The Effect of Hope on the Relationship between Personal and Disease Characteristics and Anxiety and Depression in Adolescents and Young Adults with Cancer

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The Effect of Hope on the Relationship between Personal and Disease Characteristics and Anxiety and Depression in Adolescents and Young Adults with Cancer

by

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
College of Nursing
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Dedication

This dissertation is dedicated, first and foremost to my husband, Tim. He was always so supportive and so proud of my accomplishments. His unconditional love and confidence in me have helped keep me going through all of the rough spots. I can’t say how much I wish he was here with us for this, but I know that he is watching over us and I hope he is proud and realizes how much he’s contributed to not only this dissertation but my career. I love you and miss you every day!

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Abstract

Adolescents and young adults (AYAs) with cancer face physical, psychosocial, emotional, and developmental challenges that are unique to their age group. In facing the crisis of a cancer diagnosis, both social support and hope have been shown to be tools utilized by some AYAs. However, AYAs have higher rates of anxiety and depression than in older adults which may have an effect on their levels of hope.

This cross-sectional study examined the mechanistic effects of hope on the relationship between personal characteristics of age, gender, and social support, the disease characteristics of type of cancer and length of time since diagnosis, and the outcome of global anxiety and depression in adolescents and young adults with cancer. Levels of social support, hope, anxiety, and depression were evaluated, and the effects of hope on global anxiety and depression were evaluated. The instruments used in this study are an investigator developed Demographic Tool, The Multidimensional Scale of Perceived Social Support, the Herth Hope Index, and the Hospital Anxiety and Depression Scale.

Results: A total of 63 AYAs were enrolled in the study (mean age 24.4 years, 85% white, non-Hispanic females). In general, the AYAs had high levels of perceived social support (M=66.44, SD=11.22) and moderate to high levels of hope (M=36.52, SD=5.6). A majority of the participants (83%) had borderline to abnormal levels of anxiety (M=10.79, SD=3.4), while 38% had borderline to abnormal levels of depression
(M=6.16, SD=2.9). Age, type of cancer, and length of time since diagnosis did not correlate with perceived social support, hope, or global anxiety and depression. Perceived social support is positively correlated with hope $r(61)= .359, p=.004$; and negatively correlated to global anxiety and depression $r(61)= -.247, p=0.5$. Hope is positively correlated with perceived social support $r(61)= .359, p=.004$; and negatively correlated with global anxiety and depression $r(61)= -.561, p<.001$. Hope is found to partially mediate the relationship between social support and global anxiety and depression.

Conclusion: Hope mediates the relationship between perceived social support and global anxiety and depression. Interventions need to be developed to foster hope and social support in AYAs with cancer to combat the higher levels of global anxiety and depression.
Chapter One

Introduction

Adolescents and young adults (AYAs) are a unique and distinct group of patients with cancer. They are diagnosed with biologically different types of cancers than either older or younger patients and have more toxicity and late effects than other groups (Bukowinski et al., 2015). In transitioning from a child to an adult, AYAs have unique developmental, physical, mental, and emotional needs. There is a surge in physical growth accompanied by hormonal changes and the emergence of secondary sexual characteristics. Adolescents and young adults are discovering their identity and sexuality as well as preparing to separate from their parents and start making their own way in the world (Barr & Bleyer, 2017; Barr et al., 2016; Keegan et al., 2012; Kent et al., 2013; Thomas et al., 2010; Zebrack, 2011; Zebrack et al., 2013).

Compounding the unique needs of AYAs, there is an ongoing lack of a standard definition for what ages comprise the adolescent and young adult age group across the globe. The Surveillance, Epidemiology, and End Results (SEER) report from the National Cancer Institute published in 2006 defined the age range as 15 – 29 years (Bleyer et al., 2006). In the United Kingdom, the Teenage Cancer Trust defines the age group for adolescents and young adults as 13 – 24 years of age (Birch et al., 2008). Researchers in Europe met to develop guidelines for AYA care in the European Union (Peni et al., 2017). A group of healthcare professionals who worked with AYA patients,
representing 21 countries participated in the survey (Peni et al., 2017). One of the goals of the group was to establish the age of AYA patients. After several rounds of balloting, the participants were unable to come to a consensus as to what ages should be included in the population. While 75% of the participants agreed that the age of 13-30 was an appropriate age group, but it did not meet the threshold the group had established for consensus (Pini et al., 2017). Several well-respected national organizations including the National Cancer Institute (NIH), the American Cancer Society (ACS), and the Children's Oncology Group (COG) use the age range of 15 – 39 years to define adolescents and young adults (Freyer, Felgenhauer, & Perentesis 2013; National Institutes of Health, 2013). For the purpose of this study, the age range for AYAs with cancer will be from 18 to 30. This smaller age range was used due to the different life stages and developmental tasks that occur with the broader age range, making the sample too heterogeneous.

**AYAs and the Cancer Experience**

Over the last decade and a half, there has been an increase in the incidence of cancer in AYA age group. In 2020, it is estimated there will be 89,500 AYAs diagnosed with cancer (Miller et al., 2020). In contrast to older adults, the incidence of cancer in the AYA group has increased since the year 2000 (Barr et al., 2016). During the early 1970s, AYAs with cancer experienced a better prognosis as compared to other age groups, however since that time AYAs have not seen the improvements in the overall survival rates that have been reported in different age groups (Close et al., 2019; Coccia, 2019).
While AYAs might have lymphomas and leukemias that are common in children and thyroid cancer and breast cancer more commonly found in adults, the types of cancers the AYAs develop are biologically different from those of children or older adults (Barr & Bleyer, 2017; Bukowinski et al., 2015). These include differences in the way chemotherapeutics are metabolized, potentially leading to more significant toxicities and an inadequate response to treatment (Bukowinski et al., 2015).

In addition to the physical burdens of cancer and its treatment, AYAs with cancer have their life interrupted just as they are starting to establish their independence, their careers, and intimate relationships. They encounter the loss of friendships, potential loss of career, and disrupted life plans (Smith et al., 2018; Sodergren et al., 2018). With these changes, can come anxiety and depression both of which can lead to nonadherence to treatment and potentially higher mortality rates (Bukowinski et al., 2015; Ding et al., 2019; Lauer, 2015).

The AYA with cancer has a very different experience with cancer than either the child with cancer or an older adult with cancer. Healthcare providers must acknowledge the distinctiveness of the AYA with cancer and discover what can be done to foster hope and social support while ameliorating the potential for anxiety and depression in the AYA with cancer.

**Hope in Adults with Cancer**

Hope is defined as “a multi-dimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p.380). Hope is an essential
component of how an individual approach a crisis, such as a life-threatening illness (Miller, 2007).

Studies of hope in patients with cancer have generally fallen into one of four categories: defining, conceptualizing, and measuring hope, exploring the levels of hope in cancer patients, exploring the relationship between hope and other variables, and discovering how to foster hope (Butt, 2011; Chi, 2007). In studies from the mid-1980s to the early 2000s, various researchers conducted a concept analysis of hope and developed tools to measure hope (Hendricks-Ferguson, 1997; Herth, 1991, 1992; Hinds, 1984, Miller & Powers, 1988; Nowonty, 1989; Snyder, 1995).

The concept of hope has been extensively studied in older adults with cancer, but studies of hope in AYAs with cancer are far fewer. In the older adult population, factors such as religious faith, family and social support, resilience, and self-esteem have been found to be correlated with higher levels of hope (Denewer et al., 2011; Grealish et al., 2019; Kavradim et al., 2012; Saleh & Brockopp, 2001; Solano et al., 2016; Vellone et al., 2006; Zhang et al., 2010).

Not all studies found that hope was related to age and gender. Davis and colleagues (2017) examined hope, symptoms and palliative care in 197 older adults with advanced incurable cancer. The participants in the study had an average age of 60. In this study, hope was measured by the Herth Hope Index (HHI), and scores were relatively high, with an average of 40 on the HHI (range 12-48). Hope was not found to be related to age, gender, marital status, or length of time since diagnosis (Davis et al., 2017). A study of 131 newly diagnosed Norwegian cancer patients (Rustoen & Wiklund, 2000), found that gender was not significantly related to levels of hope. Most of the
patients were found to be hopeful or moderately hopeful with a mean score on the HHI of 36.1 Researchers found that those who lived alone had lower levels of hope. Younger patients between 19 to 39, who lived alone were found to have significantly lower levels of hope (p=0.05) than those who lived with family or friends (Rustoen & Wiklund, 2000).

This conflicting information on the role of age, gender, length of time since diagnosis and type of cancer on hope indicates that further research is needed to determine what factors influence hope.

In a qualitative, longitudinal study of 12 adults between the ages of 20 to 59 with advanced cancer, Reynolds (2008) found that all patients reported having hope. Hope was negatively associated with physical symptoms such as pain, fatigue, and nausea, implying that those with a higher symptom burden had lower levels of hope. Family, friends, and social activities were all positively associated with hope (Reynolds, 2008). Another qualitative study of 16 terminally ill cancer patients (Buckley & Herth, 2001) found high levels of hope as measured by the HHI. In addition to the HHI, the researchers conducted a semi-structured interview to explore the meaning of hope. The researchers identified 7 categories of factors that foster hope – love of family and friends, spirituality/having faith, setting goals and maintaining independence, positive relationship with healthcare providers, humor, personal characteristics, and uplifting memories (Buckley & Herth, 2001). These qualitative findings underscore the importance of social support in hope.

A positive correlation was found between social support and hope in several quantitative studies of adults with cancer (Denewer et al., 2011; Grealish et al., 2019; Kavradim et al., 2012; Vellone et al., 2006; Zhang et al., 2010). However, the average
age of the participants in the studies ranged from 44 to 65. In studies of hope in persons with cancer that did not include a specified AYA group, the participants’ ages ranged from 18 to 88. However, these studies did not report any age-related sub-group analyses so there was no specific information on levels of hope in the AYA group (Denewer et al., 2011; Kavradim et al., 2012; Vellon et al., 2006; Zhang et al., 2010). The lack of AYA representation in the above mentioned studies underscores the need for further studies of hope in AYAs with cancer.

**Anxiety and Depression in Adults and AYAs with Cancer**

A cancer diagnosis often causes emotional distress including anxiety and depression at any age (Lauer, 2015). The prevalence of anxiety and depression found in the literature ranges widely from 2% up to 51% in the cancer population (Maass et al., 2015; Mielcarek et al., 2016). Anxiety and depression are found at the time of cancer diagnosis, during treatment, and after treatment completion. Several studies of both AYAs and adults with cancer concluded that cancer patients with anxiety and depression could lead to poor treatment compliance and decreased quality of life (Lauer, 2015; Linden et al., 2012; Niedzwiedz et al., 2019; Thalén-Lindström et al., 2013).

Over the course of treatment, anxiety and depression are found to be higher at diagnosis or prior to treatment initiation but decreases over the course of therapy (Mielcarek et al., 2016; Thalén-Lindström et al., 2013; Watts et al., 2015). Conversely, researchers in the Netherlands conducted a large population-based study with over 3000 cancer survivors up to ten years after their diagnosis (Mols et al., 2013). One finding was that patients who died during the study period had higher levels of
depressive symptoms as compared to those who survived despite not having a poorer prognosis (Mols et al., 2013). Chida and colleagues (2008) found that stress-related psychosocial factors, such as stressful life events, negative emotional responses and poor quality of life. Depression was noted to have a substantial effect on cancer survival and mortality (Chida et al., 2008). Stress related psychosocial issues were associated with decreased survival rates for lung cancer, breast cancer, hematological cancers, and head and neck cancers among others (Chida et al., 2008). In a meta-analysis of 76 studies with 105 distinct samples, researchers found that those with higher depressive symptoms or a confirmed diagnosis of depression had a higher risk of mortality (Pinquart & Duberstein, 2010). Patients with acute myeloid leukemia diagnosed with anxiety and depression were also found to have lower rates of overall survival (Ding et al., 2019).

A study conducted with 196 Australian adolescents and young adults between the ages of 15-25 and 204 parent caregivers explored emotional distress and post-traumatic stress syndrome in the AYAs with cancer (McCarthy et al., 2016). Both the AYAs (31%) and their parents (28%) exhibited symptoms of anxiety and depression. In this study, anxiety and depression were not measured as separate concepts but were measured together on a psychological distress scale. The factors found to impact anxiety and depression in AYAs included female gender, poor social support, and self-image and having identity issues. Germann and colleagues (2018) studied the role of hope, anxiety and depression in children with cancer (n = 60), with a mean age of 13.2 years found that children with cancer-related depressive symptoms tended to be in later adolescence (17 years). The age and demographics at which AYAs with cancer may be
at highest risk for anxiety and depression needs to be more clearly defined. The measurement of anxiety and depression in the AYA population should also be standardized to be able to replicate studies and compare findings.

**Age**

Adolescence can be described as the period of time between childhood and maturity. Traditionally, adolescence begins at puberty and progresses through to adulthood with the journey to maturity irrespective of biological age (Rice & Dolgin, 2008). Many physical, emotional, and psychosocial changes take place during the adolescent years. Developmental tasks of AYAs focuses on developing a more definite sense of their personal and sexual identity, develop positive relationships both social and romantic, attaining autonomy, the formation of identity, and becoming socially and financially independent (Lauer, 2015).

Age has been shown to be a factor in levels of anxiety and depression. Lang and colleagues (2018) examined psychosocial distress in cancer survivors compared to their age-matched peers. In a sample of over 230,000, there were 14,592 cancer survivors. AYA accounted for 881 cancer survivors with the rest of the survivors being classified as older adults (>40 years old). AYA cancer survivors reported significantly higher (p<0.001) levels of anxiety disorders than either older adults or their age-matched peers (Lang et al., 2018). Similar results were also found in a study of over 10,000 women with breast cancer. Younger women between the ages of 18 to 39 had significantly higher levels of anxiety (p<0.001) and depression (p=0.001) than older women (Naik et al., 2020).
The association between higher levels of anxiety and depression a younger age has been shown in a variety of settings. Bergerot and colleagues (2018) explored distress and quality of life in 137 Brazilian patients with a mean age of 50 years with rare cancers. Significantly higher levels of anxiety and depression in younger patients (p<0.05); however, this study failed to provide a definition of the younger patient.

In a study of 3370 German cancer survivors, it was found that cancer survivors had significantly higher levels of anxiety and depression (p=0.001) than the general public (Inhestern et al., 2017). The participants were diagnosed with cancer between the ages of 25-55 years old, at the time of the study, they had a mean age of 50. Anxiety and depression were associated with women (p<0.001), a younger age (0.001), and less social support (p<0.001). (Inhestern et al., 2017). A younger age was not explicitly named, but the two younger groups were ≤ 30 and 31-40. These two groups only comprised 9% of the total population. Comparing cancer survivors to the general population, researchers studied over 3700 cancer patients and 2700 in the general population (Hinz et al., 2010). Younger patients had higher levels of anxiety (p<0.001) and depression (p<0.001) than any of the older patients or those in the general population, but the younger age group ranged in age from 18-60 and the older group ≤ 61. Only 7% of the sample was in the AYA age group. With younger ages being so poorly defined and such a small portion of the total sample, so it is difficult to generalize these findings.

Lang and colleagues (2015) performed a scoping review of the literature to determine if a younger age or AYA group was at higher risk for depression and anxiety. In a review of 34 studies, levels of anxiety or depression were higher in younger or AYA
patients as compared to older patients. In general, being of younger age is associated with experiencing higher levels of anxiety and depression, so it is important to determine if hope has a mechanistic effect on anxiety and depression in AYAs with cancer. Additionally, what precisely constitutes a younger age has not been clearly defined. Further research is needed to determine the role of age in anxiety and depression in AYAs with cancer.

Gender

Gender, either biological sex or self-identified gender, has been shown to make a difference in how individuals experience anxiety and depression. Researchers exploring anxiety in the general population combined three national surveys for a total of over 20,000 participants (McLean et al., 2011). Women were found to have higher levels of anxiety disorders as compared to men. Women were not only more likely to have an anxiety disorder, but they were also more likely to have longer episodes of anxiety, and the anxiety experience was more debilitating in women than in men (McLean et al., 2011).

Women with cancer have been reported to have higher levels of anxiety and depression as compared to men. Bergerot and colleagues (2015; 2018) conducted two studies exploring distress, anxiety, and depression in different cancer populations. The first was a prospective, longitudinal study with 104 patients with hematologic cancers that examined distress, anxiety and depression at diagnosis, half-way through treatment and at the end of treatment. Female patients were found to have higher levels of distress, anxiety and depression. Anxiety and Depression were measured on the Hospital Anxiety and Depression Scale (HADS), which has two subscales of anxiety
(HADS-A) and depression (HADS-D). Each subscale is measured from 0 to 21, with a higher number indicating higher anxiety or depression. In the 2015 study, HADS-A ranged from 7.9 at diagnosis to 3.7 at the end of therapy and the HADS-D scores ranged from 5.9 at diagnosis and 3.0 at the end of therapy. The second study was a convenience sample of 137 patients with rare cancers exploring distress, anxiety and depression. Women had significantly higher levels of emotional distress, anxiety (p=.0002) and depression (p =.007).

In a cross-sectional study exploring the prevalence of anxiety and depression in 270 adults on their first day of chemotherapy after diagnosis (Cardosa et al., 2016) found 30% of the patients had a HADS-A score ≥ 8 and 24.1% had a HADS-D score ≥ 8. Being a woman was found to be a risk factor for elevated levels for anxiety (p=.002) and depression (p=.004). In this study, age was not a risk factor for anxiety, but older patients were at risk for higher levels of depression (Cardosa et al., 2016). Jimenez-Fonseca and colleagues (2018) studied factors associated with anxiety and depression in a cross-sectional study of 600 adults prior to starting chemotherapy. Anxiety and depression were found in 49.8% of the participants as measured on the Brief Symptom Inventory (BSI). Perceived social support, as measured by the multidimensional scale of perceived social support (MSPSS) was found to be high with a mean of 75 (range 12-84). Higher levels of anxiety and depression were found in younger, females with lower levels of hope, optimism, and perceived social support. A study of 10,153 consecutive adults newly diagnosed with cancer at two major cancer centers sought to establish the prevalence of anxiety and depression, using the psychosocial screen for cancer questionnaire. They found that 19% of the participants had clinical levels of anxiety, and
12.9% had clinical levels of depression. Women and those under the age of 50 were found to have higher levels of anxiety and depression (Linden et al., 2012).

While many studies found women to have higher levels of anxiety and depression, not all studies found this same difference. In a cross-sectional study examining reappraisal, suppression, hope, anxiety and depression in 144 adults newly diagnosed with cancer (Peh et al., 2019), researchers found that age, gender, and marital status had no impact on the levels of hope, anxiety and depression.

Gender may or may not play a role in levels of anxiety and depression in AYAs with cancer, which may influence levels of hope in AYAs with cancer. Additional research is needed to clarify the role of gender on the effect of anxiety and depression and subsequently, hope.

**Social Support**

Social support is a reciprocal relationship that provides emotional, tangible, informational, and experiential support (Breuer et al., 2017; Kyngas et al., 2001; McDonnell et al., 2018). Peer relationships are very important to AYAs, as peers often have more influence on decision making and social development as compared to parents or other family members (Breuer et al., 2015; Oudekerk et al., 2015). Keeping and maintaining relationships while undergoing oncology treatment can be challenging as AYAs report feeling isolated and apart from their peers during treatment (Peeters et al., 2018; Zebrack, 2011). Achieving the developmental tasks, such as of the AYAs can be difficult for healthy adolescents and young adults, but for those faced with cancer, such tasks can be more challenging to complete (Pennant et al., 2019).
Although peer relationships are important to AYAs, a qualitative study of 26 AYA survivors found parents, especially mothers, are a primary source of social support (McDonnell et al., 2018). In a descriptive study of 108 adolescents aged 12-18, from Turkey, parents were cited as the adolescents’ primary source of comfort and support (Ekim & Ocakci, 2015). Moderate levels of perceived social support (M=55.99, SD=11.54) were found using the multidimensional scale of perceived social support (MSPSS). The MSPSS has three subscales of family, friends, and significant other or special person. Ekim and Ocakic (2015) found the highest scores on the family subscale (M=28.64, SD=2.53), followed by friends (M=18.82, SD=7.61), and lastly special person (M=9.50, SD=5.47). On the friend subscale, girls (M=20.46, SD=6.25) were found to significantly higher levels of perceived social support than boys (M=16.73, SD=4.86) (p<.05).

Woodgate (2006) conducted a qualitative study of 15 adolescents age 12-18 with cancer and found family and friends were most often mentioned as primary sources of support. A qualitative study of 20 AYAs aged 15-25, identified not only family but also other AYAs with cancer as a source of support (Tsangaris et al., 2014).

In adult oncology patients, researchers have explored the effect of social support on feelings of hope. Bao and colleagues (2019) conducted a study of 269 Chinese patients with central nervous system (CNS) tumors that explored the relationship between social support depressive symptoms, and the mediating role of hope in the relationship. This descriptive study found that higher levels of social support were correlated with higher levels of hope and less depressive symptoms. The interaction of other demographic variables with social support and hope were not reported. The
researchers determined that hope partially mediated the relationship between social support and depressive symptoms.

In a cross-sectional, descriptive study of 294 newly diagnosed adult Saudi Arabian cancer patients, researchers examined social support and religious beliefs (Bany Hamdan et al., 2020). Findings included overall high levels of religious beliefs and high levels of social support among this population. Social support was found to be higher in males (p<.001) and those over the age of 52 (001). In this study, social support and religious beliefs were examined individually, but the relationship between religious beliefs and social support was not explored (Bany Hamdan et al., 2020).

A qualitative study exploring social support and gender was conducted in the UK among 11 melanoma patients and 5 breast cancer patients (Clarke et al., 2006). Men in the study tended to obtain their primary source of social support from their wives, although they enjoyed the interactions with staff and others. Women, on the other hand, drew support from a variety of sources – spouse, friends, and medical staff. Men found comfort in small touches, such as being given a cup of tea while women wanted more personal interactions (Clarke et al., 2006). These studies mentioned above were conducted outside the U.S. and therefore may or may not reflect the experience of social support in AYAs in the United States.

Qualitative studies of social support in AYAs with cancer have been conducted in a variety of settings. In a study of young breast cancer survivors (n= 70) between the ages of 18 to 40, Snyder and Pearse (2010) identified an important type of social support – that of experiential support. This is support that is provided by someone who has gone through the same experience and is in the same age range and stage in life
and can provide first-hand knowledge of the process. Experiential support was valued even over other family members who had breast cancer as these family members were often older than the AYAs when they were diagnosed. One descriptive, exploratory study of hope and social support utilization in women with breast cancer (150) and their spouses (n=150) found that hope partially mediated the relationship between social support and depression (Hasson-Ohayon et al., 2014). The women and their spouses were divided into two groups, younger patients (ages 28-54) and older patients (older than 54). Older women and their spouses had significantly lower scores of anxiety and depression (p<0.001) on the brief symptom inventory (BSI). The two groups utilized social support differently. Younger women appeared to rely on social support to combat depression, while older women hope was found to mediate the relationship between social support and depression (Hasson-Ohayon et al., 2014).

Social support appears to be a vital part of addressing the cancer experience at any stage. Social support is important to teens and young adults, and it is related to the experience of hope and inversely related to depression (Hasson-Ohayon et al., 2014; Hann et al., 2002; Inhestern et al., 2017). The mechanism by which hope effects the relationship between social support and anxiety and depression has not been well explored and needs to be examined.

**Type of Cancer**

The most types of cancers that AYAs are diagnosed with can vary widely. The most common type of cancer across the AYA spectrum in thyroid cancer (Miller et al., 2020). Leukemias and lymphomas are more prevalent in older teens and 20 to 24-year age groups, but unlike leukemia in children, leukemia in young adults has a very poor
prognosis and outcome (Tricoli et al., 2017). After the age of twenty, adult type cancers increase in prevalence including breast cancer, melanomas, and thyroid cancers. In those over the age of 30 years old, breast, thyroid, and other types of cancers dominate the diagnoses. Not only is the distribution of the types of cancer diverse in the AYA group, but the cancers are also biologically different. Most of these cases develop spontaneously and do not appear related to either carcinogens in the environment or genetics as in the familial cancer syndromes (Close et al., 2019; Miller et al., 2020; Tricoli et al., 2017).

In a meta-analysis of 211 articles, researchers found that depression and anxiety were highest in those with gastrointestinal (GI) tumors, central nervous system (CNS) tumors, gynecological cancers, and hematologic malignancies. Over 30% of the studies were exclusively focused on breast cancer, which is uncommon in AYAs, making it difficult to compare to less common or less well-studied types of cancer (Krebber et al., 2014). Researchers in Germany the factors associated with levels of anxiety and depression among 514 AYAs with a variety of cancers. Those with GI tumors reported the highest levels of anxiety, while those with gynecological cancers had the highest levels of depression (Geue et al., 2019). It is important to note breast cancer, GI cancer and gynecological cancers are not common in the AYA group. There have been no studies found that indicate whether a specific type of cancer is associated with hope, anxiety, or depression in the AYA group. Knowing if the type of cancer influences levels of hope, or symptoms of anxiety or depression can assist in developing interventions aimed at that specific cancer in AYAs.
Length of Time Since Diagnosis

In most research studies, the length of time since the cancer diagnosis is reported as a demographic description of the sample characteristics, but not often used as a covariate in the analysis. No studies could be found that explored hope and length of time since diagnosis. Longitudinal studies of depression and anxiety have used length of time since diagnosis to include or exclude study participants or to time the data collection.

Bergerot and colleagues (2017) conducted a longitudinal study of 548 adults (mean age 54 years) with cancer exploring the effects of anxiety, depression, and changes in living during chemotherapy treatment. Data was collected at the start of treatment, mid-treatment, and treatment completion. Levels of anxiety and depression as measured by the HADS were elevated upon diagnosis, with 37% having symptoms of anxiety and 17% with symptoms of depression. By the end of treatment, symptoms decreased to 4.6% for anxiety and 5.1% for depression which was attributed to the passage of time which was presumed to lessen the immediate crisis of diagnosis (Bergerot et al., 2017).

In an earlier study of hematological cancers in 104 patients, Bergerot and colleagues (2015) collected data at three-time points – at the start of treatment, mid-treatment, and treatment completion. The participants ranged in age from 18 to 86 years, with an average age of 52. The percentage of patients with anxiety and depression was higher at diagnosis, with 47% reported having symptoms of anxiety and 26% with symptoms of depression as measured by HADS. The percentage of those reporting symptoms of anxiety and depression fell dramatically during treatment with
9.8% reporting anxiety and 3.3% reporting symptoms of depression which was attributed to the quality of care and psychosocial counseling. While the percentage of participants reporting symptoms of anxiety and depression was elevated, the levels of anxiety and depression were all in the normal range (0 to 7) of the HADS. The highest levels which were at diagnosis were a mean of 7.9 for anxiety and 5.9 for depression. After treatment, the anxiety levels had a mean of 3.7 and anxiety levels had a mean of 3.0 (Bergerot et al., 2015).

In a longitudinal study of patients diagnosed with cancer as adolescents and young adults (n=61), researchers examined anxiety and depression over time (Ander et al., 2016). Data were collected within weeks of diagnosis, then again at 6, 12, and 18 months after diagnosis. Participants were then followed at 2, 3, 4, and 10 years post-diagnosis. At the first data collection period, 18% of participants reported depressive symptoms as measured by the HADS, as compared to 0% in the last time period (10 years). Anxiety symptoms were experienced by 15% during the first data collection period but increased to 29% at the last (10 year) measurement period. Those participants at the 10 year period reported more health concerns and fertility issues that hadn’t been noted previously. It was theorized when the participants were younger, their parents acted as a buffer against distress which is removed once the participants move out of their parents’ home and start their own families, thereby increasing their levels of anxiety (Ander et al., 2016).

German researchers examined the risk for anxiety and depression in 992 long-term hematological cancer survivors as compared to age and gender-matched peers (Kuba et al., 2017). The participants were divided into four groups based on length of
time since diagnosis – 2.5 to 5.9 years, 6-8.9 years, 9-11.9 years, and > 12 years since initial diagnosis. When examining age, the participants were divided into four groups < 45 years, 46-65 years, 66-75 years and > 75 years. Anxiety and depression were measured using the generalized anxiety disorder screener and the patient health questionnaire for depression. Participants closest to diagnosis had a higher risk for anxiety and depression as did those in the two younger age groups < 45 and 46-65 years (Kuba et al., 2017)

The lack of studies examining the length of time since diagnosis in the AYA population with cancer underscores the need to examine if length of time since diagnosis has any effect on hope, anxiety or depression in the population. In addition, the conflicting data shows the need for further research into the importance of length of time since diagnosis.

**Summary**

Hope has been studied in adults with cancer as well as adolescents with cancer. High levels of hope have been found in newly diagnosed patients as well as terminally ill patients. Factors that influence hope are not as well explored and the influence of age, gender, type of cancer, and length of time since diagnosis on hope has not been established.

The literature has demonstrated that females and younger patients are at higher risk for anxiety and depression during a cancer diagnosis and treatment, even though younger age has not been clearly defined, and few studies are using AYAs exclusively as participants.
Social support is important to the AYA population with AYAs with cancer gaining support from family, friends, and other AYAs with similar cancers. Only one study found that hope had a partial mediating effect on social support and depressive symptoms. Further studies are needed to confirm the relationship of hope to the moderating and demographic and other variables tested.

The relationship between the disease characteristics of type of cancer and length of time since diagnosis and anxiety and depression has not been well defined in AYAs with cancer and needs further investigation. Higher levels of hope are present in all phases of cancer treatment from diagnosis to the end of life. Social support has been shown to influence levels of hope, with those having higher levels of social support had higher levels of hope. Hope has an inverse relationship with anxiety and depression. Anxiety and depression are present in AYAs with cancer from diagnosis to treatment and survivorship. Over the course of active treatment, and survivorship, depression is shown to decrease. At the same time, the information on anxiety is conflicting, with some studies reporting an increase in anxiety and others reporting a decrease in anxiety levels.

**Statement of Problem**

Taken together, the previous studies show that the mechanistic effect of hope on the relationship between stressors in AYA’s cancer experience and their responses to the experience has not been explored. Therefore, the purpose of this study is to evaluate whether hope affects the relationship between personal (age, gender, and social support) and disease (cancer type and length of time since diagnosis) factors and
global anxiety and depression and determine if hope moderates this relationship in adolescents and young adults with cancer.

**Specific Aims**

The following aims are addressed in this cross-sectional study of 63 AYAs with cancer:

Aim 1) To examine the relationships between age, gender, social support, cancer type and length of time since diagnosis, hope, global anxiety and depression in adolescents and young adults with cancer.

Aim 2) To evaluate the mechanistic effect of hope on the relationship between the personal characteristics of age, gender, social support; the disease characteristics of cancer type and length of time since diagnosis with global anxiety and depression in AYAs with cancer.

**Definition of Terms**

**Adolescent and Young Adult.** An individual who is developmentally between a child and an adult. These individuals are developing their own identity, separating themselves from their parents, and participating in romantic relationships (Dolgin & Rice, 2008; Erikson, 1950). For this study, the AYA group will be limited to those between the ages of 18 to 30 years.

**Age.** For this study, age will be defined as the age of the participant at the time they are participating in the study. It will be collected in years.

**Anxiety.** A “feeling of fear and apprehension, a nagging sense of worry and anxious
ness, coupled with a sense of doubt and vulnerability about future events” (Kreitler, 2018, p.1500). Anxiety will be defined as the anxiety level determined by the Hospital Anxiety and Depression Scale - Anxiety (HADS-A).

**Cancer Type**. For this study, the type of cancer will be identified by the participant.

**Depression**. “A feeling of sadness, misery, emptiness and hopelessness coupled with concern about the bad situation that has already happened in the present” (Kreitler, 2018, p.1500). Depression will be defined as the depression level determined by the HADS-D.

**Gender**. A complex concept that includes how a person thinks and feels about themselves as well as cultural influences. While it is distinct from biological sex, the two terms are often used interchangeably (Castleberry, 2019). For this study, gender will be how the participant self-identifies.

**Global anxiety and depression**. For this study, the global anxiety and depression scores will be defined as the anxiety and depression score determined by the HADS-G score.

**Hope**. “A multi-dimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p.380). For this study, hope will be defined as the hope level determined by the Hearth Hope Index (HHI).

**Length of Time Since Diagnosis**. For this study, length of time since diagnosis will be defined by the participant at the length of time in years since they were initially diagnosed with cancer.
**Social Support.** Perceived social support is a transactional relationship that the recipient views as helpful in stressful situations (Zimet, Dalhem, Zimet & Farley, 1987). For this study, perceived social support will be defined by the score on the Multidimensional Scale of Perceived Social Support.

**Significance to Nursing**

Symptoms of anxiety and depression have been linked to a lower quality of life, reduced treatment adherence, and decreased overall survival (Ding et al., 2019; Lauer, 2015). Anxiety and depression have not been well explored in adolescents and young adults with cancer, the prevalence of anxiety and depression in AYAs has not been well documented. A review of the literature shows that age, gender, type of cancer, length of time since diagnosis and social support have all been shown to influence anxiety and depression, but not consistently (Lang et al., 2018; McCarthy et al., 2016).

Hopeful patients may be more likely to be active in their own care and more responsive to the efforts of others to assist them through cancer treatment (Lauer, 2015). While a younger age is associated with a higher risk of anxiety and depression, AYAs are also shown to have moderate to high levels of hope (Martins et al., 2018; Rosenberg et al., 2018). The link between hope and anxiety and depression has not been explored in the AYA age group.

This study evaluates whether hope effects the relationship between person (age, gender, and social support) and disease (cancer type and length of time since diagnosis) level factors with global anxiety and depression in adolescents and young adults with cancer.
Chapter Two

Review of Literature

This chapter reviews the current literature related to the areas of research. The conceptual framework for the study will be described, and current research on the variables of interest will be described.

Study Conceptual Framework

The stress process model was developed by Pearlin and colleagues (1981) to address the issue of how the sources of stress, the mediators of stress, and the manifestations of stress worked together to form the stress process. Since that time the model has been used in a variety of fields including nursing, psychology, sociology, mental health and gerontology providing evidence for the utility of the model as well allowing for comparison between studies using the model (Aneshensel, 2015; Aneshensel & Avison, 2015; Demirtepe-Saygılı & Bozo, 2011; Elliott et al., 2014; Liu et al., 2013; Pearlin, 2010; Pendergrass et al., 2017; Perry et al., 2011; Seeher et al., 2014).

In this study I used the stress process model structure to organize my variables and design my aims. The input or independent variables are age, gender, social support, type of cancer, and length of time since diagnosis. The moderating or mechanism variable is hope, and the output of dependent variables are anxiety and depression.
The Effect of Hope on the Relationship between Personal and Disease Level Factors with Anxiety and Depression in Adolescents and Young Adults with Cancer

Inputs

Age
Gender
Social Support
Type of Cancer
Length of Time Since Diagnosis

Mechanism

Hope

Outputs

Global Anxiety and Depression

Figure 1.

The adolescent period is characterized by a state of transition from childhood to adulthood (Meeus, 2016). Adolescents experience rapid changes in physical size, psychosocial, emotional and cognitive development (Rice & Dolgin). The boundaries between adolescence and young adulthood are not well defined either by age or responsibilities. Adolescence is the “period of growth between childhood and maturity” (Rice & Dolgin, 2008, p 2). Adolescents attain physical maturity at different ages, and legal maturity varies according to the activity and the state of residence. In the United States, the legal drinking age and the legal smoking age is 21 years, but the legal voting age is 18 as is the age to be drafted into the armed services and consent to participate in clinical trials (Carlisle, 2019; Knoppers et al., 2016; Rice & Dolgin, 2008). Inconsistencies in legal rights can lead to more confusion on the part of the adolescent.

Developmentally, adolescents are in the identity versus role diffusion stage
(Erikson, 1950). Developing an individual identity is a life-long process that begins in childhood and continues through adulthood, but during adolescence this process takes precedence over other tasks (Rice & Dolgin, 2008). The adolescent’s interactions with others are of utmost importance as they try on a variety of roles before developing their own identity (Erikson, 1950). Adolescents begin to look to their peers for the support and guidance they formerly received from their parents. (Rice & Dolgin, 2008). Romantic relationships first develop in adolescents and will become more important in young adulthood as the young adult become involved in intimate relationships (Rice & Dolgin, 2008).

Peer relationships are very important to AYAs and peers may often have more influence on decision making and social development than parents or other family members (Oudekerk et al., 2015; Rice & Dolgin, 2008). Keeping and maintaining those relationships while undergoing oncology treatment can be challenging as AYAs report feeling isolated and apart from their peers during treatment (Peeters et al., 2018; Zebrack, 2011). The developmental tasks of the AYAs can be difficult for healthy adolescents and young adults, but for those faced with cancer, such tasks can be more challenging to complete.

At a time AYAs are striving towards independence, the experience of cancer and its treatment forces them to become increasingly dependent upon their parents (Sondergren et al., 2018). Young adults who achieved independence may need to quit their jobs, take time off from school, or move back into their parental home (Sondergren et al., 2018). Clinic visits to receive chemotherapy can be disruptive to those trying to attend school or work (Sondergren et al., 2018). AYAs with cancer may also have to
contend with unplanned hospitalizations for nausea, vomiting, pain, and fever or febrile neutropenia (McKenzie et al., 2011).

As adolescents move into young adulthood, they move into the developmental stage of intimacy versus isolation stage (Erikson, 1950). The main task for this stage of life is to develop close, meaningful relationships. Building on the identity they established in adolescence, the young adult seeks to establish romantic relationships and potentially start a family of their own (Erikson, 1950).

Progression through these many changes is not smooth or guaranteed, and individuals progress through at their own pace (Erikson, 1950). While healthy adolescents may progress through these changes while developing plans for their future, adolescents and young adults with cancer may be faced with uncertainty and a limited life expectancy (Neville, 2000).

Cancer interrupts the progress of adolescents and young adults through their developmental stages (Sondergren et al., 2018). AYAs with cancer report feeling that cancer has interrupted their life and interfered with the plans they had started making for their future (Sodergren et al., 2018). Cancer can interfere with friendships and relationships making the AYA feel that they are not progressing or are feeling left behind (Kumar & Schapira, 2013; Mascarin & Ferrari, 2019; Sodergren et al., 2018).

Age is a variable that is collected in most studies to help define the study sample and help determine if the sample is representative of both the population in researchers intend to study and the population in general (Connelly, 2013). In studies of anxiety and depression in adult cancer patients and survivors, a younger age is commonly listed as being associated with higher levels of anxiety and depression.
Researchers in Germany studied the risk of anxiety and depression in 922 long term survivors of hematological cancers compared to age and gender matched peers from the general population (Kuba et al., 2019). The participants had relatively low rates of anxiety and depression with 9% and 15% respectively as measured by the generalized anxiety disorder screener and the patient health questionnaire for depression (Kuba et al., 2019). The length of time since diagnosis ranged widely from 2.5 years to 26 years. Survivors closer to diagnosis had higher rates of depression compared to age and gender matched peers than longer term survivors. Ages of the participants ranged from 18 to 85, with 10% of the participants from the 18-45 year age group. The younger and middle-aged adults, consisting of two groups 18-45 and 46-65 were found to have higher rates of anxiety and depression than both their age matched peers and the survivors over the age of 65 (Kuba et al., 2019).

Inhestern and colleagues (2017) conducted a study of anxiety and depression in 3370 working age cancer survivors. On average, the participants were 44 months off therapy and had a mean age of 50 years, with a range of 25 to 55 years at the time of diagnosis. Almost 40% of the patients had moderate to high anxiety (M=6.8, SD=4.1), and 20% reported moderate to high depression (M=4.1, SD=4.0) as measured on the HADS (Inhestern et al., 2017). Younger, female survivors with less social support had
higher levels of anxiety. Survivors who were unemployed with less social support had higher levels of depression. The researchers noted that the cancer survivors had lower levels of depression and higher levels of anxiety than the general population (p=.001) (Inhester et al., 2017). The researchers posited that the stress of cancer and fear of a recurrence could increase stress while a better appreciation of life and priority changes after the cancer diagnosis could lead to lower levels of depression (Inhestern et al., 2017).

Studying age and gender differences in anxiety and depression 3783 cancer patients and 2747 from the general population, Hinz and colleagues (2019) also found that cancer patients were more anxious but less depressed than the general population as measured by the HADS (Hinz et al., 2019). Cancer patients in the study had a mean age of 58 years, and 6.9% of the cohort fell in the 18-40 age group. Female cancer survivors in the 18-40 age group had the highest levels of anxiety (M=7.9; SD not reported) while women from the general population older than 71 had the highest levels of depression (M=6.6, SD not reported). (Hinz et al., 2019).

A younger age has been indicated as a factor in higher levels of anxiety and depression in adults with cancer, however many of the studies have few, if any, AYAs in their cohorts. The mean age for the above studies ranges from 50 – 69. There is no definition of a younger age. Further research is needed to clarify what a younger age means. The effect of anxiety and depression on the age of the AYA population has not been well examined and needs to be further explored.
Not all studies have found age to be a factor in anxiety and depression. A descriptive study of 211 Saudi Arabian patients with hematologic malignancies was conducted to determine the prevalence of and factors associated with anxiety and depression (Abuelgasim et al., 2016). The participants had an average age of 46. Anxiety and depression were measured using the generalized anxiety disorder 7 and the patient health questionnaire 9. Researchers found 46% of the patients had depression, 22% had anxiety, and 18% had both anxiety and depression (Abuelgasim et al., 2016). The only two factors the researchers found to influence anxiety and depression was a tense home life and co-morbidities (Abuelgasim et al., 2016). Neither age nor gender were found to be a factor in anxiety and depression (Abuelgasim et al., 2016).

In another study on the prevalence of anxiety and depression in 208 patients with AML and 200 age and gender matched controls, researchers found no relationship between anxiety and depression and age or gender (Ding et al., 2019). The participants had an average age of 48 and were fairly evenly divided between male and female. Anxiety and depression as measured by the HADS found that patients with AML had much higher levels of anxiety (M=7.4, SD=3.3) and depression (M=6.6, SD=3.0) than their peers (Anxiety M=4.7, SD 2.6, Depression M=4.2, SD=2.5). Over 50% of those with AML had elevated levels of anxiety (<8) while elevated levels were found in only 12% of the matched controls (Ding et al., 2019).

Peh and colleagues (2016) explored the mediating effects of hope on emotional regulation and anxiety and depression in 144 adults newly diagnosed with cancer. They found that higher hope was associated with lower levels of anxiety and depression.
There was no association found between anxiety and depression and age or gender (Peh et al., 2016).

The studies that did not find a relationship between age and anxiety and depression had smaller sample sizes than the studies that did detect a relationship between age and anxiety and depression. It could be that the sample sizes were too small to detect any differences, but the contradictory findings show that further investigation is warranted.

In a review of literature focusing on how age affects distress, anxiety and depression in AYAs with cancer, Lang and colleagues (2015) found 34 studies on topic. All of the studies found an association between a younger age and one of three factors of distress, anxiety and depression. The authors could not state that age was an independent risk factor for distress, anxiety, or depression, as there could be other factors influencing the relationship (Lang et al., 2015).

Salsman and colleagues (2014) examined the psychological adjustment of AYA survivors as compared to their age matched peers. They used three cohorts of AYA survivors based on length of time since the end of treatment. A group of 120 survivors 0-12 months after treatment, 102 survivors 12-24 months after treatment and 113 survivors 25-60 months after treatment were compared to 335 age, gender, education, and partner-matched peers. AYAs were found to have poorer physical health and emotional well-being than their peers, but higher levels of social well-being. No significant differences were found between cohorts. The AYA survivors were divided into three age groups 18-24, 25-29, 30-39 and found that 25-29 year group had poorer emotional and physical well-being compared to the other age groups. The 25-29 year
group were also found to have more anxiety and depression than the 30-39 year group (Salsman et al., 2014).

In a study of anxiety and depression in 551 AYAs with cancer in China, researchers found the prevalence of anxiety to be 75% and depression 90% (Xie et al., 2017). HADS scores found a mean of 12.16 (SD=2.94) on the HADS-A, 11.04 (SD=3.14) on the HADS-D, and 23.33 (SD=5.99) on the combined HADS global (HADS-G) score. AYAs between the ages of 21 to 25 had the highest levels of anxiety and depression.

While both studies in the AYA group support the finding in the adult studies that younger patients have higher levels of anxiety and depression, two different age groups within the AYA group were found to have higher levels of anxiety and depression (Salsman et al., 2014; Xie et al., 2017). More research is needed to determine if AYAs are at a higher risk for anxiety and depression based on their age and to determine what age constitutes a younger age. This study will explore the effect of age on hope, depression, and anxiety.

**Gender.** Gender is a multifaceted and evolving concept that includes cultural considerations, behaviors, and how the person sees themselves (Castleberry, 2019). While gender does not always conform to biological sex, the two terms are often used interchangeably (Frohard-Dourlent et al., 2017). Some adolescents and young adults do not identify themselves as belonging to only one gender, but most surveys and studies only offer two choices for gender – male or female (Castleberry, 2019; Frohard-Dourlent et al., 2017). The lack of options could lead to participants not wishing to participate in the research (Frohard-Dourlent et al., 2017). No studied could be found in AYAs with
cancer that offered gender options other than male and female. Participants need to be offered more choices to describe themselves to ensure patients aren't being marginalized due to their self-identified gender.

Gender is often collected as part of the demographic information of a study. It may be used simply to describe the study, but the participant's gender may influence the variable being studied. Studies of anxiety and depression in adults with cancer have found that females are more likely to have symptoms of anxiety and depression (Bergerot et al., 2018; Bergerot et al., 2015; Cardoso et al., 2016; Hasson-Ohayon et al., 2014; Inhestern et al., 2017; Jimenez-Fonseca et al., 2018; Lima et al., 2016; Linden et al., 2012; McCarthy et al., 2016; Mollerberg et al., 2019; Utne et al., 2010).

This is seen in the general population as well as the oncology population. In a large study of 20,000 healthy adults in the United States, women were found to have a higher rate of anxiety disorders than men (McLean et al., 2011).

Brazilian researchers, Bergerot and colleagues (2015, 2018) studied anxiety and depression in 137 adults with rare cancers (2018) and 104 adults with hematological cancers receiving chemotherapy (2015). They found high levels of distress, anxiety and depression in up to 50% of the participants (2015). In both studies, two of the variables associated with higher levels of anxiety and depression were younger patients and females (Bergerot et al., 2015, 2018).

Researchers exploring the prevalence of anxiety and depression in adults with cancer have found higher levels of anxiety and depression in women. In a study of 270 Portuguese newly diagnosed cancer patients, researchers found anxiety levels of 30% and depression at 24% (Cardoso et al., 2016). Females and those with more advanced
cancer had higher levels of both anxiety and depression (Cardoso et al., 2016). Jimenez-Fonseca and colleagues (2019) investigated factors associated with anxiety and depression in 600 Spanish newly diagnosed cancer patients. They found that anxiety levels at 49% and depression levels at 36%. Women and younger patients had higher levels of anxiety and depression (Jimenez-Fonseca et al., 2019).

Researchers in Brazil studied predictors for variables in anxiety and depression in 400 adult outpatient cancer patients (Lima et al., 2016). Anxiety and Depression disorders were found in 41% of the patients using a structured clinical interview to confirm the results of the patient health questionnaire and generalized anxiety disorder scale. Women and single people were found to have higher levels of anxiety and depression (Lima et al., 2016).

How each gender processes their diagnosis and cancer experience is shown to be different. As most of the studies only offered the gender options of male and female, more research is needed to discover how those who self-identify in another manner respond to a cancer diagnosis. This study will explore the effect of gender on hope, anxiety and depression. The demographic survey offers four options (male, female, non-binary, and transgender people) as well as other to explore the effects of hope, anxiety, and depression on those who identify as something other than male or female.

**Social Support.** Social support has been explored in adults and AYAs with cancer. Social support has been used as a coping mechanism by children, adolescents, and young adults with cancer. The AYAs reported that family, friends, and health care providers offered practical, emotional, material, and informational support at very critical
In a qualitative study of 70 young breast cancer survivors between the ages of 18 to 40, Snyder and Pearse (2010) identified a type of social support unique to the AYA age group – that of experiential support. This is support provided by someone the same age who has gone through the same experience and can provide first-hand knowledge of the process. Experiential support was valued even over other family members who had breast cancer. The young women wanted to hear from others their age undergoing the same experience rather than what their mothers or older family members had experienced (Snyder & Pearse, 2010).

This theme was echoed in several qualitative studies of AYA groups. A group of 20 Canadian AYA survivors also discussed the importance of being able to talk to peers with cancer (Tsangaris et al., 2014). Adolescents also value support from other teens with cancer (Kyngas et al., 2001; Ramini et al., 2008; Woodgate, 2006). In a study of 17 young adult cancer survivors, Zebrack, Mills, and Weitzman (2007) found that the need to talk to other AYAs with cancer was a highly ranked need. Young adults with cancer who participated in a two-day residential program ‘Find Your Sense of Tumour’ reported that being able to talk to others with cancer was a relief as they didn’t have to pretend or explain as they might have had to do with their other peers (Martins et al., 2017).

Exploring the sources of social support in adolescents with cancer, researchers found that adolescents perceived that the received social support from both peers and family and were satisfied with the level of support received (Breuer et al., 2017; Haluska et al., 2002). Parents, especially mothers, were perceived as more supportive than
peers and even other family members (McCarthy et al., 2016). Ritchie (2001) in a qualitative study of 45 adolescents between 12 to 18 also found the two sources of social support teens relied upon the most were family and friends. Mothers were the most frequently relied upon source, while peers were second, and fathers came in third (Ritchie, 2001). While young adults also find support in parents and friends, they also cite siblings, partners and spouses as sources of social support (Breuer et al., 2017; Iannarino et al., 2017; Kyngas et al., 2001; McDonnell et al., 2018). Epelman (2013) found that parents and health care workers were the primary sources of social support for adolescents and young adults with cancer. Some friends provided support, but some peers were scared away from their friendships by the cancer diagnosis (Breuer et al., 2017; Epelman, 2013; Iannarino et al., 2017).

Social support, especially the support of family and friends, is shown to be beneficial in AYAs with cancer. While support can be positive, other types of social support can be negative and potentially decrease the patient’s hope and outlook (Breuer et al., 2017; Iannarino et al., 2017).

Social support has been studied in conjunction with other variables. Social support was found to be positively correlated with levels of hope, increased quality of life, optimism, fighting spirit, post-traumatic growth and better mental health (Corey et al., 2008; Dougall et al., 2001; Ekim & Ocakçi, 2015; Trevino et al., 2013; Turner et al., 2018; Wells et al., 2009). Social support was found to have inverse relationships with uncertainty, psychological distress, insomnia, depressed mood, and anxiety in a descriptive study of 199 AYAs (Corey et al., 2008). In a longitudinal study of 212 adults undergoing a hematopoietic stem cell transplant, researchers found that higher levels of
social support correlated with less distress during the whole hematopoietic stem cell transplant process (Wells et al., 2009).

Social support is important to adolescents and young adult with cancer. It has been reported to help the AYA deal with the crisis of a cancer diagnosis. Social support and hope have been shown to be positively correlated. This study will explore how that relationship affects anxiety and depression in the AYA population.

**Type of Cancer and Length of Time since Diagnosis.** Type of cancer and length of time since diagnosis is often collected and used to describe the study populations. In a review of literature, researchers found that 30% of the studies reviewed were conducted with breast cancer patients highlighting the need for research into other types of cancer (Niedzwiedz et al., 2019).

Researchers have explored psychosocial factors such as hope, anxiety and depression in specific cancer groups such as patients with hematologic cancers (Abuelgasim et al., 2016; Bergerot et al., 2015; Ding et al., 2019; Kuba et al., 2019), breast cancer (Balsaneli & Grossi, 2016; Hasson-Ohayon et al., 2014; Naik et al., 2020; Park et al., 2018) and gynecological cancers (Hammer et al., 2013; Lui et al., 2017). While this provides insight for that patient population, it is not generalizable to the cancer population at large.

Researchers have also used larger and more diverse groups of cancer patients to explore psychosocial factors. In a study of over 10,000 adult cancer patients in Canada, researchers found that those with lung, gynecologic, and hematologic cancers experience more anxiety and depression than other types of cancer (Linden et al., 2012). In a study of young adult cancer patients in Germany, researchers found that
patients with gastrointestinal cancer had higher levels of anxiety while those with gynecologic cancer had higher levels of depression (Geue et al., 2019).

More research is needed to be conducted to determine if the type of cancer and length of time since diagnosis are factors in psychosocial concerns such as hope, anxiety, and depression.

**Mechanisms**

**Hope.** As a concept, hope has been studied in a variety of fields including theology, philosophy, psychology, psychiatry and nursing (Abu Sharour et al., 2014; Mesera, 2010; Miller, 2007; Nweze et al., 2013). Hope has been described as being essential to life and an important element in dealing with illness (Broadhurst & Harrington, 2016; Nweze et al., 2013). Hope has many usages in common language: as a noun, a verb, a name, and a place name. In Greek mythology, Pandora releases all the ills into the world; hope is all that is left in the jar to combat these evils (Littleton, 2005).

Dufault and Martocchio (1985) developed a conceptual model of hope, through their qualitative work with elderly cancer patients. Hope was conceptualized as having two spheres with six common dimensions. The two spheres of hope identified were generalized hope and particularized hope. Generalized hope refers to hope without a specific event or object in mind while the latter form of hope refers to hope for a specific event or object. Six dimensions of hope were identified: affective, cognitive, behavioral, affiliative, temporal, and contextual. The affective dimension focuses on sensations and emotions, and the cognitive dimension is the process a person uses to wish, imagine, learn, and interpret in relationship to hope. The actions one takes that are motivated by
Hope form the behavioral dimension. An individual’s social interactions and involvement with others, including family, friends, God, and pets make up the affiliative dimension. The temporal dimension is composed of one’s experiences of time concerning hopes and hoping. The final dimension is the contextual dimension or the life situation that surrounds hope. This model and definition of hope influenced the development of both the Herth Hope Index (Herth, 1992) and the Miller Hope Scale (Miller & Powers, 1988).

Hinds (1984, 1988, 2004) was one of the first researchers to study hope in adolescents with cancer using grounded theory to examine hope in both well adolescents and adolescents on a substance abuse unit. Twenty-five adolescents were interviewed using a semi-structure format to elicit descriptions of hope and hopefulness. Based on these interviews, hope was defined as “the degree to which an adolescent believes that a personal tomorrow exists” (p. 360). Hope was found to have four levels: forced effort, personal possibilities, expectation of a better tomorrow, and anticipation of a positive personal future. Hinds (1988) then introduced the concept of hopefulness which is defined as “the degree to which an adolescent possesses a comforting life-sustaining belief that a personal and positive future exists” (p. 83). Adolescent hopefulness was found to have the same four levels as hope. In addition, a distinction was made between hopefulness and wishing. Hopefulness acknowledges the difficulties in the present situation and recognition of the effort required to change the present circumstances. Wishing contains an element of denial of the seriousness of the situation and does not have a strong element of reality.

Hope has been conceptualized and defined in several ways. Aspects of hope that are common to all conceptualizations include the positive attributes of the person, the
reliance on inner resources and the effects of physical functioning. Studies also found hope to have a temporal dimension (Dufault & Martocchio, 1985; Hinds, 1984; Nweze et al., 2013; Piccinelli et al., 2015). The need for setting realistic goals, meaning in life, spirituality, and the importance of social relationships were common themes in most of the definitions of hope (Hammer et al., 2013; Juvakka & Kylma, 2009; Mattioli et al., 2008; Proserpio et al., 2015; Saleh & Brockopp, 2001). The definitions and attributes derived in the above studies confirm the definitions and attributes in the definitions by Dufault and Martocchio (1985) and Hinds (1984, 1988).

**Influences on hope in oncology patients.** Hope influences all phases of the cancer diagnosis. High levels of hope have been found in those newly diagnosed (Duggleby et al., 2013; Hammer at al., 2013; Rostoen & Wiklund, 2000) as well as those with advanced disease (Broadhurst & Harrington, 2016; Fischer et al., 2018; Mollerberg et al., 2019) and even terminally ill patients (Broadhurst & Harrington, 2016; Buckley & Herth, 2004; Davis et al., 2017).

Some of the factors that have been found to influence hope include religious faith, family and social support, mood changes and self-esteem (Acquaye et al., 2016; Balsanelli & Grossi, 2016; Bao et al., 2019; Hasson-Ohayon et al., 2014; Mattioli et al., 2008; Proserpio et al., 2015; Vellone et al., 2006). Factors such as age, gender and marital status have been found to both influence hope and have no effect on hope (Acquaye et la., 2016; Davis et al., 2017; Vellone et al., 2006).

In a study of hope and mood changes in 82 adults with primary CNS tumors, researchers found that those with higher levels of hope had lower levels of mood disturbances (Acquaye et la., 2016). Lower levels of hope were associated with those
who were not married, had a prior history of depression, and a lower performance score as measured by the Karnofsky Performance Score. Patients who had a recurrence of their cancer had lower hope scores than those who had not relapsed (Acquaye et al., 2016).

A study of 480 Chinese women with cervical cancer examined the intrinsic and extrinsic factors related to hope and psychological distress while undergoing radiation therapy (Li et al., 2017). Most of the patients had middle to high levels of hope, with 3% of the participants having a low level of hope. Researchers found that older, married women with a higher level of education and lower disease stage had higher levels of hope. Pain was also significantly associated with hope. Women with higher hope had lower levels of pain, while women with higher levels of pain had lower levels of hope (Li et al., 2017).

Davis and colleagues (2017) conducted a study on hope, symptoms, and palliative care with 197 adults with incurable cancer. The hope scores of the participants had a mean of 40 out of 48, even in the face of advanced disease. The researchers explored the effects of symptoms burden, pain, cancer site, length of time since diagnosis, age, gender, and marital status on levels of hope (Davis et al., 2019). Age, gender, marital status, and length of time since diagnosis were all found to have no effect on levels of hope. In a univariable analysis, anxiety and depression were found to inversely correlate with anxiety and depression, but in a multi-variable analysis, only depression was correlated with depression (Davis et al., 2017).

Balsanelli and Grossi (2016) explored predictors of hope in 122 Brazilian women with breast cancer. In a longitudinal study, the researchers explored hope, anxiety and
depression, coping, fatigue, religiosity, self-esteem, performance scores and pain during the first round of chemotherapy and the end of chemotherapy. The average length of time between the two points in time was 4.2 months. The women had a mean age of 50 years and most were married and practicing Catholics (Balsanelli & Grossi, 2016). Hope increased throughout treatment and was found to be associated with Karnofsky Performance Status scores, delay in starting treatment, depression, self-esteem and pain. Religiosity, coping, and fatigue were not associated with hope (Balsanelli & Grossi, 2016).

Researchers in Italy explored the determinants of hope in 320 adults with cancer (Proserpio et al., 2015). In a cross-sectional study, all of the participants were recruited and completed the study on the same day. Participants were drawn from both in and outpatient units with a variety of diseases. The researchers developed a questionnaire to address medical, psychological, spiritual, and religious content. Hope was found to be associated with women, limited formal education, and a high level of religiosity. In a univariate analysis hope was associated with support from others, those who didn’t feel like they were a burden, who trusted others and felt trust in others ability to help them and those who had trust in religion (Peroserpio et al., 2015). In a multivariate analysis, a stronger sense of hope was associated with the care and support of others. Researchers noted that 20% of the participants reported little or no hope (Peroserpio et al., 2015). There was no further information given specifically on the participants with little or no hope.

Researchers explored the relationship between hope and resilience in 54 adults with advanced, metastatic colorectal cancer (Solano et al., 2016). There was a stronger
relationship between hope and resilience, but no relationship was found between age, gender, or social support. Almost half of the study had depressive symptoms, and those with depressive symptoms had lower levels of hope and resilience (Solano et al., 2016).

Factors shown in studies of adults with cancer to affect hope include pain, age, marital status, physical function and social support, but the results are contradictory (Acquaye et al., 2016; Balsanelli & Grossi, 2016; Bao et al., 2019; Davis et al., 2017; Hasson-Ohayon et al., 2014; Li et al., 2017; Peroserpio et al., 2015). Factors associated with hope in the AYAs have not been clearly defined; more research is needed to clarify the factors associated with hope.

A longitudinal study of hope, distress, and quality of life was conducted in 37 AYAs newly diagnosed with cancer (Rosenberg et al., 2018). Researchers wanted to determine what was more predictive of later quality of life hope alone, distress alone, or a composite of hope/distress score. Data was collected at baseline and 3 to 6 months later. Higher levels of hope were associated with higher levels of quality of life. Early distress predicted later distress and early hope predicted later hope. Distress and hope alone didn’t predict quality of life (Rosenberg et al., 2018).

Researchers investigated the relationship between hope, anxiety, and quality of life in 211 children and adolescents with cancer (Martins et al., 2018). The participants ranged in age from 8 to 19 and were divided into two groups, with 97 on treatment and 114 off treatment. Levels of hope and quality of life were not significantly different between the two groups. Hope was negatively correlated with anxiety and positively correlated with quality of life in both groups of children. The association between anxiety and quality of life was found to be mediated by clinical group (Martins et al., 2018).
Hopefulness in adolescents has been examined in relationship to several other variables including: age, gender, symptom distress, self-esteem, social support and spiritual well-being (Hinds, 2004). High levels of hope were found in the adolescents with cancer (Cantrell & Lupinacci, 2004, Hinds, 2004, Hinds et al., 1988) and one study found the cancer patients had higher levels of hope than the healthy control group (Cantrell & Lupinacci, 2004). The contradiction about age and gender was found in adolescents as well. Hendricks-Ferguson (2006) found girls had higher levels of hope than boys while other studies found no difference in hope scores based on age and gender (Cantrell & Lupinacci, 2004; Hinds et al., 1988).

Due to the small number of studies conducted in the adolescent age group and the lack of studies that explore hope in the AYA age group, additional research needs to be conducted in this age group. The factors that influence or foster hope in older adults and younger children may not be the same factors that influence hope in the AYA group.

The relationship between demographic or disease characteristics with hope was not explored in the studies with the AYA population. This need to be further explored to determine what patients may be at risk for lower levels of hope.

In addition to the quantitative studies exploring hope in conjunction with other variables, hope has been studied qualitatively as well. Hammer and colleagues (2013) examined hope with women diagnosed with gynecological cancer on the day of diagnosis and asked them to draw their representation of hope. The women drew images of inner strength, religious or spiritual strength, and their relationship with family and friends as a way of describing their hope. Reynolds (2008) found similar themes in 12 adults with advanced cancer. They described religious support, strength from within,
and family and friends as supports for hope (Reynolds, 2008). Mattioli and colleagues (2008) explored hope in 14 adults undergoing cancer treatment and found family and social support were important sources of hope.

The qualitative studies echo the results of the quantitative studies in that hope and social support are closely related. Family and friends are an important source of social support. The relationship between hope, social support, and anxiety and depression needs to be further examined to determine the role hope plays.

**Hope as a Mediator.** Hope has been explored as a mediating variable in several studies. Peh and colleagues (2017) examined the mediating role of hope between emotional regulation and depression in 144 adults newly diagnosed with cancer patients from Singapore. The researchers were interested in two types of emotional regulation. Emotional reappraisal is the “process of changing the way one thinks about an emotion eliciting situation before the emotion is fully elicited” (Peh et al., 2017, p 1192). Emotional suppression is the process of stopping the expression of that emotion once it is fully elicited (Peh et al., 2017). Rates of anxiety and depression in the sample were 39.6% and 25% respectively. Researchers found that physical symptom severity was related to both anxiety and depression. None of the other personal variables including age, gender and marital status or clinical variables including type of cancer, stage of cancer and length of time since diagnosis, were found to be associated with anxiety or depression (Peh et al., 2017). Higher reappraisal was associated with lower levels of anxiety and depression, whereas higher emotional suppression was associated with higher levels of anxiety and depression. Higher hope was found to be inversely related to anxiety and depression and positively related to emotional reappraisal (Peh et al.,
2017). Results of a path analysis conducted by the researchers suggested that hope mediates the relationship between reappraisal and anxiety/depression (Peh et al., 2017).

Bao and colleagues (2019) explored the relationship between hope, anxiety and depression in 269 adult Chinese patients with CNS tumors. The average age of the participants was 50 years old. The researchers found that less social support was associated with less hope and more depression. In contrast, higher levels of social support were associated with higher levels of hope and less depression. Hope was found to partially mediate the relationship between social support and depression.

In a study of 150 Israeli women with breast cancer and their spouses, researchers explored hope and social support utilization (Hasson-Ohayon et al., 2014). The women and spouses were divided into four groups based on age – younger women (54 and under), their spouses, older women (55 and over) and their spouses. Depression was found to be lower in the older patients and their spouses, while the support of family and friends was higher in the older patients and spouses (Hasson-Ohayon et al., 2014). In younger patients, the relationship between hope and social support as well as social support and depression were significant, but not the relationship between hope and depression. In older patients, the relationship between hope and social support and hope and depression were significant (Hasson-Ohayon et al., 2014). The researchers found that in the older patient group, the relationship between social support and depression was mediated by hope. The younger spouses had a different pattern in that there was a relationship between hope and social support, social support and depression, and hope and depression (Hasson-Ohayon et al., 2014).
Overall, the levels of depression were lower and perceived social support was higher in older patients and their spouses. Levels of hope were not significantly different between groups, but hope was influenced by social support (Hasson-Ohayon et al., 2014).

Researchers exploring anxiety and depression in 198 women with ovarian cancer found 47% of the participants had symptoms of depression and 51% had symptoms of anxiety (Liu et al., 2017). Women with lower levels of education, lower income levels, and a higher stage cancer had higher levels of anxiety and depression. Symptoms of anxiety and depression were inversely associated with levels of hope and resilience, while perceived stress was positively associated with anxiety and depression (Liu et al., 2017). The researcher found that hope had a partially mediating effect on perceived stress and symptoms of anxiety (Liu et al., 2017).

Hope has been found to mediate or partially mediate relationships with anxiety and depression, perceived stress and anxiety, as well as social support and depression. Still, the mechanism by which hope may mediate anxiety and depression in AYAs with cancer has not been fully explored. Age, gender, and social support have all been identified in the literature as factors that influence hope. The disease factors such as type of cancer and length of time since diagnosis have not been identified as factors in hope. This study will explore the relationship between personal and disease characteristics and hope.

**Outputs**

**Anxiety and Depression.** Anxiety and depression are often seen in those with a cancer diagnosis. Studies have found the prevalence of anxiety to range from 9 to 49% and the prevalence of depression ranges from 10 to 50% of the participants. Two
factors that have overwhelmingly been shown to be associated with higher levels of anxiety and depression are female gender and a younger age (Bergerot et al., 2018; Bergerot et al., 2015; Cardoso et al., 2016; Inhestern et al., 2017; Jimenez-Fonseca et al., 2018; Kaul et al., 2017; Kuba et al., 2019; Lang et al., 2015; Lang et al., 2018; Lima et al., 2016; Linden et al., 2012; McCarthy et al., 2016; Mollerberg et al., 2019; Naik et al., 2020; Utne et al., 2010; Yang et al., 2017).

Researchers studied predictors of anxiety and depression, focusing on hope and optimism in 84 adults with advanced cancer (Fischer et al., 2018). The participants were found to have higher levels of hope and optimism and average levels of anxiety and depression (Fischer et al., 2018). Higher levels of optimism were associated with lower levels of anxiety while higher levels of hope were associated with lower levels of depression (Fischer et al., 2018).

A longitudinal study of the changes in anxiety and depression was conducted in 548 adult Brazilian cancer patients receiving chemotherapy (Bergerot et al., 2017). Data was collected on the first day of chemotherapy (T1), the planned midway point (T2) and on the last day of chemotherapy (T3). On the first day of chemotherapy, 37% of patients were found to have symptoms of anxiety, with 17% having symptoms of depression. Levels of anxiety were significantly lower at T2 and T3 while levels of depression were significantly lower at T3. At T3 levels of anxiety were 4.6% while levels of depression were 5.1% showing a decrease in anxiety and depression throughout treatment (Bergerot et al., 2017). The overall mean age for the participants was 54 years, and the researchers divided the sample into four age groups – less than 40, 40-55, 56-70, and greater than 70. Patients in the 45-55 age group were found to have higher levels of
anxiety than the over 70 group. Females were found to have higher levels of physical, emotional, and family problems than males (Bergerot et al., 2017). Time since diagnosis was found to be a factor in anxiety and depression. The youngest age group of under 40 comprised 18% of the sample, but the researchers did not indicate any findings particular the AYA age group (Bergerot, 2017).

German researchers studied rates of anxiety and depression in 1529 adults with cancer compared to 2037 participants from the general population (Hinz et al., 2010). Anxiety and depression were both found to be higher in cancer patients than the general population. Younger cancer patients between the ages of 18 to 60 were found to have significantly higher levels of anxiety and depression than both the general population and older patients. Women were found to be more anxious and more distressed than men (Hinz et al., 2010). Participants under the age of 18 comprised 6% of the population, but the factors in anxiety and depression in this age group were not explicitly mentioned (Hinz et al., 2010). The younger age of under 60 identified by the researchers, is so large a range that it is not helpful when talking about AYAs.

In the AYA population, researchers have explored mental or emotional distress rather than anxiety and depression (Kaul et al., 2017; McCarthy et al., 2016; Sodergren et al., 2018; Zebreck et al., 2014). In a study of 196 Australian AYA patients and their parents, females and those at a younger age were found to have more psychological distress. Social support, especially from family, was found to be associated with lower levels of anxiety and depression (McCarthy et al., 2016).

Salsman and colleagues (2014) explored physical, emotional, and social health in YA (young adult) cancer survivors and age-matched peers. Anxiety and depression
scores were significantly higher in the 25-29 year age group as compared to the 30-39 year age group. YA cancer survivors reported poorer physical health and emotional well-being than their age-matched peers, but they reported higher social well-being.

A study into mental distress in 875 AYA cancer survivors found those diagnosed at a younger age were more likely to have mental distress. Those who were married had less stress than those who were single, widowed, or divorced (Kaul et al., 2017).

Studies in the general population found that women and younger people were at risk for higher anxiety depression than males and older people (Essau et al., 2010; McLean et al., 2011). A cancer diagnosis may simply amplify an already existing trend of women and younger people being at higher risk for anxiety and depression.

**Summary**

A cancer diagnosis during adolescence and young adulthood can be a crisis leading to higher levels of anxiety and depression. Anxiety and depression are markedly higher in women and younger people but can be mitigated by social support and hope. Social support has been found to be associated with increased levels of hope, as well as decreased levels of anxiety and depression. Hope is found in all phases of cancer treatment from diagnosis to treatment to palliative care. Higher levels of hope are associated with lower levels of anxiety and depression.

The mechanism by which hope influences the relationships between personal and disease level factors with anxiety and depression in the AYA group has not been explored. The relationship needs to be explored in the AYA population.
Chapter Three

Methods

Chapter three presents the methods that will be used in this study. Included in this chapter are the study aims, study design, sample, setting, power analysis, data collection instruments, procedures, and the plan for data analysis.

Study Aims

Aim 1) To examine the relationships between age, gender, social support, cancer type and length of time since diagnosis, hope, anxiety and depression in adolescents and young adults with cancer.

Aim 2) To evaluate the mechanistic effect of hope on the relationship between the personal characteristics of age, gender, social support; the disease characteristics of cancer type and length of time since diagnosis with anxiety and depression in AYA with cancer.

Study Design

Variables and planned measures. The input or independent variables for this study are age, gender, social support, type of cancer, and length of time since diagnosis. The proposed mechanism for change is hope. The output or dependent variables are anxiety and depression.
There are four instruments to be used: demographic tool, the Multidimensional Scale of Perceived Social Support, the Herth Hope Index, and Hospital Anxiety and Depression Scale.

**Demographic Tool.** An investigator-developed demographic tool will be used to capture data needed for characterizing the study sample, and the independent variables of the study that may be associated with hope in AYAs with cancer. The demographic data to be collected includes age, self-identified gender, type of cancer, and length of time since diagnosis. To better describe the sample, the demographic tool will obtain data concerning the stage of cancer and the type of treatment the participant received, educational level, employment status, and marital status and if they have children.

**Multidimensional Scale of Perceived Social Support.** The Multidimensional Scale of Perceived Social Support (MSPSS) is a 12 item Likert-type scale that measures the perceived support from family, friends, and significant others. The scale includes items such as “My family tries to help me”, “There is a special person with whom I can share my joys and sorrows”, and “I can talk about my problems with my friends.” Each item is rated on a scale from 1 very strongly disagree to 7 very strongly agree. Scores can be calculated for the three subscales of family, friends, and significant other or a total score for perceived social support is calculated by summing the items. The total score for each subscale can range from 4 to 28, and the total instrument score can range from 12 to 84, with a higher score indicating higher perceived social support (Dalhem et al., 1991; Hardan-Khalil & Mayo, 2015; Zimet et al., 1988). It can be helpful to divide the responses into groupings. One suggested grouping
is 12-35 low perceived social support, 36-60 moderate perceived social support, and 61-84 high perceived social support (Greenspace Mental Health, 2019)

The MSPSS has been tested in college students between the ages of 18 – 51, urban adolescents, and young adults in the community (Conty-Mitchell & Zimet, 2000; Dalhem, Zimet, & Walker, 1991; Winefield, Winefield, & Tiggemann, 1992; Zimet, Dalhem, Zimet, & Farley, 1988), and was found to be a reliable and valid measure of perceived social support in these populations. Internal consistency for the total scale was demonstrated by a Cronbach’s alpha of .91. Reliability for the subscales of family, friends, and significant others was shown by Cronbach’s alphas of .90, .94, and .95 for each subscale respectively (Dahlem, Zimet, & Walker, 1991). Construct reliability was shown with inverse correlations between social support and anxiety (r=-0.18, p<0.01) and depression (r= -24, p<0.01) (Dambi et al., 2018). Test-retest reliability was established in college students who were retested after 2 to 3 months with a test-retest reliability score of (r=0.85) which is considered good reliability (Zimet et al., 1988). The MSPSS has been used in the AYA population (McCarthy et al., 2016) and was found to have a high internal consistency with a Cronbach’s alpha of 0.94 in that study. In this study, the Cronbach’s alpha was 0.89 for the total scale, 0.91 for the significant other subscale, 0.90 for the family subscale, and 0.92 for the friends subscale.

**Herth Hope Index.** The Herth Hope Index (HHI) is a 12 item Likert-type scale that was designed to assess hope in a clinical setting. The HHI has been tested in those acutely ill, chronically ill, as well as terminally ill in a variety of settings: inpatient, outpatient, rural, suburban, and urban (Herth, 1992). The HHI has been tested in adults
aged 22 – 92, in an adolescent population, and again in adults with cancer. It has been translated into at least five other languages (Herth, 2000)

The HHI has been tested in adolescents and young adults with cancer. Researchers conducted two studies, one with 74 newly diagnosed AYAs and the other with 127 AYA at any stage of treatment, including some long term survivors. The participants ranged in age from 10 to 26 years. Cronbach’s alpha for the two groups were reported as .78 for the newly diagnosed AYAs and .84 for the AYAs at any treatment point (Phillips-Salimi et al., 2007).

The instrument includes statements such as “I believe that each day has potential” and the subjects are asked to choose from strongly agree, (4) agree, (3) disagree, (2) and strongly disagree (1). Scores on the HHI can range from 12 – 48, with a higher score indicating a higher level of hope. It takes 1 to 4 minutes to complete this scale (Herth, 1992). The HHI is a shortened version of the longer Herth Hope Scale (HHS). The HHS was developed using Dufault and Martocchio’s Model of Hope (1985). The original six dimensions of hope in the model are affective, cognitive, behavioral, affiliative, temporal, and contextual. For the HHS the dimensions were combined into three factors – cognitive-temporal, affective-behavioral, and affiliative-contextual (Herth, 1992). The HHS was tested in healthy adults, adults with cancer, and elderly adults. A Cronbach alpha coefficient was obtained for the entire scale of 0.74 to 0.94 (Herth, 1992). In this study, the Cronbach’s alpha was 0.87.

Construct validity was assessed during the initial construction of the HHI. The factor analysis identified three factors that paralleled the factors from the HHS with eigenvalues greater than one: temporality and future, positive readiness and
expectancy, and interconnectedness. Each of the twelve items of the HHI load onto one of the three factors identified (Herth, 1992; Phillips-Salimi et al., 2007).

The validity of the HHI has been established through face validity, concurrent criterion validity was established by correlating the HHI to the HHS (r=0.92), the Existential Well Being Scale (0.84), and the Nowotny Hope Scale (r= 0.81), and divergent validity was established correlating the HHI to the Hopelessness Scale (r=-0.69). Instrument reliability of the HHI was reported by Herth (1992) and a Cronbach alpha coefficient of 0.97 was achieved. There was a strong correlation of HHI test scores when tested for test-retest reliability using a three-week interval (Herth, 1992).

The Hospital Anxiety and Depression Scale (HADS) is a 14-item self-administered questionnaire that has 7 anxiety items and 7 depression items which can be utilized as individual scales of anxiety and depression or as a combined scale of global anxiety and depression (Unseld et al., 2019). It was designed to be used in a non-psychiatric setting and has been used in clinical settings, and has been used extensively in the oncology population (Bjelland et al., 2002; Osborne et al., 2004; Unseld et al., 2019; Zigmond & Snaith, 1983). The HADS has been used in AYAs with cancer as well as long term survivors of childhood, adolescent and young adult cancer (Fisher et al., 2015; Geue et al., 2019; Inhestern et al., 2017; Park et al., 2017; van der Geest et al., 2013; Xie et al., 2019). The items are scored 0 to 3. An example of an anxiety item is ‘I get a sort of frightened feeling like ‘butterflies’ in the stomach’ and an example of a depression item is ‘I still enjoy the things I used to enjoy’. The scale does not ask about physical symptoms to avoid any false positives (Norton et al., 2013). The total for each subscale is obtained by adding the scores together. Each subscale can
range from 0 to 21. The suggested ranges are 0-7 = normal, 8-10 is a borderline case, and 11-21 is abnormal. For using the global score, the two subscales are added together with a range from 0 to 42. The suggested ranges are 0-14 = normal, 15-20 is borderline, and 22-42 is abnormal (Unseld et al., 2019).

The HADs has been found to have good internal consistency with reported Cronbach’s $\alpha$ between 0.8 and 0.9 (Roberts et al., 2001). In this study, the Cronbach’s alpha was 0.78 for the global, combined score, with a Cronbach’s alpha of 0.66 for the depression subscale and 0.75 for the anxiety subscale.

The test-retest scores were reported to be 0.89 for the anxiety subscale, 0.90 for the depression subscale, and 0.91 for the total scale after three weeks (Roberts et al., 2001). When comparing the two scales, researchers have reported a higher than expected correlation between the two subscales (0.63) (Roberts et al., 2001). To better explore the relationship between the two subscales, researchers conducted a meta-analysis of the data from 28 previously published studies (Norton et al., 2013). Ten different models were developed include two, three and four factor groupings. The model recommended was using a global score with a bifactor model (Norton et al., 2013; Roberts et al., 2001). As the HADS is not meant to diagnosis anxiety and depression, the use of a global score ranging between 0 to 42 is appropriate to use when describing the combined scores of anxiety and depression (Norton et al., 2013).
Procedures

Study Design

This is a cross-sectional study using a convenience sample of 63 adolescents and young adults with cancer who were recruited online through social media (FaceBook and Instagram) supporting the AYA cancer group.

Sample and Setting

A convenience sample of 63 adolescents and young adults between the ages 18 to 30 years who are either under treatment for cancer or within 5 years of diagnosis will be recruited online through an IRB approved flyer placed on Facebook pages and Instagram feeds of groups that support AYAs with cancer.

Inclusion/Exclusion Criteria

The inclusion criteria are: 1) male and female AYAs with any cancer diagnosis (age between 18 to 30 years); 2) currently undergoing any classification of anti-neoplastic therapy or who have had anti-neoplastic treatment within the past five years; and 3) the ability to read and write English. Exclusion criteria include 1) patients currently enrolled in hospice; 2) diagnosed with a terminal or life-limiting illness.

Protection of Human Subjects

This online study used questionnaires available in one form through Qualtrics Survey Software. Participants were be recruited through an institutional review board (IRB) approved flyer placed on the social media of groups that support AYAs with cancer. Permission to advertise the study will be sought from support groups that cater to the age group in question. The study was approved by the IRB for the protection of
human subjects at the University of South Florida (USF) and given the USF IRB #000646.

IRB-approved flyers describing the study were posted on the Facebook pages and Instagram feeds of groups that support AYAs with cancer. By clicking on a link in the flyer, potential participants were taken to the study documents. The first page contains three screening questions to ensure the participants meet the inclusion criteria. If the participant did not meet the study criteria, they were unable to progress onto the study. Instead, a second screen would be displayed informing the potential participant of study ineligibility and thanking them for their interest. Once study eligibility is confirmed, an informed consent explaining the study purpose, risks and benefits, and contact information of both the IRB and the PI is displayed. Consent was then provided by the participant clicking on the box to agree to participate. In this study, no protected health information was gathered during this study. AYAs who did not wish to participate could simply leave the website. A Qualtrics survey was accessible that contained all of the instruments related to the study, with a total of 58 questions consisting of the demographic form, Multidimensional Scale of Perceived Social Support, the Herth Hope Index, and the Hospital Anxiety and Depression Scale. Data from the website demonstrated that it took an average of 7.9 minutes (range 2 minutes 37 seconds to 45 minutes 32 seconds) for participants to complete the surveys.

Once the participant completed the instrument survey, the website was exited. If the participant did not wish to complete the study, they could exit at any time. The accompanying data would be excluded from the database. The PI accessed the data from the Qualtrics survey from a password-protected computer in the PIs home office.
The data was placed in an Excel spreadsheet for tracking purposes. Data was scanned for outliers and incomplete data, and those entries were removed. Recruitment and data collection was continued until three weeks passed without gaining any new participants. The flyer and website for the surveys were then be deactivated.

**Recruitment**

Participants were recruited through social media platforms using Facebook or Instagram. Permission to advertise the study was sought from cancer support groups that cater to AYAs in the age group appropriate to this study. Facebook pages of groups that support AYAs with cancer, including Stupid Cancer, the Leukemia and Lymphoma Society, Young Adult Cancer Canada, Young Adult Cancer Connection, and Breast Cancer Now were used as a means of recruitment. A flyer describing the study with a link was placed on Facebook pages and Instagram feeds once permission from the organization was granted. A link to the study was embedded in the flyer.

IRB-approved flyers describing the study were posted on at least 10 websites and shared via Facebook and Instagram.

**Sampling Procedure**

The study convenience sample consisted of self-identified AYAs with cancer who met eligibility criteria and agreed to participate in the study. The sample was recruited online through social media platforms, and participants were directed to answer three screening questions before preceding to the survey to ensure that participants meet the criteria for the study.
Power Analysis

A G*power a priori power analysis was conducted using variables named in Aims 1 and 2: age, gender, social support, type of cancer, length of time since diagnosis, hope, anxiety and depression with a medium effect size and an $\alpha$ of 0.05, estimates that the sample size should be at least 75 subjects (Faul et al., 2009). A series of one-tailed t-tests will be performed to determine any relationship between the independent variables, the mechanistic variable, and the outcome variables. The t-tests will be one tailed as the relationships are expected to go in only one direction. A medium effect is anticipated between hope and anxiety and depression as well as the relationship between social support and hope and social support and anxiety and depression. A small effect is anticipated on the relationship between the type of cancer and length of time since diagnosis. To calculate a mediating/moderating model with a medium effect size, the sample size should be at least 75 subjects (Baron & Kenny, 1986; Hertzog, 2018).

Data Integrity and Management.

Qualtrics provides secure server access that has high-end firewalls and is scanned regularly for any irregularities. Transport Layer Security encryption is used by Qualtrics to transmit all data. No personal identifying information was revealed to the researcher, making the data is HIPPA compliant. The de-identified information was then downloaded by the researcher and stored in a password-protected computer in the researcher’s home office.

The downloaded data was imported into an SPSS database for analysis. Each submission was checked for missing data by the study PI. If any of the demographic
data was missing or any of the tools were not completed, the submission was not included in the study.

**Data Analysis Plan for Study Aims**

All analyses were performed using SPSS version 26 (Armonk, NY) with an a priori $\alpha = 0.05$ to determine significance. Descriptive statistics including frequencies, proportions, mean, range and standard deviation will be used to characterize the sample and variables studied. The SPSS PROCESS Macro version 3.5 (Hayes, 2018) will be used to examine the mediation model.

Aim 1) To examine the relationships between age, gender, perceived social support, cancer type and length of time since diagnosis, hope anxiety and depression in adolescents and young adults with cancer.

To address this aim, individual scores for perceived social support scores, hope and anxiety and depression were calculated. The anxiety and depression scores were calculated and classified as normal, borderline, and abnormal per the HADS instrument instructions. A global anxiety/depression score was also calculated by adding the sum of the two subscales. The Pearson’s correlation coefficients were calculated between the levels of social support and hope as well as the levels of hope and anxiety and depression. The composition of the sample precluded any testing for gender differences, as the sample contained only 86% (n=9) males. There was no significant difference in the independent, moderating, and dependent variables based on those on and off therapy or those with hematological cancer versus solid tumors.

Aim 2) To evaluate the mechanistic effect of hope on the relationship between the personal characteristics of age, gender, perceived social support; the disease
characteristics of cancer type and length of time since diagnosis with anxiety and depression in AYA with cancer.

A mediating variable is one that makes the difference in the relationship between the independent variable and the dependent (Baron & Kenny, 1986; Liu & Ulrich, 2016; MacKinnon et al., 2007). As discussed in the review of literature, hope has been identified as a potential mediator between social support and depressive symptoms (Bao et al., 2019; Hasson-Ohayon et al., 2014).

In this study, the relationship between independent variables (age, gender, type of cancer, length of time since diagnosis, and perceived social support) the mechanistic variable (hope) and the dependent variable (anxiety and depression) was explored. The relationship between age, gender, type of cancer, and length of time since diagnosis with the variable of hope, anxiety and depression were not significant. They were not included in the regression analysis. If any of the variables are not determined to be significant, they will not be included in the regression analysis.

A series of regression analysis were carried out using the PROCESS Macro (Hayes, 2018) to determine if hope is a mediating variable in the study. First, a regression analysis was performed between the independent variables of perceived social support and the variable of hope. Second, a regression analysis was performed between perceived social support and the dependent variable of global anxiety/depression. Third, a regression analysis will be performed between hope and the dependent variable of global anxiety/depression. Lastly, a regression analysis will be performed with the independent variable, hope and the dependent variable of global anxiety/depression. The series of regression analysis was also performed between
perceived social support, hope, and anxiety and depression separately to determine which model is most appropriate.

The effect of the independent variable on the dependent variable should be less than the effect of the mediating variable on the dependent variable if mediation is present (Baron & Kenny, 1986). In a case of perfect mediation, the independent variable no longer has any effect on the dependent variable; it is the mediating variable that causes the effect (Baron & Kenny, 1986). As there may be more than one mediating variable, variables are often considered partially mediating (Baron & Kenny, 1986).

The effect of the independent variable on the mediating variable while controlling for the dependent variable must be significant, and the direct effect of the independent variable on the dependent variable adjusted for the mediator must not be significant (Baron & Kenny, 1986; Fritz & MacKinnon, 2007). The amount of mediation is called the indirect effect and this indirect effect should be tested. A test of joint significance should be done to ensure that the variables (i.e. social support and hope) are not too closely correlated. The variables should not be too closely correlated indicating multicollinearity, but if the relationship is not significant, those variables can be dropped from future calculations (Fritz & MacKinnon, 2007). An additional test of indirect effect is bootstrapping. The PROCESS Macro includes the bootstrapping method in calculating results. This involves drawing a sample from the original data and replacing the n and resampling the data many thousands of times. Indirect effect and a sampling distribution are calculated from each sample (Fritz & MacKinnon, 2007). The indirect effect and the confidence interval were calculated to determine if the relationship between the independent variables and anxiety and depression are partially mediated by hope.
A path model was generated from the results of the regression analysis. A path model is a visual representation of the relationship between all of the variables. Figure 2 shows a potential path model for this study. The relationship on path a should be significant as should the relationship on path b. The relationship depicted on path c should be an indirect or mediated relationship.

Figure 2.

*Predicted path model of the Mediating effect of Hope on Personal and Disease Characteristics and Anxiety and Depression*
Chapter Four

Results

This chapter presents the results of the study. First, the demographic characteristics and disease characteristics of the participants are presented. Social support, hope, and global anxiety and depression scores are discussed, followed by the answers to the research questions.

Sample Characteristics

This study was conducted from May to August 2020, online using FaceBook, Instagram, and other social media sites of groups that support AYAs with cancer. The link to the study was accessed 147 times with 63 people (43%) completing the study. Of those who didn’t complete the study, 35 didn’t meet the inclusion criteria, 33 met the criteria but only completed the screening questions, eight completed part of the study, and eight accessed the study without completing anything including the screening. On average, it took 7.9 minutes (SD=6.4) to complete the study with a low of 2 minutes and 37 seconds and a high of 45 minutes and 32 seconds.

The participants in this study (n= 63) were predominantly non-Hispanic, white n=53 (85%). The average age of the participants was 24 years (SD=4.4), ranging from 18 to 30 years old. Most of the participants were female n= 54 (86%) and single n=43 (68%) without children n=58 (92%). Many of the participants worked either full or part-time n=26 (41%) while others were students n=17 (27%), unemployed n=11(17%) or on medical leave n=5 (8%). The highest level of education for just over half of the
participants was college or some college n=32 (51%), followed by high school/technical school n=17(27%), and graduate school n=14 (22%).

A majority of the participants self-identified as Christian n=34 (54%) which included Catholics (n=12), Protestants (n=2), Baptists (1), and Mormon (n=1); five of the participants were Jewish, and the remaining participants (n=24) did not consider themselves religious. Many of the participants did not attend religious services (n=25), however, among those who attended services, most attended services at least twice a year (n=19), once a week (n=8), once or twice a month (n=6), or more than once a week (n=5). This is shown in Table 1.

As this study was conducted online, the participants came from a variety of countries. A majority of the participants came from the United States n=46 (73%), while others came from Europe n=5 (8%), Canada n=3 (5%), Australia/New Zealand n=3 (5%), the Caribbean n=2 (3%), and Israel n=1 (2%). Participants from the United States came from 18 different states the most common being New York n=8 (17%), California n=7(15%), and Texas n=6 (13%). Tables 2 and 3.

Out of a total sample of 63 AYAs, the most common cancer diagnosis was lymphoma n=23 (37%), followed by leukemia n=16 (25%). Together leukemia and lymphoma accounted for over half the diagnosis n=39 (62%) with the remaining participants diagnosed with solid tumors, including breast cancer n=5 (8%), Ewing’s Sarcoma n=3 (5%), thyroid cancer n = 3 (5%), ovarian cancer n= 2 (3%), brain tumor n=2 (3%), sarcoma n=2 (3%), liver cancer n= 2 (3%), melanoma n= 2 (3%), squamous cell carcinoma n=1 (2%), testicular cancer n=1 (2%), and neuroendocrine tumor n=1
(2%). For most of the participants, this was their first cancer diagnosis n= 54 (86%) with only n=9 (14%) experiencing relapse.

Just over half of the participants were finished with or off therapy n=34 (54%), while the other n=29 (46%) were still receiving some form of cancer therapy such as chemotherapy, radiation, or biotherapy. Most of the patients received chemotherapy either alone (37%) or in combination with other therapy (42%). Most of the participants reported receiving multimodal therapy (56%).

The length of time since cancer diagnosis varied, ranging from <1 year to 15 years, with a mean of 2.30 years (SD=2.65) and a median of 1 year. The majority of participants n=9 (16%) were less than one year or one year n=26 (41%) from diagnosis. There were n=7 (10%) participants who were two years from diagnosis, n=16 (25%) participants were 3 to 5 years from diagnosis, and n=5 (8%) of the participants were greater than five years from diagnosis. For those who were relapsed, time from diagnosis started at the initial date of diagnosis. Table 4.

**Variable Characteristics**

Participants had relatively high levels of perceived social support (M=66.44, SD=11.22) with a range of 31 to 84—Table 5. Perceived social support scores of 61 to 84 are generally considered high (Greenspace Mental Health, 2019).
Table 1.

Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (Mean)</strong></td>
<td>24.4 years</td>
<td>SD 4.4</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Female</td>
<td>54</td>
<td>86</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>53</td>
<td>85</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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<td></td>
</tr>
<tr>
<td>American Indian/Native American</td>
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<td>1</td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Black/African America</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>White</td>
<td>53</td>
<td>85</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
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<tr>
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<td>43</td>
<td>68</td>
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<tr>
<td>Married</td>
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<td>24</td>
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<tr>
<td>Domestic Partnership</td>
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<td>6</td>
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<td>2</td>
</tr>
<tr>
<td><strong>Have Children</strong></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>58</td>
<td>92</td>
</tr>
<tr>
<td><strong>Highest Level of Education</strong></td>
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<td></td>
</tr>
<tr>
<td>High School/Technical School</td>
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<td>27</td>
</tr>
<tr>
<td>College</td>
<td>32</td>
<td>51</td>
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<tr>
<td>Graduate School</td>
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<td>22</td>
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<tr>
<td><strong>Employment Status</strong></td>
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<td>26</td>
<td>41</td>
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<tr>
<td>Unemployed</td>
<td>11</td>
<td>17</td>
</tr>
<tr>
<td>Student</td>
<td>17</td>
<td>27</td>
</tr>
<tr>
<td>Employed + Student</td>
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<td>5</td>
</tr>
<tr>
<td>Medical Leave</td>
<td>5</td>
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<tr>
<td>Homemaker</td>
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<td>2</td>
</tr>
<tr>
<td><strong>Religious Preference</strong></td>
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<td></td>
</tr>
<tr>
<td>None</td>
<td>24</td>
<td>38</td>
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<tr>
<td>Christian</td>
<td>34</td>
<td>54</td>
</tr>
<tr>
<td>Jewish</td>
<td>5</td>
<td>8</td>
</tr>
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</table>
Table 2.

Country of Origin

<table>
<thead>
<tr>
<th>Country</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States of America</td>
<td>46</td>
<td>73</td>
</tr>
<tr>
<td>Canada</td>
<td>3</td>
<td>5</td>
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<td>New Zealand</td>
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<td>3</td>
</tr>
<tr>
<td>Australia</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Belgium</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Cayman Islands</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Dominican Republic</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>France</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Israel</td>
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<td>2</td>
</tr>
<tr>
<td>Malta</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Slovakia</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Sweden</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

The highest levels of perceived social support were found in the significant other (M=23.08, SD=5.225), followed by family (M=22.43, SD=4.812), and friends (M=21.05, M=5.081). The difference in the scores were significant $\chi^2 (2)= 13.017$, $p=.001$.

Hope scores ranged from 25 to 48 (M=36.52, SD=5.6). Although hope is usually conceived of as occurring on a continuum and it was measured as a continuum in this study, some researchers have used a classification of low (12 – 24), moderate (25 to 36), and high (37 to 48) (K. Herth, personal communication, September 2, 2020). Most of the participants (n=37) had a moderate level of hope, while the remaining participants
(n=26) had high levels of hope. None of the participants fell in the low range of hope scores.

**Table 3.**

*State of Origin*

<table>
<thead>
<tr>
<th>State</th>
<th>n</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>New York</td>
<td>8</td>
<td>17</td>
</tr>
<tr>
<td>California</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Texas</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Florida</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Illinois</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Georgia</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Kansas</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Michigan</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Ohio</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Washington</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Wisconsin</td>
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<td>4</td>
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<tr>
<td>Indiana</td>
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<tr>
<td>Massachusetts</td>
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<td>2</td>
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<tr>
<td>Nevada</td>
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<td>2</td>
</tr>
<tr>
<td>New Mexico</td>
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<td>2</td>
</tr>
<tr>
<td>North Carolina</td>
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<td>2</td>
</tr>
<tr>
<td>Tennessee</td>
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<td>2</td>
</tr>
</tbody>
</table>
### Table 4.

*Disease Characteristics*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Cancer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphoma</td>
<td>23</td>
<td>37</td>
</tr>
<tr>
<td>Leukemia</td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>Breast Cancer</td>
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<td>8</td>
</tr>
<tr>
<td>Thyroid Cancer</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Ewing’s Sarcoma</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Ovarian</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Brain Tumor</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Liver Cancer</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Melanoma</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Squamous Cell Carcinoma</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Testicular Cancer</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Neuroendocrine Tumor</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Relapse</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>No</td>
<td>54</td>
<td>86</td>
</tr>
<tr>
<td><strong>Length of Time since diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>9</td>
<td>16</td>
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<tr>
<td>1 to 2 years</td>
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<td>2 to 3 years</td>
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<td>10</td>
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<tr>
<td>3 to 5 years</td>
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<td>25</td>
</tr>
<tr>
<td>&gt; 5 years</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td><strong>Therapy</strong></td>
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<td></td>
</tr>
<tr>
<td>On</td>
<td>29</td>
<td>46</td>
</tr>
<tr>
<td>Off</td>
<td>34</td>
<td>54</td>
</tr>
<tr>
<td><strong>Type of Therapy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>23</td>
<td>36.5</td>
</tr>
<tr>
<td>Chemotherapy + Radiation, Surgery, or Biotherapy</td>
<td>20</td>
<td>31.7</td>
</tr>
<tr>
<td>Chemotherapy + BMT, Radiation, or Biotherapy</td>
<td>13</td>
<td>20.6</td>
</tr>
<tr>
<td>Surgery</td>
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<td>3.2</td>
</tr>
<tr>
<td>Surgery + Biotherapy or Radiation</td>
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<td>4.8</td>
</tr>
<tr>
<td>Radiation</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>Watching and waiting</td>
<td>1</td>
<td>1.6</td>
</tr>
</tbody>
</table>

*Note: BMT = Blood and Marrow Transplant*
The average HADS score for anxiety was elevated (M=10.79, SD=3.4) and fell between the categories designated borderline and abnormal anxiety. There were 11 participants in the normal range (0 to 7), 22 participants in the borderline range (8 to 10), and 30 in the abnormal range (11 to 21), for a total of n=52 (83%) of the participants with elevated levels of anxiety. The average HADS score for depression fell in the normal range (M=6.16, SD=2.9). There were 39 participants in the normal range (0 to 7), 19 in the borderline range (8 to 10), and 5 in the abnormal range (11 to 21), for a total n= 24 (38%) of the participants with elevated levels of depression. Tables 6 and 7.

Table 5.

**MSPSS Subscale Scores**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSPSS-Fr</td>
<td>4</td>
<td>28</td>
<td>21.05</td>
<td>5.19</td>
</tr>
<tr>
<td>MSPSS-Fa</td>
<td>10</td>
<td>28</td>
<td>22.32</td>
<td>4.81</td>
</tr>
<tr>
<td>MSPSS-SO</td>
<td>5</td>
<td>28</td>
<td>23.08</td>
<td>5.23</td>
</tr>
</tbody>
</table>

*Note: MSPSS-Fr= Multidimensional Scale of Perceived Social Support-Friends, MSPSS-Fa= Multidimensional Scale of Perceived Social Support- Family, MSPSS-SO= Multidimensional Scale of Perceived Social Support-Significant Other*

**Research Variables and Aims**

The research variables in this study were examined using a conceptual model based on the stress process model. The input or independent variables consist of age, gender, perceived social support scores, type of cancer and length of time since diagnosis. The mechanistic variable is hope score, and the output variable is global anxiety and depression scores.
Table 6.

Hope Scores, Social Support Scores, and Anxiety and Depression Scores

<table>
<thead>
<tr>
<th>Scale</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>MSPSS</td>
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<td>84</td>
<td>66.44</td>
<td>11.42</td>
</tr>
<tr>
<td>HHI</td>
<td>25</td>
<td>48</td>
<td>36.52</td>
<td>5.64</td>
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<tr>
<td>HADS-A</td>
<td>5</td>
<td>18</td>
<td>10.79</td>
<td>3.36</td>
</tr>
<tr>
<td>HADS-D</td>
<td>0</td>
<td>12</td>
<td>6.16</td>
<td>2.93</td>
</tr>
<tr>
<td>HADS-G</td>
<td>8</td>
<td>27</td>
<td>16.92</td>
<td>5.31</td>
</tr>
</tbody>
</table>

*Note:* MSPSS= Multidimensional Scale of Perceived Social Support, HHI=Herth Hope Index, HADS-A= Hospital Anxiety and Depression Scale – Anxiety, HADS-D= Hospital Anxiety and Depression Scale – Depression, HADS-G= Hospital Anxiety and Depression Scale – Global

Table 7.

HADS scores categorized

<table>
<thead>
<tr>
<th>Scale</th>
<th>Normal (0 to 7)</th>
<th>Borderline (8 to 10)</th>
<th>Abnormal (11 to 21)</th>
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*Note:* HADS-A= Hospital Anxiety and Depression Scale – Anxiety, HADS-D= Hospital Anxiety and Depression Scale – Depression

Aim 1) To examine the relationships between age, gender, social support, cancer type and length of time since diagnosis, hope and global anxiety and depression in adolescents and young adults with cancer.
The relationships between the personal characteristics of age, and perceived social support with hope, anxiety, and depression, as well as global anxiety and depression, were examined using Pearson’s Correlation in a 6x6 bivariate correlation table (Table 8). The two dichotomous variables of gender and type of cancer were compared to social support, hope, and global anxiety and depression using an independent t-test. Type of cancer was not related to perceived social support, hope, or global anxiety and depression. Gender was found to be related to social support. Using an independent t-test, a statistically significant difference was found between the perceived social support of men (M=57.6, SD=13.26) and women (M=67.9, SD=10.51); t(61) = -2.64, p = .01. There was no significant difference in hope, anxiety, and depression scores based on gender.

Perceived social support scores were not correlated with age, type of cancer or length of time since diagnosis. Using Pearson’s correlation, perceived social support scores were positively correlated with hope scores r(61) = .359, p = .004 and negatively correlated with anxiety and depression as measure by the global anxiety and depression score; r(61) = -.247, p = .05.

Next, the disease characteristics were examined to deduce if relationships existed between the type of cancer, length of time since diagnosis and personal characteristics of age, gender, perceived social support score, with the mechanistic variable of hope score and outcome variables of global anxiety and depression scores. No cancer related characteristics were found to be related to the perceived social support score, hope score, or global anxiety and depression score.
The hypothesized mechanistic variable hope was not correlated with age, gender, type of cancer, or length of time since diagnosis. As mentioned above, using Pearson’s Correlations, hope scores were positively correlated with perceived social support scores $r(61)= .359$, $p=.004$. Hope scores were negatively correlated with anxiety scores $r(61)= -.386$, $p=.002$; depression scores $r(61)= -.567$, $p<.001$; and global anxiety and depression scores $r(61)= -.561$, $p<.001$.

The outcome variables of anxiety and depression were measured separately and as a global measurement to determine which was a better fit for the data. Results of a Pearson’s correlation found levels of anxiety ($M=10.79$, $SD=3.4$) were significantly higher than levels of depression ($M=6.16$, $SD=2.9$); $t(62)=10.79$, $p<.001$; however, anxiety and depression are highly correlated $r(61)= .417$, $p<.001$.

As reported above, perceived social support is only correlated to the global anxiety and depression score, but hope is negatively correlated with anxiety, depression, and the global anxiety and depression score. Both anxiety $r(61)= .826$, $p<.001$ and depression $r(61)= .820$, $p<.001$ are highly correlated with the global anxiety and depression score. The outcome variable to be measured will be the combine global anxiety and depression score.

In answer to aim 1; age, type of cancer and length of time since diagnosis were not correlated to any of the other variables. Gender was correlated with perceived social support, but none of the other variables. Perceived social support was found to be positively correlated with hope and negatively correlated with global anxiety and depression. Hope was negatively correlated with anxiety, depression, and global anxiety and depression. Table 8.
Table 8.

Correlation Matrix

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<th>Age</th>
<th>Time since dx</th>
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<th>HHI</th>
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<th>HADS-D</th>
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<tr>
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<td>-.561**</td>
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<td>.001</td>
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</table>

* Correlation is significant at the 0.05 level  ** Correlation is significant at the 0.01 level

Note: MSPSS= Multidimensional Scale of Perceived Social Support, HHI=Herth Hope Index, HADS-A= Hospital Anxiety and Depression Scale – Anxiety, HADS-D= Hospital Anxiety and Depression Scale – Depression, HADS-G= Hospital Anxiety and Depression Scale – Global

Aim #2

To evaluate the mechanistic effect of hope on the relationship between the personal characteristics of age, gender, social support; the disease characteristics of cancer type and length of time since diagnosis with global anxiety and depression in AYA with cancer. From the previous analysis, of the five independent variables
identified in my conceptual model, the only variable with a significant relationship to hope, anxiety and depression was perceived social support, therefore perceived social support was the only independent variable examined in the regression analysis.

A series of regression analysis were used to explore the role of hope as a mediating variable in the relationship between perceived social support and anxiety and depression in the manner described by Baron and Kenney (1986). Prior to the interpretation of each regression analysis, a preliminary regression was conducted to ensure there was no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Once all assumptions were met, interpretation commenced. The series of regression analysis was repeated two more times using first anxiety and then depression as the dependent variable.

Results of the regression analyses indicate that perceived social support was a significant predictor of global anxiety and depression, $B = -.115$, $SE = .058$, $p = .050$ 95% CI [-.2306, .0005]. Perceived social support was also a significant predictor of hope, $B = .178$, $SE = .059$, $p = .004$ 95% CI [.0595, .2964]. Hope is a significant predictor of global anxiety and depression, $B = -.509$, $SE = .107$, $p <.001$ 95% CI [-.7242, -.2946]. Perceived social support was no longer a significant predictor of global anxiety and depression after controlling for the mediator, hope, $B = -.024$, $SE = .053$, $p=.648$ 95% CI[-.1309, .0821], which is not significant. Figure 3. Perceived social support accounted for 6% of the variance of global anxiety and depression. When hope was added to the model, it accounted for 32% of the variance in the model. The indirect effect was tested using the bootstrap estimated method with 5000 samples using the PROCESS Macro.
3.5 (Hayes, 2018). The results indicate that indirect coefficient was significant, B= -.091, SE= .037 95% CI [-.1676, -.0210]. When the variables of anxiety and depression were run separately, the model is still significant. However, is it only significant through the indirect effect, that is through the mediating variable of hope. This is consistent with the correlation results as well; perceived social support was not correlated with the subscales of anxiety and depression, but is correlated with the global score. The model using the global anxiety and depression scores showed the direct effect of social support on anxiety/depression as well as the indirect effect through the mediating variable of hope.

Figure 3.
Path Model of the Mediating Effect of Hope on Social Support and Global Anxiety and Depression

Summary of Findings
This sample of 63 AYAs had an average age of 24.4 years and was mainly comprised of single, non-Hispanic, white females. The participants of this study were
found to have high levels of social support and moderate to high levels of hope. Most of the participants (83%) had borderline to abnormal levels of anxiety, but only 38% had borderline to abnormal levels of depression. In exploring the relationships between variables, perceived social support was found to be positively correlated with hope and negatively correlated with global anxiety and depression. Males were found to have lower levels of perceived social support than females. No differences were found in perceived social support, hope, and global anxiety and depression based on age, type of cancer, or length of time since diagnosis. Hope was found to partially mediate the relationship between perceived social support and global anxiety and depression.
Chapter Five

Discussions, Conclusions, and Recommendations

This final chapter presents a brief synthesis of the results from this dissertation study of the relationship between perceived social support, hope, and global anxiety and depression in adolescents and young adults with cancer. The implications of the study results and conclusions will also be discussed.

Summary of Study

This study explored the relationship between the input variables of age, gender, type of cancer, length of time since diagnosis and social support; the mechanistic variable of hope; and the outcome variable of global anxiety and depression. A cross-sectional research design was utilized to collect data social media sites from AYAs with cancer. The convenience sample consisted of 63 AYAs between the ages of 18 to 30 who currently have cancer or who were diagnosed within the past five years. The participants were recruited via FaceBook pages for organizations supporting AYAs with cancer such as Stupid Cancer, The Leukemia and Lymphoma Society, Young Adult Cancer Connection, and Breast Cancer Now. Participants came from the United States, Europe, the Caribbean, the Middle East, Australia, and New Zealand.

Demographic Characteristics

Demographic data were collected to characterize the study sample. Most of the participants were white, non-Hispanic women. While the incidence of cancer in AYAs is
typically higher in women and non-Hispanic whites (Miller et al., 2020), this study has an over-representation of non-Hispanic white, females. The demographic makeup of the present study is consistent with studies that utilize social media, such as FaceBook to recruit their sample. Young, white females tend to be highly represented in studies conducted via Facebook (Topolovec-Vranic & Natarajan, 2016; Whitaker et al., 2017).

The two most common types of cancer in this study were lymphoma and leukemia. These results do not reflect the national statistics which show that thyroid cancer is the most common type of cancer in AYAs ages 20 to 29, followed by lymphomas. Leukemias are more common in children with cancer than AYAs (Miller et al., 2020). The overabundance of participants with leukemia and lymphoma in this study may be attributed to the fact that the Leukemia and Lymphoma Society was one of the websites that advertised this study.

Most of the participants in this study had been diagnosed one year or less. One possible reason for such a large percentage of recently diagnosed participants may be the use of a social media platform for study recruitment. Many AYAs use the internet as a source of information about their cancer and treatment and to meet others with the same lived experiences (Peat et al., 2019; Welch Cline, 2007). AYAs who are newly diagnosed may be spending more time online researching specific information or seeking to connect to others in the same situation. Spending more time online may have increased the likelihood that those who are newly diagnosed would participate in the study. There was a bimodal distribution with another spike at those 3 to 5 years from treatment. It is possible that as the AYAs are finishing therapy or looking towards
the future, they may be spending more time online looking for information and support from other AYAs.

Discussion

Aim 1) To examine the relationships between age, gender, perceived social support, cancer type and length of time since diagnosis, hope and global anxiety and depression in adolescents and young adults with cancer.

The participants in this study were found to have moderate to high levels of hope. In studies which utilized the HHI in cancer patients, the reported hope scores have been moderate ranging between 31.78 to 36.15 (Herth, 1992; Li et al., 2017; Rustoen et al., 2010; Shen et al., 2020) or high ranging between 37.6 to 43 (Acquaye et al., 2015; Balsanelli & Grossi, 2016; Ebright & Lyon, 2002; Phillips-Salimi et al., 2007; Wonghongkul et al., 2000).

As hope has been identified as a positive force that can provide a help people fight a cancer diagnosis, it is vital to ensure that as health care professionals we know what hope means in our patients so we can provide appropriate interventions to foster hope. There is a dearth of studies on hope in the AYA population; most of the hope studies have been conducted in older adults. More research needs to be conducted to establish average hope scores in the AYA population and discover what factors may foster hope in AYAs with cancer.

The participants in this study had high levels of perceived social support. They received the most social support from their significant other, followed by family and friends. These findings are different from other studies. In two studies of perceived
social support in adolescents with cancer, the adolescents found more perceived social support from family, followed by friends, and significant other. (Çavuşoğlu & Sağlam; 2015; Ekim & Ocakci, 2015). As both of those study populations were younger, that could explain why they received more social support from family and friends.

Even though a majority of participants in this study were single, they have a significant other or special person upon whom they can rely. The MSPSS provides only three options, family, friends and significant others. We know from qualitative work that has been done that AYAs with cancer receive a lot of social support from not only other AYAs with cancer, but also health care providers (Breuer et al., 2017; Corey et al., 2009; Kyngas et al., 2001; Martins et al., 2017). As healthcare providers, it is important to discover who the patient relies upon for social support so we may ensure they have access to that person either in person or virtually.

This study found that women had higher levels of perceived social support than men; this is a unique finding. Other studies using the MSPSS did not find any differences based on gender (Çavuşoğlu & Sağlam, 2015; Ekim & Ocakç, 2015; Tanriverd et al., 2012; Pennant et al., 2020). Many of the studies conducted in social support have been qualitative studies, and others have been conducted exclusively in women with breast or gynecological cancers, so gender is not often a variable studied in relation to social support. Women are often more vocal about their need for social support, so men may need more attention to determine what their needs may be. Further research is needed to determine the role of gender in perceives social support.

Levels of anxiety and depression among the participants in this study were elevated with 83% having an anxiety score > 7 on the HADS-A and 38% with levels of
depression > 7 on the HADS-D. The prevalence of anxiety found in this study is higher as compared to findings from prior research exploring anxiety levels experienced by AYAs. The prevalence of anxiety in young adult with cancer and young adult survivors was found to be 45% in a study of young adults with cancer (n=514) (Geue et al., 2019), 40% in working age young adult survivors (n =3370) (Inhestern et al., 2017), 44% in young women with metastatic breast cancer (n=54) (Park et al., 2018) and 75% in AYAs in China (Xie et al., 2017).

While the cross-sectional design of the present study makes it difficult to ascertain the potential reasons for the elevated levels of anxiety in this population of AYAs with cancer, one possible explanation may be related to anxiety over the Coronavirus Disease 2019 (COVID19) global pandemic. This study was conducted from May to August 2020 during which time many Americans were being asked to stay home, self-isolate, and America had the highest number of COVID19 cases than anywhere in the world (Kantis et al., 2020). Schools closed and many people have lost their jobs, increasing financial stress and concern. Social isolation can increase anxiety and stress. The American Medical Association reported that one in three Americans show symptoms of stress and anxiety (Zarefsky, 2020). It is possible that those receiving current cancer treatments may have had higher anxiety due to potential immunocompromised states that made them more vulnerable to COVID-19 infection. The exact cause of the high levels of anxiety in this study cannot be determined.

Aim 2) To evaluate the mechanistic effect of hope on the relationship between the personal characteristics of age, gender, social support; the disease characteristics of
Anxiety and depression are a common reaction to a cancer diagnosis, adding in the uncertainty of self-isolation and fear of a deadly pandemic, it is not although surprising that the participant in this study had such high levels of anxiety and depression. As AYAs recover from cancer and begin regaining their independence, there are new worries, including financial concerns and fertility concerns. The AYAs may not have been concerned money issues or fertility until they have to support themselves or attempting to establish an intimate relationship or begin a family (Smith et al., 2018; Sodergren et al., 2018). However, increased levels of anxiety and depression can lead to a decrease in quality of life and a decrease in adherence to treatment. The decreased quality of life and treatment adherence can lead to poor outcomes and increased rates of death (Ding et al., 2019; Lauer, 2015; Linden et al., 2012; Niedzwiedz et al., 2019; Thalén-Lindström et al., 2013).

Social support and hope have both been suggested as factors that can diminish symptoms of anxiety and depression in the cancer population (Grealish et al., 2019; Martins et al., 2018; Mattioli et al., 2008; Pennant et al., 2020). This study explored the relationship between perceived social support, hope, and anxiety and depression.

A key finding from this study is that hope partially mediates the relationship between perceived social support and global anxiety and depression. When hope was added to the model, the relationship between social support and anxiety and depression was no longer significant.
The mediating role of hope highlights the importance of hope in AYAs with cancer. Hope has been poorly studied in the AYA group as compared to children and older adults. There needs to be more research into the factors that foster and enhance hope in the AYA age group. Once the meaning of hope to the AYA is more apparent, interventions can be developed to enhance and foster hope.

There is more research into social support in the AYA age group. Social support plays a role in hope, so healthcare personnel need to help the AYAs maintain the relationships that are sustaining them and provide support in the face of unhealthy or negative social support (Breuer et al., 2017; Iannarino et al., 2017; Martins et al., 2017; Tillery et al., 2017).

Helping the AYA might involve developing encouraging participation in AYA support groups or local events either in person or virtual or sponsoring workshops such as ‘Find your Sense of Tumour’ that help AYAs connect in a non-clinical setting (Martins et al., 2017). Taylor and associates (2011) asked AYAs what they would like in an AYA unit, and the top three responses were a dedicated unit, contact with peers, and the ability for partners or parents to stay on the unit with them. This study found the AYAs gained more social support from their significant others which supports the findings of the study conducted by Taylor and associates (2011).

Nursing can advocate for policy changes that allow non-married partners to stay with their loved one in the hospital and to allow for flexibility in visitation policies to encourage friends and family to visit. Nursing can also encourage the AYA to use technology to keep in contact with loved ones during prolonged hospitalizations. In the
era of COVID19, it is more important than ever to encourage social support and communication with loved ones.

Particular attention should be paid to male patients who in this study had lower levels of social support than female patients. Perhaps male patients depend on different forms of social support, not captured in this study; this finding needs to be explored in more detail, perhaps with a study targeting only males. Improving perceived social support in AYAs with cancer may increase levels of hope which in turn may decrease levels of anxiety and depression.

Limitations

This was the first study to examine the role of social support, hope, and global anxiety and depression in AYAs with cancer. Understanding this relationship can help healthcare providers develop interventions to foster hope and provide opportunities for social support to decrease levels of global anxiety and depression.

There are several limitations of this study. The cross-sectional design limits the ability of this study to predict any changes over time. The sample size of 63 limits the strength and generalizability of the results. This study did not utilize any paid advertisements on FaceBook or other social media sites nor were incentives offered for completing the study, which may have resulted in a smaller sample size. The participants are a largely homogenized group which can also limit the generalizability of the results. The people who are participating in online research may be different in some fundamental way to those who are not participating in online research. AYAs with higher levels of anxiety and depression may not be going online as often and may not
be captured in an online study. More of an effort needs to be undertaken to reach out to minorities and males to determine if they have similar results.

The study was conducted during a worldwide pandemic that as of September has killed over 1,000,000 worldwide (Kantis et al., 2020). It is impossible to tell what impact that may have had on this study. The pandemic may have limited the sample size as potential participants may have been too worried to complete the study. The effects of living in lockdown may have elevated levels of anxiety and depression that have nothing to do with a cancer diagnosis, or it could have exacerbated anxiety due to perceived COVID-19 infection risk during cancer treatment. For months, medical personnel have encouraged those at high risk to self-isolate. This social isolation and disruption to established routines due to COVID-19 may have also exacerbated levels of anxiety.

The age range in this study was limited to 18 to 30 instead of the generally accepted AYA age range of 15 to 39. The lack of standardized age ranges that either defines AYAs, or that is too broad makes comparison with study findings in the literature difficult, and limits generalizability.

**Implications for Nursing**

The findings of this study suggest that while both hope and social support play a role in reducing anxiety and depression among AYAs with cancer, it appears that hope plays a more central role. By understanding the importance of both perceived social support and hope, nursing can develop interventions to allow the AYA to receive social support from family, friends, and significant others using a variety of methods, such as in-person encounters and social media. Interventions might come in the form of
developing a specific unit for the AYA or creating a virtual AYA lounge to foster support and provide information.

At present, many institutions do not have visitation policies that allow families and friends to visit frequently. If AYAs are receiving hospital-based treatments or are admitted for disease or treatment complications, they might be able to receive the support they need due to hospital policies limiting visitors. Presently, institutions limit the number of visitors and time permitted with in-patients due to COVID-19. The same is true for clinic visits for intravenous chemotherapy regimens, increasing social isolation, and potentially, anxiety and depression. Nurses may need to lead policy changes to allow for increased visitation time, once it is safe to do so. Nurses can be creative to assist the AYA in keeping in touch with family and friends while still social distancing.

Interventions have been developed to foster levels of hope, but they have only been implemented on a small scale (Martins et al., 2017; Stegenga, 2014). Nursing can collaborate with the AYA to develop programs to foster hope and provide support.

The high prevalence of anxiety and depression in the AYA group suggests that anxiety and depressive symptoms should be screened for upon admission or during a clinic visit. Increasing awareness of the prevalence of anxiety and depression in the AYA population among hospital and clinic staff members can be a beginning step towards combating anxiety and depression and encouraging social support and thus hope.

**Recommendations for the Future Study**

Based on the AYA literature and the findings of this study, the following are recommended. This is the first study to examine the role of hope and perceived social support in the AYA with cancer. Due to the small and homogenous sample, this study
should be repeated with a larger and more diverse sample, seeking males as well as ethnic and racial minorities.

Further studies should be conducted to determine what other factors may affect hope in the AYA group; some factors that have been identified are spirituality, pain, and fatigue. The role of religion and spirituality in AYAs with cancer needs to be explored. The role that these factors play needs to be explored.

As the AYA cancer population remains understudied, a mixed-methods study should be conducted to capture the qualitative data concerning the lived experience and concerns of the AYA that may not be fully captured through the use of quantitative tools. Information provided in the participants own words could provide more insight into the relationship between perceived social support, hope and anxiety and depression than is captured on a survey. They may provide a factor important to them that has not been considered previously.
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Appendices
Appendix A

IRB Approval

EXEMPT DETERMINATION

April 15, 2020

Sharon McNeil
1971 Sapphire Ln
Clearwater, FL 33760

Dear Mrs. Sharon McNeil:

On 4/14/2020, the IRB reviewed and approved the following protocol:

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The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BulsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about
whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

Sincerely,

Tatyana Harris
IRB Research Compliance Administrator

Institutional Review Boards / Research Integrity & Compliance
FWA No. 00001669
University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813-974-5638

Page 2 of 2
Appendix B

Demographic Form

Age_______

Year of Diagnosis: _____________

Type of Cancer: _______________________________________________

What stage was your cancer?

Stage I ________________

Stage II________________

Stage III________________

Stage IV________________

Was this a relapse of a previously diagnosed cancer?

Yes ___________

No_____________

If yes, when were you originally diagnosed? _______________________

Are you currently: On therapy______________

Off therapy___________

If you are off therapy when did you complete your therapy?__________

What type of therapy did you receive (you may choose more than one):

Chemotherapy _____________

Surgery _______________

Radiation Therapy _____________

Biological Therapy _____________
Bone Marrow or Stem Cell Transplant

Please put an X on the line next the appropriate answer

1. Gender: Male
   Female
   Transgendered
   Non-Binary
   Other

2. Race/Ethnicity: American Indian/Native American
   Asian
   Black/African American
   Hispanic/Latino
   White/Caucasian
   Pacific Islander
   Other

3. Are you currently attending college? Yes/No
   If yes, what year are you in?

4. If you are not currently in school, what is your highest level of education?
   High school, not graduated
   High school, graduated
   Some college, not graduated
   Two-year degree
   Four-year degree
   Some graduate school
   Master’s degree
   Doctoral degree

5. What is your employment status?
   Employed full time
   Employed part time
   Unemployed – looking for work
   On Medical Leave
   Student
   Homemaker

6. What is your marital status?
   Single
   Married
   Domestic partnership
7. Do you have any children? 
   Yes/No
   If yes, how many children do you have __________

8. What is your religious preference?
   Baptist __________
   Catholic __________
   Christian __________
   Jewish __________
   LDS/Mormon __________
   Methodist __________
   Muslim __________
   Protestant __________
   No Preference/ No Affiliation __________
   Other: ________________________________ (please explain)

9. Apart from events such as weddings or funerals, how often do you attend religious services?
   More than once a week __________
   Once a week __________
   Once or twice a month __________
   A few times a year __________
   Never __________
## Appendix C

### Herth Hope Index

<table>
<thead>
<tr>
<th>Study No. _______</th>
</tr>
</thead>
<tbody>
<tr>
<td>HERTH HOPE INDEX</td>
</tr>
</tbody>
</table>

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I have a positive outlook toward life.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I have short and/or long range goals.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I feel all alone.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I can see possibilities in the midst of difficulties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I have a faith that gives me comfort</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I feel scared about my future.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>I can recall happy/joyful times.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I have deep inner strength.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I am able to give and receive caring/love.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>I have a sense of direction.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>I believe that each day has potential.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>I feel my life has value and worth.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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1999 items 2 & 4 worded
Appendix D

Multidimensional Scale Perceived Social Support

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you Very Strongly Disagree
Circle the “2” if you Strongly Disagree
Circle the “3” if you Mildly Disagree
Circle the “4” if you are Neutral
Circle the “5” if you Mildly Agree
Circle the “6” if you Strongly Agree
Circle the “7” if you Very Strongly Agree

1. There is a special person who is around when I am in need. 1 2 3 4 5 6 7 SO
2. There is a special person with whom I can share my joys and sorrows. 1 2 3 4 5 6 7 SO
3. My family really tries to help me. 1 2 3 4 5 6 7 Fam
4. I get the emotional help and support I need from my family. 1 2 3 4 5 6 7 Fam
5. I have a special person who is a real source of comfort to me. 1 2 3 4 5 6 7 SO
6. My friends really try to help me. 1 2 3 4 5 6 7 Fri
7. I can count on my friends when things go wrong. 1 2 3 4 5 6 7 Fri
8. I can talk about my problems with my family. 1 2 3 4 5 6 7 Fam
9. I have friends with whom I can share my joys and sorrows. 1 2 3 4 5 6 7 Fri
10. There is a special person in my life who cares about my feelings. 1 2 3 4 5 6 7 SO
11. My family is willing to help me make decisions. 1 2 3 4 5 6 7 Fam
12. I can talk about my problems with my friends. 1 2 3 4 5 6 7 Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).
Appendix E

Hospital Anxiety and Depression Scale

<table>
<thead>
<tr>
<th>D</th>
<th>A</th>
<th>D</th>
<th>A</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Most of the time</td>
<td>3</td>
<td>Nearly all the time</td>
</tr>
<tr>
<td>2</td>
<td>A lot of the time</td>
<td>2</td>
<td>Very often</td>
</tr>
<tr>
<td>1</td>
<td>From time to time, occasionally</td>
<td>1</td>
<td>Sometimes</td>
</tr>
<tr>
<td>0</td>
<td>Not at all</td>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Definitely as much</td>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>Not quite so much</td>
<td>1</td>
<td>Occasionally</td>
</tr>
<tr>
<td>2</td>
<td>Only a little</td>
<td>2</td>
<td>Quite Often</td>
</tr>
<tr>
<td>3</td>
<td>Hardly at all</td>
<td>3</td>
<td>Very Often</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Definitely and quite badly</td>
<td>0</td>
<td>I have lost interest in my appearance</td>
</tr>
<tr>
<td>1</td>
<td>Yes, but not too badly</td>
<td>1</td>
<td>I may not take quite as much care</td>
</tr>
<tr>
<td>2</td>
<td>A little, but it doesn't worry me</td>
<td>2</td>
<td>I take just as much care as ever</td>
</tr>
<tr>
<td>3</td>
<td>Not at all</td>
<td>3</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>As much as I always could</td>
<td>0</td>
<td>Very much indeed</td>
</tr>
<tr>
<td>1</td>
<td>Not quite so much now</td>
<td>1</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>2</td>
<td>Definitely not so much now</td>
<td>2</td>
<td>Not very much</td>
</tr>
<tr>
<td>3</td>
<td>Not at all</td>
<td>3</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>A great deal of the time</td>
<td>0</td>
<td>As much as I ever did</td>
</tr>
<tr>
<td>1</td>
<td>A lot of the time</td>
<td>1</td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td>2</td>
<td>From time to time, but not too often</td>
<td>2</td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td>3</td>
<td>Only occasionally</td>
<td>3</td>
<td>Hardly at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Not at all</td>
<td>0</td>
<td>Very often</td>
</tr>
<tr>
<td>1</td>
<td>Not often</td>
<td>1</td>
<td>Quite often</td>
</tr>
<tr>
<td>2</td>
<td>Sometimes</td>
<td>2</td>
<td>Not very often</td>
</tr>
<tr>
<td>3</td>
<td>Most of the time</td>
<td>3</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Definitely</td>
<td>0</td>
<td>Often</td>
</tr>
<tr>
<td>1</td>
<td>Usually</td>
<td>1</td>
<td>Sometimes</td>
</tr>
<tr>
<td>2</td>
<td>Not often</td>
<td>2</td>
<td>Not often</td>
</tr>
<tr>
<td>3</td>
<td>Not at all</td>
<td>3</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>

Please check you have answered all the questions.

Scoring:
Total score: Depression (D) ________ Anxiety (A) ________
0-7 = Normal
8-10 = Borderline abnormal (borderline case)
11-21 = Abnormal (case)
About the Author

Sharon B. McNeil has almost thirty years of experience as a registered nurse with extensive experience in pediatric hematology/oncology and pediatric blood and marrow transplant. She worked as a staff nurse and clinical nurse specialist at All Children’s Hospital in St Petersburg, Florida. While there she was in the inaugural group of Certified Pediatric Oncology Nurses (CPON) and became part of the first class of Pediatric Chemotherapy and Biotherapy Instructors. Involved in the Association of Pediatric Hematology/Oncology Nurses, Sharon founded the Gulf Coast Chapter of the Pediatric Hematology/Oncology Nurses. She currently works as a pediatric clinical instructor at Galen College of Nursing and has earned her Certified Academic Clinical Nurse Educator (CNEcl). She received her Bachelor of Science in Nursing from George Mason University in 1991 and her Master of Science in Nursing specializing in pediatrics and pediatric oncology from the University of South Florida in 1998. Her research interests include adolescent and young adult oncology, hope, and spirituality. Her doctoral degree was partially funded by an American Cancer Society Doctoral Scholarship.