities, spiritual growth, appreciation for life, and increased personal strength.

#### *Psychological Correlates of Posttraumatic Growth among Cancer Patients and Survivors*

In a qualitative interview study on posttraumatic growth among survivors of a variety of cancers in Australia, common themes included facing death and re-evaluating priorities, increased appreciation for life, increased spirituality, and improved communication with loved ones (Connerty & Knott, 2013). Posttraumatic growth was inversely correlated with posttraumatic stress among a cohort of long-term survivors of childhood cancer (Yi & Kim, 2014).

A number of psychological coping mechanisms have been found to correlate with posttraumatic growth among cancer survivors. A study by Cordova et al. (2001) on breast cancer survivors found that the level of posttraumatic growth was positively correlated with the time

since the diagnosis and the amount of time spent talking about breast cancer. It appears that growth emerged gradually and was facilitated by reflection and processing of experiences related to their diagnoses in these individuals. Another study on breast cancer survivors found that the emotional impact of the cancer and use of coping mechanisms (e.g. seeking support and positively reinterpreting the situation) were related to the level of posttraumatic growth endorsed (Bellizzi & Blank, 2006). Survivors who had received bone marrow transplantation showed greater posttraumatic growth when they recalled their experiences with treatment and their pre-morbid functioning more negatively than their peers. A study using a sample of gynecological cancer survivors found that one proposed aspect of posttraumatic growth, finding meaning in life, was associated with lower levels of mental health concerns and physical health limitations (Simonelli et al., 2008). Ho, Chan, Yau, and Yeung (2011) showed that posttraumatic growth in Chinese breast cancer patients appeared to be related to using a stable, internal, and global attributions to explain positive events. As such, these participants indicated that their personal qualities (e.g. strength) were the cause of the positive events and that changes would be long lasting and impact multiple domains in their lives beyond the original event.

There is some indication that personality differences among cancer survivors predict the level of posttraumatic growth experienced. Posttraumatic growth positively correlated with the tendency to express gratitude among breast cancer survivors in Italy (Ruini & Vescovelli, 2013). A set of studies on posttraumatic growth among cancer patients in Poland indicated that individuals displaying higher levels of basic trust, using Erikson's (1950) definition, were more likely to experience positive growth (Trzebinski & Zieba, 2013). This effect appeared to have been mediated by the degree to which participants engaged in positive reinterpretations of their experience with cancer and negative coping styles (e.g. hopelessness/helplessness).

Structural equation modeling has helped indicate potential pathways between cancer related distress and posttraumatic growth. In a sample of adult cancer survivors under 55 years old, posttraumatic growth was demonstrated to moderate the link between unwanted/involuntary thoughts and adjustment (Park, Chmielewski, & Blank, 2010). That is, individuals experiencing high level of posttraumatic growth, unwanted/involuntary thoughts predicted better adjustment as compared to those without such unwanted/involuntary thoughts. In a study on adult cancer survivors in Australia, the perceived severity of their diagnoses were shown to be related to survivors' level of distress and their level of social support (Morris & Shakespeare-Finch, 2011). The level of social support endorsed by survivors mediated the relationship between the perceived severity of the diagnosis and posttraumatic growth. Unwanted/involuntary thoughts versus purposeful positive thoughts moderated the relationships between the perceived severity of the diagnosis, distress, and posttraumatic growth.

Morris and colleagues (2011) conducted a qualitative study on changes in personal identity of a cohort of breast cancer survivors involved in Amazon Heart Thunder, a unique motorcycle-based peer support network in Australia and the United States. In pre-intervention interviews, participants' descriptions of the degree to which they identified with the term *breast cancer survivor* varied and participants focused on cancer-related distress. Following the first motorcycle ride, many of the participants discussed increases in personal strength, finding role models, revisiting life priorities, and some who had not previously identified with the term *breast cancer survivor* changed their self-identity (Morris et al., 2011). Affiliation with survivors of a similar diagnosis during this empowering activity appeared to facilitate posttraumatic growth among these individuals.

*Correlates of Posttraumatic Growth among Cancer Patients and Survivors*



Demographic variables and health-related QOL have been shown to correlate with posttraumatic growth in multiple studies with cancer patients. Several indicators of socioeconomic status were positively correlated with posttraumatic growth in survivors of breast cancer (Cordova et al., 2001; Bellizzi & Blank, 2006). However, demographic variables and health-related distress did not predict posttraumatic growth in adult cancer survivors under the age of 55 (Park et al., 2010). Park and Blank (2012) investigated the demographic correlates of positive and negative changes following cancer care across various diagnoses. A younger age at onset, more medical co-morbidities, and lower income were associated with increased survivorship distress. Females and survivors with fewer co-morbidities reported more posttraumatic growth than their peers (Park & Blank, 2012). Smith, Williams, Zimmer, and Zimmerman (2010) found that posttraumatic growth mediated the relationship between general aspects of QOL (e.g. social/family wellbeing) and their antecedents (e.g. social support) in non-Hodgkin lymphoma survivors. However, this study did not utilize a measure of QOL that specifically addressed cancer survivorship concerns.

Higher severity of diagnoses also appears to positively impact the level of posttraumatic growth seen in cancer survivors. Barakat and colleagues (2005) found that the physician-rated severity of the cancer diagnosis and treatment were predictive of posttraumatic growth in adolescent cancer survivors and their parents. Higher levels of posttraumatic growth have also been found among individuals with recurrent ovarian cancer, a typically fatal form of gynecological cancer, than in breast cancer survivors (Ponto et al., 2010). A study on childhood cancer survivors at least five years following treatment showed that individuals who received high risk chemotherapy or radiation therapy showed higher levels of posttraumatic growth than those who did not receive chemotherapy or radiation therapy (Zebrack et al., 2012). Survivors

who developed secondary malignancies or recurrence also endorsed higher levels of posttraumatic growth than their peers. Later age of diagnosis and shorter time since diagnosis were also related to a higher level of posttraumatic growth than other groups of survivors (Zebrack et al., 2012).

#### *Increased Health Behaviors among Cancer Survivors*

Increases in specific health-promoting behaviors following cancer treatment have also been found. In a study of increased positive physical and psychosocial health behaviors following cancer treatment across diagnoses, Harper et al. (2007) found that changes were most frequent in re-evaluating life priorities and eating healthy. The least frequent changes involved increasing physical exercise. Connerty and Knott (2013) found an increased involvement in researching their diagnoses and treatments, engaging in exercise, and healthy eating among survivors of multiple types of cancer. Several participants also reported being involved with support and advocacy groups. Another study from Australia on endometrial cancer survivors showed that participants endorsed a higher level of positive changes than negative changes 3-5 years post-treatment (Rowlands et al., 2013). Health awareness was the most commonly endorsed positive change.

#### *Posttraumatic Growth in Caregivers of Cancer Survivors*

Little research on posttraumatic growth in the caregivers of cancer survivors has been conducted to date. The studies that have been completed have indicated that caregivers of cancer survivors and patients display some level of posttraumatic growth in response to their loved ones' illness. Weiss (2004) found posttraumatic growth in the husbands of breast cancer survivors that corresponded with the posttraumatic growth of their wives and the strength of their marital relationship. Childhood cancer survivors have been shown to display higher levels of

posttraumatic growth than their siblings (Zebrack et al., 2012). A study on posttraumatic growth among caregivers of cancer patients across diagnoses in Italy found that caregivers who were male and in the younger age-range endorsed higher levels of physical activity and more vitality than their peers.

Bekteshi and Kayser (2013) studied relationship changes between mothers with breast cancer and their daughters under the age of 18 in the United States. Emerging themes from their interviews included: heightened awareness of the impact cancer had on each other and increased efforts to lessen such impacts, increased empathy and authenticity towards each other, and greater mutual empowerment. Mothers often reported transient periods of disconnectedness in their relationships with their daughters that were eventually repaired through mutual support and empathy (Bekteshi & Kayser, 2013). Kim and colleagues (2007) found higher levels of spirituality among female caregivers of breast cancer and ovarian cancer than female caregivers of gender non-specific cancers in the United States. Spirituality was shown to decrease psychological distress in caregivers of gender non-specific cancer survivors.

One study from Kyoto, Japan suggested that posttraumatic growth among bereaved caregivers is associated with their loved one going through a “good death,” a concept related to patients’ comfort, relationships with others, and psychological well-being (Hatano, Fujimoto, & Fukui, 2015).

In summary, cancer survivorship and caregiving for cancer survivors is often accompanied by a variety of positive and negative biopsychosocial changes. Non-solid tumor diagnoses, classified as leukemia or lymphoma, are associated with a greater degree of disease heterogeneity and an increased likelihood of recurrence following successful treatment compared to many solid tumor diagnoses, such as breast cancer or thyroid cancer. Survivors of leukemia

and lymphoma often endorse different understandings of their prognoses and likelihood of recurrence than their providers, which may be partially due to limited publicly accessible information on specific subtype diagnoses of leukemia and lymphoma. Positive biopsychosocial changes following a trauma, such as a cancer diagnosis, is referred to as posttraumatic growth and has been found in several populations of cancer survivors and caregivers of cancer survivors. Greater degrees of posttraumatic growth have been found to be related to greater severity of the diagnoses, as rated by physicians.

### *Current Study*

The current study investigates the relationship between negative biopsychosocial changes following cancer diagnoses, posttraumatic growth, the diagnosis of a solid versus non-solid tumor, and the perceived severity of diagnoses among cancer survivors and caregivers. The experiences of this group of survivors and their caregivers differ greatly from the experiences of other cancer survivors for a variety of reasons including different evidence-based treatment modalities and the heterogeneity of the courses and outcomes of each disease. This heterogeneity often has the effect of reducing access to opportunities for financial and social support that are available to survivors of more common and relatively homogenous cancers.

Post-traumatic growth is expected to increase with the perceived severity of diagnosis and among caregivers and survivors of non-solid versus solid tumors. To date, no study to our knowledge has addressed the differences in degrees of posttraumatic growth experienced between caregivers and survivors of non-solid versus solid tumors. Few studies have directly addressed the relationship between posttraumatic growth and negative biopsychosocial changes specific to the unique needs of cancer survivors and caregivers of cancer survivors. Due to the variance in prognoses and heterogeneity in age groups affected, diagnoses within these

categories, available treatment options, and financial burdens caused by leukemia and lymphoma, it is expected that the degree to which participants report post-traumatic growth will also vary widely. Past studies on posttraumatic growth in cancer survivors and their caregivers suggest that the severity of the diagnosis and health-related QOL will impact the level of posttraumatic growth experienced by participants following treatment. Previous studies suggest that the level of survivorship concerns might be higher among caregivers than LLS. However, few studies on cancer survivorship concerns and posttraumatic growth have been conducted since the administration of the Affordable Care Act. Perhaps this relationship will be attenuated now that the Affordable Care Act is in effect.

The primary goal of this study is to investigate the impact of the diagnosis of a non-solid versus solid tumor, being a caregiver versus survivor of cancer, and the perceived severity of a cancer diagnosis across various domains implicated in cancer survivorship. This study will evaluate the following hypotheses: 1) a non-solid tumor diagnosis, being a cancer survivor, and a higher degree of perceived disease severity will predict higher scores on the Posttraumatic Growth Inventory; 2) higher scores on the Impact of Cancer Positive Impact Scale will be predicted by being a survivor versus a caregiver, a diagnosis of a non-solid versus a solid tumor, and a higher degree of perceived disease severity; 3) higher scores on the Impact of Cancer Negative Impact scale will be predicted by being a caregiver versus a survivor, a diagnosis of a non-solid versus a solid tumor, and a higher degree of disease severity; 4) survivors of non-solid tumors will endorse lower scores on the Center for Disease Control Health Related Quality of Life Healthy Days Index than survivors of solid tumors; and 5) caregivers and survivors of non-solid tumors will endorse lower scores on the Oslo Social Support scale than caregivers and survivors of solid tumors

## Chapter 2. Methods

### *Participants*

Eighty adult cancer survivors and caregivers were recruited for this study. Twenty-nine participants were excluded due to not having completed any of the outcome questionnaire items, leaving 51 participants who were retained in the data analyses. Eligibility criteria included: either a previous diagnosis of cancer or a history of having assisted in caring for a cancer survivor, being at least 18 years of age, and residing in the United States. Research on posttraumatic growth in cancer survivors has used variable timeframes following their initial diagnosis in which they were recruited to participate (e.g. Zebrack et al., 2012, Rowlands et al., 2013). To increase the breadth of this study, time since diagnosis and/or treatment cessation was not restricted as part of the eligibility criteria. This projected sample-size was calculated using G\*Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009) with the effect-size estimate for a regression analysis of the impact of solid versus non-solid tumor diagnosis on posttraumatic growth. The effect-size estimation was based on calculations from the Cordova and colleagues (2001) study investigating posttraumatic growth among breast cancer survivors using the PTGI. The sample-size projection estimated that at least 49 participants would be required to obtain statistically significant results using linear regressions.

Participants were recruited between October 23, 2017 and June 2, 2018 nationwide from various websites offering classified advertisements for research participation, including *Craigslist*, *Reddit*, and *ClassifiedAds.com* and social media outlets for recruiting research participants (e.g. Swap Survey). Please see Appendix B for a list of locations in which advertisements were placed on Craigslist. Locations were selected based on the presence of a hospital recognized as a Center of Excellence in treating Leukemia and/or Lymphoma and/or

based on population size to maximize recruitment of LLS and their caregivers. Several organizations providing information and support for cancer survivors and caregivers were also contacted and requested to assist with recruitment (e.g. stupidcancer.org and CancerLiving Today), however, they declined to participate or did not respond. At the end of the questionnaire, participants were provided with a link to the survey and asked to share the link with members of their social media network, thereby allowing for snowball sampling. Participants were not required to be pairs of cancer survivors and caregivers, however with the use of snowball sampling as a recruitment technique, some of the caregivers may have provided care for the survivors in the sample. Please see Appendix C for a copy of the advertisement placed on these websites.

### *Measures*

Demographic questions were asked to gather information on the sample make-up. These included solid vs. non-solid tumor diagnosis, the specific diagnosis, perception of cancer severity, recurrence or additional cancers since initial diagnosis, age, gender, and ethnicity. Such variables have been found in previous studies to be related to the level of post-cancer distress experienced by LLS (Jones et al., 2015; Parry et al., 2011; See the demographic questions in Appendices D and E).

The Post Traumatic Growth Inventory (PTGI) is a 21-item questionnaire that utilizes a 6-point Likert scale, from 0 = “I did not experience this change as a result of my crisis” to 5=I experienced this change to a very great degree as a result of my crisis” (Tedeschi & Calhoun, 1995; See Appendices F and G). A composite score on the PTGI is obtained by summing responses to all of the items. The authors have uncovered the following five-factor structure: Factor 1: Relating to Others, Factor 2: New Possibilities, Factor 3, Personal Strength, Factor 4:

Spiritual Change, and Factor 5: Appreciation of Life (Tedeschi & Calhoun, 1995). Taku, Cann, Calhoun, and Tedeschi (2008) conducted a confirmatory analysis using a sample of traumatic event survivors to determine if the PTGI functioned best as a 5-factor model, 3-factor model, or a 1-model. They found that a 5-factor model allowing correlations among the factors was the best fit.

The PTGI has been tested with undergraduate college students (Baker, Kelly, Calhoun, Cann, & Tedeschi 2008; Morris, Shakespeare-Finch, Rieck, & Newbery, 2005; Shakespeare-Finch & Enders, 2008; Tedeschi & Calhoun, 1995) and survivors of traumatic events (Taku et al., 2008). It has shown good internal reliability (Cronbach's  $\alpha = .90$ ; Baker et al., 2008; Tedeschi & Calhoun, 1995) and acceptable test-retest reliability over two months ( $r=.71$ ; Tedeschi & Calhoun, 1995). The PTGI has been correlated with experiences of trauma (Shakespeare-Finch & Enders, 2008), post-traumatic stress (Morris et al., 2005), optimism, and extraversion (Tedeschi & Calhoun, 1995). There is some indication that scores indicating higher levels of posttraumatic growth are associated with higher severity of the trauma experienced (Tedeschi & Calhoun, 1995). Gender differences have been found in one study; with women reporting greater growth (Tedeschi & Calhoun, 1995) but no significant gender differences were found in another study (Baker et al., 2008). For the purposes of this study, the word "crisis" has been changed to "cancer" in the questionnaire instructions and items. This was done with the permission of the authors.

The Impact of Cancer version 2 (IOCv2) is a 46-item questionnaire consisting of statements about the potential positive and negative changes that cancer survivors report following treatment (see Appendices H and I for the questionnaire and Appendix J for the scoring instructions; Zebrack, Ganz, Bernaards, Petersen, & Abraham, 2006). Items are



measured on a 5-point Likert scale, from Strongly Disagree to Strongly Agree. The IOCv2 is comprised of the following scales: Positive Impact of Cancer, Negative Impact of Cancer, Employment Concerns, Relationship Concerns (not partnered) and Relationship Concerns (partnered). Within the Positive Impact Scale, there are four subscales: Altruism and Empathy, Health Awareness, Meaning of Cancer, and Positive Self-Evaluation. The Negative Impact Scale contains the following subscales: Appearance Concerns, Body Change Concerns, Life Interferences, and Worry (Zebrack et al., 2006). The IOCv2 has been used with survivors of non-Hodgkin lymphoma (Smith et al., 2010), breast cancer survivors in the United States (Crespi, Ganz, Petersen, Castillo, & Caan, 2008) and France (Blanchin et al., 2015), and endometrial cancer in the Netherlands (de Boer et al., 2015). An exploratory factor analysis and confirmatory factor analysis indicate that the 42 items that make up the Positive Impact Scale and the Negative Impact Scale load together using an oblique rotation to create an 8-factor solution, corresponding with the eight subscales (Crespi et al., 2008). This factor structure was upheld in a sample of non-Hodgkin lymphoma survivors (Smith et al., 2010). Two higher-order factors were found, which correspond to the two scales. The internal consistencies of each of the subscales are good, with Cronbach's  $\alpha$  ranging from .76 (Employment Concerns) to .89 (worry). As the construct of positive impact of cancer appears to be similar to posttraumatic growth in cancer at face value, it is expected that responses on the PTGI and the IOCv2 Positive Impact Scale will correlate highly with each other. Due to the association between more severe forms of cancer and higher posttraumatic growth (e.g., Ponto et al., 2010; Zebrak et al., 2012), it is possible that the other scales of the IOCv2 will positively correlate with the PTGI as well. A caregiver version of the IOCv2 was created by adding "my loved one" before each mention of cancer. Permission was obtained from the authors to make this change to the IOCv2.

The Center for Disease Health Related Quality of Life Healthy Days Questionnaire Core Module (CDC HRQoL) is a 14-item questionnaire that assesses the number of days over the past 30 days that an individual has been affected by physical and/or mental health problems (Hennessy, Moriarty, Zach, Scherr, & Brackbill, 1994; see Appendix K for the CDC HRQoL). It consists of a Core Module (4-items), an Activities Limitations Module (5-items), and a Symptoms Module (5-items). It has been tested on patients and survivors of a variety of health conditions in the United States, including myelodysplastic syndromes (Sekeres et al., 2011), metabolic syndrome (Ford & Li, 2008), smoking (McClave, Dube, Strine, & Mokdad, 2009), and coronary heart disease (Ford et al., 2008). The CDC HRQoL Core Module is scored by calculating a summary index of unhealthy days by adding the number of days over the past 30 that the individual endorsed having not good physical health and the number of days they endorsed having not good mental health (Centers for Disease Control and Prevention, 2000). The sum is then set to a maximum of 30 days. A Healthy Days Index was computed by subtracting the Unhealthy Days Index from 30, as recommended by the Centers for Disease Control (2000). There is no composite scoring system for the CDC-HRQoL Symptom Module, so each item was evaluated individually. The CDC HRQoL demonstrates good test-retest reliability after two weeks ( $r=.75$  Andersen, Catlin, Wyrwich, & Jackson-Thompson, 2003). For the current study, the CDC HRQoL Core Module and Symptoms Module were administered as part of the battery assessing adjustment to cancer diagnoses among cancer survivors and their caregivers.

The Oslo Social Support Scale (OSS-3) is a 3-item questionnaire designed to provide an efficient measure of social support available to participants across a range of international and interdisciplinary settings (Nosikov & Gudex, 2003). A composite score is obtained by summing the three items (Dalgard et al., 2006). See Appendix L for the OSS-3 and its scoring system. It

has found to predict risk for clinical depression among a large sample of participants from Finland, England, Ireland, Spain, and Norway (Dalgard et al., 2006). In a study of older persons living at home in Norway, social support as measured by the OSS-3 was found to mediate the relationship between psychological distress and somatic health problems (Bøen, Dalgard, & Bjertness, 2012).

### *Procedure*

All measures were administered online via Qualtrics. Informed consent was obtained prior to questionnaire administration. The study was piloted with two cancer survivors. Both indicated that the questionnaires took approximately 20 minutes in total to complete and did not seem burdensome. No significant concerns were raised about the questionnaires' content by the volunteers who piloted the study or participants of the study.

The initial question presented asked if the participant was a cancer survivor, the caregiver of a cancer survivor, or both. Based on that answer, participants were directed to either the survivor or caregiver battery of questionnaires. Participants who endorsed being both survivors and caregivers were administered the survivor battery. The survivor battery consisted of the following questionnaires: the PTGI, the IOCv2, the CDC HRQoL-4, the CDC Healthy Days Symptom Module, the Oslo 3-item Social Support Scale, and a demographic questionnaire developed for the study. The caregiver battery consisted of the PTGI, the IOCv2 modified for caregivers, the CDC HRQoL Core Module, the CDC Healthy Days symptom module, the Oslo 3-item Social Support Scale, and the caregiver version of the demographic questionnaire.

### *Data Analyses*

Missing data mechanism was examined by applying Little's (1988) test for missing completely at random (MCAR) using IBM SPSS Version 20. Only 5 participants (9.8%)

completed less than 50% of the items. The data were found to be MCAR for the PTGI ( $\chi^2=69.132, p=0.988$ ), the IOCV2 ( $\chi^2=369.199, p=0.658$ ), the HRQoL ( $\chi^2=43.097, p=0.227$ ), the Oslo3 ( $\chi^2=2.043, p=0.360$ ), and the variables related to participant characteristics ( $\chi^2=464.432, p=0.988$ ). The percent of data missing ranged from 2% to 5.9% on the PTGI, 2% to 17.6% on the IOCV2, 9.8% to 17.6% on the CDC HRQoL, and 9.8% to 62.7% (income) for the participant characteristics variables. Under the assumption that the data is MCAR, any standard missing data handling technique would be appropriate (Enders, 2010), including listwise deletion, single imputation, and multiple imputation. For the current study, missing data was handled with multiple imputation in SPSS using 100 multiply-imputed datasets. This number of multiply-imputed datasets was based on recommendations from Graham, Olchowski, and Gilreath (2007) to reduce the values for Standardized Error (SE) and the probability of false negative results. In the current study, the information obtained from observed data for the independent variables was limited. Therefore, in accordance with recommendations from Little (1992), data for the dependent and independent variables were imputed together to maximize the accuracy of the multiple imputations and the power for analyses based on the multiple imputations.

Descriptive statistics were calculated to describe participant characteristics including: whether participants were caregivers or survivors, whether they/their loved ones were diagnosed with a solid versus a non-solid tumor, the perceived severity of their diagnosis, treatments received, age, gender, marital status, employment status, number of people living in their household, annual household income, estimated direct cost of cancer treatment, and estimated indirect costs of cancer/cancer treatment. For categorical variables, such as whether the participant was a survivor or a caregiver, whether they/their loved one was diagnosed with a solid or a non-solid tumor, the cancer treatments received, marital status, employment status, and

gender, the frequency and percentages of participants who endorsed each response category were reported. The mean, standard deviation, median, minimum value, and maximum value were reported for the quantitative variables, such as the number of people living in the home, annual household income, the estimated direct cost of cancer care, and the estimated indirect cost of cancer and cancer care. As these data was analyzed to describe the characteristics of the sample obtained, all results are reported using the original data prior to the multiple imputation with pairwise deletion of missing data.

Descriptive statistics and were also conducted on the composite scores of PTGI, IOCV2, CDC HRQoL Healthy Days Index, the CDC HRQoL Symptom Module scores, and the OSS-3 among caregiver and survivor subsamples to understand the degree to which participants endorsed items on each scale. These statistics include the means, standard deviations, medians, minimum values, and maximum values endorsed for each scale across the survivor and caregiver subgroups. T-tests were conducted to test the differences in mean scores between cancer survivor and caregiver subsamples. These data present descriptive statistics about the sample obtained, the results were reported using the original data prior to the multiple imputation with pairwise deletion of missing data.

To demonstrate the reliability of the PTGI, IOCV2, CDC HRQoL Healthy Days Index, and the OSS3, Cronbach Alphas were calculated in both caregiver and survivor subgroups of the sample. For measures which Cronbach Alphas were similar, subsequent analyses utilized combined data from the caregiver and survivor subgroups. For measures which the Cronbach Alphas were substantially dissimilar among survivors and caregivers, analyses were separated for each group. All results from the multiply imputed datasets were pooled.

Two correlation matrices were constructed to investigate the relationships between the outcome measures: the PTGI, the IOCV2 Positive Impact Scale, the IOCV2 Negative Impact Scale, the CDC HRQoL Healthy Days Index, and the OSS3 among caregivers and survivors. The correlation matrices were calculated separately among the caregiver and survivor subsamples. The correlation matrices were separated to demonstrate the degree to which the caregiver and survivor subsamples experienced adjustment to cancer survivorship similarly and that the data from both groups could be analyzed together. All correlations are presented using pooled data from the multiple imputations.

To address hypothesis one, that a non-solid tumor diagnosis, being a cancer survivor, and a higher degree of perceived disease severity will predict higher scores on the PTGI, a multiple regression was conducted. Composite scores on the PTGI were set as the independent variable and the diagnosis of a solid versus non-solid tumor, whether the participants were cancer survivors or caregivers, and the degree of perceived severity were the predictor variables. Results from the multiply-imputed datasets were pooled.

The second hypothesis, that higher scores on the IOCV2 Positive Impact Scale will be predicted by being a survivor versus a caregiver, a diagnosis of a non-solid versus a solid tumor, and a higher degree of perceived disease severity, was assessed using a multiple regression. This regression utilized the composite scores on the IOCV2 Positive Impact Scale as the independent variable and the diagnosis of a solid versus non-solid tumor, whether participants were survivors or caregivers, and the degree of perceived severity as the predictor variables. The resulting t-tests are presented using pooled analyses from the multiply-imputed datasets.

To test the third hypothesis, that higher scores on the IOCV2 Negative Impact Scale will be predicted by being a caregiver versus a survivor, a diagnosis of a non-solid versus a solid

tumor, and a higher degree of disease severity, a third multiple regression was conducted. The composite scores on the IOCV2 Negative Impact Scale were set as the independent variable and the diagnostic category, being a caregiver versus a survivor, and the perceived severity of the cancer diagnosis were used as the predictor variables. Results from the multiply-imputed datasets were pooled.

To address the fourth hypothesis, that survivors of non-solid tumors will endorse a lower level of health-related quality of life than survivors of solid tumors, a t-test was conducted evaluating the difference in mean composite scores on the CDC HRQoL Healthy Days Index between survivors of solid and non-solid tumors. The results from the multiply-imputed datasets were pooled.

The final hypothesis, that caregivers and survivors of non-solid tumors will endorse lower levels of social support than caregivers and survivors of solid tumors, was assessed with two t-tests. The first t-test evaluated the differences in means on OSS-3 composite scores between survivors of solid versus non-solid tumors. The second t-test assessed differences in mean composite scores on the OSS-3 between caregivers of cancer survivors with solid versus non-solid tumors. The t-tests were presented using data pooled from the multiple imputations.

## Chapter 3. Results

### *Participants*

Participant characteristics are summarized in Tables 1-3. Table 1 demonstrates the proportions of each measured categorical demographic variable. Table 2 summarizes the descriptive statistics of the quantitative demographic and cancer/treatment-related variables. Table 3 describes the proportions of each measured cancer/treatment-related variables among participants in the sample. Of note, 56.9% of participants were cancer survivors and 43.1% were caregivers of cancer survivors. More participants had solid versus non-solid tumors (47.1% versus 31.3%).



Table 1

*Frequency and Percentages of Participants Endorsing Demographic Variables (Categorical)*

Demographic Variable	Frequency	Percentage
<b>Gender</b>		
Males	14	27.5%
Females	31	60.8%
Transgender	1	2.0%
Did not disclose	5	9.8%
<b>Ethnicity</b>		
Caucasian	36	70.6%
Asian	6	11.8%
African American	2	3.9%
Multi-ethnic	2	3.9%
Did not disclose	5	9.8%
<b>Insurance</b>		
No	3	5.9%
Yes	36	70.6%
Did not disclose	12	23.5%
<b>Employment status</b>		
Unemployed	22	43.1%
Employed part-time	3	5.9%
Employed full-time	18	35.3%
Did not disclose	8	15.7%
<b>Marital status</b>		
Married	17	33.3%
Cohabiting	10	19.6%
Single	6	11.8%
Divorced	9	17.6%
Widowed	1	2.0%
Did not disclose	8	15.7%

Table 2

*Descriptive Statistics of Quantitative Demographic and Disease/Treatment-Related Variables*

Variable	N	Mean	Standard Deviation	Median	Range
Age	45	49.71	15.35	53.0	24 – 77
Number of people living in the house	40	2.8	1.62	2.0	1 - 8
Annual household income	19	\$97 315.79	\$87 195.22	\$73 000	\$6000 - \$305 000
Direct out-of-pocket cost of treatment	31	\$16849.03	\$32 227.30	\$2000	\$0 – \$122 000
Indirect out-of-pocket cost of cancer/treatment	26	\$123 400.00	\$497 147.53	\$0	\$0 - \$2 500 000

Table 3

*Frequency and Percentages of Participants Who Endorsed Disease and Treatment-Related Variables (Categorical)*

Variable	Frequency	Percentage
Survivor vs. caregiver		
Survivors	29	56.9%
Caregivers	22	43.1%
Diagnosis		
Solid tumor	24	47.1%
Leukemia	4	7.8%
Lymphoma	12	23.5%
Did not disclose	11	21.6%
Perceived Severity		
Not severe	2	3.9%
Slightly severe	7	13.7%
Moderately severe	16	31.4%
Very severe	7	13.7%
Extremely Severe	11	21.6%
Did not disclose	8	15.7%
Recurrence		
No	32	62.7%
Yes	9	17.6%
Did not disclose	10	19.6%
Secondary Malignancy		
No	36	70.6%
Yes	7	13.7%
Did not disclose	8	15.7%
Treatment		
Chemotherapy	28	54.9%
Radiation therapy	19	37.3%
Bone marrow transplant	1	2.0%
Watchful waiting	5	9.8%
Surgery	21	41.2%
Treatment end date		
Less than 1 year ago	3	5.9%
Greater than 1 year ago	22	43.1%
Still in treatment	13	25.5%
Deceased (for caregivers only)	2	3.9%
Did not disclose	11	21.6%

### *Descriptive statistics and t-tests for the questionnaire data*

Caregivers ( $M = 68.31$ ,  $SD = 26.14$ ) of cancer survivors endorsed a higher level of posttraumatic growth on the PTGI than survivors ( $M = 57.58$ ,  $SD = 21.79$ ), however this difference was not significant at the  $p \leq 0.05$  level ( $t(43) = 1.5$ ,  $p = 0.14$ ). There was a small, non-significant difference in means between cancer survivors and caregivers on the IOCv2 Positive Impact Scale, with survivors ( $M = 59.63$ ,  $SD = 10.03$ ) reporting greater cancer-specific positive changes than caregivers ( $M = 54.54$ ,  $SD = 11.77$ ,  $t(38) = -1.42$ ,  $p = 0.16$ ). Caregivers ( $M = 65.00$ ,  $SD = 14.79$ ) also endorsed higher scores on the IOCv2 Negative Impact Scale than survivors ( $M = 62.48$ ,  $SD = 19.48$ ), however this difference was also not statistically significant ( $t(41) = 0.45$ ,  $p = 0.66$ ). Cancer survivors ( $M = 17.18$ ,  $SD = 11.11$ ) reported slightly higher scores on the CDC HRQoL Healthy Days Index than caregivers ( $M = 16.28$ ,  $SD = 10.86$ ), although this difference in scores was not significant at the  $p \leq 0.05$  level ( $t(44) = -0.27$ ,  $p = 0.79$ ). On the CDC HRQoL Symptom Module Pain question, survivors ( $M = 6.40$ ,  $SD = 10.07$ ) reported more days with pain over the past 30 days than caregivers ( $M = 4.83$ ,  $SD = 8.11$ ), however this difference was not statistically significant ( $t(41) = -0.55$ ,  $p = 0.59$ ). Survivors ( $M = 9.36$ ,  $SD = 9.47$ ) also endorsed statistically non-significantly more days with depression on the CDC HRQoL Symptom Module Depression question than caregivers ( $M = 8.33$ ,  $SD = 9.15$ ,  $t(44) = -0.36$ ,  $p = 0.72$ ). On the CDC HRQoL Symptom Module Anxiety question, survivors ( $M = 11.15$ ,  $SD = 10.92$ ) endorsed a non-significantly greater amount of days that they experienced problematic anxiety than caregivers ( $M = 8.35$ ,  $SD = 8.08$ ,  $t(42) = -0.91$ ,  $p = 0.37$ ). Survivors ( $M = 12.44$ ,  $SD = 9.12$ ) also endorsed more days without sufficient sleep or rest than caregivers ( $M = 9.39$ ,  $SD = 10.79$ ) on the CDC HRQoL Symptom Module Sleeplessness question, although this difference was not significant ( $t(43) = -1.02$ ,  $p = 0.31$ ). Caregivers ( $M = 11.53$ ,  $SD = 1.74$ ) endorsed a significantly higher level

of social support than survivors on the OSS-3 ( $M = 9.68$ ,  $SD = 3.14$ ,  $t(43) = 2.23$ ,  $p = 0.031$ ). See Table 4.

Table 4

*Descriptive statistics for the PTGI, the IOCV2, the CDC HRQoL Healthy Days Index, the CDC HRQoL Symptom Module, and the OSS-3 among cancer survivors versus caregivers.*

Survivor/ Caregiver	Variable	N	Mean	SD	Median	Minimum/ Maximum	t-test	P
Survivor	PTGI	26	57.58	21.79	58.50	6 to 89		
Caregiver	PTGI	19	68.31	26.14	71.00	19 to 105	1.50	0.14
Survivor	IOCV2 Positive Impact Scale	27	59.63	10.03	61.00	39 to 76		
Caregiver	IOCV2 Positive Impact Scale	13	54.54	11.77	57.00	21 to 69	-1.42	0.16
Survivor	IOCV2 Negative Impact Scale	27	62.48	19.48	59.00	26 to 93		
Caregiver	IOCV2 Negative Impact Scale	16	65.00	14.79	68.00	34 to 89	0.45	0.66
Survivor	CDC HRQoL Healthy Days Index	28	17.18	11.11	21.00	0 to 30		
Caregiver	CDC HRQoL Healthy Days Index	18	16.28	10.86	20.00	0 to 30	-0.27	0.79
Survivor	CDC HRQoL Symptom Module Pain	25	6.40	10.07	0.00	0 to 30		
Caregiver	CDC HRQoL Symptom Module Pain	18	4.83	8.11	1.50	0 to 30	-0.55	0.59
Survivor	CDC HRQoL Symptom Module Depression	28	9.36	9.47	5.50	0 to 30		
Caregiver	CDC HRQoL Symptom Module Depression	18	8.33	9.15	6.00	0 to 30	-0.36	0.72
Survivor	CDC HRQoL Symptom Module Anxiety	27	11.15	10.92	8.00	0 to 30		
Caregiver	CDC HRQoL Symptom Module Anxiety	17	8.35	8.08	8.35	0 to 30	-0.91	0.37
Survivor	CDC HRQoL Symptom Module Sleeplessness	27	12.44	9.12	10.00	0 to 30		
Caregiver	CDC HRQoL Symptom Module Sleeplessness	18	9.39	10.79	5.00	1 to 30	-1.02	0.31
Survivor	OSS-3	28	9.68	3.14	10.50	3 to 14		
Caregiver	OSS-3	17	11.53	1.74	12.00	9 to 14	2.23	0.031

### *Cronbach Alphas*

In the current sample, the PTGI demonstrated excellent internal consistency overall ( $\alpha=0.95$ ) and for the survivor ( $\alpha=0.91$ ) and caregiver ( $\alpha=0.98$ ) subgroups. The IOCV2 Positive Impact scale showed good internal consistency overall ( $\alpha=0.83$ ) and for the survivor ( $\alpha=0.80$ ) caregiver ( $\alpha=0.88$ ) subgroups. Cronbach Alphas suggest that the IOCV2 Negative Impact scale demonstrated excellent internal consistency with the entire sample ( $\alpha=0.91$ ) and with the survivor subgroup ( $\alpha=0.93$ ), while the Cronbach Alpha fell within the good range for the caregiver group ( $\alpha=0.877$ ). The CDC HRQoL Healthy Days Index showed poor internal consistency across the overall sample ( $\alpha=0.53$ ), the survivor subgroup ( $\alpha=0.49$ ), and the caregiver subgroup ( $\alpha=0.58$ ). The OSS3 demonstrated fair internal consistency overall ( $\alpha=0.75$ ) but good internal consistency in the survivor subgroup ( $\alpha=0.80$ ) and poor internal consistency in the caregiver subgroup ( $\alpha=0.50$ ).

### *Correlations*

The correlation matrices for the cancer survivor and caregiver subgroups displaying correlations between the composite scores on the outcome measures related to cancer survivorship are presented in Table 5. Among the cancer survivor subsample, the following correlations were statistically significant at the  $P \leq 0.01$  level: between composite scores on the PTGI and the IOCV2 Positive Impact Scale ( $r(27) = 0.73, p < 0.001$ ), the IOCV2 Negative Impact Scale and the CDC HRQoL Healthy Days index ( $r(27) = -0.58, p = 0.001$ ), the IOCV2 Negative Impact Scale and the CDC HRQoL Symptom Module Depression score ( $r(27) = 0.57, p = 0.001$ ), the CDC HRQoL Healthy Days Index and the CDC HRQoL Symptom Module Pain score ( $r(27) = -0.51, p = 0.004$ ), the CDC HRQoL Healthy Days Index and the CDC HRQoL Symptom Module Depression score ( $r(27) = -0.69, p < 0.001$ ), the CDC HRQoL Healthy Days Index and

the CDC HRQoL Symptom Module Anxiety score ( $r(27) = -0.57, p = 0.001$ ), the CDC HRQoL Symptom Module Depression score and the CDC HRQoL Symptom Module Anxiety score ( $r(27) = 0.82, p < 0.001$ ), and the CDC HRQoL Symptom Module Depression score and the CDC HRQoL Symptom Module Sleeplessness score ( $r(27) = 0.51, p = 0.005$ ). Correlations within the survivor subsample that reached the 0.05 level of significance were: between the IOCV2 Negative Impact Scale and the CDC HRQoL Symptom Module Pain score ( $r(27) = 0.42, p = 0.25$ ), the IOCV2 Negative Impact Scale and the CDC HRQoL Symptom Module Anxiety Score ( $r(27) = 0.41, p = 0.025$ ), the CDC HRQoL Healthy Days Index and the OSS-3 ( $r(27) = 0.40, p = 0.032$ ), the CDC HRQoL Symptom Module Pain score and the CDC HRQoL Symptom Module Depression Score ( $r(27) = 0.38, p = 0.045$ ), CDC HRQoL Symptom Module Pain score and the CDC HRQoL Symptom Module Sleeplessness score ( $r(27) = 0.43, p = 0.018$ ), CDC HRQoL Symptom Module Depression score and the OSS-3 ( $r(27) = -0.40, p = 0.032$ ), and the CDC HRQoL Symptom Module Anxiety score and the CDC HRQoL Symptom Module Sleeplessness score ( $r(27) = 0.41, p = 0.029$ ). Correlations among the cancer survivor subsample that were statistically non-significant included the correlation between the PTGI and the IOCV2 Negative Impact Scale ( $r(27) = 0.10, p = 0.62$ ), the PTGI and the CDC Healthy Days Index ( $r(27) = -0.012, p = 0.95$ ), the PTGI and the CDC HRQoL Symptom Module Pain score ( $r(27) = 0.032, p = 0.87$ ), the PTGI and the CDC HRQoL Symptom Module Depression score ( $r(27) = 0.080, p = 0.68$ ), the PTGI and the CDC HRQoL Anxiety score ( $r(27) = -0.10, p = 0.60$ ), the PTGI and the CDC HRQoL Sleeplessness score ( $r(27) = 0.10, p = 0.61$ ), the PTGI and the OSS-3 ( $r(27) = 0.17, p = 0.38$ ), the IOCV2 Positive Impact Scale and the IOCV2 Negative Impact Scale ( $r(27) = 0.052, p = 0.79$ ), the IOCV2 Positive Impact Scale and the CDC HRQoL Healthy Days Index ( $r(27) = 0.22, p = 0.25$ ), the IOCV2 Positive Impact Scale and the CDC HRQoL Symptom Module Pain



score ( $r(27) = 0.038, p = 0.85$ ), the IOCV2 Positive Impact Scale and the CDC HRQoL Symptom Module Depression score ( $r(27) = -0.15, p = 0.44$ ), the IOCV2 Positive Impact Scale and the CDC HRQoL Symptom Module Anxiety score ( $r(27) = -0.33, p = 0.081$ ), the IOCV2 Positive Impact Scale and the CDC HRQoL Symptom Module sleeplessness score ( $r(27) = -0.075, p = 0.70$ ), the IOCV2 Positive Impact Scale and the OSS-3 ( $r = 0.22, p = 0.70$ ), the IOCV2 Negative Impact Scale and the CDC HRQoL Symptom Module Sleeplessness score ( $r(27) = 0.23, p = 0.23$ ), the IOCV2 Negative Impact Scale and the OSS-3 ( $r(27) = -0.20, p = 0.30$ ), the CDC HRQoL Healthy Days Index and CDC HRQoL Symptom Module Sleeplessness score ( $r(27) = -0.25, p = 0.19$ ), the CDC HRQoL Symptom Module Pain score and the CDC HRQoL Symptom Module Anxiety score ( $r(27) = 0.27, p = 0.16$ ), the CDC HRQoL Symptom Module Pain score the OSS-3 ( $r(27) = -0.011, p = 0.95$ ), the CDC HRQoL Symptom Module Anxiety score and the OSS-3 ( $r(27) = -0.28, p = 0.15$ ), and the CDC HRQoL Symptom Module Sleeplessness score and the OSS-3 ( $r(27) = -0.20, p = 0.30$ ).

Table 5

*Correlation matrix for outcome variables related to adjustment to cancer among cancer survivors and caregivers.*

	PTGI	IOCv2 Positive Impact Scale	IOCv2 Negative Impact Scale	CDC HRQoL Healthy Days Index	CDC HRQoL Symptom Module: Pain	CDC HRQoL Symptom Module: Depression	CDC HRQoL Symptom Module: Anxiety	CDC HRQoL Symptom Module: Sleeplessness	OSS-3
<u>PTGI</u>	1	0.73**	0.10	-0.012	0.032	0.080	-0.10	0.10	0.17
<u>IOCv2 Positive Impact Scale</u>	0.75**	1	0.052	0.22	0.038	-0.15	-0.33	-0.075	0.22
<u>IOCv2 Negative Impact Scale</u>	0.66**	0.74**	1	-0.58**	0.42*	0.57**	0.41*	0.23	-0.20
<u>CDC HRQoL Healthy Days Index</u>	-0.32	-0.31	-0.28	1	-0.51**	-0.69**	-0.57**	-0.25	0.40*
<u>CDC HRQoL Symptom Module: Pain</u>	0.25	0.16	0.060	-0.62**	1	0.38*	0.27	0.43*	-0.011
<u>CDC HRQoL Symptom Module: Depression</u>	0.31	0.32	0.15	-0.64**	0.50*	1	0.82**	0.51**	-0.40*
<u>CDC HRQoL Symptom Module: Anxiety</u>	0.28	0.27	0.19	-0.62**	0.62**	0.83**	1	0.41*	-0.28
<u>CDC HRQoL Symptom Module: Sleeplessness</u>	0.30	0.32	0.16	-0.78**	0.672**	0.78**	0.78**	1	-0.20
<u>OSS-3</u>	-0.15	-0.37	-0.15	0.094	0.093	0.025	-0.033	0.015	1

*Note:* the top diagonal of the table presents the correlation matrix for cancer survivors and the bottom diagonal presents the correlation matrix for caregivers of cancer survivors.

\* indicates that the correlation was significant at the 0.05 level

\*\* indicates that the correlation was significant at the 0.01 level

For the caregiver subgroup, correlations at the  $p \leq 0.01$  level were found between the PTGI and the IOCV2 Positive Impact Scale ( $r(20) = 0.75, p < 0.001$ ), the PTGI and the IOCV2 Negative Impact Scale ( $r(20) = 0.66, p = 0.001$ ), the IOCV2 Positive Impact Scale and the IOCV2 Negative Impact Scale ( $r(20) = 0.74, p < 0.001$ ), the CDC HRQoL Healthy Days Index and the CDC HRQoL Symptom Module Pain score ( $r(20) = -0.62, p = 0.002$ ), the CDC HRQoL Healthy Days Index and the CDC HRQoL Symptom Module Depression score ( $r(20) = -0.64, p = 0.001$ ), the CDC Healthy Days Index and the CDC HRQoL Symptom Module Anxiety score ( $r(20) = -0.62, p = 0.002$ ), the CDC Healthy Days Index and the CDC HRQoL Symptom Module Sleeplessness score ( $r(20) = -0.78, p < 0.001$ ), the CDC HRQoL Symptom Module Pain score and the CDC HRQoL Symptom Module Anxiety score ( $r(20) = 0.62, p = 0.002$ ), the CDC HRQoL Symptom Module Pain score and the CDC HRQoL Symptom Module Sleeplessness score ( $r(20) = 0.67, p < 0.001$ ), the CDC HRQoL Symptom Module Depression score and the CDC HRQoL Symptom Module Anxiety score ( $r(20) = 0.83, p < 0.001$ ), the CDC HRQoL Symptom Module Depression score and the CDC HRQoL Symptom Module Sleeplessness score ( $r(20) = 0.78, p < 0.001$ ), and the CDC HRQoL Symptom Module Anxiety score and the CDC HRQoL Sleeplessness score ( $r(20) = 0.775, p < 0.001$ ). The correlation between the CDC HRQoL Symptom Module Pain score and the CDC HRQoL Depression score ( $r(20) = 0.50, p = 0.018$ ) fell between the  $p = 0.05$  and  $p = 0.01$  significance levels among the caregiver subsample. Correlations between the following variables were not found to be significant below the  $p \leq 0.05$  significance level in the caregiver subsample: the PTGI and the CDC HRQoL Healthy Days Index ( $r(20) = -0.32, p = 0.16$ ), the PTGI and the CDC HRQoL Symptom Module Pain score ( $r(20) = 0.25, p = 0.28$ ), the PTGI and the CDC HRQoL Symptom Module Depression score ( $r(20) = 0.31, p = 0.16$ ), the PTGI and the CDC HRQoL Symptom Module Anxiety score ( $r(20)$

= 0.28,  $p = 0.21$ ), the PTGI and the CDC HRQoL Symptom Module Sleeplessness score ( $r(20) = 0.30, p = 0.18$ ), the PTGI and the OSS-3 ( $r(20) = -0.15, p = 0.53$ ), the IOCv2 Positive Impact Scale and the CDC HRQoL Healthy Days Index ( $r(20) = -0.31, p = 0.16$ ), the IOCv2 Positive Impact Scale and the CDC HRQoL Symptom Module Pain score ( $r(20) = 0.16, p = 0.47$ ), the IOCv2 Positive Impact Scale and the CDC HRQoL Symptom Module Depression score ( $r(20) = 0.32, p = 0.15$ ), the IOCv2 Positive Impact Scale and the CDC HRQoL Symptom Module Anxiety score ( $r(20) = 0.27, p = 0.23$ ), the IOCv2 Positive Impact Scale and the CDC HRQoL Symptom Module Sleeplessness score ( $r(20) = 0.32, p = 0.16$ ), the IOCv2 Positive Impact Scale and the OSS-3 ( $r(20) = -0.37, p = 0.10$ ), the IOCv2 Negative Impact Scale and the CDC HRQoL Healthy Days Index ( $r(20) = -0.28, p = 0.22$ ), the IOCv2 Negative Impact Scale and the CDC HRQoL Symptom Module Pain score ( $r(20) = 0.060, p = 0.79$ ), the IOCv2 Negative Impact Scale and the CDC HRQoL Symptom Module Depression score ( $r(20) = 0.15, p = 0.51$ ), the IOCv2 Negative Impact Scale and the CDC HRQoL Symptom Module Anxiety score ( $r(20) = 0.19, p = 0.40$ ), the IOCv2 Negative Impact Scale and the CDC HRQoL Symptom Module Sleeplessness score ( $r(20) = 0.16, p = 0.48$ ), the IOCv2 Negative Impact Scale and the OSS-3 ( $r(20) = -0.15, p = 0.53$ ), the CDC HRQoL Healthy Days Index and the OSS-3 ( $r(20) = 0.094, p = 0.68$ ), the CDC HRQoL Symptom Module Pain score and the OSS-3 ( $r(20) = 0.093, p = 0.69$ ), the CDC HRQoL Symptom Module Depression score and the OSS-3 ( $r(20) = 0.025, p = 0.91$ ), the CDC HRQoL Symptom Module Anxiety score and the OSS-3 ( $r(20) = -0.033, p = 0.89$ ), and the CDC HRQoL Symptom Module Sleeplessness score and the OSS-3 ( $r(20) = 0.015, p = 0.95$ ).

Correlations between the CDC HRQoL Healthy Days Index and the OSS-3, the CDC HRQoL Symptom Module Depression score and the OSS-3, the IOCv2 Negative Impact Scale and the CDC HRQoL Healthy Days Index, the IOCv2 Negative Impact Scale and the CDC

HRQoL Symptom Module Pain score, the IOCV2 Negative Impact Scale and the CDC HRQoL Symptom Module Depression score, and the IOCV2 Negative Impact Scale and the CDC HRQoL Symptom Module Anxiety score were significant at the  $p \leq 0.05$  level among cancer survivors but not among caregivers of cancer survivors. The correlations between the PTGI and the IOCV2 Negative Impact Scale and between the IOCV2 Positive Impact Scale and IOCV2 Negative Impact Scale were significant at the  $p \leq 0.05$  level among caregivers but not among cancer survivors. Based on these results and the Cronbach Alphas, the cancer survivor and caregiver subsamples demonstrate substantial differences and data for the hypothesis testing analyses will be analyzed separately for each subsample group.

#### *Hypotheses testing*

The results from the multiple regression testing hypothesis one, that a non-solid tumor diagnosis, being a cancer survivor, and a higher degree of perceived disease severity will predict higher scores on the PTGI, did not find any of the proposed predictor variables significantly predicted PTGI composite scores. As the cancer survivor and caregiver subsamples were associated with different Cronbach Alphas and correlations for several of the measures, separate regressions were completed for each subsample and the survivor versus caregiver predictor variable was removed from the analyses. In the survivor group, neither solid versus non-solid tumor diagnosis ( $\beta = 5.30, t(28) = 0.57, p = 0.57$ ) nor the perceived severity of the cancer diagnosis ( $\beta = 0.14, t(28) = 0.035, p = 0.97$ ) significantly predicted PTGI scores. Solid versus non-solid tumor diagnosis ( $\beta = 8.83, t(21) = 0.58, p = 0.56$ ) and the perceived severity of the cancer diagnosis ( $\beta = 0.92, t(21) = 0.16, p = 0.87$ ) also did not predict PTGI scores among caregivers (see Table 6).

Table 6

*Multiple regression based on hypothesis 1 testing whether PTGI summary scores were predicted by a solid versus non-solid diagnosis and the perceived severity of the cancer diagnosis among cancer survivor and caregiver subsamples.*

Predictors	<i>B</i>	<u>Survivors</u>			<u>Caregivers</u>			
		<i>SE β</i>	t-test	<i>p</i>	<i>β</i>	<i>SE β</i>	t-test	<i>p</i>
(Constant)	56.25	12.92	4.35	<0.001	60.09	24.34	2.47	0.014
Solid versus non-solid tumor diagnosis	5.30	9.28	0.57	0.57	8.83	15.19	0.58	0.56
Perceived severity of diagnosis	0.14	3.95	0.035	0.97	0.92	5.62	0.16	0.87

Hypothesis two, that higher scores on the IOCV2 Positive Impact Scale would be predicted by being a survivor versus a caregiver, a diagnosis of a non-solid versus a solid tumor, and a higher degree of perceived disease severity, was also not supported. The survivor versus caregiver predictor variable was also dropped from these analyses and the data was analyzed separately for cancer survivors and caregivers due to dissimilar Cronbach Alphas and correlations between outcome variables among survivors and caregivers. In the survivor group, a solid versus non-solid tumor diagnosis ( $\beta = 0.47$ ,  $t(28) = 0.11$ ,  $p = 0.91$ ) and the perceived severity of the cancer diagnosis ( $\beta = 0.78$ ,  $t(28) = 0.42$ ,  $p = 0.68$ ) did not significantly predict scores on the IOCV2 Positive Impact Scale. Neither a solid versus non-solid diagnosis ( $\beta = 0.26$ ,  $t(21) = 0.038$ ,  $p = 0.97$ ) nor the perceived severity of the cancer diagnosis ( $\beta = -1.74$ ,  $t(21) = -0.72$ ,  $p = 0.47$ ) significantly predicted scores on the IOCV2 Positive Impact Scale (see Table 7).

Table 7

*Multiple regression based on hypothesis 2 testing whether the IOCv2 Positive Impact Scale summary scores were predicted by a solid versus non-solid tumor diagnosis and the perceived severity of the cancer diagnosis among cancer survivors and caregivers.*

Predictors	<u>Survivors</u>				<u>Caregivers</u>			
	$\beta$	$SE \beta$	t-test	$p$	$B$	$SE \beta$	t-test	$P$
(Constant)	57.14	6.10	9.37	<0.001	61.39	10.55	5.82	<0.001
Solid versus non-solid tumor diagnosis	0.47	4.31	0.11	0.91	0.26	6.83	0.038	0.97
Perceived severity of diagnosis	0.78	1.86	0.42	0.68	-1.74	2.43	-0.72	0.47

The results from the multiple regression testing hypothesis three, that higher scores on the Impact of Cancer Negative Impact scale would be predicted by being a caregiver versus a survivor, a diagnosis of a non-solid versus a solid tumor, and a higher degree of disease severity, were also not statistically significant. These analyses were also conducted separately for the caregiver and survivor groups and the caregiver versus survivor predictor variable was dropped from the analyses due to discrepant Cronbach Alphas and correlations among outcome variables between caregivers and survivors. A diagnosis of a solid versus a non-solid tumor ( $\beta = 11.03$ ,  $t(28) = 1.34$ ,  $p = 0.18$ ) and the perceived severity of the cancer diagnosis ( $\beta = 0.85$ ,  $t(28) = 0.24$ ,  $p = 0.81$ ) did not predict scores on the IOCv2 Negative Impact Scale for cancer survivors. In the caregiver group, neither a diagnosis of a solid versus non-solid tumor ( $\beta = 6.20$ ,  $t(21) = 0.87$ ,  $p = 0.38$ ) nor the perceived severity of the cancer diagnosis ( $\beta = 0.85$ ,  $t(21) = -0.47$ ,  $p = 0.64$ , see Table 8) predicted scores on the IOCv2 Negative Impact Scale.

Table 8

*Multiple regression based on hypothesis 3 testing whether the IOCv2 Negative Impact Scale summary scores were predicted by a solid versus non-solid tumor diagnosis and the perceived severity of the cancer diagnosis among cancer survivors versus caregivers.*

<u>Predictor</u>	<u>Survivor</u>				<u>Caregiver</u>			
	<i>B</i>	<i>SE β</i>	t-test	<i>p</i>	<i>B</i>	<i>SE β</i>	t-test	<i>p</i>
(Constant)	57.42	11.51	4.99	<0.00	65.61	11.37	5.77	<0.001
Solid versus non-solid tumor diagnosis	11.03	8.26	1.34	0.18	6.20	7.13	0.87	0.38
Perceived severity of diagnosis	0.85	3.51	0.24	0.81	-1.23	2.60	-0.47	0.64

The t-test examining hypothesis four, that survivors of non-solid tumors would endorse a lower level of health-related quality of life than survivors of solid tumors, did not support this hypothesis. The t-test value of 0.162,  $p = 0.871$  fell below the  $p \leq 0.05$  level of significance.

The analyses for the fifth hypothesis, that caregivers and survivors of non-solid tumors will endorse lower levels of social support than caregivers and survivors of solid tumors, did not show a significant difference in social support endorsed by diagnostic category in either subgroup. The t-tests comparing the means between cancer survivors diagnosed with solid versus non-solid tumors ( $t(21) = 1.17, p = 0.24$ ) and comparing the means between caregivers of cancer survivors diagnosed with solid versus non-solid tumors ( $t(28) = -0.076, p = 0.94$ ) did not reach the  $p \leq 0.05$  level of significance.



## Chapter 4. Discussion

### *Summary of results and implications*

The primary purpose of this study was to investigate the potential impact of a diagnosis of a non-solid versus solid tumor and the perceived severity of a cancer diagnosis on several measures related to biopsychosocial adjustment to cancer and its treatment among cancer survivors and caregivers. Cronbach Alphas indicated that the OSS-3, the measure of social support utilized in this study, demonstrated good internal consistency among survivors but fair internal consistency among caregivers. This may have contributed to findings from the correlation matrix that the OSS-3 was significantly positively correlated with overall health-related QOL and negatively correlated with depression among survivors but not caregivers. The OSS-3 scores could also moderate the relationships between various domains related to cancer survivorship and caregiving, although mediation analysis is beyond the scope of this study.

The IOCv2 Negative Impact Scale was significantly negatively correlated with the CDC HRQoL Healthy Days Index and positively correlated with the CDC HRQoL Symptom Module pain, depression, and anxiety questions for survivors but not for caregivers. This could potentially be because for many cancer survivors, health problems captured by these measures of health related QOL are directly caused by the sequelae of cancer and its treatment (e.g. Parry et al., 2004; Jones et al., 2015), however direct relationships between cancer care and such health problems are less likely for caregivers. Another potential explanation for the differences in relationships between negative impacts of cancer and health related QOL is that the IOCv2, which was modified for caregivers from the cancer survivor version for this study, may not have accurately measured the unique experiences of caregivers. Among caregivers, the IOCv2 Negative Impact Scale scores were significantly correlated with scores on the PTGI and IOCv2

Positive Impact Scale, which further indicated that there might be notable differences in adjustment to cancer among caregivers and survivors and/or measurement issues. As a result, the data for caregivers and survivors was analyzed separately to test the hypotheses.

There were five hypotheses for this study. The first three evaluated whether a diagnosis of a solid versus non-solid tumor or the perceived severity of the cancer diagnosis predicted scores on the PTGI, the IOCv2 Positive Impact Scale, and the IOCv2 Negative Impact Scale among cancer survivors and caregivers. Neither the diagnosis of a solid versus non-solid tumor nor the perceived severity of the cancer diagnosis predicted scores on the outcome measures among the cancer survivor or caregiver group. However, this is likely, in part, due to the small sample size used in this study. As the sample size was split between cancer survivors and caregivers *post hoc* based on the results of the reliability analyses and correlation matrices, it was particularly small, which reduced the power to detect significant results. The t-test value assessing the diagnosis of a solid versus non-solid tumor as a predictor variable for composite scores on the IOCv2 Negative Impact Scale among survivors approached significance in this small sample. This may have emerged as a significant predictor of IOCv2 Negative Impact Scale scores with a larger sample. The other t-test values were small and would potentially require a much larger sample to demonstrate significant effects of a solid versus non-solid tumor diagnosis or the perceived severity of the cancer diagnosis on PTGI or IOCv2 composite scores.

Several studies found that increased medical severity of cancer diagnoses were associated with higher levels of posttraumatic growth (e.g. Barakat et al., 2005, Ponto et al., 2010). While the current study was not able to assess medical severity of participants' and/or their loved ones' cancer diagnoses, participants' perceptions of the severity of their/their loved ones' cancer diagnoses did not appear to predict posttraumatic growth. Several studies have found that cancer

survivors' perception of the severity of their cancer often does not match their medical providers' understanding of the severity of their cancer (e.g. El-Jawahri et al., 2017; Shimer et al., 2018). Other studies have suggested that the physical impact of cancer and its treatment, including neuropathy and fatigue, can last for years following diagnosis (e.g. Parry et al., 2011; Jones et al., 2015). It is possible that the physical severity of the cancer diagnoses predicts posttraumatic growth to a greater degree than perceived severity. This possibility would fit with the hypothesis that posttraumatic growth functions to facilitate adjustment to new life circumstances among individuals who have experienced trauma (Zoellner & Maercker, 2006). However, since the current study utilized self-reported outcome measures assessing perceived biopsychosocial changes due to cancer and its treatment, it would be expected that the perceived severity of cancer would be a stronger predictor of scores on these measures than the medical severity of their diagnoses.

As the time since diagnosis and treatment cessation were not standardized as an inclusion criterion for this study, another possible explanation for the result that perceived severity of the diagnosis did not predict posttraumatic growth is that perceived severity of the diagnosis could mean different things to participants. Some participants were still in treatment and/or had not achieved remission during the study. For these participants, the perceived severity of their diagnosis may have reflected the perceived severity of their current symptoms and level of functioning. Other participants had been in remission for years and the perceived severity of their diagnosis might have reflected their past experiences with cancer that they had overcome. Previous studies have indicated that the levels of posttraumatic growth endorsed by cancer survivors varies based on the time since diagnosis (Rowlands et al., 2013; Zebrack et al., 2012).

It is possible that time since diagnosis and/or treatment cessation moderates the relationship between posttraumatic growth and the perceived severity of the cancer diagnosis.

While this study investigated the impact of a non-solid tumor diagnosis on adjustment to cancer as a proxy for the unique challenges that LLS often face, such as the rarity of specific diagnoses and the likelihood of recurrence, these challenges are not necessarily universal to LLS and their caregivers. For example, the diagnosis of Hodgkin's lymphoma is more common than certain solid tumors, such as renal cell carcinoma (Leukemia and Lymphoma Society, 2014) and is curable with chemotherapy (Girinsky et al., 2006). Few participants in the current study provided information about their specific cancer diagnoses, beyond leukemia, lymphoma, or a solid tumor. It is possible that the diagnosis of a solid versus non-solid tumor did not significantly predict scores on the PTGI and the IOCV2 partially because the general diagnosis of a solid versus non-solid tumor was not an accurate estimation of these challenges. Perhaps understanding of the diagnosis, the availability of resources to address biopsychosocial needs following a cancer diagnosis, and the likelihood of recurrence would be better predictors of scores on these measures than generally a solid versus non-solid tumor diagnosis.

The fourth hypothesis investigated the differences in mean CDC HRQoL Healthy Days Index scores between survivors of solid versus non-solid tumors. The t-test value for this analysis was small and non-significant, indicating that it is unlikely that health related QOL was significantly different for survivors of solid versus non-solid tumors in this sample. This is somewhat unexpected given the increased rates of recurrence and greater heterogeneity of diagnoses classified as non-solid tumors versus solid tumors. It is possible the medical severity of the diagnosis and the time since treatment cessation could moderate this result. Other health-related comorbidities were not assessed in the current study and have been found to impact

health-related QOL in another study of cancer survivors (Park and Blank, 2012). The presence of such comorbidities might also moderate possible differences in health-related QOL among survivors of solid versus non-solid tumors. Alternatively, as many of the participants were at a higher than expected income level, this lack of significant difference between health related QOL among survivors of solid versus non-solid tumors may represent a more homogeneous level of access to health care and prevention services.

The fifth hypothesis addressed differences in mean levels of social support endorsed by caregivers and survivors of solid versus non-solid tumors. Although the t-tests assessing these differences were non-significant for both the caregiver and survivor groups, the t-test value for the survivor group was large enough that it may have been significant with a larger sample size, with survivors of non-solid tumors reporting non-significantly higher levels of social support than survivors of solid tumors. Whether there is truly no significant difference between social support among survivors of solid versus non-solid tumors or if this non-significantly higher level of social support endorsed by survivors of non-solid versus solid tumors would be significant with a larger sample size, this finding is unexpected. Several researchers have proposed that the heterogeneity of non-solid tumor diagnoses might lead to higher levels of social isolation among survivors of these diagnoses, compared to survivors of more homogeneous and/or common solid tumors (Jones et al., 2015; Parry et al., 2011). The results from the current study do not support this assertion and suggest that survivors of non-solid tumors may be able to compensate for the decreased availability of support from other survivors of their diagnosis in maintaining their support networks. Alternatively, as the OSS-3 is a brief and broad measure of social support, it is possible that it did not fully tap into the facets of social support that have been hypothesized in past studies to be lower among survivors of solid versus non-solid tumors. The rarity of the

specific solid and non-solid tumor diagnoses of the participants in this study may have also confounded these results. The t-test value in the caregiver group was small, which may have been partially an artifact of the internal consistency of the OSS-3 being low among caregivers in this sample.

### *Strengths*

This study was the first to examine the association between solid and non-solid tumor types on psychosocial adjustment to cancer. It was also one of a small number of studies to look at the psychosocial adjustment of cancer among caregivers. No published study to date has investigated the impact of perceived severity of cancer diagnoses on adjustment to cancer.

The breadth of the data collected regarding adjustment to cancer allowed for analysis of adjustment to cancer diagnoses in a variety of domains, including positive and negative psychosocial changes, posttraumatic growth, quality of life, and social support. This facilitated a greater understanding of the relationship between adjustment to cancer among these domains. Furthermore, the breadth of information collected on participant characteristics facilitated more comprehensive analyses of the impact that clinical and demographic characteristics could potentially have on various domains of adjustment to cancer diagnoses.

By utilizing an online method of data collection, a diagnostically diverse national sample was able to be obtained. Despite research suggesting that online samples tend to capture younger participants at a greater rate than older participants (Kaplowitz, Hadlock, and Levine, 2004), this study recruited participants across a diverse range of ages. As participants were recruited primarily from online classified advertisements, rather than from websites geared towards providing information and support to cancer survivors and caregivers, it is possible that they

were more neutral than individuals actively seeking support and information on survivorship. Since the study was completed online, it may have been less of a burden to participate in than in-person studies, which could have increased the rate of participation among cancer survivors who were more physically impaired than in-person studies tend to include.

### *Limitations*

The sample size from this study was small, which may have increased the possibility of false-negative findings. Outside of the medical system, this population was difficult to reach and it was hard to obtain a larger number of participants. Several of the results obtained, notably the multiple regression used to test hypothesis three among cancer survivors and the t-test used to evaluate hypothesis five, showed values that were large enough that they might demonstrate statistically significant results with a larger sample size. While using an anonymous online convenience sample allowed us to obtain a geographically broader national sample of cancer survivors and caregivers, there were a number of limitations inherent in this type of sample. Most studies on cancer survivors and caregivers recruited participants from hospitals and thus were able to utilize data from the participants' medical records to confirm participant characteristics, such as the diagnosis and treatments (e.g. Jones et al., 2015; Kim et al., 2010). As this data was not available for the current study, it is possible that participants' recollection of their/their loved ones' diagnoses, perceived severity, and treatments were not accurate or were missing due to a limited understanding of these variables and the diverse range of the amount of time that passed since their initial diagnosis/treatment.

The mean and median income levels of participants who disclosed their income on the demographic questionnaire was much higher than the national average income. The majority of

participants did not disclose their income levels; however, it seems that participants at higher income levels were overrepresented in this study. The median household income of cancer survivors and caregivers in the United States is unknown. As cancer care is very expensive, it is possible that the high household income levels reported in the study are representative and potentially point towards people at higher levels of household income receiving better cancer-related outcomes, which would increase the likelihood that they could participate in the study. Alternatively, this finding could represent a sampling bias and/or a bias in reporting household income.

Due to concerns of the questionnaires being completed by automated computerized software, we did not compensate participants for their participation in this study. While this may have protected the data from including such automated responses, it may have introduced sampling bias into the study. People who chose to participate in an unpaid online study may have been more likely to have been at a higher income level and retired/working fewer hours than people who declined to participate. Since this study required internet access to participate, people at low income levels might have been less likely to participate due to limited internet access. As there was no monetary incentive to participate in this study, participants may have been motivated by a strong interest in cancer survivorship and/or caregiving for cancer survivors. They may have had more intense perceptions about the positive and negative biopsychosocial changes due to cancer.

The IOCV2 was initially designed for cancer survivors and demonstrates good psychometric properties among cancer survivors (e.g. Zebrack et al., 2006; Crespi et al., 2008; Smith et al., 2010). However, it was modified for the current study for caregivers and has not been thoroughly psychometrically evaluated as a measure of biopsychosocial changes associated



with being a caregiver of a cancer survivor. The wording of the questionnaire items was minimally changed for caregivers and it is unknown whether this questionnaire truly assesses common biopsychosocial changes that caregivers experience when their loved one is diagnosed with cancer.

### *Future Directions*

As the small sample size was a major limitation in this study, in part due to the online recruitment strategy, it is recommended that future studies in the area of adjustment to cancer diagnoses be conducted with partnership with medical systems to increase access to participants. Recruiting participants through medical systems could also assist researchers in reimbursing participants while minimizing the risk of obtaining fraudulent responses from automated software. This may increase participation among caregivers and survivors at lower levels of social economic status.

The statistically significant correlations among the standardized questionnaires indicate that the relationships between various domains of adjustment to cancer survivorship among survivors and caregivers may be more complex than originally hypothesized. Mediation analyses using structural equation modeling (SEM) may provide a better understanding of the interactions between these domains. This could broaden our understanding of the mechanisms by which we can help cancer survivors and their caregivers to increase positive biopsychosocial changes following cancer diagnoses while meeting ongoing biopsychosocial needs. SEM investigating the relationship between different domains of cancer survivorship is beyond the scope of this study. Such analyses will be completed in a follow-up study. This will require a larger sample size and further data collection is currently underway.

More research is needed on assessing positive and negative biopsychosocial changes in caregivers following their loved ones' cancer diagnosis to understand how cancer impacts the lives of caregivers and how to best support caregivers. The psychometric properties of the IOCv2 could be tested in future research or alternatively, a separate tool specifically designed to measure biopsychosocial changes related to providing care for a loved one with cancer could be developed and evaluated. It is possible that some of the most pertinent concerns among caregivers of cancer survivors are unique to caregivers and are not addressed in the IOCv2.

### *Conclusions*

Cancer survivorship and caregiving for cancer survivors has been found to be related to a number of positive and negative biopsychosocial changes in several populations of cancer survivors and caregivers. Survivors of leukemia and lymphoma and their caregivers may face a particularly unique set of circumstances in that these diagnoses are very heterogeneous, and the probability of recurrence is often higher than it is for survivors of solid tumors. This study addressed five hypotheses related to differences in biopsychosocial adjustment to cancer among survivors and caregivers of solid versus non-solid tumors and by the perceived severity of cancer diagnoses. The results did not suggest that a solid versus non-solid tumor or the severity of cancer diagnoses predicted positive or negative biopsychosocial changes related to cancer or were associated with differences in mean indicators of health-related QOL or social support among survivors or caregivers. However, the sample size for the study was small and may have yielded false-positive findings in some of the analyses. The diagnoses of solid versus non-solid tumors and the perceived severity of cancer diagnoses may not be sufficient information to significantly predict the degree to which survivors and caregivers experience positive and negative biopsychosocial changes due to cancer. More research is needed to clarify the potential

relationships between cancer diagnoses, perceptions of cancer severity and biopsychosocial changes experienced by cancer survivors and caregivers due to cancer and its treatment.

## Appendices

### Appendix A

#### *List of Non-Hodgkin Lymphoma Subtypes*

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##### Subtype of Non-Hodgkin Lymphoma

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##### Myeloid and lymphoid neoplasms

With eosinophilia and abnormalities of PDGFRA

With eosinophilia and abnormalities of PDGFRB

With eosinophilia and abnormalities of FGFR1

##### Lymphoid neoplasms

B Lymphoblastic leukemia/lymphoma, not otherwise specified (NOS)

B lymphoblastic leukemia/lymphoma with recurrent genetic abnormalities

B lymphoblastic leukemia/lymphoma with t(9;22)(q34;q11.2); BCR-ABL1

B lymphoblastic leukemia/lymphoma with t((v;11q23); MLL rearranged

B lymphoblastic leukemia/lymphoma with t(12;21)(p13;q22); TEL-AML1 (ETV6-RUNX1)

B lymphoblastic leukemia/lymphoma with hyperdiploidy

B lymphoblastic leukemia/lymphoma with hypodiploidy (Hypodiploid ALL)

B lymphoblastic leukemia/lymphoma with t(5;14)(q31;q32); IL3-IGH

B lymphoblastic leukemia/lymphoma with t(1;19)(q23;p13.3); E2A-PBX1(TCF3-PBX1)

T lymphoblastic leukemia/lymphoma

##### Mature B-cell neoplasms

Chronic lymphocytic leukemia/small lymphocytic lymphoma

Splenic marginal zone lymphoma

Splenic B-cell lymphoma/leukemia, unclassifiable

Splenic diffuse red pulp small B-cell lymphoma

Lymphoplasmacytic lymphoma

Heavy chain disease

Alpha heavy chain disease

Extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue (MALT lymphoma)

Nodal marginal zone lymphoma

Follicular lymphoma

Primary cutaneous follicle center lymphoma

Mantle cell lymphoma

Diffuse large B-cell lymphoma (DLBCL), NOS

T cell/histiocyte-rich large B-cell lymphoma

Primary DLBCL of the CNS

Primary cutaneous DLBCL, leg type

Subtype of Non-Hodgkin Lymphoma (cont.)

EBV positive DLBCL of the elderly

DLBCL associated with chronic inflammation

Lymphomatoid granulomatosis

Primary mediastinal (thymic) large B-cell lymphoma

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Intravascular large B-cell lymphoma  
ALK positive large B-cell lymphoma  
Plasmablastic lymphoma  
Large B-cell lymphoma arising in HHV8-associated multicentric Castleman disease  
Primary effusion lymphoma  
Burkitt lymphoma  
B-cell lymphoma, unclassifiable, with features intermediate between DLBCL and Burkitt lymphoma  
B-cell lymphoma, unclassifiable, with features intermediate between DLBCL and classical Hodgkin lymphoma

Mature T-and NK-cell neoplasms

Chronic lymphoproliferative disorder of NK cells  
Ebstein-Barr virus (EBV) positive T-cell lymphoproliferative diseases of childhood  
Systemic EBV+ T-cell lymphoproliferative diseases of childhood  
Hydroa vacciniforme-like lymphoma  
Adult T-cell leukemia/lymphoma  
Extranodal NK/T-cell leukemia/lymphoma  
Enteropathy-associated T-cell lymphoma  
Hepatosplenic T-cell lymphoma  
Subcutaneous panniculitis-like T-cell lymphoma  
Mycosis fungoides  
Sézary syndrome  
Primary cutaneous CD30 positive T-cell lymphoproliferative disorders  
Primary cutaneous peripheral T-cell lymphomas, rare subtypes  
Primary cutaneous gamma-delta T-cell lymphoma  
Primary cutaneous CD8 positive aggressive epidermotropic cytotoxic T-cell lymphoma  
Primary cutaneous CD4 positive small/medium T-cell lymphoma  
Peripheral T-cell lymphoma, NOS  
Angioimmunoblastic T-cell lymphoma  
Anaplastic large cell lymphoma, ALK positive  
Anaplastic large cell lymphoma, ALK negative

Immunodeficiency-associated lymphoproliferative disorders

Lymphoproliferative diseases associated with primary immune disorders  
Lymphomas associated with HIV infection  
Post-transplant lymphoproliferative disorders (PTLD)  
Plasmacytic hyperplasia and infectious-mononucleosis-like PTLN  
Polymorphic PTLN  
Subtype of Non-Hodgkin Lymphoma (cont.)  
Monomorphic PTLN  
Other iatrogenic immunodeficiency-associated lymphoproliferative disorders

Histiocytic and dendritic cell neoplasms

Interdigitating dendritic cell sarcoma  
Follicular dendritic cell sarcoma  
Other rare dendritic cell tumors

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## Appendix B

### *List of Locales Recruited from via Craigslist*

Locale	State
New York City	New York
Houston	Texas
Cleveland	Ohio
San Francisco	California
Oahu	Hawai`i
Rochester	Minnesota
Ann Arbor	Michigan
Durham	North Carolina
Baltimore	Maryland
Phoenix	Arizona
State College	Pennsylvania
Jacksonville	Florida
Indianapolis	Indiana
Philadelphia	Pennsylvania
Seattle	Washington
Denver	Colorado
Atlanta	Georgia
Boston	Massachusetts
Chicago	Illinois
Washington	District of Columbia
Los Angeles	California
Pittsburgh	Pennsylvania
Austin	Texas
Portland	Oregon
San Antonio	Texas
San Jose	California

## Appendix C

### Study Advertisement

Do you or a loved one  
have a history of  
cancer?

We would like to hear from you! Adults who have been diagnosed with cancer and their caregivers are invited to participate in an online survey on life after cancer diagnosis/treatment. Please follow the link below to the survey site. We are excited to hear from you!

[https://manoahawaii.ss.az1.qualtrics.com/SE/?SID=SV\\_5z3QEfJEIKACKzH](https://manoahawaii.ss.az1.qualtrics.com/SE/?SID=SV_5z3QEfJEIKACKzH)

## Appendix D

### Demographic Questions - Survivors

Age [drop-down menu]

Gender (self-identify) \_\_\_\_\_

Ethnicity (click all that apply)

- Caucasian
- African American
- American Indian
- Alaskan Native
- Asian
  - Chinese
  - Korean
  - Japanese
  - Filipino
  - Vietnamese
  - Other Asian (please specify) \_\_\_\_\_
- Native Hawaiian
- Pacific Islander
- Other (please specify) \_\_\_\_\_

In which country did you receive your cancer treatment? \_\_\_\_\_

Diagnosis

- Leukemia



- Lymphoma
- Solid tumor (please describe) \_\_\_\_\_

How severe do you consider your cancer?

- Extremely severe
- Very severe
- Moderately severe
- Slightly severe
- Not severe
- Not sure

Have you been diagnosed with recurrence since your initial diagnosis?

- Yes
- No

Have you been diagnosed with any other cancer since your initial diagnosis?

- Yes
- No

Do you have healthcare insurance?

- Yes
  - Medicare
  - Medicaid
  - Other (please specify) \_\_\_\_\_
- No

How much money do you estimate you have paid for treatment out-of-pocket? \_\_\_\_\_

How much money do you estimate you lost due to your cancer, not including treatment costs?

\_\_\_\_\_

Are you currently employed?

- Yes, full-time
- Yes, part-time
- No

How many people live in your household? [drop-down menu]

What is your annual household income? \_\_\_\_\_

What is your marital status?

- Married
- Cohabiting
- Single
- Divorced
- Widowed

What treatments did you receive for your cancer? (click all that apply)

- Chemotherapy
- Radiation therapy
- Bone marrow transplant
- Watchful waiting
- Other (please describe)

When did your treatment end?

- Date \_\_\_\_\_
- I am still receiving treatment

## Appendix E

### Demographic Questions - Caregivers

Age [drop-down menu]

Gender (self-identify) \_\_\_\_\_

Ethnicity (click all that apply)

- Caucasian
- African American
- American Indian
- Alaskan Native
- Asian
  - Chinese
  - Korean
  - Japanese
  - Filipino
  - Vietnamese
  - Other Asian (please specify) \_\_\_\_\_
- Native Hawaiian
- Pacific Islander
- Other (please specify) \_\_\_\_\_

In which country did your loved one receive cancer treatment? \_\_\_\_\_

Diagnosis received by your loved one:

- Leukemia
- Lymphoma

- Solid tumor (please describe) \_\_\_\_\_

How severe do you consider your loved one's cancer?

- Extremely severe
- Very severe
- Moderately severe
- Slightly severe
- Not severe
- Not sure

Has your loved one been diagnosed with recurrence since your initial diagnosis?

- Yes
- No

Has your loved one been diagnosed with any other cancer since your initial diagnosis?

- Yes
- No

Does your loved one have healthcare insurance?

- Yes
  - Medicare
  - Medicaid
  - Other (please specify) \_\_\_\_\_
- No

How much money do you estimate your family has paid for treatment out-of-pocket?

\_\_\_\_\_

How much money do you estimate your family lost due to your cancer, not including treatment costs? \_\_\_\_\_

Are you currently employed?

- Yes, full-time
- Yes, part-time
- No

How many people live in your household? [drop-down menu]

What is your annual household income? \_\_\_\_\_

What is your marital status?

- Married
- Cohabiting
- Single
- Divorced
- Widowed

What treatments did your loved one receive for cancer? (click all that apply)

- Chemotherapy
- Radiation therapy
- Bone marrow transplant
- Watchful waiting
- Other (please describe)

When did your loved one's treatment end?

- Date \_\_\_\_\_
- She/he is still receiving treatment

## Appendix F

### PTGI - Survivor

Indicate for each of the statements below the degree to which this change occurred in your life as a result of cancer, using the following scale.

0 = I did not experience this change as a result of my cancer.

1 = I experienced this change to a very small degree as a result of my cancer.

2 = I experienced this change to a small degree as a result of my cancer.

3 = I experienced this change to a moderate degree as a result of my cancer.

4 = I experienced this change to a great degree as a result of my cancer.

5 = I experienced this change to a very great degree as a result of my cancer.

#### Possible Areas of Growth and Change

- |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|
| 1. I changed my priorities about what is important in life.           | 0 | 1 | 2 | 3 | 4 | 5 |
| 2. I have a greater appreciation for the value of my own life.        | 0 | 1 | 2 | 3 | 4 | 5 |
| 3. I developed new interests.   | 0 | 1 | 2 | 3 | 4 | 5 |
| 4. I have a greater feeling of self-reliance.                         | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. I have a better understanding of spiritual matters.                | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. I more clearly see that I can count on people in times of trouble. | 0 | 1 | 2 | 3 | 4 | 5 |
| 7. I established a new path for my life.                              | 0 | 1 | 2 | 3 | 4 | 5 |
| 8. I have a greater sense of closeness with others.                   | 0 | 1 | 2 | 3 | 4 | 5 |
| 9. I am more willing to express my emotions.                          | 0 | 1 | 2 | 3 | 4 | 5 |
| 10. I know better that I can handle difficulties.                     | 0 | 1 | 2 | 3 | 4 | 5 |

11. I am able to do better things with my life. 0 1 2 3 4 5
12. I am better able to accept the way things work out. 0 1 2 3 4 5
13. I can better appreciate each day. 0 1 2 3 4 5
14. New opportunities are available which wouldn't have been otherwise. 0 1 2 3 4 5
15. I have more compassion for others. 0 1 2 3 4 5
16. I put more effort into my relationships. 0 1 2 3 4 5
17. I am more likely to change things which need changing. 0 1 2 3 4 5
18. I have a stronger religious faith. 0 1 2 3 4 5
19. I discovered that I'm stronger than I thought I was. 0 1 2 3 4 5
20. I learned a great deal about how wonderful people are. 0 1 2 3 4 5
21. I better accept needing others. 0 1 2 3 4 5

## Appendix G

### PTGI - Caregivers

Indicate for each of the statements below the degree to which this change occurred in your life as a result of cancer, using the following scale.

0 = I did not experience this change as a result of my loved one's cancer.

1 = I experienced this change to a very small degree as a result of my loved one's cancer.

2 = I experienced this change to a small degree as a result of my loved one's cancer.

3 = I experienced this change to a moderate degree as a result of my loved one's cancer.

4 = I experienced this change to a great degree as a result of my loved one's cancer.

5 = I experienced this change to a very great degree as a result of my loved one's cancer.

#### Possible Areas of Growth and Change

- |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|
| 1. I changed my priorities about what is important in life.           | 0 | 1 | 2 | 3 | 4 | 5 |
| 2. I have a greater appreciation for the value of my own life.        | 0 | 1 | 2 | 3 | 4 | 5 |
| 3. I developed new interests.   | 0 | 1 | 2 | 3 | 4 | 5 |
| 4. I have a greater feeling of self-reliance.                         | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. I have a better understanding of spiritual matters.                | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. I more clearly see that I can count on people in times of trouble. | 0 | 1 | 2 | 3 | 4 | 5 |
| 7. I established a new path for my life.                              | 0 | 1 | 2 | 3 | 4 | 5 |
| 8. I have a greater sense of closeness with others.                   | 0 | 1 | 2 | 3 | 4 | 5 |
| 9. I am more willing to express my emotions.                          | 0 | 1 | 2 | 3 | 4 | 5 |
| 10. I know better that I can handle difficulties.                     | 0 | 1 | 2 | 3 | 4 | 5 |



11. I am able to do better things with my life. 0 1 2 3 4 5
12. I am better able to accept the way things work out. 0 1 2 3 4 5
13. I can better appreciate each day. 0 1 2 3 4 5
14. New opportunities are available which wouldn't have been otherwise. 0 1 2 3 4 5
15. I have more compassion for others. 0 1 2 3 4 5
16. I put more effort into my relationships. 0 1 2 3 4 5
17. I am more likely to change things which need changing. 0 1 2 3 4 5
18. I have a stronger religious faith. 0 1 2 3 4 5
19. I discovered that I'm stronger than I thought I was. 0 1 2 3 4 5
20. I learned a great deal about how wonderful people are. 0 1 2 3 4 5
21. I better accept needing others. 0 1 2 3 4 5

## Appendix H

### IOCV2 - Survivors

Indicate your agreement with each item on a 5-point scale:

1 = Strongly Disagree

2 = Disagree

3 = Neutral

4 = Agree

5 = Strongly Agree

1. I do not take my body for granted since the cancer.
2. Having had cancer has made me more concerned about my health.
3. I am more aware of physical problems or changes in my body since having had cancer.
4. Having had cancer has made me take better care of myself (my health).
5. I consider myself to be a cancer survivor.
6. I feel a sense of pride or accomplishment from surviving cancer.
7. I learned something about myself because of having had cancer.
8. I feel that I am a role model to other people with cancer.
9. Having had cancer makes me feel unsure about my future.
10. I feel like time in my life is running out.
11. I worry about the cancer coming back or about getting another cancer.
12. Having had cancer makes me feel uncertain about my health.
13. I worry about my future.
14. New symptoms (e.g. aches, pains, getting sick or the flu) make me worry about the cancer coming back.

15. I worry about my health.
16. I am concerned that my energy has not returned to what it was before I had cancer.
17. I am bothered that my body cannot do what it could before having had cancer.
18. Having had cancer has made me feel old.
19. I worry about how my body looks.
20. I feel disfigured.
21. I sometimes wear clothing to cover up parts of my body I don't want others to see.
22. I feel a special bond with people with cancer.
23. Because I had cancer, I am more understanding of what other people may feel when they are seriously ill.
24. Having had cancer has made me more willing to help others.
25. I feel that I should give something back to others because I survived cancer.
26. I feel guilty today for not having been available to my family when I had cancer.
27. I feel like cancer runs my life.
28. Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me.
29. Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to school).
30. Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family).
31. On-going cancer-related or treatment-related symptoms (for example, bladder or bowel control, lymphedema, hair loss, scars, infertility, premature menopause, lack of energy, impotence//sexual problems, aches, pain, or physical discomfort) interfere with my life.

32. Having had cancer turned into a reason to make changes in my life.
33. Because of cancer I have become better about expressing what I want.
34. Because of cancer I have more confidence in myself.
35. Having had cancer has given me direction in life.
36. Because of having had cancer I feel that I have more control of my life.
37. Uncertainties about my health or future have made me delay getting married or getting involved in a serious relationship.
38. I wonder how to tell a potential spouse, partner, boyfriend or girlfriend that I have had cancer.
39. I worry about not having a spouse, partner, boyfriend or girlfriend.
40. I am open and willing to discuss my cancer with my spouse/partner.
41. My spouse/partner is open and willing to discuss my cancer with me.
42. Uncertainties about my health has caused problems in my relationship with my spouse/partner.
43. I worry about my spouse/partner leaving me if I were to become ill again.
44. I am concerned about not being able to work if I become ill again.
45. Concerns about losing health insurance keep me in the job I have now.
46. I worry about being forced to retire or quit work before I am ready.

## Appendix I

### IOCv2 - Caregivers

Indicate your agreement with each item on a 5-point scale:

1 = Strongly Disagree

2 = Disagree

3 = Neutral

4 = Agree

5 = Strongly Agree

1. I do not take my body for granted since the cancer.
2. Having a loved one who had cancer has made me more concerned about my health.
3. I am more aware of physical problems or changes in my body since my loved one's cancer.
4. My loved one's cancer has made me take better care of myself (my health).
5. I consider my loved one to be a cancer survivor.
6. I feel a sense of pride or accomplishment from helping my loved one survive cancer.
7. I learned something about myself because of my loved one's cancer.
8. I feel that I am a role model to other caregivers of people with cancer.
9. My loved one's cancer makes me feel unsure about my future.
10. I feel like time in my life is running out.
11. I worry about the cancer coming back or about her/him getting another cancer.
12. Our experience with cancer makes me feel uncertain about my health.
13. I worry about my future.

14. New symptoms (e.g. aches, pains, getting sick or the flu) make me worry about the cancer coming back.
15. I worry about my health.
16. I am concerned that my energy has not returned to what it was before my loved one had cancer.
17. I am bothered that my body cannot do what it could before my loved one had cancer.
18. My loved one's cancer has made me feel old.
19. I feel a special bond with caregivers of people with cancer.
20. Because of cancer, I am more understanding of what other people may feel when they are seriously ill.
21. My loved one's cancer has made me more willing to help others.
22. I feel that I should give something back to others because my loved one survived cancer.
23. I feel guilty today for not having been available to my family when my loved one had cancer.
24. I feel like cancer runs my life.
25. My loved one's cancer has made me feel like some people (friends, family, co-workers) do not understand me.
26. Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to school).
27. My loved one's cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family).
28. My loved one's on-going cancer-related or treatment-related symptoms (for example, bladder or bowel control, lymphedema, hair loss, scars, infertility, premature menopause,

lack of energy, impotence//sexual problems, aches, pain, or physical discomfort) interfere with my life.

29. My loved one's cancer turned into a reason to make changes in my life.
30. Because of my loved one's cancer I have become better about expressing what I want.
31. Because of cancer I have more confidence in myself.
32. My loved one's cancer has given me direction in life.
33. Because of my loved one's cancer I feel that I have more control of my life.
34. Uncertainties about my loved one's health or future have made me delay getting married or getting involved in a serious relationship.
35. I wonder how to tell a potential spouse, partner, boyfriend or girlfriend that my loved one had cancer.
36. I worry about not having a spouse, partner, boyfriend or girlfriend.
37. I am open and willing to discuss my loved one's cancer with my spouse/partner.
38. My spouse/partner is open and willing to discuss my loved one's cancer with me.
39. Uncertainties about my health has caused problems in my relationship with my spouse/partner.
40. I worry about my spouse/partner leaving me if my loved one became ill again.
41. I am concerned about not being able to work if my loved one became ill again.
42. Concerns about losing health insurance keep me in the job I have now.
43. I worry about being forced to retire or quit work before I am ready.

## Appendix J

### Scoring Instructions for the IOCV2

Reverse code items 40 and 41 by subtracting the score obtained from 6.

Sum the item scores in each scale/subscale:

Positive Impact Scale: 1, 2, 3, 4, 5, 6, 7, 8, 22, 23, 24, 25, 33, 34, 35, 36, 37

Altruism and Empathy Subscale: 22, 23, 24, 25

Health Awareness Subscale: 1, 2, 3, 4

Meaning of Cancer Subscale: 33, 34, 35, 36, 37

Positive Self-Evaluation Subscale: 5, 6, 7, 8

Negative Impact Scale: 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 26, 27, 28, 29, 30, 31, 32

Appearance Concerns Subscale: 19, 20, 21

Body Change Concerns Subscale: 16, 17, 18

Life Interferences Subscale: 26, 27, 28, 29, 30, 31, 32

Worry Subscale: 9, 10, 11, 12, 13, 14, 15

Employment Concerns: 44, 45, 46

Relationship Concerns (Not Partnered): 37, 38, 39

Relationship Concerns (Partnered): 40, 41, 42, 43



## Appendix K

### CDC HRQoL – Survivors and Caregivers

1. Would you say that in general your health is:
  - a. Excellent 1
  - b. Very good 2
  - c. Good 3
  - d. Fair 4
  - e. Poor 5
  - f. Don't know/not sure 7
  - g. Refused 9
  
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
  - a. Number of days \_\_\_\_
  - b. None 88
  - c. Not sure 77
  - d. Refused 99
  
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
  - a. Number of days \_\_\_\_
  - b. None 88
  - c. Not sure 77
  - d. Refused 99

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

- a. Number of days \_\_\_\_
- b. None            88
- c. Not sure        77
- d. Refused         99

### Symptom Module

1. During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?

- a. Number of days \_\_\_\_
- b. None            88
- c. Not sure        77
- d. Refused         99

2. During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?

- a. Number of Days \_\_\_\_
- b. None            88
- c. Not sure        77
- d. Refused         99

3. During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?

- a. Number of Days \_\_\_\_

- b. None 88
- c. Not sure 77
- d. Refused 99

4. During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?

- a. Number of Days \_\_\_\_
- b. None 88
- c. Not sure 77
- d. Refused 99

5. During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?

- a. Number of days \_\_\_\_
- b. None 88
- c. Not sure 77
- d. Refused 99

## Appendix L

### The OSS-3 and Scoring System – Survivors and Caregivers

1. How easy can you get help from neighbors if you should need it?
  - a. Very easy 5 points
  - b. Easy 4 points
  - c. Possible 3 points
  - d. Difficult 2 points
  - e. Very difficult 1 point
2. How many people are so close to you that you can count on them if you have serious problems?
  - a. None 1 point
  - b. 1-2 2 points
  - c. 3-5 3 points
  - d. 6+ 4 points
3. How much concern do people show in what you are doing?
  - a. A lot 5 points
  - b. Some 4 points
  - c. Uncertain 3 points
  - d. Little 2 points
  - e. None 1 point

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