

WHERE THERE IS A WILL THERE IS A WAY:  
DEFINING THE PATH BETWEEN HOPE, PAIN AND QUALITY OF LIFE IN  
PEDIATRIC ACUTE LYMPHOBLASTIC LEUKEMIA SURVIVORS

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## ACKNOWLEDGEMENTS

I owe many thanks to many people without whom my graduate training would have been impossible. My deepest gratitude is to my mentor, Dr. Julie Germann who has given me the opportunity to learn and grow professionally both as a clinician and researcher. Her ability to teach and guide while fostering independence has not gone unrecognized, and her endless reserve of patience and thought-provoking guidance is truly inspirational. I extend my sincerest appreciation to Dr. Sunita Stewart, whose knowledge, experience and ability to understand and teach any research related difficulty I encountered is absolutely amazing. I am so fortunate to have both as professional role models and something to aspire to. I am indebted to my dissertation committee, Dr. Deb Wiebe, Dr. Alan Farrow-Gillespie, Dr. Tom Carmody and Dr. Jean Claude Wakim for their assistance with this project from medical and statistical expertise to suggestions for a better overall product. I owe gratitude to the After the Cancer Experience Clinic physicians and staff at CMCD for their dedication to improving the lives of childhood cancer survivors and putting forth the thought and effort in designing this study. A special thanks goes to Terri Griffith who helped me with data collection and without whom this project would be incomplete.

I would also like to acknowledge the Clinical Psychology Graduate Program for providing me with excellent clinical and research opportunities. Of great recognition is Dr. Betsy Kennard, who is not only one of the most accomplished

department chairs, but also a wonderful mentor and role model. I am grateful for her professional and personal guidance and countless letters of recommendations. I must mention my co-chief resident and dear friend, Jodi Mahoney, whose friendship and support I cherish and whose intelligence and skills I admire. Her knowledge and ability to explain pretty much any topic is impeccable and her selflessness and availability both personally and professionally is astounding. Much thanks is due to all my classmates, especially Kyle Noll, Maria Grosch, and Deidre Edwards whose ability to come up with possible distractions from my productivity is beyond appreciated. I am grateful for their endless support and friendship in the last four years. I would also like to thank Andrea Croom for her detailed and clear explanation of statistical analyses and willingness to take the time from her extremely busy schedule to help when needed.

Finally, my gratitude toward my friends and family for their love and support cannot be expressed enough. In particular, my parents who have given my unconditional support and love throughout my life and during this journey. Lastly, I cannot begin to express my appreciation to my husband, Josh Foxwell, without whose support, encouragement and incredible patience this journey would have been impossible. I am extremely fortunate to have him in my life.

June 2011

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by

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DISSERTATION

Presented to the Faculty of the Graduate School of Biomedical Sciences

The University of Texas Southwestern Medical Center at Dallas

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY

The University of Texas Southwestern Medical Center at Dallas

Dallas, Texas, August, 2011

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Acute Lymphoblastic Leukemia (ALL) is the most common childhood cancer, with an expected long-term survival rate of approximately 80 – 85%.

Observations have lead researchers to believe that adolescent and young adult survivors of childhood ALL have an unexpectedly high frequency of lower back pain. This increase of pain is attributed to the number of lumber punctures during treatment. Various factors influence levels of pain (i.e. BMI, exercise and neuroticism) and pain has been shown to have a negative effect on quality of life.

Hope, a construct that has not been widely studied in the oncology literature, may be a buffer between pain and quality of life, meaning that those with higher hope are able to cope with their pain more effectively and in turn have a better quality of life. Moreover, because survivors have had an aversive experience, they may have increased levels of hope, thus despite high pain levels have a positive quality of life. Results suggested that ALL survivors reported higher pain ratings than siblings, but lower total hope and agency. Agency and total hope were significant predictors of QoL at time 2 over and above QoL at time 1 and mediated the relationship between pain time 1 and QoL time 2 when QoL time was not a covariate. These results conclude that hope and more specifically, agency, should be further examined in pediatric oncology and merits the development and investigation of a hope intervention.

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## PRIOR PUBLICATIONS

### **Peer Reviewed Journal Articles:**

Tamm, L., Hughes, C., Ames, L., Pickering, J., Silver, C., Stavinoha, P., Castillo, C., Rintelmann, J., Moore, J., **Foxwell, A.**, Bolanos, S.G., Hines, T.K., Emslie, G.J. (2009). Attention Training for School-Aged Children with ADHD: Results of an Open Trial. *Journal of Attention Disorders*.

Mayer, T., **Aceska, A.**, & Gatchel, R.J. (2006). Is obesity overrated as a “risk factor” for poor outcomes in chronic occupational spinal disorder? *The Spine Journal*.

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## LIST OF ABBREVIATIONS

ALL – Acute Lymphoblastic Leukemia

EPQ-BV– Eysenck Personality Questionnaire – Brief Version

PedsQL – Pediatric Quality of Life Questionnaire

QoL – Quality of Life

T1 – Time 1 data collection

T2 – Time 2 data collection

DV – Dependent Variable

IV – Independent Variable

## **CHAPTER ONE**

### **Introduction**

Acute Lymphoblastic Leukemia (ALL) is the most common childhood cancer, with an expected long-term survival rate of approximately 80 – 85%. Clinicians in the After the Cancer Experience (ACE) program at Children’s Medical Center have informally observed that adolescent and young adult survivors of childhood ALL report an unexpectedly high frequency of lower back pain. This increase of pain is attributed to the number of lumbar punctures children with ALL receive throughout treatment, although research on this association is limited. Thus, this study first proposes to examine whether survivors will have a higher prevalence of back pain versus healthy controls.

According to the multidimensional model of chronic pain, pain is not only impacted by physiological factors (i.e. injury, weight, exercise, etc.) but also by personality variables. Exercise is known to be of benefit in reducing weight and therefore is said to decrease chronic pain. Neuroticism, which is a tendency to experience chronic, negative, distressing emotions, has also been linked to increased subjective ratings of chronic pain. Although much of the literature suggests that childhood cancer survivors have a positive quality of life despite their struggle with cancer, late effects such as back pain could cause a decrease in overall functioning and outlook of life. Furthermore, the literature indicates that pain has a negative impact on physiological and psychosocial aspects of life.



Hope, defined in the positive psychology literature as will power and way power to achieving goals, is gaining significant interest because it is associated with many positive outcomes, appears protective against negative affect, and is modifiable; however, the impact of hope on pain coping and quality of life is unclear.

One goal of the current study is to examine whether survivorship status influences back pain and levels of hope. Although there are several known contributors to back pain, (i.e. exercise, BMI, neuroticism), this study will, in addition to these contributors, explore the construct of hope and its predictive relationship to pain. Hope has been of very little focus in the oncology literature; however, understanding whether hope influences (i.e. moderates) the relationship between pain and quality of life in survivors versus healthy controls would contribute significantly to the chronic illness literature. If hope has an effect on this relationship between pain and quality of life, it would be a promising target for intervention.

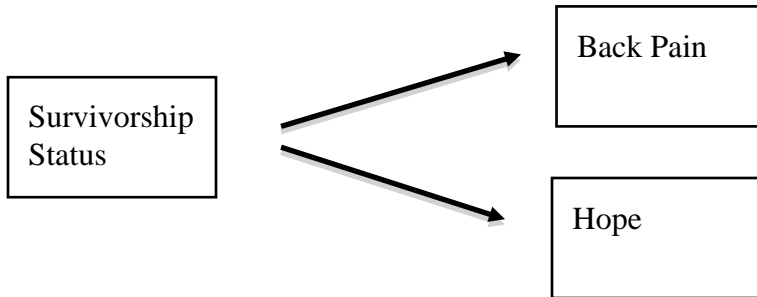
The positive psychology literature provides little information about the natural influences that determine the degree of an individual's hopefulness. It does suggest that individuals that go through an aversive experience, such as cancer, could have higher levels of hope by successfully encountering and overcoming obstacles to their goals throughout the course of the aversive experience. However, little is known about how physiological late effects, such

as pain contribute to levels of hope. Additionally, chronic negative emotion and distress could influence hope. Therefore, hope could itself be influenced by late-effects including pain or personality traits such as neuroticism. By exploring these variables longitudinally, we would have a better understating of the impact of these variables on hope in cancer survivors versus healthy controls.

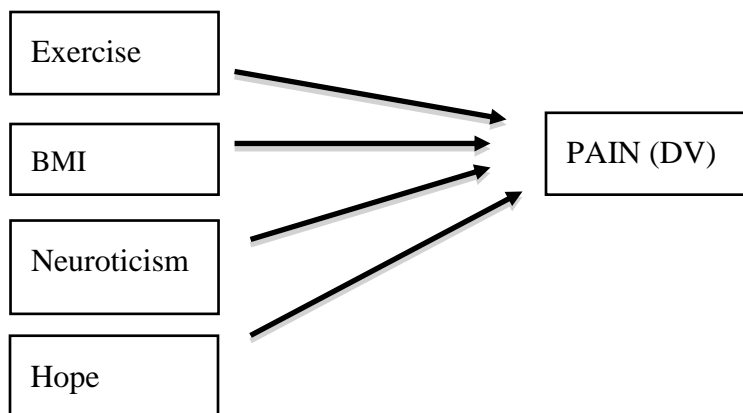
**Primary Aims:**

- 1.** The study's first aim is to determine whether ALL survivors have higher ratings of back pain than healthy controls. Additionally, the study will explore whether cancer survivors differ with regards to hope when compared to healthy controls (Figure 1).
- 2.** Second, the study will examine whether pain is influenced by exercise, BMI, neuroticism and hope and whether these variables predict pain ratings. These relationships will be analyzed in both bivariate and multivariate analyses (Figure 2).
- 3.** Third and of great interest to this study is to explore the role of hope as a construct in understanding pain and quality of life in cancer survivors; specifically, whether hope moderates subjective pain ratings and overall quality of life (Figure 3).
- 4.** The study will also examine whether pain and neuroticism influence or predict hope (Figure 4). These relationships will be analyzed in both bivariate and multivariate analyses

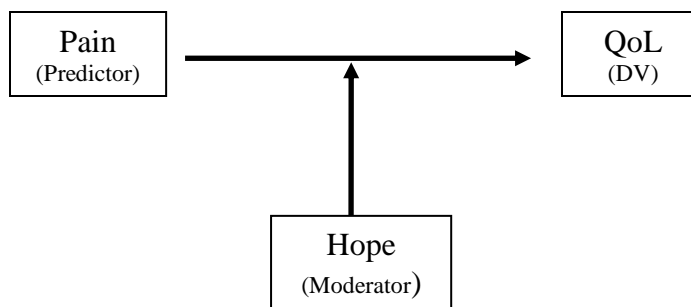
5. Finally, in aims 2-4 the study will assess whether these relationships are different for ALL survivors versus controls.



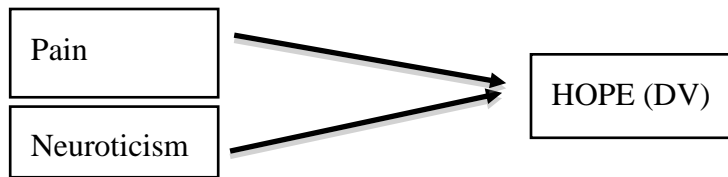
*Figure 1.* Differences between survivors and siblings on back pain and hope



*Figure 2.* Influences on Pain



*Figure 3.* Pain as a Predictor of QoL with Hope as a Moderator between the relationship



*Figure 4.* Influences on Hope

## **CHAPTER TWO**

### **Review of the Literature**

#### **DEFINITION OF HOPE**

C.R. Snyder originally defined hope as “the sum of perceived capabilities to produce routes to desired goals, along with the perceived motivation to use those routes” (Snyder, 1994, 2000); however, this definition has since somewhat been altered. Snyder and colleagues, with additional research on the history of hope, suggested more detailed and delineated definitions of hope. One such specific definition of hope was, “a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy) and (b) pathways (planning to meet goals)” (Snyder, Harris, et al., 1991; Snyder, Irving, & Anderson, 1991). Snyder and colleagues further explained hope as “a cognitive set that is based on a reciprocally-derived sense of successful agency (goal-directed determination) and pathways (planning to meet goals)” (Snyder, Irving, et al., 1991).

Historically, much skepticism was directed towards the idea of hope, which appeared to be a result of the vagueness of the concept and lack of an anchor for hope (Snyder, 2000). As described by Snyder, this anchor was set by his earliest research participants who described themselves as pursuing some desired goal (Snyder, 2000), which Snyder conceptualized as endpoints of mental action sequences (Snyder, 1994). Overall, the successful pursuit and

achievement of a goal is described as the crucial variable for increased levels of hope.

Goals are described as any objects, experiences or outcomes that people imagine and desire. A goal's definition can vary from something that is wanted, such as an object that one desires, to something to attain, such as an accomplishment of happiness in life. Moreover, goals may range from concrete, i.e., a new car, to the search for happiness, which is truly vague. Individuals pursue goals that can be achieved quickly, as well as set goals that may take planning and a long time to reach (Snyder, 1994). Hope theory is largely based on those goals that are of some magnitude or importance (Irving, Snyder, & Crowson, 1998; Snyder, Harris, et al., 1991). These goals are specific, may take a longer time to achieve, and are of great significance to the person; however, it is important that goals that are of such magnitude and importance remain realistic and within reach (Snyder, 1994). Although goals of such magnitude may be more difficult to achieve, setting smaller goals en route to more significant goals has shown to benefit levels of hope. Hope theory explains two forces by which these goals can be achieved: willpower (agency) and waypower (pathway).

Willpower is the crucial driving force in hopeful thinking and it is explained as the sense of mental energy that over time helps the individual strive toward the goal (Snyder, 1994). Also known as agency, Snyder (1994) describes this concept as a "reservoir of determination and commitment" that can help move

a person in the direction of their goal. Moreover, agency reflects the person's perception that he or she can begin moving toward one's pathway as well as reflects one's evaluation of the capability to persist in pursuing the goal ((Snyder, 2000). Thoughts such as "I can" or "I am ready to do this, and I've got what it takes" are what constitute agentic thinking (Snyder, 1994). These thoughts can initiate and sustain actions directed at a desired goal. Willpower or agency thoughts are provoked more easily when there is a clear and understandable goal. Conversely, vague goals do not provide the "mental spark" that would enable a person to sustain movement towards a goal (Snyder, 1994). The ability to produce this mental willfulness is based, somewhat, on a previous history of successfully activating the mind to pursue goals (Snyder, 1994).

A complement to agentic thinking is the notion of waypower or pathway thinking, which is described as the perceived ability to produce plausible routes toward goals ((Snyder, 2000). Pathways to the desired goals are essential for successful hopeful thought. Factors influencing the mental waypower are similar to those of willpower. Waypower or planning capabilities can be applied to many different goals, but it is generally easier to plan effectively when a goal is well defined. Similarly to willpower, waypower is based, in part, on a previous history of successfully finding one or more avenues to goal (Brunstein, 1993).

It is thus theorized that together, the agency (willpower) and pathways (waypower) enhance and continually affect each other in the pursuit of a goal.

Therefore, hope reflects a mental set in which there is perceived willpower and waypower to get to the desired goal (Snyder, 2000). However, according to Snyder, his research has consistently supported that people may at times have willpower thinking, but may lack waypower thoughts (Snyder, Harris, et al., 1991). Based on hope theory, if a person does not have both the willpower and waypower for achieving a goal, there cannot be high hope (Snyder, 1994). Overall it is crucial that for high hope both agency (willpower) and pathways (waypower) are incorporated in the road to achieving that goal. As previously mentioned, agency and pathway thinking both develop through a history of successful goal attainment. Thus it is important to understand how a barrier or blockage to achieving a desired goal can affect willpower and waypower and in turn levels of hope.

According to hope theory, unobstructed goals usually yield positive emotions, whereas barriers to goals produce negative feelings. A study by Snyder and colleagues (1996) using correlational and causal designs concluded that goal barriers were related to negative emotional responses; similarly, past research has indicated that difficulties in goal pursuits undermine well-being (Diener, 1984; Ruhlman & Wolchik, 1988). Although these barriers can produce negative emotions, it has been shown that high hope individuals appear to have a more adaptive emotional response to barriers. Thus, those with higher hope develop alternate paths to achieving their goals. Moreover, when confronted with



blockage, higher hope individuals perceive that they have alternate routes and have the predisposed agentic thinking that could lead them to exploring those alternate routes (Snyder, 1994, 2000). It is understood that those that have been able to overcome such barriers build resiliency and therefore show higher levels of hope (Snyder, 1994, 2000). This is of particular interest to the present study as children who have suffered leukemia and its course of treatment have faced a significant barrier to their goals. Considering these individuals' aversive experience, exploring levels of hope in ALL survivors could help better understand the concept of building resiliency in this population. It is assumed that the chronic illness as well as the general population will experience a barrier or blockage to goals at some point in their lives, and the way they overcome these barriers and develop hope is important to understand.

The definition of hope per Snyder, although similar, differs slightly from other constructs such as optimism and self-efficacy. Optimism focuses on the attributional process and implicitly assumes that the negative outcomes are momentous for individuals. In turn people distance themselves from the past negative outcome to which they are attached (Seligman, 1991; Snyder, 2000). Hope theory on the other hand, emphasizes agency and pathways thinking and suggests that individuals learn from negative past experience and these negative experiences may enhance they future goal pursuits (Snyder, 2000). Self-efficacy is defined as the conviction that one can successfully perform a certain task or

produce a desired outcome (Bandura, 1977). The concept of self-efficacy however is situational and the use of willpower and waypower vary based upon that situation. Conversely, the agency and pathways described in hope theory can be undertaken at both the cross-situational and situational goal pursuits (Snyder, 2000).

Exploring the construct of hope can add additional value to the oncology literature by explaining the processes of childhood cancer survivors and their methods of coping with obstacles that may come their way. Survivors of childhood cancer have already overcome an aversive experience, which could lead them to have a different outlook when thinking about and pursuing goals after their cancer experience.

#### **ACUTE LYMPHOBLASTIC LEUKEMIA**

Acute lymphoblastic leukemia is the most common type of childhood cancer in children under the age of 15 years (Society, 2009). The incidence of ALL is 1 to 2 cases per 100,000 inhabitants in Western countries per year (Munker & Sakhalkar, 2007). A bimodal age peak is usually seen in ALL: most cases occur in children (with peak incidence of 10 per 100,000 at 3 yrs) and young adults followed by a second age peak beyond 60 yrs (The Leukemia and Lymphoma Society, 2009). ALL is more pronounced in Caucasians, higher socioeconomic strata, and industrialized nations in the Western hemisphere (Munker & Sakhalkar, 2007). Additionally, there is a slight male predominance

across all age groups (Onciu, 2009). Little is known about the risk factors for childhood ALL, however it is suggested that prenatal exposure to radiation and specific genetic syndromes, such as Down's Syndrome have been associated with the disease (National Cancer Institute, 2002). The survival rate of children with ALL has greatly increased over the past 35 years. In the 1960s, 5-10% of children with ALL survived for more than five years. In contrast, the long-term survival rate today is estimated at 80-85% (National Cancer Institute, 2002).

Treatment options for children with ALL include chemotherapy, which is divided into three phases: induction, consolidation and maintenance. Due to the large number of leukemia cells at diagnosis (approximately 100 billion), killing 99.9% of these cells during the 1-month induction treatment nonetheless allows for approximately 100 million cells to remain in the body. Considering that these cells also need to be destroyed, a four to eight week intensive program of consolidation treatment and two years of maintenance chemotherapy allows for these cells to be completely destroyed (American Cancer Society, 2009).

Standard treatments usually consist of approximately 18-22 lumbar punctures (eg., spinal taps) throughout the stages of treatment, with injections of chemotherapy into the intrathecal space as treatment and prevention of leukemia relapse in the central nervous system (American Cancer Society, 2009).

Although pediatric cancer is considered a highly stressful, burdensome and even at times traumatic experience for children, children with cancer are

generally as well-adjusted as children who do not have cancer (Kazak, 2005; Patenaude & Kupst, 2005). Furthermore, studies have found that children who have been diagnosed and treated for cancer report lower symptom levels of depression and anxiety than controls (Bennett, 1994; Dejong & Fombonne, 2006). The adult oncology literature suggests that many cancer patients report gains such as deepened sense of purpose, closer relationships with family and friends, reappraisal of their life's priorities, and an enhanced spiritual life (Affleck & Tennen, 1996; Carver & Antoni, 2004). This could imply that cancer patients may adjust to life following their cancer diagnosis and treatment more adeptly due to their increased positive outlook given their experiences (i.e. deepened sense of purpose, closer relationships with family and friends, etc.); however, the child oncology literature in this area is limited.

Despite the overall positive adjustment, childhood cancer survivors often suffer late effects of treatment, including neurocognitive, psychological, cardiopulmonary, endocrine, musculoskeletal complications and second malignancies (Oeffinger, et al., 2006). A subset of ALL survivors treated with chemotherapy have shown a reduction of cortical white matter volume, which can lead to decreased performance in various domains of neurocognitive functioning, including executive function and working memory (Burgess, 1998; Carey, et al., 2008). Although, most studies report that childhood cancer survivors exhibit positive psychological adjustment, comparable to that of healthy peers (Burgess,

1998; Dejong & Fombonne, 2006; Noll, et al., 1999), results from several studies from the Children's Cancer Group (CCG); (Glover, 2003) and the Childhood Cancer Survivors Study (CCSS); (Hudson, Mertens, Yasui, Hobbie, Chen, Gurney, Yeazel, Reclitis, et al., 2003; Schultz, 2007) examining psychosocial outcomes in adolescent and adult childhood cancer survivors suggest that those particularly treated for leukemia reported some elevations in depressed mood, somatic symptoms, anxiety, and social/interpersonal problems as compared to healthy controls. These studies of long-term childhood ALL survivors suggest that some individuals may be susceptible to psychological distress; however, little appears to be known regarding the reasons why some survivors function better psychosocially and others may not. One hypothesis may be that some ALL survivors experience negative late physiological effects that could in turn affect their psychosocial functioning.

A late effect of childhood cancer therapy that is suggested in the current study and has not been widely researched is lower back pain. Although there is a paucity of literature of back pain related to childhood cancer treatment, a recent study examining the late occurring effects among childhood ALL survivors and their siblings concluded that relative to the sibling control group, ALL survivors were at an elevated risk for "late pain sensation" (Goldsby, Taggart, & Ablin, 2006). The current study proposes trauma from lumbar punctures during the

standard course of leukemia treatment as one possible mechanism for back pain among this group of cancer survivors.

As noted, previous research has indicated that both psychological and physical factors are a part of the late effects of ALL treatment. Of particular interest in this study is the prevalence and mechanisms of back pain in leukemia survivors. Considering that known mechanisms of back pain include both physiological and psychological factors, examining these aspects could contribute greatly to the oncology late effects literature.

### **BACK PAIN**

Chronic localized and widespread pain affects about 50 percent and 10 percent of Americans, respectively (Croft, Rigby, Boswell, Schollum, & Silman, 1993; Portenoy, Ugarte, Fuller, & Haas, 2004). The prevalence of chronic back pain in the general adult population is estimated at 10 to 20 percent (Blyth, et al., 2001; Dekkers, 1998; Gureje, Von Korff, Simon, & Gater, 1998). Throughout the literature, chronic pain is associated with substantial psychological distress, functional impairment, and disability (Von Korff, Ormel, Keefe, & Dworkin, 1992; Wolfe & Haveman, 1990).

Anecdotal evidence, gathered from the cancer survivor clinic at Children's Medical Center in Dallas has pointed to increased prevalence of back pain in ALL survivors. As previously mentioned, this increase of reported pain among survivors is suggested to be a result from the multiple lumbar punctures these

individuals receive during treatment. Although to date no research has examined increased prevalence of back pain in ALL survivors, it has been suggested that childhood survivors of ALL experience some pain attributed to vertebral periosteal infiltration, malignant expansion of the marrow cavity, or severe osteoporosis. The onset of these complications is usually during or following treatment of ALL (Abbas, et al., 2004).

The mechanism of pain is described as multidimensional, and it is thus important to understand a person's perception and response to pain and illness from not only a biological perspective, but psychological status and sociocultural context (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). Therefore, in addition to the proposed hypothesis of increased back pain in ALL survivors, other physiological and lifestyle factors that contribute to chronic pain are examined. Increased weight or obesity is one of several factors that are suspected of exacerbating back pain. Other studies have indicated a positive relationship between chronic back pain and obesity and sedentary lifestyle (Adera, Deyo, & Donatelle, 1994). From a psychological perspective, factors such as neuroticism and general view of quality of life (QoL) can additionally impact pain perception. Experiencing negative, distressing emotion and having an overall negative view of life has pointed to increased ratings of subjective pain in much of the literature (Calabrese, Lyness, Sorensen, & Duberstein, 2006; Eisenberger, Jarcho,

Lieberman, & Naliboff, 2006; Melzack & Wall, 1965; Petersen, Hagglof, & Bergstrom, 2009; Russo, et al., 1997).

Although the literature is very limited with regards to the role of hope as related to pain perception, some studies have examined the impact of a similar construct, self-efficacy, on chronic pain. In chronic pain, these studies concluded that self-efficacy beliefs predict pain tolerance and positively affects physical and psychological functioning (Asghari & Nicholas, 2001; Keefe, Lefebvre, Maixner, Salley, & Caldwell, 1997; Rudy, Lieber, Boston, Gourley, & Baysal, 2003). These findings could be an indicator that the construct of Hope highlighted in the present study could potentially have influence on ALL survivors' pain ratings. Together, with exercise, neuroticism and QoL, the current study hopes to thoroughly examine the role of these variables in ALL survivors versus healthy controls.

### **Influences on Pain**

#### *Exercise*

In the general population, physical activity decreases the risk of mortality and may also prevent the development of various cancers (Lee, 1995; Leon, 1987; Ness, et al., 2007). Some evidence supports the notion that a healthy lifestyle, which includes an adequate amount of physical activity, has potential to prevent many of the long-term problems experienced by childhood cancer survivors (Clark, 2007). Due to the treatment necessary for cancer remission, ALL



survivors are at an increased risk for obesity and this risk increases with length of follow-up (Warner, 2008). Moreover, they may experience diminished strength and mobility, decreased participation in physical exercise and total daily energy expenditure (Ness, et al., 2007; Warner, 2008). Florin and colleagues (2007) followed a large sample in the Childhood Cancer Survivor Study (CCSS) to determine the level of physical activity in adult survivors of childhood ALL. They concluded that long-term survivors of ALL are less likely to meet physical activity recommendations and more likely to report leisurely levels of physical activity (Florin, et al., 2007). Physical activity is important for both chronically ill populations and the general populations and, as noted above, has an impact on health and life longevity and could affect an individuals' overall QoL.

There is substantial amount of literature that points to a link between exercise and QoL. A long running longitudinal study that examined exercise and mental well-being concluded that exercise improves one's ability to enjoy life (Vaillant, 2003). Moreover, exercise was found to improve depressive symptoms, decrease stress and improve QoL (Atlantis, Chow, Kirby, & Singh, 2004). However, little is known regarding the relationship of hope and exercise. Considering that individuals that exercise set goals of how often and long to exercise, high levels of hope may be beneficial for this particular aspect of life-style. If those individuals that have higher levels of hope indeed exercise more, it would be interesting to understand how physical activity influences levels of

reported pain over and above physiological (BMI) and psychological (neuroticism) contributors to pain.

### *Neuroticism*

Neuroticism is a relatively stable trait and is characterized by a tendency to experience negative, distressing emotion. Moreover, individuals high in neuroticism are marked by hypervigilance and by reacting overly emotionally without having the capacity to regulate emotion adequately (Costa & McCrae, 1985; Ormel & Wohlfarth, 1991). With regards to chronic illness, individuals high on the neuroticism trait are assumed to be predisposed to worry, regardless of the presence or absence of threats, and report more subjective health complaints (Costa & McCrae, 1980a, 1980b, 1985). Additionally, research has supported the hypothesis that personality traits such as neuroticism have been related to the perception of health rather than to objective health status (Smith & Williams, 1992).

Larsen (1992) reported that neuroticism appears to be associated with a tendency to recall physical symptoms as being worse than they were in reality. Several other studies have concluded that those individuals with higher levels of neuroticism, as measured by the MMPI-2, the NEO Five Factor Inventory (NEO-FFI) or the Eysenck Personality Questionnaire (EPQ), reported lower self-rated health status and higher levels of pain (Chapman, Duberstein, & Lyness, 2007; Gilhooly, Hanlon, Cullen, Macdonald, & Whyte, 2007; Pheasant, Gilbert,

Goldfarb, & Herron, 1979). Recently, Jerant and colleagues (2008), in a study measuring personality traits and self-reported health, concluded that neuroticism was associated with worse subjective health ratings as well as worse depression and anxiety (Jerant, Chapman, & Franks, 2008).

Exercise is a lifestyle choice that may already be significantly declined in patients with chronic illness, particularly individuals who have experienced cancer (Courneya & Friedenreich, 1999). Research has shown that personality traits may be an additional determinant of exercise behavior (Courneya & Friedenreich, 1999). Rhodes, Courneya and Bobick (2001) investigated the relationship between personality and exercise participation across the breast cancer experience. They concluded that neuroticism was associated with maladaptive exercise patterns during treatment. Furthermore, higher levels of neuroticism may not only impair regular exercise during treatment, but also post treatment (Rhodes, Courneya, & Bobick, 2001).

Considering that research suggests that neuroticism has an impact on perceived health and pain as well as lifestyle choices in those with chronic illness, it is possible that those individuals high in neuroticism would indicate poorer QoL. Kempen, Jelicic and Ormel (1997) studied the impact of personality traits on the association between chronic medical morbidity and six different domains of health related QoL in patients with varying chronic medical conditions. The study concluded that personality factors, such as neuroticism, influenced self-

reported QoL, regardless of the type of medical morbidity. (Kempen, Jelacic, & Ormel, 1997).

Unfortunately, hope and neuroticism has not been vastly studied; however, there have been associations between neuroticism and general self-efficacy. One study found that the estimated correlation of the population between neuroticism and self-efficacy is  $-0.62$  (Judge, Erez, Bono, & Thoresen C.J, 2002).

Neuroticism would be interesting to explore in the current study to determine how it affects both survivors' and controls' QoL, pain perception, levels of hope and lifestyle choices.

### **QUALITY OF LIFE**

The World Health Organization (WHO) defines QoL as “individuals' perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards and concerns” ((WHO), 1995). Fortunately, research has shown that the majority of cancer survivors do not appear to suffer negatively from their illness experience (Zebrack & Chesler, 2002). These individuals appear to be in good physical health and function well psychologically and socially (Calaminus & Kiebert, 1999; Langeveld, Stam, Grootenhuis, & Last, 2002). Similarly, most of the literature that specifically focuses on psychological and/or social ratings of QoL indicates that cancer survivor do not differ than healthy controls in ratings of these domains of QoL; however, some studies found conflicting results.

Several studies reported that psychological or emotional aspects of QoL were found to have small to no significant differences between survivors and comparison groups (Blaauwbroek, et al., 2007; Langeveld, Grootenhuis, Voute, de Haan, & van den Bos, 2004; Maunsell, Pogany, Barrera, Shaw, & Speechley, 2008; Speechley, Barrera, Shaw, Morrison, & Maunsell, 2006; Stam, Grootenhuis, Caron, & Last, 2006). Other studies reported higher psychological quality of life in terms of depression, anxiety, somatization and global distress when comparing cancer survivors and controls (De Clercq, De Fruyt, Koot, & Benoit, 2004; Pemberger, et al., 2005; Zeltzer, et al., 2008). Yet others reported that if survivors experienced late-effects, they were likely to report lower psychosocial quality of life (Zebrack & Chesler, 2002).

Social well-being was also variable in the literature. Most studies found small to no significant differences between survivors and comparison groups (Blaauwbroek, et al., 2007; De Clercq, et al., 2004; Gurney, et al., 2007; Zeltzer, et al., 2008). On the contrary, several studies reported that survivors had significantly poorer ratings than matched comparison groups or population samples with respect to social role limitations due to physical functioning as well as emotional functioning. These studies also varied with regards to gender, type of cancer and age since diagnosis (Maunsell, et al., 2008; Speechley, et al., 2006).

When considering physical functioning alone, most studies indicated that cancer survivors report better or as good overall physical functioning as same age-

and sex- matched population samples (De Clercq, et al., 2004; Speechley, et al., 2006). Stam and colleagues (2006), however, found that survivors showed worse QoL than an age- and sex-matched comparison group with respect to overall physical summary score (Stam, et al., 2006). Several other studies that compared survivors to age- and sex-matched comparison groups found small, yet significant differences indicating that survivors rated poorer QoL in the physical functioning domain, general health and vitality (Langeveld, et al., 2004; Zeltzer, et al., 2008). Additionally, Speechley et al. (2006) reported seven survivor diagnostic groups that had considerably poorer mean physical summary scores compared to controls, one of which was childhood survivors of leukemia. These scores varied with demographic variables as well as treatment type (Speechley, et al., 2006).

Although it is encouraging that most childhood cancer survivors report an overall positive QoL in domains of physical and psychosocial functioning, it is important to note that survivors of childhood cancer may experience late negative consequences related to the disease. Approximately 60 percent of childhood cancer survivors have reported one or more late physical effects (Stevens, 1998; von der Weid & Beck, 1993). These include cardiopulmonary, renal, or endocrine dysfunction, neurocognitive impairments, the development of secondary cancers and infertility (McDougall & Tsonis, 2009). Considering that ALL is one of the most common childhood cancers, individuals who have been treated for this type of cancer may be at a risk for developing some of these

physiological late effects. Furthermore, in view of the hypotheses that ALL survivors have a higher prevalence of back pain resulting from multiple lumbar punctures, it is expected that survivors of ALL may have additional physiological late effects that could hinder QoL.

The burden of these physiological late effects may increase the likelihood that survivors who experience them will also experience psychological and functional impairments. Studies have found that survivors who report substantial late physical effects demonstrate that their happiness, feeling useful, life satisfaction and ability to cope as a result of having had cancer is overwhelmed with uncertainty (Zebrack & Chesler, 2002). A recent study from the Childhood Cancer Survivor Study (CCSS) conducted a study measuring QoL of 9535 childhood survivors from which results suggested that the general health as perceived by adults surviving childhood cancer is very good with only 10.9 percent reporting generally fair or poor health; however, long-term adverse effects in specific aspects of health were relatively common as reflected by 43.6 percent of the cohort, reporting impairment in one or more of the health domains evaluated in the study (Hudson, Mertens, Yasui, Hobbie, Chen, Gurney, Yeazel, Recklitis, et al., 2003; Hudson, Mertens, Yasui, Hobbie, Chen, Gurney, Yeazel, Reclitis, et al., 2003). As discussed, considerable difficulties remain for survivors with respect to late-effects and although doing well overall, some continue to

express concerns about the quality of their lives with respects to certain aspects of physical, psychological, and social well-being (Zebrack & Chesler, 2002).

One such late-effect that is proposed in the current study is back pain. Although most chronic pain conditions are not life threatening, they may constitute considerable burden for adolescents and young adults. Studies of chronic pain (i.e. chronic back pain or headache) and its relationship to QoL suggest a positive relationship between pain and psychological distress as well as somatic complaints (Andrasik, et al., 1988; Balague, et al., 1995; Brattberg, 1994; Hunfeld, et al., 2001). Other studies found the presence of pain to interfere with schoolwork or leisure activities (Taimela, Kujala, Salminen, & Viljanen, 1997). Similarly, recent studies suggest that children with recurrent pain conditions may experience general impairment of their QoL (Varni, Limbers, & Burwinkle, 2007).

Overall, most of the literature suggests variable findings with regards to the different domains of QoL of cancer survivors, ranging from no differences to poorer QoL for cancer survivors. This variability may be contributed to physiological late-effects, such as back pain, which could lower ratings of QoL. However, the literature does suggest that survivors of childhood cancer are capable of having an overall positive QoL in domains of physical and psychological health as well as social functioning. It is suggested that this positive QoL in most survivors could be contributed to other constructs, such as



hope or optimism in general. Despite the lack of research on hope and QoL some studies have tested similar constructs with regards to functioning and overall life satisfaction.

Weinberg and colleagues (1979) developed an adaptive style paradigm, which uses subjective distress (e.g., trait anxiety) and defensiveness as a measurement to determine level of coping and well-being. Weinberg and colleagues have shown that the repressive adaptive style, which is characterized by awareness of emotional distress, having a positive sense of self and thoughts of being well adjusted, self-controlled and content, was found in patients with cancer (Weinberger, Schwartz, & Davidson, 1979). Furthermore, when assessing QoL in children with cancer, children identified as having a repressive adaptive style reported higher QoL regardless of their health status (children with cancer versus controls); (Jurbergs, Russell, Long, & Phipps, 2008). Therefore, the repressive adaptive style in children with cancer has been beneficial and could provide some guidance as to these children's lack of adjustment difficulties. In general, the positive psychology literature suggests that optimism, finding meaning during the cancer experience, and having a positive sense of self may lead to an increased QoL, well-being and adjustment in children and adults with cancer.

The construct of hope proposed in the current study could better explain why some survivors, despite late physical effects, have overall positive QoL

ratings. Moreover, those with higher hope may cope with their pain more effectively and in turn have higher QoL.

## HOPE

### **Influences on Hope**

#### *Developmental Aspects*

Goal directed thinking begins as a child is born (Snyder, 2000). Children quickly begin to understand the chronology to the important events in their lives, i.e., signs that would lead them to being fed (Schulman, 1991). Thus pathways to achieving goals are developed as early as birth and arise prior to agency thoughts. Agency thoughts, on the other hand, begin to develop the first few months to 21 months as children begin to recognize their capacities and volitions and even begin using words that suggest that they understand they are the instigator of their happenings (i.e. I want); (Snyder, 2000). It is important to note that the rise of both agentic and pathways thinking is fostered by basic guidance from a caregiver who is a positive model (Snyder, 1994). However, due to the stressful challenges that the adolescent years bring, it has been suggested that levels of hope have a tendency to somewhat decline during this stage of development (Heaven & Ciarrochi, 2008; Larson, Moneta, Richards, & Wilson, 2002). As the adolescent moves in to adulthood, hope appears to generally be more stable (Snyder, 2000).

*Chronic Illness and Hope*

Chronic illness can affect hope through its impact on both agentic and pathways thinking and hindering the achievement of goals. Although hope is a relatively new construct and not widely studied in chronic illness populations, studies have shown that patients suffering a sudden, severe physical trauma or illness, achieving even the small usual tasks such as going to work or doing household chores can be more difficult. While some may be able to maintain goal-directed willpower despite their physical limitations, many view that their goal pursuits and even lives come to a stop (Snyder, 2000); accordingly, people with physical disabilities were found to have lower levels of hope, which was predictive of depression and psychological impairment (T. R. Elliott, Witty, Herrick, & Hoffman, 1991). In addition, these researches concluded that individuals with a low sense of agency had higher levels of impairment following injury, whereas individuals with low pathways thinking had greater psychological impairment as the length of disability increased (T. R. Elliott, et al., 1991; Rustoen & Wiklund, 2000).

A study which included patients with heart failure, showed higher levels of hope than healthy controls; however, the study suggested that heart patients with comorbid disorders, such as skin conditions and psychiatric difficulties, had lower levels of hope (Rustoen & Wiklund, 2000). This suggests that cancer survivors in the current study may show higher levels of hope versus controls,

with the exception of those participants that are experiencing a comorbid condition, such as back pain.

### *Cancer and Hope*

ALL is one such illness that can be a significant barrier to goals, and due to its prominence in children, it has the potential to disrupt the development of hope. Conversely if individuals with ALL have high hope, which may be due to overcoming an obstacle such as cancer, their levels of hope may make them more adept at coping with elevated levels of pain. This is of particular interest to the current study, as any evidence that levels of hope in ALL survivors differ from that in controls can provide further justification for intervention with children suffering from this illness.

Hope as defined by Snyder has not been widely researched in the cancer population; however, several studies using the Hearth Hope Index and interviews revealed that hope scores were relatively high among patients with cancer regardless of a hope intervention and closeness to death (Ballard, Green, McCaa, & Logsdon, 1997; Benzein & Berg, 2003; Hammer, Mogensen, & Hall, 2009). Hammer, Mogensen and Hall (2009), conducted a study using the Hearth Hope Index as well with women suffering from gynecological cancer, which found hope to be related to love and being loved. Additionally, love and close relationships activated thoughts and feelings of well-being and “released hope into energy and action” (Hammer, et al., 2009). This finding relates to those in

the positive psychology literature, which suggest that adults with cancer often form closer relationships with friends and family through the cancer experience, therefore having a greater sense of well-being.

Although the adult literature suggests that hope did not differ or was at times even higher among patients with chronic illness, children with chronic illness may experience their illness differently. Snyder (2002) explained that a child's hopeful thinking may be disrupted in two ways by chronic illness: it may be impeded as a child fails to establish or learn hopeful thinking, and second, established hopeful thinking may be blocked by such a traumatic event. In addition, chronic illness may deprive children and parents of the desire to engage in life's normal goal pursuits (Snyder, 2000). Conflicting results have been found with regards to hope levels upon diagnosis and through the course of a chronic illness. (Zook & Yasko, 1983) reported a decrease in hope as time since diagnosis in cancer patients; however, (Greene, O'Mahony, & Rungasamy, 1982) suggested that there was no correlation between hope and time since diagnosis. An explanation for these conflicting findings may be the presence of other variables that can have an impact on levels of hope. Research findings have pointed to several factors that influence higher hope levels throughout chronic illness including, self-efficacy, spirituality and positive social functioning (Choenarom, Williams, & Hagerty, 2005).

Given the conflicting research on the impact of chronic illness on hope as well as the paucity in literature on childhood leukemia survivors, the present study will attempt to delineate the role that hope plays in survivors of ALL. Although some of the adult literature suggests that hope does not differ in those with and without chronic illness, it has been shown that the possibility of comorbid conditions could affect hope. One goal is to understand how survivorship contributes to levels of hope as well as determine a better understanding of the relationship between hope, chronic pain and QoL.

### **Impact of Hope**

There is a growing body of literature that the notion of hope functions to drive adaptive behavior. Hope has been positively associated with behavioral outcomes, including coping and problem solving (Bellizzi & Blank, 2006), academic and athletic performance (Ciarrochi & Heaven, 2008), and higher job performance (Peterson & Bayron, 2008). Studies have also found hope to be of great benefits on well-being and coping with chronic illness (Snyder, 2000). Higher hope has been related to better pain management in arthritis (Laird, 1992), fibromyalgia (Affleck & Tennen, 1996) and motor vehicle injuries (Elliot & Kurylo, 2000). Moreover, Snyder et al. (2005) concluded that high hope students evidenced higher pain thresholds, higher pain tolerance, and lower reported pain severity on a cold pressor task. This suggests that with regards to pain, hope may

promote the search for alternative goals, such as minimizing pain, or new routes to existing goals (Snyder, et al., 2005).

The benefits of having increased hope are clearly delineated by the literature, particularly in individuals with chronic illness or those suffering from pain. Considering all of the factors that contribute to the development and maintenance of hope, the current study's goal is to better understand the role that hope plays in the relationship between pain and QoL in ALL survivors compared to their siblings. Results from the study could lead to implications for a hope intervention with children diagnosed with ALL during early stages of diagnosis or throughout treatment.

### **HYPOTHESES**

**Aim 1:** The study's first aim is to determine whether ALL survivors have higher ratings of back pain than healthy controls. Additionally, the study will explore whether cancer survivors differ with regards to hope when compared to healthy controls.

Hypothesis 1: ALL survivors will have higher pain ratings than healthy controls.

Hypothesis 2: Survivors of ALL will exhibit higher levels of hope when compared to controls. Based on the literature, children who experience aversive events (i.e. childhood leukemia) build resilience and may therefore have higher levels of hope.

**Aim 2:** Second, the study will examine whether pain is influenced by exercise, BMI, neuroticism and hope and whether these variables predict pain ratings. These relationships will be analyzed in both bivariate and multivariate analyses. When looking at pain as a dependent variable and exercise, BMI, Neuroticism and hope as independent variables both cross-sectionally and longitudinally, the study hypothesizes the following relationships:

Hypothesis 3: Exercise will have an inverse relationship with pain

Hypothesis 4: BMI will have a positive relationship with pain

Hypothesis 5: Neuroticism will have a positive relationship with pain

Hypothesis 6: Hope will have an inverse relationship with pain

The study will also examine the differences in these relationships for survivors and controls (Aim 5).

Hypothesis 7: Survivor status will not have an impact on the relationship between pain and the variables of exercise, BMI and neuroticism; however, as mentioned in Hypotheses 1 and 2, it is expected that survivors will have both higher hope levels and higher pain levels than healthy controls. Therefore the study suggests that when interacting with survivorship status (moderator), the strength of the relationship between hope and pain will decrease.

**Aim 3:** Third and of great interest to this study is to explore the role of hope as a construct in understanding pain and quality of life in cancer survivors;



specifically, whether hope moderates subjective pain ratings and overall quality of life.

Hypothesis 8: Pain will predict QoL and the two will have an inverse relationship; however, the relationship will be moderated by hope. Having higher levels of hope will buffer (moderate) the detrimental effects of pain on QoL. Therefore, it is expected that those with high hope will have higher QoL despite pain, while those with low hope will have poorer quality of life.

**Aim 4**: The study will also examine whether pain and neuroticism influence or predict hope. These relationships will be analyzed in both bivariate and multivariate analyses

Hypothesis 9: The study hypothesizes that both pain and neuroticism will have an inverse relationship with hope.

The study will also examine the differences in these relationships for survivors versus controls (Aim 5)

Hypothesis 10: When examining interaction effects of survivor status on the relationship between pain and hope, there will be a weaker relationship between pain and hope for survivors only (as compared to healthy controls). The literature suggests that hope is fostered when an individual successfully overcomes barriers, which indicates that they may maintain

hope despite pain. Survivor interaction with relationship between neuroticism and hope is not expected.

## **CHAPTER THREE**

### **Methodology**

The proposed study has been reviewed and approved by both The University of Texas Southwestern Medical Center Institutional Review Board as well as Children's Medical Center Dallas.

### **PARTICIPANTS**

Participants in the study included survivors of childhood acute lymphoblastic leukemia (ALL) for more than five years. ALL survivors' siblings between ages 13 to 25 were used as a control group. Subjects were identified through the After the Cancer Experience (ACE) database of survivors of childhood (<18 years old at diagnosis) ALL and range from 13 to 25 years of age. The study included N=165 participants that were identified through the database. Identified survivors must be in first complete remission and had not undergone stem cell transplant. Additionally, patients with a history of prior surgical procedures on the spine and known orthopedic abnormalities of the spine (e.g., severe scoliosis, spina bifida, osteoarthritis, ankylosing spondylitis, degenerative disk disease, etc.) were excluded from the study.

## **PROCEDURE**

Identified survivors (N=165) were mailed a survey packet (packets were mailed in January, 2010) which included a cover letter informing the potential participants of the nature of the study, stating the study is voluntary and asking them to complete the survey and to identify a sibling(s) within the age range to also complete the survey. Upon completion of the survey, study participants and their siblings were asked to mail the survey back to the investigators in a self-addressed and stamped envelope. Three consecutive mailings (approximately one month apart; February, March and April of 2010), to those who had not yet responded, were conducted to increase response rate. Reminder phone calls were also completed at the time of the third mailing. Participants who indicated agreement by providing contact information on the initial survey were contacted via phone or e-mail 3 months following completion of the mail-in survey (process began in June).

## **MEASURES**

The mailed packets included self-report measures such as an investigator generated Pain and Coping Survey, Physical Activity Questionnaire (Centers for Disease Control and Prevention, 2009), Peds QL: Pediatric Pain Questionnaire (Varni, Seid, & Kurtin, 2001), and Peds QL: Pediatric QoL Inventory (Varni, et al., 2001). Psychological measures included the Adult Dispositional Hope Scale (Snyder, Harris, et al., 1991) and Eysenck Personality Questionnaire-Brief

Version (EPQ-BV); (Sato, 2007). At the 3 month time point, participants were asked to complete the Adult Dispositional Hope Scale, Peds QL:Pediatric Pain Questionnaire and Peds QL: Pediatric Quality of Life Inventory to assess any changes over time in hope, pain, and QoL, respectively.

### **Pain and Coping Survey**

The Pain and Coping Survey, which was developed by the research investigators, included demographic data such as gender, age, ethnicity, height and weight. In addition, the survey measured presence, duration, frequency and severity of pain as well as contributors to pain and ALL treatment variables (Appendix A).

### **Physical Activity Questionnaire**

The Physical Activity Questionnaire (Appendix A), was adapted from the National Center for Chronic Disease Prevention and Health Promotion Behavioral Risk Factor Surveillance Survey (CDC, 2009). The questionnaire was slightly modified for the purposes of this study with the permission of the Center for Disease Control and Prevention (CDC). It contains items referring to the number of days and time of moderate and vigorous activity as well requirement for both types of activity. It is required that the participant exercise five or more days a week for at least thirty minutes in order to meet requirements for moderate activity and three or more days a week for at least 20 minutes for vigorous activity (CDC, 2009).

**PedsQL: Pediatric Pain Questionnaire (PPQ)**

The PPQ (Appendix A) was developed as an adaptation for children and adolescents from the adult McGill Pain Questionnaire (Melzack, 1975) and designed to be sensitive to the cognitive-developmental conceptualizations of children and adolescents. Given that the measure was adapted and modified from an adult measure for pain, the PPQ, in the present study, was used as indicated by the PPQ (age range 13 to 18 years) as well as the study's young adult population (18 to 25 years). The questionnaire consisted of a 10 cm horizontal line with no numbers, marks, or descriptive vocabulary words along the length of the line. The rating included present pain and worst pain intensity for the previous week. Additionally, the questionnaire asked individuals to indicate the location of their pain by marking it on a body diagram (Varni, Thompson, & Hanson, 1987).

Reliability and Validity for the PPQ are well established with test-retest reliability ranging from .29 to .41 and inter-rater correlations of .40 to .85. Convergent validity with disease status ranged from .27 to .68 and psychological functioning ranged from .06 to .45 (Varni, et al., 1987).

**Peds QL: Pediatric Quality of Life Inventory**

The PedsQL: Pediatric Quality of Life Inventory (Appendix A), developed at Children's Hospital and Health Center, San Diego, California, is an instrument measuring health related quality of life in children, adolescents and young adults ages 2 to 25 (Varni, et al., 2001). The PedsQL Generic Core Scales consist of 23

items applicable for health school and community populations, and pediatric populations with acute and chronic health conditions. These scales measure functioning in four different domains: physical, emotional, social, and school or work.

Studies have shown that the PedsQL demonstrates both good reliability and validity. Internal consistency for the Total Scale Score ( $\alpha = 0.88$ ), Physical Health Summary Score ( $\alpha = 0.80$ ), and Psychosocial Health Summary Score ( $\alpha = 0.83$ ) were as so for group comparisons. Validity was demonstrated using the know-group methods, correlations with indicators of morbidity and illness burden, and factor analysis. The PedsQL was able to distinguish between healthy children and pediatric patients with acute or chronic health conditions, was related to indicators of morbidity and illness burden, and displayed a factor derived solution consistent with the a priori conceptually-derived scales (Varni, et al., 2001).

### **Adult Dispositional Hope Scale (“The Goals Scale”)**

The Hope Scale (Snyder, Harris, et al., 1991); (Appendix A) is a self-report inventory consisting of 12-items to tap an individual’s dispositional hope in adolescents and adults, ages 15 and older. Labeled the “Goals Scale,” it requires approximately 2 to 5 minutes to be completed and does not require a high level of reading ability. Due to some of the overlap in items with the Children’s Hope Scale and the minimal reading requirement, the current study used this measure in

adolescents and adults that are 13 years of age or older. In order to encourage more diverse responding, the scale is on an 8-point continuum (1=Definitely False to 8= Definitely True). The total score ranges from a low of 8 and a high of 64. The scale is divided into four items reflecting agency, four reflect pathways and four items are distracters.

Reliability studies indicated that Cronbach alpha for the total score ranged from 0.74 to .84 for six samples of undergraduate college students and two samples of individuals in psychological treatment. Test-retest correlations have been .80 or above over periods exceeding 10 weeks (Snyder, Harris, et al., 1991). Exploratory and confirmatory factor analysis revealed the existence of a two-component model of hope (i.e., pathways and agency). Concurrent construct validity indicated that the Hope Scale is highly correlated with responses to several scales tapping similar psychological processes, i.e. 0.50 to 0.60 with scores on measures of optimism, expectancy for attaining goals, the amount of expected control, and self-esteem. The Hope Scale also correlated inversely with the Beck Hopelessness Scale and the Beck Depression Inventory,  $r = -0.51$  and  $-0.42$ . Discriminant validity was measured by comparing the Hope Scale to the Self-Consciousness Scale. Results revealed that the scores of the Hope Scale and the two subscales of public and private self-consciousness were not highly correlated,  $r$ s of .06 and  $-0.03$  respectively (Snyder, Harris, et al., 1991).

#### **Eysenck Personality Questionnaire- Brief Version (EPQ-BV)**



The EPQ-BV (Appendix A) is a newly revised version of the Eysenck Personality Questionnaire-Short to measure individuals on two primary personality traits in Eysenck's (1990) theory. It consists of two measures, one for extraversion and one for neuroticism. The questionnaire consists of 24 items; 12 extraversion and 12 neuroticism. For the purpose of this study, only the 12 neuroticism items were utilized. Items on this scale range in responses from (1) not at all to (5) extremely (Sato, 2005).

In validation studies of the EPQ-BV, two hundred and sixty eight participants completed the original EPQR-S and the 24-item newly revised briefer version of the EPQR-S (EPQ-BV) two times. The findings revealed that the EPQ-BV has good internal consistency (0.92 and .90 test-retest reliability (0.92), and concurrent validity. A principal component analysis revealed a solution with factor loadings that accurately reflected the primary measures of the EPQR-S, i.e., extraversion and neuroticism (Sato, 2005).

## **DATA ANALYSIS**

### **Data Collection Procedures**

To maintain confidentiality and protect data, all data was stored in locked filing cabinets in locked offices. Data was entered into the latest version of Microsoft *Excel*. To ensure accuracy of data entry, all data was double-entered by separate research assistants. Values were compared using Microsoft *Excel*,

according to the procedures outlined by A. C. Elliott, Hynan, Reisch, & Smith (2006). Any inconsistencies in the data entry were resolved by agreement between at least two research assistants and re-entered. Clean data was transferred and analyzed using Statistical Package for the Social Sciences, Version 17.0 (SPSS).

### **Statistical Analyses**

Descriptive statistics were used to identify demographic features, height, weight, BMI, physical activity, and treatment-related variables [cranial radiation therapy (yes vs. no)] for a possible association with the subsequent development of back pain.

#### *Differences between ALL survivors versus controls*

One-Way Analysis of Variance (ANOVA) was utilized in order to determine group (i.e., survivors versus controls) differences on measures of back pain and hope.

#### *Influences on Pain*

Influences on pain (i.e., exercise, BMI, neuroticism and hope) were analyzed using multivariate regression analysis. In order to determine if these variables are predictors of back pain (DV), pain measures collected at Time 2 (3-month follow-up) and all other variables (exercise, BMI, neuroticism and hope) collected at Time 1 were used, controlling for pain ratings at Time 1 in the longitudinal analysis. A multiple linear regression can also help us determine

which of these predictors accounts for most of the variance contributing to pain. The interaction of the predictors with survivorship status was also tested and was utilized to better understand whether ALL survivors differ with regards to these variables from healthy controls.

#### *Hope as a Moderator for Pain and QoL*

Multivariate regression analyses were also utilized to determine the predictive relationship between pain (predictor) and QoL (dependent variable). While controlling for QoL at Time 1 the study looked at the predictive quality of pain from Time 1 to QoL at Time 2. Within the regression analysis we examined hope as a moderator between pain and QoL (Time 1 hope; Time 1 hope x pain and Time 2 QoL). An interaction of predictors with survivorship status was also tested using this model.

#### *Influences on Hope*

Possible influences on hope (i.e., pain and neuroticism) were analyzed using multivariate regression analysis. In order to determine if these variables are predictors of hope (DV), hope measures collected at Time 2 (3-month follow-up) and all other variables collected at Time 1 were used, while controlling for Time 1 hope. A test for interaction of the predictors with survivorship status was utilized to better understand whether ALL survivors differ with regards to these variables from healthy controls.

## CHAPTER FOUR

### Results

#### Descriptive Statistics

Descriptive statistics of the overall sample during the initial and follow-up screening are detailed in Table 1. The overall sample for the initial mailing included  $N = 145$  participants; of these, 66.2% ( $n = 96$ ) were ALL survivors and 33.8% were siblings (control group) ( $n = 49$ ). For the 3-month follow up,  $N = 107$  returned the survey, 78.5% ( $n = 84$ ) of which were ALL survivors and 21.1% ( $n = 23$ ) were siblings. There were no differences at time 1 (T1) and time 2 (T2) data collections between survivors and siblings on age, gender, and ethnicity. Additionally, no differences between groups or time points were found in height, weight, BMI, vigorous exercise, neuroticism, hip pain or other variables such as smoking and treatment with radiation therapy. Results indicated a difference between groups for minutes of moderate exercise at T1 only,  $F(1, 77) = 6.40, p < .05$ .

#### Age and gender difference in neuroticism, pain, hope and QoL

Psychological variables and pain were analyzed for differences according to age and gender. Differences based on age were not found in the sample for pain, hope, neuroticism or QoL. Women ( $M = 2.36, SD = 3.09$ ) endorsed higher back pain ratings than men ( $M = 1.38, SD = 2.25$ ),  $F(1, 148) = 4.95, p < .05$ ,

Partial  $\eta^2 = .032$ , and women ( $M = 77.38$ ,  $SD = 15.65$ ) also reported lower QoL than men ( $M = 87.26$ ,  $SD = 10.88$ ),  $F(1, 136) = 18.61$ ,  $p < .01$ , Partial  $\eta^2 = .120$ . Neuroticism scores were higher in women ( $M = 26.38$ ,  $SD = 9.77$ ) than men ( $M = 21.52$ ,  $SD = 6.92$ ),  $F(1, 149) = 12.52$ ,  $p < .01$ , Partial  $\eta^2 = .078$ . Gender was not associated with hope scores. Age and gender were used as covariates in all regression analyses.

Additional hierarchical regression analyses on the interaction between neuroticism and gender were performed cross-sectionally to determine whether gender moderated the relationship between neuroticism and pain and neuroticism and hope. Results suggested that significant neuroticism by gender interaction did not exist with back pain ratings,  $p > .05$ . A significant neuroticism by gender interaction was, however, concluded for hope scores (total hope:  $R^2 = .11$ ,  $\Delta R^2 = .05$ ,  $p < .01$ ; agency:  $R^2 = .17$ ,  $\Delta R^2 = .06$ ,  $p < .01$ ; pathways:  $R^2 = .06$ ,  $\Delta R^2 = .04$ ,  $p < .05$ ).

### **Differences between groups on pain and hope variables**

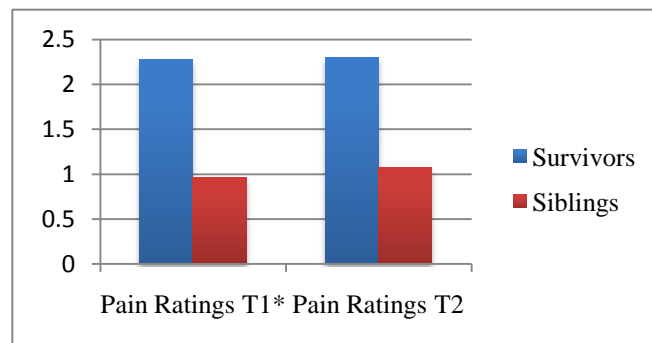
*AIM 1.* The study's first aim was to determine whether ALL survivors and healthy controls differed with regards to lower back pain and hope.

Hypothesis 1: ALL survivors will have higher low back pain ratings than healthy controls.

Chi-square analyses were used to analyze the difference between ALL survivors and siblings on categorical variables of pain presence and chronicity

(i.e. “Do you have back pain?” “Has your back pain been present for longer than 6 months?”). Results indicated that survivors reported back pain more frequently than their siblings,  $\chi^2 = 5.97, p < .05$  at T1; however, a significant difference between the two groups was not concluded at 3-month follow-up. Pain lasting longer than 6 months (chronic pain) was also non-significant between the two groups at both time points (results detailed in Table 2).

Participants also rated back pain on a visual analog scale at T1 and T2 (with 0 = not severe at all and 10 = most severe). One-way analysis of variance (ANOVA) results were significant,  $F(1, 142) = 7.95, p = .005, \eta^2 = .053$ , with ALL survivors endorsing higher pain ratings than controls at T1 only (differences between means are detailed in Table 2). Although the difference between groups was significant, estimates of effect size demonstrated minimal practical significance.



*Figure 5.* Back Pain Ratings in ALL Survivors and Siblings at T1 and T2

Hypothesis 2: Survivors of ALL will exhibit higher levels of hope when compared to controls.

Differences between means for hope are detailed in Table 3. One-way ANOVAs were computed to determine the differences between ALL survivors and siblings on hope scores. Hope as the dependent variable was examined as a total score of hope, as well as by the two separate domains: agency (willpower) and pathways (waypower). ANOVA results concluded significant differences between groups at T1 data collection for Total Hope Scores,  $F(1, 135) = 5.87, p = .017, \eta^2 = .042$  and Pathway Score,  $F(1, 135) = 7.94, p = .006, \eta^2 = .056$ . These results indicate that contrary to the direction hypothesized, siblings tended to have higher pathway and total hope scores than ALL survivors. Estimates of effect size demonstrated minimal practical significance. Differences between groups for agency scores were not significant,  $F(1, 135) = .736, p > .05$ .

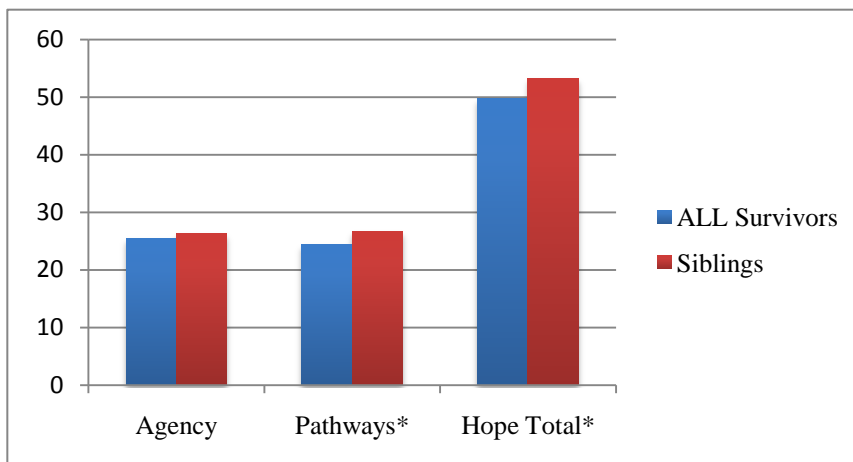


Figure 6. Hope Scores in ALL Survivors and Siblings at T1

## **Influences on Back Pain**

*AIM 2.* The second aim of the study examined whether back pain was influenced by exercise, BMI, neuroticism and hope, and whether these variables predicted pain ratings.

Influences on back pain were analyzed cross-sectionally and longitudinally. Pearson product correlations were utilized to determine the relationship between exercise, BMI, neuroticism and hope with pain at T1 and T2 (Tables 4 and 5). Multiple regression analyses were conducted to determine whether these variables suggested directionality and predicted back pain ratings. Exercise, BMI, neuroticism and hope were entered as independent variables (IVs), back pain ratings at T2 as the dependent variable (DV), and pain ratings at T1 were controlled for in the regression equations.

Hypothesis 3: Exercise will have an inverse relationship with pain.

Exercise was measured as self-reported moderate exercise per day in minutes and vigorous exercise per day in minutes. Moderate exercise was positively, but marginally correlated with pain at T1 and T2. Vigorous exercise was also marginally correlated with pain at T1 and with T2 pain (Table 4 and 5).

Hypothesis 4: BMI will have a positive relationship with pain.

BMI was positively correlated with T1 pain and inversely correlated with T2 pain; however, neither correlation was significant (Tables 4 and 5).

Hypothesis 5: Neuroticism will have a positive relationship with pain.



Hypothesis 5 was supported in that neuroticism (EPQ-BV), was significant and positively correlated with back pain at T1 and T2,  $r = .36, p < .01$  and  $r = .45, p < .01$ , respectively.

Hypothesis 6: Hope will have an inverse relationship with pain.

Results were consistent with hypothesis 6 as total hope was significantly and inversely correlated with pain at T1 and 2,  $p < .05$ . Pearson product correlations also suggested that the agency domain was significantly correlated with pain at T1,  $p < .05$ . Although, agency scores were inversely correlated with pain at T2 and pathways scores were inversely correlated with pain at T1 and 2, these relationships were not significant (Please refer to the correlation matrix on Tables 4 and 5).

*Multiple regression analyses.* Multiple linear regression analyses were used to examine the predictive relationship between these variables. Several models were used to examine these relationships. Pain at T2 was used as the DV, pain at T1 was controlled, and exercise, BMI, neuroticism and hope were the IVs. The first regression analysis included T1 pain as model 1 followed by all physical variables (BMI, CDC requirement for exercise). No significant predictor was suggested and no significant amount of variance was accounted for by physical variables over and above pain at T1. The second analysis included T1 back pain in model 1 followed by all psychological variables (neuroticism and hope subscales). Results suggested that there were no significant psychological

predictors and no significant amount of variance was accounted for by psychological factors over and above pain at T1 (detailed results in Table 6).

*Aim 2b.* The study also examined the differences in the relationships between exercise, BMI, neuroticism and hope with pain for survivors and controls.

Hypothesis 7: Survivor status will not moderate or have an impact on the relationship between pain and the variables of exercise, BMI and neuroticism; however, will have an interaction effect with the predictor (hope) or moderate the relationship between hope and pain.

Hierarchical multiple regression analyses were conducted to assess whether survivorship status moderated the relationship between the independent variables of exercise, BMI, neuroticism, and hope with the dependent variable of pain. Moderation was analyzed both longitudinally and cross-sectionally. All independent variables were centered at their means in order to decrease multicollinearity and ensure that the intercept slopes differ. Interaction terms between IVs and survivorship status were created to test moderation. The variables were entered into the regression equation as follows:

DV: pain at T2

Model1: centered pain at T1

Model 2: IV (centered exercise, BMI, neuroticism or hope), Moderator (survivorship status)

Model 3: Centered IV X Moderator interaction variable.

Detailed results are outlined in Table 7. Most of the variance was accounted for by T1 pain and the interaction term was concluded to be non significant, thus survivorship status did not moderate the relationship between the IVs and Pain. The hope score (IV) was analyzed both as the total score as well as the two separate domains of agency and pathways. Similarly, results indicated that survivorship status was not a significant moderator between hope subscales and pain. Please refer to Table 8 for detailed moderation results. Additionally, when moderation was analyzed cross-sectionally, survivorship status was not a significant moderator between the above variables and pain.

### **Relationship between pain, QoL and hope**

*AIM 3.* The third aim was to explore the role of hope as a construct in understanding pain and quality of life in cancer survivors; specifically, whether hope moderated subjective pain ratings and overall quality of life.

Hypothesis 8: Pain will predict QoL and the two will have an inverse relationship; however, the relationship will be moderated by hope. Having higher levels of hope will buffer (moderate) the detrimental effects of pain on QoL; therefore, it is expected that those with high hope will have higher QoL despite pain, while those with low hope will have poorer quality of life.

Prediction and moderation analyses were computed via multiple regression analysis, first examining whether pain ratings (T1) predicted QoL (T2),

and second, whether hope (T1) acted as a moderator between the two variables. Subscales of QoL (physical, psychosocial and overall QoL) were analyzed separately. Additionally, the moderator, hope, was analyzed by looking at the hope domains (agency, pathways, total score) separately in the regression analyses. Age, gender and neuroticism were used as covariates in the regression analyses. Pain and hope variables were centered at their means to decrease multicollinearity. Regression equations were entered as follows:

DV: QoL at T2 (physical, psychosocial and total separately)

Model 1: QoL at T1 (physical, psychosocial and total)

Model 2: centered pain ratings T1, centered hope scores T1 (agency, pathways, total separately)

Model 3: centered pain ratings by centered hope scores interaction term.

*QoL Subscales with Total Hope as Moderator.* The following analyses are presented in Table 9. The study first examined the relationship between pain and overall QoL, using the hope total score as a moderator. The first equation revealed controlling for QoL at T1 accounted for 83% of the variance,  $p < .01$ . The second equation, which included pain and total hope scores as predictors of QoL, indicated that pain ratings and total hope scores together did not significantly predict overall QoL at T2 over and above QoL at T1. The third and final equation, which calculated the interaction between the IV, pain, and the moderator, hope, concluded that interaction effects were not significant ( $R^2$

$Change = .00, F(4, 86) = 116.18, p > .05$  thus disputing the study's hypothesis that hope moderates the relationship between pain and QoL.

Next the physical subscale of QoL was examined using the total hope score as the moderator. The regression analysis suggested that pain ratings and total hope ( $R^2 Change = .01, F(3, 89) = 292.07, p < .01$ ) predicted physical QoL at T2 over and above baseline ratings of QoL. Further, results indicated that total hope at T1 was a unique predictor of physical QoL at T1. Total hope did not, however, moderate the relationship between pain and physical QoL. A final parallel analysis was conducted with pain ratings and the subscale of psychosocial QoL. Results were non-significant, concluding that pain and total hope scores did not predict psychosocial QoL over and above psychosocial QoL at T1 nor was the relationship moderated by total hope.

*QoL Subscales with Agency as a Moderator.* The following analyses are detailed in Table 10. Agency scores were examined separately as a moderator between pain and QoL by creating a variable of agency TI by pain ratings at T1. Results suggested that agency was an independent predictor of physical, psychosocial and overall QoL. Regression analysis for the relationship between pain, overall QoL and agency indicated pain and agency predicted QoL and accounted for a significant amount of the variance,  $p < .05$ , over and above QoL at T1, where agency was a discrete predictor of QoL. Similar findings were concluded for physical QoL where pain and agency were found to significantly

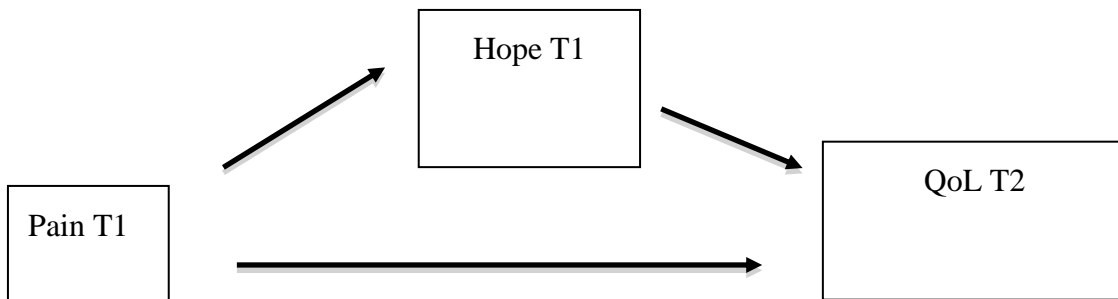
predict physical QoL at T2 over and above QoL at T1,  $p < .05$ , with agency being a discrete predictor of QoL. Psychosocial QoL at T2 was also predicted by pain and agency at T1 over and above QoL T1,  $p < .05$ , with agency being a discrete predictor for QoL T1. Agency, however, was not a significant moderator for the relationship between pain and overall physical or psychosocial QoL.

*QoL Subscales with Pathways as a Moderator* The following analyses are detailed in Table 11. The relationship between pain, QoL and pathways scores all resulted in non-significant results. Pathways scores were not discrete predictors and did not moderate the relationship between pain and physical, psychosocial and overall QoL. Age, gender and neuroticism were not significant covariates for any of the above analyses.

Interactions between pain and hope scores was also analyzed cross-sectionally. Similarly to longitudinal results, hope scores did not significantly moderate the relationship between pain and subscales of QoL.

#### *Mediation Analysis*

The cross-sectional analyses (Table 12) revealed that pain was inversely related to QoL, pain was inversely related to hope and hope was positively related to QoL. Furthermore, total hope and agency were found to predict domains of QoL in the regression analyses. Considering these results, the study examined whether hope mediates the relationship between pain and QoL.



*Figure 7.* Hope as a mediator between pain and QoL

Mediation was tested using the bootstrapping technique recommended by (Preacher & Hayes, 2004) which is the preferred method when sample sizes are limited or parametric assumptions are not met. In the bootstrap analysis, multiple samples are randomly drawn from the larger dataset and statistics are computed on each of those sets of data, providing a distribution of the statistic across the random samples. The estimates presented in the current study are based on 10,000 bootstrap samples. Initially, covariates (i.e. age and QoL T1) were included in all bootstrap methods. Bootstrapping was used to analyze mediation cross-sectionally and longitudinally to determine if pain ratings at baseline were indirectly linked to physical, psychosocial and overall quality of life through hope variables (agency, pathway and total hope). Tests were conducted separately for the three potential mediators from the hope scale as well as the three domains of the dependent variable, QoL. The bootstrap method examined the relationship between the IV (pain ratings) and DV (QoL domains) and mediator (hope scores at) using four steps: 1) the relationship between the IV and mediator, 2) the

relationship between the mediator and DV, 3) the IV and DV and 4) the IV and DV after controlling for the mediator. Significant mediation is concluded if the confidence interval for the indirect effect (IV to DV after controlling for the mediator) does not cross zero.

Cross-sectional bootstrap analyses were utilized by using the IV, pain ratings, DV, QoL subscales and mediator, hope subscales, all at baseline. Age was used as a covariate and was not significant. Results suggested that total hope scores were a partial mediator for overall, physical and psychosocial QoL (Table 13). Additionally, agency was found to partially mediate the relationship between the three subscales of QoL (Table 14). Conversely, pathways scores were not a significant mediator for the relationship between pain and all subscales of QoL (Table 15).

Please refer to Table 16 for detailed longitudinal bootstrap analyses. The longitudinal bootstrap analyses results suggested that when controlling for QoL at T1, total hope, agency and pathways scores did not mediate the relationship between pain and physical, psychosocial and overall QoL. Considering the limited time span of 3 months between the T1 and T2 data collections, lack of intervention, and absence of age related developmental milestones during the three-month study period, the study also performed bootstrap analyses without covarying for the dependent variable (QoL) measured at T1. Age was used as covariate because of the study's age range of 13 to 25.



Detailed results are presented in Table 17 for total hope as the mediator. Bootstrap results concluded that total hope may account at least partially for the relationship between pain and overall QoL. Total hope also mediated the relationship between pain and physical and psychosocial QoL scores. Results were similar for agency scores resulting in significant mediation between pain and all three subscales of QoL (Table 18). Pathways scores did not mediate the relationship between pain ratings and physical, psychosocial or overall QoL (Table 19).

### **Pain, Neuroticism and Hope**

*AIM 4.* The study also examined whether pain and neuroticism influence or predict hope in both bivariate and multivariate analyses.

Hypothesis 9: The study hypothesizes that both pain and neuroticism will have an inverse relationship with hope.

Cross-sectional correlation analyses were conducted to examine the relationship between pain and hope scores as well as neuroticism and hope scores. As previously discussed, pain was significantly and inversely correlated with agency and total hope,  $p < .01$ , respectively, whereas pathways did not result in significant correlations. Neuroticism was significantly associated with agency,  $p < .01$ , and total hope score,  $p < .01$ , however, neuroticism was not significantly correlated with pathways (Detailed correlations matrix is presented in Table 4).

Longitudinal analyses were performed using multiple regression analyses. Pain and neuroticism at T1 were used as IVs, hope scores at T2 (agency, pathways and total) were the DV, and hope scores at T1 were utilized as the control variable. These analyses concluded that hope at T1 accounted for most of the variance, indicating that neither pain nor neuroticism independently predicted hope scores.

*Aim 4b.* The study also examined the differences in these relationships for survivors versus controls.

Hypothesis 10: When examining interaction effects of survivor status on the relationship between pain and hope, there will be a weaker relationship between pain and hope for survivors only (as compared to healthy controls). Survivor interaction with the relationship between neuroticism and hope was not expected. Detailed results of moderation analyses for neuroticism and hope are presented in Tables 20 and 21 respectively.

Hierarchical multiple regression analyses were conducted in order to determine whether survivorship status moderated the two relationships: 1) pain and hope scores and 2) neuroticism and hope scores. Pain and neuroticism were centered at their mean prior to running the regression analyses to decrease multicollinearity. An interaction term for pain and neuroticism by survivorship status was created to test moderation. The variables were entered into the equation as follows:

DV: Hope scores T2 (agency, pathways, total hope)

Model 1: Hope scores T2

Model 2: centered IV variables (pain T1 or neuroticism T1), moderator

Model 3: centered IVs X survivorship status interaction variable

These analyses all concluded that survivorship status did not moderate the relationship between pain and hope variables or neuroticism and hope variables. Results were similar when interactions were analyzed cross-sectionally, suggesting that survivorship status interactions with either pain or neuroticism were not significant with subscales of hope.

## **CHAPTER FIVE**

### **Discussion**

#### **Differences between ALL survivors and Siblings**

Childhood Acute Lymphoblastic Leukemia is one of the most common childhood cancers, with a high rate of survival as a result of advancements in treatment through chemotherapy and radiation (National Cancer Institute, 2002). Although the survival rate has increased in the last several decades, the literature has shown that ALL survivors experience many physical, neurological and psychosocial late effects that arise as a result of their treatment (Oeffinger, et al., 2006). The study focused primarily on the exploration of back pain, a late effect that has gained no recognition in the literature. Anecdotal evidence at the ACE clinic at CMC Dallas and several potential reasons, including side effects from lumbar punctures, increased risk for obesity and treatment with corticosteroids, led to the justification for creating a preliminary study to examine the late effects of pain. We concluded that differences between survivors of ALL and their siblings exist and survivors did in fact report more back pain than the control group. In addition, they reported higher subjective pain ratings than controls (Bowers, et al. in progress, Griffith et al, 2011). Hip pain was also measured in survivors and controls and was not significantly different between the two groups. This finding further indicates that the pain presented by the study's sample of ALL survivors is more specific to the lumbar area rather than general pain.

These preliminary findings add an important contribution to the medical literature, as this is one of the first studies to document higher levels of pain in ALL survivors. Understanding of onset and length of back pain may be beneficial in determining and implementing strategies to minimize this particular late effect, i.e. altering spinal taps techniques or implementing pain management interventions. Although widely studied in general, little is known about the influences on back pain in this population and understanding physical factors as well as psychosocial factors (Blythe, et al., 2001; Dekkers, 1998; Gureje, Von Korff, Simon, & Gater, 1998; Wolf & Havemeier, 1990) may be of particular importance to continue minimizing late effects in survivors of childhood cancer.

In addition to the known influences on pain, the primary focus was on hope, a construct that has received limited acknowledgment and research with regards to its relationship to back pain. Of particular interest was not only hope's relationship to back pain, but its impact on overall functioning in this specific population. The literature suggests that higher hope, which is defined by the attainment of goals through agency (willpower) and pathways (waypower), develops and strengthens through several means (Snyder, 1994, 2000). One such means of developing higher hope is undergoing an aversive experience or obstacle such as cancer and being able to overcome that experience successfully. This in turn may contribute to more resilience and persistence in achieving goals when other challenges are presented, thus raising levels of hope (Snyder, 1994,

2000). Based on this notion, we hypothesized that ALL survivors would have higher ratings of hope than their siblings. Our findings did not support this hypothesis. In fact, siblings were found to have both higher overall hope scores as well as pathways scores.

One possible explanation of lower hope scores in ALL survivors that should be examined further is the role of back pain in this population. If ALL survivors exhibited higher back pain ratings, it may be that the late effect of back pain is the contributing factor to survivors' lower hope scores. Furthermore, the ALL survivors in the current study ranged from ages 13 to 25 who were at least 5 years post cancer remission. Although levels of hope may have been higher shortly following remission, hope was not studied at the time of remission. Unknown confounding variables, including other late effects, illnesses or traumatic events, could decrease levels of hope in cancer survivors, which raises further questions in understanding the hope construct in this health populations.

### **Influences on pain**

To understand the influences on pain, we measured both physical and psychological variables and concluded that physical variables in this case were not significantly associated with back pain. We found that contradictory to the literature, BMI and exercise were not related to back pain ratings. It was especially surprising that BMI was not related to back pain as is often the case in the literature; however, our sample primarily consisted of individuals in the

average BMI range rather than higher BMI ranges, which is what back pain is typically linked to in the literature (Adera, Deyo, & Donatelle, 1994). Exercise was also non-significant with regards to its relationship to pain, indicating that pain was present or absent regardless of whether individuals spent more or less time engaging in physical activity.

Aside from the physical factors, psychological factors were also examined. We concluded that psychological variables, such as neuroticism and hope, were cross-sectionally related to back pain ratings, indicating that those who scored higher on the neuroticism scale had higher pain ratings. Neuroticism, which is a stable trait and characterized by a tendency to experience negative, distressing emotion has been associated with back pain; however, the research does not support causality (Larsen, 1992). We also concluded that neuroticism did not predict pain, meaning that current neuroticism scores did not predict future pain ratings. This is not surprising as this relationship may be bidirectional, with both neuroticism contributing to pain and increased pain contributing to neurotic characteristics. Considering that the onset of pain was unknown and not measured by the study, it was difficult to determine whether the neuroticism trait was present prior to the back pain in this sample or as a result of the back pain.

Snyder, Brown, Hackman, and Odle (1999) concluded that individuals with higher levels of hope showed higher pain tolerance when presented with a

cold compressor task, but research in this area has been very limited. As expected, cross-sectional results suggested that agency, pathways and total score were all inversely related to pain, with agency and total hope having a slightly stronger relationship with pain. Hope did not predict pain as most of the variance was accounted by controlling for pain at T1, although total hope at T1 was significant and inversely correlated with T2 pain ratings.

The stability in the hope and pain ratings, which precluded the finding for hope as a prediction, were not surprising given the study design. First, the interval of data collection between T1 and 2 was very limited (3 months). Second, we did not implement an intervention between the time periods that would have contributed to change in pain or hope scores. Finally, based on the age range of 13 to 25, it is unlikely that any major developmental milestones were achieved in a 3-month period to cause much variability in the variables. Another possibility for the lack of predictive results could be the nature of pain. It is possible that pain and hope, similar to neuroticism and pain, have a bidirectional relationship and one does not cause the other: Higher pain may predict lower hope; however, lower hope may predict higher pain. The significant relationship between hope at T1 and pain at T2 merits further assessment. Although directionality cannot be assumed due to the need to control for initial pain, a relationship between these two variables cross-sectionally both at T1 and T2 is



evident. This strongly suggests a common link between hope and pain, either direct and bidirectional or attributable to a third variable.

Survivorship status was not a statistically significant moderator between hope and pain, which indicates that the relationship between hope and pain does not change regardless of whether an individual is an ALL survivor or a healthy control. Considering that survivors had higher pain ratings than their siblings and siblings had higher hope, which was contrary to our hypothesis based on the hope literature, these results could imply that this relationship is independent of whether an individual experienced illness. Moreover, being hopeful may not necessarily depend on whether an individual has survived an illness or not; rather, it could play an important role in how these individuals handle stressors and perceive their health related quality of life, thus having implications for a hope intervention.

### **Pain, Hope and QoL**

We concluded that a relationship between pain and QoL existed when data was assessed cross-sectionally, indicating that higher pain was associated with poorer physical, psychosocial and overall QoL. For similar reasons stated earlier, pain was not found to be a significant predictor of QoL after controlling for QoL at T1. Results, however, pointed to a strong association between hope and QoL and suggested that hope is an independent predictor of predicts. This implies that having higher hope currently predicts higher QoL in the future and could have

positive implications for the benefits of high hope on overall functioning. More specifically, both total hope and agency were significantly related to and predicted higher future QoL. Previous studies have pointed to an association between hope and positive adjustment and emotional states (Bellizzi & Blank, 2006; Ciarrochi & Heaven, 2008). These results, however, are further justification about the importance of hope on health related quality of life and the ability of individuals with higher hope to adjust to stressors more adeptly. The relationship between these two variables has positive implications for the pediatric psychology literature, considering that implementing interventions to increase hope could provide children struggling with chronic illness not only a more positive outlook but also better overall functioning.

The most striking result from our analyses was the role of agency in the relationships between pain, hope and QoL. Agency (which is the willpower or drive to achieve goals), played a greater role than pathways (which is the waypower or strategies required to achieve goals) both in predicting quality of life directly and influencing the relationship between pain and QoL. The hope literature mainly focuses on the collaboration between pathways and agency in the production of high hope; thus, agency individually has not received much any attention. Our results suggest that in the instance of health related QoL, agency or willpower may be the driving force that leads to higher hope and in turn higher QoL. The relationship between agency alone and all aspects of QoL could point

to the need for an intervention that is perhaps of greater focus on willpower, cognition and motivation. Agency reflects the person's perception that he or she can begin movement along the imagined pathways to goals and can reflect one's appraisal of the capability to persevere in the goal journey (Snyder, 2000).

Unfortunately, meditational analyses were nonsignificant after controlling for T1 QoL variables as most of the variance was accounted for by T1 QoL. Mediation between pain and QoL was concluded, however, with agency and total hope when QoL T1 was removed as a covariate. Results indicated stability of scores between QoL measured at T1 and T2, which was the justification for exploring the meditational analyses after removing QoL at T1 as a covariate. QoL was stable mostly due to similar reasons as pain at hope in earlier analyses. These include the interval of 3 months between T1 and 2 data collection, no intervention targeting the constructs and the lack of major developmental changes in the age range.

The bootstrap analyses, when QoL at T1 was not accounted for, suggested that agency and total hope mediated the relationship between pain and three domains of QoL. Furthermore, these findings conclude that the relationship between pain and QoL decreased because of hope, meaning that those with higher agency and total hope were able to have a better QoL despite having back pain. This further supports the justification for a hope intervention with particular focus on agency, as those individuals who had higher willpower were likely to have

improved physical, psychosocial and overall QoL. Hope interventions have been explored through story narratives with children and adults. These interventions usually include both aspects of agency and pathways in the narratives, focusing on increasing both domains for the achievement of goals (Snyder, 2000). Based on our conclusions, assessing other evidenced based interventions that have a greater focus on cognition and willpower such as motivational interviewing (Britt, Stephen, & Blampied, 2004; Burke, Arkowitz, & Menchola, 2003; Rubak, Sandback, T, & Christensen, 2005) may be of interest in future studies when examining the role of hope on overall well-being.

In conclusion, the current study was designed to explore the differences between ALL survivors and siblings on back pain and hope variables and examine how these variables interact and impact health related quality of life. ALL survivors reported higher back pain, suggesting that further research is necessary in this area. In both cross-sectional and longitudinal analyses, there were significant relationships between pain and QoL, not surprisingly implying that individuals experiencing more pain rated their QoL as poorer. Total hope and agency were associated with pain and play an important role in increasing all aspects of QoL. Independent of individuals' ratings of pain, hope was associated with higher QoL. Thus, these results merit the exploration and implementation of a hope intervention (with specific focus on agency) in individuals struggling with back pain.

### **Limitations and future direction**

Although the study provided interesting results that could contribute to the literature with regards to back pain ratings in ALL survivors and hope's positive influences on QoL, several limitations should be noted. The study included ALL survivors and their siblings only as the control group and although differences were confirmed, using siblings alone may not be the best control group when looking at differences in pain variables. First, there are many environmental factors that are similar in families that have the potential to confound the results, including lifestyle, eating habits, family stressors, etc. Further, comparing ALL survivors to other childhood cancer survivors that may have received different treatment, i.e. treatment that did not include lumbar punctures and specific corticosteroids, would provide a more complete picture of whether the back pain is specific to this cancer population.

Another limitation is that the study data was collected via mail in surveys completed by ALL survivors and siblings. No clinician rated measures were collected and no data was obtained via medical records. The method of data collection could be a potential limitation considering that research study staff was not present at the time participants completed the surveys. Additionally, clinician rated measures were not collected and all information is based on self-report. There are many limitations of using self-report alone over clinician report combined with self-report data such as objectivity. Finally, using limited

subjective pain measures rather than more robust subjective and objective may be a limitation in fully understanding pain in ALL survivors. Future studies should allow for data collection to occur in the clinic to maintain consistency and quality control as well as include objective measures of pain, other physical variables and psychological variables.

Finally, a limitation of the study is the time interval between measurements. Follow-up data was collected only 3-months after initial data collection, which limitations that have all been previously discussed. The largest limitation is that it may be difficult to see a change in constructs over such a short period of time, especially without intervention.

Future longitudinal research should focus on designing more comprehensive studies to better understand back pain and hope in childhood ALL survivors. Further exploring the findings in this study with regards to the relationship between pain, hope and QoL would provide the literature with direction as to the positive effects of hope. Suggestions for future research include measuring pain, hope and QoL in childhood cancer patients at diagnosis, throughout treatment and post remission. Developing hope interventions with a focus on agency for children currently in treatment or survivors of childhood cancer would provide information about whether hope is modifiable as is suggested by the literature. Finally, studying hope's positive implication on QoL

over a longer period of time could point to the positive effects of hope on long-term functioning following chronic illness.





**EPQ-BV**

*Instructions:* Please indicate your characteristics by circling one of the letters on the left of each of the items.

A= Not at all    B=Slightly    C=Moderately    D=Very much    E=Extremely

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| A | B | C | D | E | 1. Does your mood often go up and down?                       |
| A | B | C | D | E | 2. Do you ever feel 'just miserable' for no reason?           |
| A | B | C | D | E | 3. Are you an irritable person?                               |
| A | B | C | D | E | 4. Are your feelings easily hurt?                             |
| A | B | C | D | E | 5. Do you often feel 'fed-up'?                                |
| A | B | C | D | E | 6. Would you call yourself a nervous person?                  |
| A | B | C | D | E | 7. Are you a worrier?   |
| A | B | C | D | E | 8. Would you call yourself tense or 'highly strung'?          |
| A | B | C | D | E | 9. Do you worry too long after an embarrassing<br>Experience? |
| A | B | C | D | E | 10. Do you suffer from 'nerves'?                              |
| A | B | C | D | E | 11. Do you often feel lonely?                                 |
| A | B | C | D | E | 12. Are you often troubled about feelings of guilt?           |

**Adult Dispositional Hope Scale**  
**“The Goals Scale”** (ages 15 and older)

*Directions:* Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1 = Definitely False  
2 = Mostly False  
3 = Somewhat False  
4 = Slightly False

5 = Slightly True  
6 = Somewhat True  
7 = Mostly True  
8 = Definitely True

- \_\_\_ 1. I can think of many ways to get out of a jam.
- \_\_\_ 2. I energetically pursue my goals.
- \_\_\_ 3. I feel tired most of the time.
- \_\_\_ 4. There are lots of ways around any problem.
- \_\_\_ 5. I am easily downed in an argument.
- \_\_\_ 6. I can think of many ways to get the things in life that are important to me.
- \_\_\_ 7. I worry about my health.
- \_\_\_ 8. Even when others get discouraged, I know I can find a way to solve the problem.
- \_\_\_ 9. My past experiences have prepared me well for my future.
- \_\_\_ 10. I've been pretty successful in life.
- \_\_\_ 11. I usually find myself worrying about something.
- \_\_\_ 12. I meet the goals that I set for myself.

## APPENDIX B- Results Tables

Table 1  
Demographic Characteristics of Patients at T1 and T2. (T1 N=145, T2 N=107)

Characteristic	Survivors T1 N=96	Siblings T1 N=49	Survivors T2 N=84	Siblings T2 N=23
	N (%)		N (%)	
<b>Gender</b>				
Male	55 (57.3)	21 (42.9)	46(54.8)	10(43.5)
Female	41 (42.7)	28 (57.1)	38 (45.2)	13 (56.5)
<b>Ethnicity</b>				
White, Non- Hispanic	56 (58.9)	36 (73.5)	49 (58.3)	17(73.9)
African American	7 (7.4)	3 (6.1)	6 (7.1)	0
Hispanic	28 (29.5)	10 (20.4)	25 (39.8)	6(26.1)
Other	4 (4.3)	0	4 (4.8)	0
<b>BMI Category</b>				
Underweight	7 (8.3)	3 (7.0)	6(7.9)	0
Normal	43 (51.2)	32 (74.4)	44(57.9)	13(72.2)
Overweight	23 (27.4)	4 (9.3)	17(22.4)	3(16.7)
Obese	11(13.1)	4 (9.3)	9(11.8)	2 (11.1)
CDC Exercise Requirement	47 (71.2)	26 (86.7)	N/A	N/A
Smoking	3 (3.1)	2 (4.3)	4(4.8)	2(9.1)
Treated with radiation	26 (28.6)	N/A	21(26.6)	N/A
	<i>M (SD)</i>		<i>M (SD)</i>	
Age	18.15 (3.31)	17.88 (3.66)	18.76(3.34)	18.59(3.10)
Height	66.39(4.36)	67.33(3.76)	66.49(4.36)	66.61(4.03)
Weight	153.64(34.69)	153.72(38.45)	154.42(34.07)	158.26(40.38)
BMI	24.5 (5.14)	23.82(5.74)	24.45(4.92)	25.20(7.31)
Moderate Exercise	69.35(54.85)	131.4(162.3)**	N/A	N/A
Vigorous Exercise	73.85(49.46)	78.71(78.67)	N/A	N/A
Neuroticism	23.27(7.98)	24.88(9.25)	N/A	N/A

\*\* $p < .01$ . Note. BMI was in the normal range for most participants.

### Aim 1 Tables

Table 2

*Aim 1 Differences in Pain Variables between ALL Survivors and Siblings*

Characteristic	Survivors T1	Siblings T1	Survivors T2	Siblings T2
	N (%)		N (%)	
Hip Pain	9 (9.4)	2 (4.2)	7 (8.4)	0 (0.0)
Hip Pain > 6mo	6 (23.1)	1 (7.7)	5 (14.3)	0 (0.0)
Back Pain	42 (43.8)*	11 (22.9)	37 (44.0)	5 (23.8)
Back Pain > 6mo	25 (53.2)	6 (31.6)	29 (56.9)	3 (27.3)
	<i>M (SD)</i>		<i>M (SD)</i>	
Pain Ratings	2.27 (2.89)*	0.96 (1.97)	2.30 (3.03)	1.07 (2.37)

Note. \* $p < .05$  between survivors and siblings

Table 3

*Aim 1 Differences in Hope Variables between ALL Survivors and Siblings*

Characteristic	Survivors T1	Siblings T1	Survivors T2	Siblings T2
	N=145	N=145	N=107	N=107
	<i>M (SD)</i>		<i>M (SD)</i>	
Hope Agency	25.47 (5.2)	26.64 (4.5)	25.41 (5.1)	26.62 (3.1)
Hope Pathways	24.33 (4.9)	26.64 (3.4)*	24.85 (4.8)	25.61 (3.7)
Hope Total	49.67 (8.7)	53.20 (6.2)*	50.27 (8.9)	52.22 (6.1)

Note. \* $p < .05$  between survivors and siblings

### Cross-sectional Correlation Analyses Tables

Table 4

*Summary of Correlations between Pain, Neuroticism (EPQ), Exercise, and Hope Scores at T1*

	BMI	Pain Severity	Neuroticism	Exercise Moderate	Exercise Vigorous
BMI					
Pain Severity	.01				
Neuroticism	.19*	.36**			
Exercise Moderate	.09	.09	.02		
Exercise Vigorous	.13	-.01	.13	.58**	
Agency	-.10	-.17*	-.28**	-.06	-.04
Pathways	-.02	-.15	-.13	-.04	.08
Hope Total	-.06	-.21*	-.22**	-.02	-.01

*Note.* \* $p < .05$ ; \*\* $p < .01$

### Aim 2 Tables

Table 5

*Aim 2 Correlations for Variables and Pain at T2*

	Time 2 Pain
BMI	-.07
EPQ Total	.45**
Moderate Exercise Min	.14
Vigorous Exercise Min	.08
GS Agency	-.20
GS Pathways	-.13
GS Total Score	-.21*

*Note.* \* $p < .05$ ; \*\* $p < .01$

Table 6  
 Aim 2 Summary of Multiple Regression Analyses for Physical and Psychological Variables  
 predicting Pain at T2 with Pain T1 as a covariate

Variable	Model 1 Pain at T1		Model 2 Physical Variables	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=56)</b>				
Pain Ratings T1	0.90	0.93**	0.92	0.92**
BMI			-0.03	-0.06
Moderate or Vigorous Exercise			0.4	-0.07
$R^2$	0.87**		0.87	
<i>F</i> for change in $R^2$	352.99**		123.72	
<b>Regression 2 (N=86)</b>				
	Pain at T1		BMI	
Pain Ratings T1	0.97	0.96**	0.97	0.96**
BMI			-0.01	-0.04
$R^2$	0.88**		0.88	
<i>F</i> for change in $R^2$	239.22**		58.58	
<b>Regression 3 (N=93)</b>				
	Pain at T1		Psychological Variables	
Pain Ratings T1	0.97	0.94**	0.96	0.94**
Neuroticism			0.01	0.01
Total Hope			0.00	0.01
$R^2$	0.88**		0.88	
<i>F</i> for change in $R^2$	938.42**		307.53	

Note. \*\* $p < .01$ ; Most of the variance was accounted for by pain at time 1. Age and gender were not significant covariates.

Table 7  
 Aim 2 Summary of Hierarchical Regression Analyses for BMI, Exercise and Neuroticism  
 Variables as Predictors of Pain at T2 and Survivorship Status as a Moderator (while controlling  
 for T1 Pain)

Variable	Model 1		Model 2		Model 3	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=47)</b>						
Pain Ratings T1	0.95	0.93**	0.97	0.95**	0.96	0.94**
Moderate Exercise			-0.00	-0.05	-0.00	-0.05
Survivor Status			-0.45	-0.05	-0.44	-0.04
Mod Ex X Survivor Status					-0.00	-0.02
$R^2$	0.87**		0.87		0.87	
<i>F</i> for change in $R^2$	301.99**		100.12		73.52	
<b>Regression 2 (N=49)</b>						
Pain Ratings T1	0.92	0.94**	0.93	0.94**	0.92	0.93**
Vigorous Exercise			-0.00	-0.04	-0.00	-0.03
Survivor Status			-0.15	-0.01	0.00	0.00
Vig Ex X Survivor Status					-0.00	-0.07
$R^2$	0.88**		0.88		0.88	
<i>F</i> for change in $R^2$	348.79**		113.19		83.82	
<b>Regression 3 (N=82)</b>						
Pain Ratings T1	0.98	0.95**	0.98	0.96**	0.98	0.96**
BMI			-0.02	-0.04	-0.02	-0.03
Survivor Status			-0.17	-0.04	-0.17	-0.02
BMI X Survivor Status					-0.00	-0.01
$R^2$	0.92**		0.92		0.92	
<i>F</i> for change in $R^2$	913.85**		304.50		225.49	
<b>Regression 4 (N=93)</b>						
Pain Ratings T1	0.98	0.95**	0.97	0.95**	0.97	0.94**
EPQ			0.01	0.02	-0.00	0.02
Survivor Status			-0.21	-0.02	-0.20	-0.02
EPQ X Survivor Status					-0.02	0.04
$R^2$	0.91**		0.91		0.91	
<i>F</i> for change in $R^2$	914.71**		302.57		224.75	

*Note.* BMI, exercise, and neuroticism were centered at their means. Most of the variance was accounted for by pain ratings T1. \*\* $p < .05$ . Age and gender were not significant covariates.

Table 8

*Aim 2 Summary of Hierarchical Regression Analyses for Hope Subscales as Predictors of Pain at T2 and Survivorship Status as a Moderator (while controlling for Pain at T1)*

Variable	Model 1		Model 2		Model 3	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=89)</b>						
Pain Ratings T1	0.97	0.95**	0.97	0.95**	0.97	0.95**
Hope Total			-0.01	-0.01	-0.06	-0.18
Survivor Status			-0.25	-0.03	-0.12	-0.01
Total Hope X Survivor Status					0.06	0.18
$R^2$	0.91**		0.91		0.91	
<i>F</i> for change in $R^2$	866.01**		285.26		215.59	
<b>Regression 2 (N=89)</b>						
Pain Ratings T1	0.02	0.95**	0.97	0.95**	0.97	0.95**
Hope Agency			-0.02	-0.02	-0.08	-0.15
Survivor Status			-0.25	-0.03	-0.19	-0.01
Agency X Survivor Status					0.06	0.12
$R^2$	0.91**		0.91		0.91	
<i>F</i> for change in $R^2$	866.05**		287.26		215.37	
<b>Regression 3 (N=89)</b>						
Pain Ratings T1	0.97	0.95**	0.98	0.96**	0.97	0.95**
Hope Pathways			-0.00	-0.00	-0.09	-0.15
Survivor Status			-0.24	-0.03	-0.18	-0.02
Pathways X Survivor Status					0.08	0.15
$R^2$	0.91**		0.91		0.91	
<i>F</i> for change in $R^2$	866.05**		284.69		214.34	

*Note.* Hope scores were centered at their means. Most of the variance was accounted for by pain ratings T1. \*\* $p < .05$ . Age and gender were not significant covariates.



### Aim 3 Tables

Table 9  
 Aim 3 Hierarchical Regression Analyses for Pain as Predictor of Subscales of QoL T2 and Total Hope as a Moderator (while controlling for QoL T1)

Variables	Model 1		Model 2		Model 3	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=95)</b>						
Quality of Life T1	0.94	0.91**	0.92	0.89**	0.93	0.90**
Pain Ratings			0.11	0.02	0.09	0.01
Hope Total Score			0.20	0.11*	0.20	0.14*
Pain X Total Hope					-0.02	-0.02
$R^2$	0.83**		0.84		0.84	
<i>F</i> for change in $R^2$	444.70**		156.17		116.18	
<b>Regression 2 (N=95)</b>						
Physical QoL T1	.91	.95**	.88	.92**	.89	.92**
Pain Ratings			-0.06	-0.01	-0.08	-0.01
Hope Total Score			.23	.10**	.23	.10**
Pain X Total Hope					-0.02	-0.02
$R^2$	.90**		.91**		.91	
<i>F</i> for change in $R^2$	795.80		292.07**		217.59	
<b>Regression 3 (N=95)</b>						
Psychosocial QoL T1	.94	.88**	.91	.86**	.92	.86**
Pain Ratings			.06	.01	.04	.01
Hope Total Score			.201	.10*	.20	.10
Pain X Total Hope					-0.019	-0.02
$R^2$	.78**		.79		.79	
<i>F</i> for change in $R^2$	320.47		110.63		82.30	

*Note.* Pain ratings and Hope were centered at their means. QoL at T1 accounted for most of the variance. \* $p < .05$ , \*\* $p < .01$ . Age and gender were not significant covariates.

Table 10

*Aim 3 Hierarchical Regression Analyses for Pain as a Predictor of Subscales QoL T2 and Agency as a Moderator (while controlling for QoL T1)*

Variables	Model 1		Model 2		Model 3	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=95)</b>						
Quality of Life T1	0.94	0.91**	0.89	0.86**	0.90	0.87**
Pain Ratings			0.03	0.01	0.03	0.01
Agency			0.41	0.13**	0.41	0.13**
Pain X Agency					-0.01	-0.01
$R^2$	0.83**		0.85*		0.85	
<i>F</i> for change in $R^2$	444.70**		161.34*		0.773	
<b>Regression 2 (N=95)</b>						
Physical QoL T1	.91	.95**	.87	.91**	.88	.92**
Pain Ratings			-.14	-.02	-.13	-.02
Agency			.35	.09**	.36	.10**
Pain X Agency					-.042	-.03
$R^2$	.90**		.91*		.91	
<i>F</i> for change in $R^2$	796.80**		284.85*		213.23	
<b>Regression 3 (N=95)</b>						
Psychosocial QoL T1	.94	.88**	.88	.83**	.88	.83**
Pain Ratings			.00	.00	-.00	.00
Agency			.47	.15**	.47	.17**
Pain X Agency					-.01	-.01
$R^2$	.78**		.80*		.80	
<i>F</i> for change in $R^2$	320.47**		116.40*		86.34	

*Note.* Pain ratings and Hope were centered at their means. QoL at T1 accounted for most of the variance. \* $p < .05$ , \*\* $p < .05$ . Age and gender were not significant covariates.

Table 11  
 Aim 3 Hierarchical Regression Analyses for Pain as a Predictor of Subscales of QoL T2 and Pathways as a Moderator ( while controlling for QoL T1)

Variables	Model 1		Model 2		Model 3	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=95)</b>						
Quality of Life T1	.94	.91**	.95	.92**	.95	.99
Pain Ratings			.09	.02	.08	.01
Pathways			.15	.05	.16	.05
Pain X Pathways					-.04	-.03
$R^2$	.83**		.84		.84	
<i>F</i> for change in $R^2$	444.69**		147.31		110.18	
<b>Regression 2 (N=95)</b>						
Physical QoL T1	.91	.95**	.90	.93	.89	.93
Pain Ratings			-.09	-.01	-.08	-.01
Pathways			.31	.08	.31	.08
Pain X Pathways					.01	.01
$R^2$	.90**		.90		.90	
<i>F</i> for change in $R^2$	795.80**		278.63		206.74	
<b>Regression 3 (N=95)</b>						
Psychosocial QoL T1	.94	.88**	.94	.88**	.95	.88**
Pain Ratings			.02	.00	.00	.00
Pathways			.10	.03	.11	.03
Pain X Pathways					-.06	-.05
$R^2$	.78**		.78		.78	
<i>F</i> for change in $R^2$	320.47**		105.04		79.04	

*Note.* Pain ratings and Hope scores were centered at their means. QoL at T1 accounted for most of the variance. \* $p < .05$ , \*\* $p < .01$ . Age and gender were not significant covariates.

Table 12

*Aim 3 Cross-sectional Correlation Analyses between Pain, Quality of Life and Hope at T1*

	Pain Ratings	QoL Physical	QoL Psychosocial	QoL Total
Pain Ratings				
QoL Physical	-.58**			
QoL	-.46**	.73**		
Psychosocial				
QoL Total	-.52**	.85**	.98**	
Hope Agency	-.17*	.25** <sup>a</sup>	.41** <sup>a</sup>	.40** <sup>a</sup>
Hope Pathways	-.15	.02	.07	.06
Hope Total	-.21*	.17	.31**	.29**

*Note.* \* $p < .05$ ; \*\* $p < .01$ . <sup>a</sup>Fisher's  $r$  to  $z$  scores were calculated and concluded that agency scores when compared to pathways scores were more strongly correlated with physical, psychosocial and overall QoL

Table 13  
 AIM 3 Cross-Sectional Bootstrap Mediation Analyses for Pain on Subscales of QoL through Hope Total (N=129)

Variables	Direct and Total Effects			Indirect Effect
	<i>Coeff</i>	<i>SE</i>	<i>t</i>	<i>CI</i>
<b>DV: QoL Total T1; IV= Pain T1; Mediator: Hope Total T1</b>				
<b>Bootstrap Matrix 1</b>				
IV on Mediator	-5.39	1.8	-2.92**	
Mediator on DV	0.34	0.14	2.34*	
IV on DV	-19.36	3.05	-6.36**	
IV on DV through Mediator	-17.53	3.09	-5.67**	-4.24 to -.32 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.27		
<i>F</i>		23.67**		
<b>DV: Physical QoL T1; IV= Pain T1; Mediator: Hope Total T1</b>				
<b>Bootstrap Matrix 2</b>				
IV on Med	-5.39	1.86	-2.90**	
Med on DV	0.09	0.17	0.49	
IV on DV	-25.72	3.72	-6.91**	
IV on DV through Mediator	-25.24	3.85	-6.26**	-2.77 to -1.32 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.27		
<i>F</i>		23.88**		
<b>DV: Psychosocial QoL T1; IV= Pain T1; Mediator: Hope Total T1</b>				
<b>Bootstrap Matrix 3</b>				
IV on Med	-5.4	1.83	-2.94*	
Med on DV	0.39	0.15	2.68**	
IV on DV	-18.05	3.14	-5.75**	
IV on DV through Mediator	-15.90	3.17	-5.02**	-4.72 to -0.47 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.25		
<i>F</i>		20.95**		

Note. Age was used as a covariate and was not significant.

<sup>a</sup>Mediation is concluded if the confidence interval does not cross zero, meaning total hope was found to mediate the relationship between pain and all subscales of QoL.

\* $p < .05$ , \*\* $p < .01$

Table 14  
 AIM 3 Cross-Sectional Bootstrap Mediation Analyses for Pain on Subscales of QoL through Agency (N=129)

Variables	Direct and Total Effects			Indirect Effect
	<i>Coeff</i>	<i>SE</i>	<i>t</i>	<i>CI</i>
<b>DV: QoL Total T1; IV=Pain T1; Mediator: Agency T1</b>				
<b>Bootstrap Matrix</b>				
IV on Mediator	-2.63	1.11	-2.35*	
Mediator on DV	0.98	0.23	4.30**	
IV on DV	-19.36	3.04	-6.36**	
IV on DV through Mediator	-16.79	2.92	-5.76**	-5.39 to -0.50 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.34		
<i>F</i>		32.27**		
<b>DV: Physical QoL T1; IV=Pain T1; Mediator: Agency T1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-2.68	1.12	-2.41*	
Med on DV	0.54	0.29	1.87	
IV on DV	-25.72	3.72	-6.91**	
IV on DV through Mediator	-24.26	3.76	-6.44**	-4.28 to -0.05 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.29		
<i>F</i>		26.12**		
<b>DV: Psychosocial QoL T1; IV=Pain T1; Mediator: Agency T1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-2.60	1.11	-2.34*	
Med on DV	1.07	0.23	4.59**	
IV on DV	-18.05	3.14	-5.75**	
IV on DV through Mediator	-15.26	2.98	-5.13**	-5.82 to -0.53 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.32		
<i>F for change in R</i> <sup>2</sup>		29.75**		

Note. Age was used a covariate and was not significant.

<sup>a</sup>Mediation is concluded if the confidence interval does not cross zero, meaning agency was found to mediate the relationship between pain and all subscales of QoL. \*p<.05, \*\*p<.01

Table 15  
 AIM 3 Cross-Sectional Bootstrap Mediation Analyses for Pain on Subscales of QoL through Pathways (N=129)

Variables	Direct and Total Effects			Indirect Effect
	<i>Coeff</i>	<i>SE</i>	<i>t</i>	<i>CI</i>
<b>DV: QoL Total T1; IV = Pain T1; Mediator: Pathways T1</b>				
<b>Bootstrap Matrix</b>				
IV on Mediator	-2.22	1.07	-2.06*	
Mediator on DV	0.03	0.25	-0.13	
IV on DV	-19.36	3.04	-6.36**	
IV on DV through Mediator	-19.43	3.11	-6.25**	-1.01 to 1.27
<i>R</i> <sup>2</sup>		0.24		
<i>F</i>		20.06**		
<b>DV: Physical QoL T1; IV=Pain T1; Mediator: Pathways T1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-2.18	1.07	-2.04*	
Med on DV	-0.25	0.36	-0.81	
IV on DV	-25.72	3.72	-6.91**	
IV on DV through Mediator	-26.26	3.78	-6.94**	-0.41 to 2.69
<i>R</i> <sup>2</sup>		0.27		
<i>F</i>		24.17**		
<b>DV: Psychosocial QoL T1; IV=Pain T1; Mediator: Pathways T1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-2.26	1.07	-2.10*	
Med on DV	0.02	0.26	0.09	
IV on DV	-18.05	3.14	-5.75**	
IV on DV through Mediator	-17.99	3.20	-5.62**	-1.48 to 0.99
<i>R</i> <sup>2</sup>		0.21		
<i>F for change in R</i> <sup>2</sup>		16.43**		

Note. Age was used as a covariate and was not significant.

Mediation is concluded if the confidence interval does not cross zero, meaning pathways was not found to be a significant mediator between pain and subscales of QoL.

\*p<.05, \*\*p<.01

Table 16

*AIM 3 Longitudinal Bootstrap Mediation Confidence Intervals for the Relationship between Pain and QoL with Hope as a Mediator after controlling for Time 1 QoL*

Bootstrap Matrix	Confidence Intervals
DV: Total QoL T2; IV: Pain T1; Med: Hope Total T1	-0.34 to 0.04
DV: Total QoL T2; IV: Pain T1; Med: Agency T1	-0.10 to 0.33
DV: Total QoL T2; IV: Pain T1; Med: Pathways T1	-0.26 to 0.01
DV: Physical QoL T2; IV: Pain T1; Med: Hope Total T1	-0.38 to 0.04
DV: Physical QoL T2; IV: Pain T1; Med: Agency T1	- 0.19 to 0.06
DV: Physical QoL T2; IV: Pain T1; Med: Pathways T1	-0.29 to 0.03
DV: Psychosocial QoL T2; IV: Pain T1; Med: Hope Total T1	-0.92 to 0.07
DV: Psychosocial QoL T2; IV: Pain T1; Med: Agency T1	-0.64 to 0.35
DV: Psychosocial QoL T2; IV: Pain T1; Med: Pathways T1	-0.64 to 0.35

*Note.* Mediation is concluded if the confidence interval does not cross zero, meaning that none of the hope scores were found to mediate the relationship between pain T1 and QoL T2 after controlling for QoL at time 1.



Table 17  
 AIM 3 Bootstrap Mediation Analyses for Pain on Subscales of QoL through Hope Total (N=95)

Variables	Direct and Total Effects			Indirect Effect
	<i>Coeff</i>	<i>SE</i>	<i>t</i>	<i>CI</i>
<b>DV: QoL Total T2; IV= Pain T1; Mediator: Hope Total T1</b>				
<b>Bootstrap Matrix 1</b>				
IV on Mediator	-0.64	0.29	-2.19*	
Mediator on DV	0.52	0.17	3.01**	
IV on DV	-2.66	0.50	-5.34**	
IV on DV through Mediator	-2.32	0.49	-4.75**	-0.79 to -0.07 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.31		
<i>F</i>		13.38**		
<b>DV: Physical QoL T2; IV= Pain T1; Mediator: Hope Total T1</b>				
<b>Bootstrap Matrix 2</b>				
IV on Med	-0.60	0.29	-2.07*	
Med on DV	0.45	0.19	2.36**	
IV on DV	-3.75	0.55	-6.77**	
IV on DV through Mediator	-3.48	0.55	-6.28**	-0.78 to -0.03 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.38		
<i>F</i>		18.32**		
<b>DV: Psychosocial QoL T2; IV= Pain T1; Mediator: Hope Total T1</b>				
<b>Bootstrap Matrix 3</b>				
IV on Med	-0.64	0.29	-2.22*	
Med on DV	0.52	0.18	2.82**	
IV on DV	-2.42	0.53	-4.60**	
IV on DV through Mediator	-2.08	0.52	-4.01**	-0.80 to -0.06 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.25		
<i>F</i>		10.26**		

*Note.* Age was used as a covariate and was not significant.

<sup>a</sup>Mediation is concluded if the confidence interval does not cross zero, meaning total hope was found to mediate the relationship between pain and all subscales of QoL.

\**p*<.05, \*\**p*<.01

Table 18  
 AIM 3 Bootstrap Mediation Analyses for Pain on Subscales of QoL through Agency (N=95)

Variables	Direct and Total Effects			Indirect Effect
	<i>Coeff</i>	<i>SE</i>	<i>t</i>	<i>CI</i>
<b>DV: QoL Total T2; IV=Pain T1; Mediator: Agency T1</b>				
<b>Bootstrap Matrix</b>				
IV on Mediator	-0.33	0.17	-1.88	
Mediator on DV	1.27	0.27	4.72**	
IV on DV	-2.66	0.49	-5.34**	
IV on DV through Mediator	-2.24	0.46	-4.91**	-0.97 to -0.03 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.39		
<i>F</i>		19.18**		
<b>DV: Physical QoL T2; IV=Pain T1; Mediator: Agency T1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-0.32	0.16	-1.85	
Med on DV	1.07	0.31	2.46**	
IV on DV	-3.75	0.55	-6.77**	
IV on DV through Mediator	-3.40	0.53	-6.38**	-0.92 to -0.04 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.42		
<i>F</i>		21.62**		
<b>DV: Psychosocial QoL T2; IV=Pain T1; Mediator: Agency T1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-0.33	0.17	-1.90	
Med on DV	1.30	0.29	4.52**	
IV on DV	-2.42	0.53	-4.60**	
IV on DV through Mediator	-1.98	0.49	-4.09**	-0.99 to -0.04 <sup>a</sup>
<i>R</i> <sup>2</sup>		0.34		
<i>F for change in R</i> <sup>2</sup>		15.39**		

Note. Age was used a covariate and was not significant.

<sup>a</sup>Mediation is concluded if the confidence interval does not cross zero, meaning agency was found to mediate the relationship between pain and all subscales of QoL. \*p<.05, \*\*p<.01

Table 19

*AIM 3 Bootstrap Mediation Analyses for Pain on Subscales of QoL through Pathways (N=95)*

Variables	Direct and Total Effects			Indirect Effect
	<i>Coeff</i>	<i>SE</i>	<i>t</i>	<i>CI</i>
<b>DV: QoL Total T2; IV = Pain T1; Mediator: Pathways T1</b>				
<b>Bootstrap Matrix</b>				
IV on Mediator	-0.21	0.17	-1.22	
Mediator on DV	0.21	0.34	0.66	
IV on DV	-2.66	0.49	-5.34**	
IV on DV through Mediator	-2.61	0.50	-5.19**	-0.34 to 0.05
$R^2$		0.24		
$F$		9.59**		
<b>DV: Physical QoL T2; IV=Pain T1; Mediator: PathwaysT1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-0.19	0.17	-1.11	
Med on DV	0.31	0.34	0.92	
IV on DV	-3.75	0.55	-6.77**	
IV on DV through Mediator	-3.69	0.58	-6.61**	-0.41 to -0.05
$R^2$		0.34		
$F$		15.99**		
<b>DV: Psychosocial QoL T2; IV=Pain T1; Mediator: Pathways T1</b>				
<b>Bootstrap Matrix</b>				
IV on Med	-0.22	0.17	-1.25	
Med on DV	0.14	0.32	0.43	
IV on DV	-2.42	0.51	-4.60**	
IV on DV through Mediator	-2.39	0.53	-4.46**	-0.31 to 0.08
$R^2$		0.19		
$F$ for change in $R^2$		7.07**		

*Note.* Age was used as a covariate and was not significant.

Mediation is concluded if the confidence interval does not cross zero, meaning pathways was not found to be a significant mediator between pain and subscales of QoL.

\* $p < .05$ , \*\* $p < .01$

## Aim 4 Tables

Table 20

*Aim4 Hierarchical Regression Analyses for Pain as a Predictor of Subscales of Hope T2 and Survivorship Status as a Moderator (with Hope T1 and as Covariate)*

Variables	Model 1		Model 2		Model 3	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=98)</b>						
Hope Total T1	0.72	0.71**	0.73	0.72**	0.73	0.72**
Pain Ratings			0.17	0.06	0.43	0.15
Survivorship Status			-0.62	-0.03	-0.76	-0.04
Pain X Survivorship					-0.32	-0.10
$R^2$	0.51**		0.51		0.52	
$F$ for change in $R^2$	99.94		33.12		24.75	
<b>Regression 2 (N=98)</b>						
Hope Agency T1	0.68	0.70**	0.67	0.70**	0.67	0.70**
Pain Ratings			0.02	0.01	-0.02	-0.01
Survivorship Status			-0.48	-0.04	-0.46	-0.04
Pain X Survivorship					0.04	0.02
$R^2$	0.49**		0.49		0.49	
$F$ for change in $R^2$	92.54**		30.41		22.57	
<b>Regression 3 (N=98)</b>						
Hope Pathways T1	0.68	0.74**	0.68	0.74**	0.68	0.74**
Pain Ratings			0.08	0.05	0.07	0.05
Survivorship Status			-0.47	-0.04	-0.46	-0.04
Pain X Survivorship					0.01	0.01
$R^2$	0.74**		0.75		0.75	
$F$ for change in $R^2$	118.08**		39.16		29.06	

*Note.* Pain ratings were centered at their means. Hope variables at time 1 accounted for most of the variance of hope scores at time 2. \* $p < .05$ , \*\* $p < .01$ . Age and gender were not significant covariates.

Table 21

*Aim4 Hierarchical Regression Analyses for Neuroticism as a Predictor of Subscales of Hope T2 and Survivorship Status as a Moderator (with Hope T1 and as Covariate)*

Variables	Model 1		Model 2		Model 3	
	<i>B</i>	$\beta$	<i>B</i>	$\beta$	<i>B</i>	$\beta$
<b>Regression 1 (N=98)</b>						
Hope Total T1	0.72	0.71**	0.69	0.68**	0.68	0.67**
Neuroticism			-0.08	-0.08	0.07	0.67
Survivorship Status			-0.20	-0.08	-0.10	-0.01
Neuroticism X Survivorship					-0.20	-0.18
$R^2$	0.50**		0.51		0.51	
$F$ for change in $R^2$	97.35**		32.50		24.86	
<b>Regression 2 (N=98)</b>						
Hope Agency T1	0.68	0.70**	0.67	0.69**	0.66	0.769**
Neuroticism			-0.15	-0.03	0.02	0.03
Survivorship Status			-0.44	-0.04	-0.44	-0.04
Neuroticism X Survivorship					-0.05	-0.07
$R^2$	0.49**		0.49		0.49	
$F$ for change in $R^2$	93.39**		30.72		22.90	
<b>Regression 3 (N=98)</b>						
Hope Pathways T1	0.69	0.75	0.67	0.73	0.66	0.72
Neuroticism			-0.03	-0.06	0.02	0.04
Survivorship Status			-0.28	-0.03	-0.24	-0.02
Neuroticism X Survivorship					-0.07	-0.12
$R^2$	0.75**		0.75		0.75	
$F$ for change in $R^2$	124.68**		41.34		31.12	

*Note.* Neuroticism scores were centered at their means. Hope variables at time 1 accounted for most of the variance of hope scores at time 2 .

\* $p < .05$ , \*\* $p < .01$ . Age and gender were not significant covariates.

**APPENDIX C**  
**Statistical Analyses Outline**  
**Significant results are bolded**

**I. Preliminary**

c. *Time 1*: Descriptives

- Differences between Leukemia survivors and Siblings on categorical variables (Chi Square)
  1. Gender =NS
  2. Ethnicity=NS
  3. BMI Category= NS
  4. Hip Pain and Hip Pain longer than 6months= NS
  5. Treatment Variables (Radiation)
  6. Smoking= NS
  7. Do they meet CDC criteria for exercise? = NS
- Differences between Leukemia survivors and Siblings on continuous variables (ANOVA)
  1. Age=NS
  2. Height=NS
  3. Weight=NS
  4. BMI= NS
  5. Neuroticism = NS
  - 6. Moderate exercise in minutes= S**
  7. Vigorous exercise in minutes= NSS

d. *Time 2*: Descriptive 3 month follow up

- Differences between Leukemia survivors and siblings on categorical variables (Chi Square)
  1. Gender=NS
  2. Ethnicity=NS
  3. BMI Category=NS
  4. Hip Pain and Hip Pain longer than 6months= NS
  5. Treatment Variables (Radiation)
  6. Smoking= NS
- Differences between Leukemia survivors and Siblings on continuous variables (ANOVA)
  1. Age=NS

2. Height=NS
  3. Weight=NS
  4. BMI= NS
- e. Consistency of ratings over time. Is there consistency between ratings of Pain, Hope, QoL and BMI from Time 1 to Time 2?  
(Paired sample t-tests)
1. Pain = NS
  2. Hope = NS
  3. QoL= NS
  4. BMI =NS
- \*\*There appears to be consistency between these measures at T1 and T2

## ii. AIM 1:

**-To determine whether ALL survivors have higher ratings of back pain than healthy controls**

**-To explore whether cancer survivors differ with regards to hope when compared to controls**

- c. Hypothesis 1: ALL survivors will have higher low back pain ratings than healthy controls- **Hypothesis supported by results for Time 1/initial data collection**
- *Time 1*
    1. **Back Pain categorical variable (Chi-square) = S (ALL survivors higher)**
    2. Back Pain lasting longer than 6 months categorical variable (Chi-square)= NS
    3. **Back pain ratings (ANOVA) = S (ALL survivors higher)**
  - *Time 2*
    1. Back Pain Categorical variable (Chi-Square) = NS (reasons: sample size, time period, no intervention)
    2. Back Pain lasting longer than 6 months categorical variable (Chi-Square)= NS
    3. Back Pain ratings (ANOVA)= NS
- d. Hypothesis 2: Survivors of ALL will exhibit higher levels of hope when compared to controls- Hypothesis not supported. Results

indicated that siblings have higher total hope and higher pathway than ALL survivors at time 1/initial data collection

- *Time 1*
  1. Hope (ANOVA):
    - h. Total Hope = S (siblings higher)**
    - i. Agency (willpower)= NS
    - j. Pathways (waypower)= S (siblings higher)**
- *Time 2*
  1. Hope (ANOVA):
    - h. Total Hope = NS
    - i. Agency = NS
    - j. Pathways= NS
  2. Hope Change Score between T1 and T 2 (T2-T1)
    - h. Total Hope= NS
    - i. Agency Change = NS
    - j. Pathways Change = NS

### III. AIM 2

*Time 1:* Cross sectional correlations for exercise, bmi, neuroticism, hope with PAIN (DV)

*Time 2:* Correlations for time 1 exercise, bmi, neuroticism, hope with PAIN T2 (DV)

**-Examine whether pain is influenced by exercise, BMI, neuroticism and hope and whether these variables predict pain ratings**

- a. Hypothesis 3: Exercise will have an inverse relationship with pain- Hypothesis supported, but non significant
  - Exercise T1 with Pain T1:
    1. Moderate activity measured in minutes=NS (positive)
    2. Vigorous activity measured in minutes= NS (inverse)
  - Exercise T1 with Pain T2:
    1. Moderate activity measured in minutes=NS (positive)



2. Vigorous activity measured in minutes= NS  
(positive)
- b. Hypothesis 4: BMI will have a positive relationship with pain-  
Hypothesis supported, but not significant
    - BMI T1 with Pain T1= NS (positive)
    - BMI T1 with Pain T2= NS (inverse)
  - c. Hypothesis 5: Neuroticism will have a positive relationship  
with pain- **Hypothesis supported and significant**
    - **Neuroticism T1 with Pain T1= S (positive)**
    - **Neuroticism T1 with Pain T2= S (positive)**
  - d. Hypothesis 6: Hope will have an inverse relationship with pain-  
**Hypothesis supported and significant for agency and total hope**
    - **Hope Total T1 with Pain T1 = S (inverse)**
      1. **Agency T1 and Pain T1 = S (inverse)**
      2. Pathway T1 and Pain T1 = NS (inverse)
    - **Hope Total T1 and Pain T2 = S (inverse)**
      - Agency T1 and Pain T2= NS (inverse)
      - Pathway T1 and Pain T2 = NS (inverse)
  - e. *Time 1* Cross-sectional Correlations between variables: exercise,  
bmi, neuroticism and hope
    - **Significant:**
      - **BMI and Neuroticism = S (positive)**
      - **Agency and Neuroticism = S (pnverse)**
      - **Total Hope and Neuroticism = S (inverse)**
      - **Moderate exercise and Agency = (positive)**
  - f. Simple multiple linear regression of variables predicting pain
    - DV: pain ratings at T2  
Step 1: Pain ratings at T1  
Step 2: Moderate exercise, vig exercise, BMI, Neuroticism,  
Agency Pathway and Total Hope = NS (most of  
variance accounted for by pain at T1)
  - g. Prediction of Exercise, BMI, Neuroticism and hope (Multiple  
Regression)

- DV: pain ratings at T2  
Step 1: pain ratings T1  
Step 2: BMI Total, Total Time Mod Activity, Total Time Vig Activity  
Step 3: Neuroticism, Total Hope Score, Agency, Pathway =NS (Most of variance accounted for by pain at T1)
- DV: pain ratings at T2\*\*  
Step 1: pain ratings T1  
Step 2: BMI Total, Activity per CDC (categorical)  
Step 3: Neuroticism, Total Hope Score, Agency, Pathway =NS (Most of variance accounted for by pain at T1)
- DV: pain ratings at T2\*\*  
Step 1: pain ratings T1  
Step 2: Neuroticism, Total Hope Score, Agency, Pathway  
Step 3: BMI Total, Activity per CDC (categorical) =NS (Most of variance accounted for by pain at T1)

\*\*NOTE: The regressions were run two ways to see if physical variables (BMI and exercise) account for the variance over and above psychosocial variables (hope and neuroticism) and vice versa

### **AIM 2b**

- **The study will also examine the differences in these relationships (Exercise, BMI, Neuroticism and Hope with Pain) for survivors and controls**

Hypothesis 7a: Survivor status will not have an impact on the relationship between pain and the variables of exercise, BMI and neuroticism- hypothesis not supported. No significant interaction found between survivor status and variables. Most of the variance is accounted for by pain at T1

Analysis: Moderation (Hierarchical Multiple Linear Regression)  
IV: Moderate Exercise, DV: Pain, Moderator: Survivorship Status

- DV: Pain ratings at T2  
Step 1: Pain ratings at T1  
Step 2: centered moderate exercise, survivorship status

Step 3: centered moderate exerciseXsurvivorship status  
=NS (Most of variance accounted for by pain at T1)

IV: Vigorous Exercise, DV: Pain, Moderator: Survivorship Status

- DV: Pain ratings at T2

Step 1: Pain ratings at T1

Step 2: vigorous exercise, survivorship status

Step 3: centered vigorous exerciseXsurvivorship status  
=NS (Most of variance accounted for by pain at T1)

IV: BMI, DV: Pain, Moderator: Survivorship Status

- DV: Pain ratings at T2

Step 1: Pain ratings at T1

Step 2: centered BMI, survivorship status

Step 3: centeredBMIXsurvivorship status =NS (Most of  
variance accounted for by pain at T1)

IV: Neuroticism, DV: Pain, Moderator: Survivorship Status

- DV: Pain ratings at T2

Step 1: Pain ratings at T1

Step 2: centered neuroticism, survivorship status

Step 3: centeredneuroticismXsurvivorship status =NS  
(Most of variance accounted for by pain at T1)

Hypothesis 7b. It is expected that survivors will have both higher hope levels and higher pain levels than healthy controls – hypothesis partially supported in Aim 1

Hypothesis 7c. Therefore when interacting with survivorship status (moderator), the strength of the relationship between hope and pain will decrease

Moderation (Hierarchical Multiple Linear Regression Analyses)

IV: Hope, DV: Pain, Moderator: Survivorship Status (controlling for pain at T1)

- DV: Pain ratings at T2

Step 1: Pain ratings at T1

Step 2: centered hope, survivorship status

Step 3: centeredhopeXsurvivorship status =NS (Most of  
variance accounted for by pain at T1)

- DV: Pain ratings at T2  
Step 1: Pain ratings at T1  
Step 2: centered agency, survivorship status  
Step 3: centeredagencyXsurvivorship status =NS (Most of variance accounted for by pain at T1)
- DV: Pain ratings at T2  
Step 1: Pain ratings at T1  
Step 2: centered pathway, survivorship status  
Step 3: centeredpathwayXsurvivorship status =NS (Most of variance accounted for by pain at T1)

Note: Moderation without controlling for T1 Pain- Moderation was also considered without controlling for T1 for several reasons: lack of intervention between T1 and T2, change in pain not expected in a 3 month period and no significant developmental milestones in age range

- DV: Pain ratings at T2  
Step 1: centered hope, survivorship status  
Step 2: centeredhopeXsurvivorship status =NS
- DV: Pain ratings at T2  
Step 1: centered agency, survivorship status  
Step 2: centeredagencyXsurvivorship status =NS
- DV: Pain ratings at T2  
Step 1: centered pathway, survivorship status  
Step 2: centeredpathwayXsurvivorship status =NS

#### IV. AIM 3 **\*\*Focus of manuscript for publication**

**Of great interest to this study is to explore the role of hope as a construct in understanding pain and quality of life; specifically, whether hope moderates subjective pain ratings and overall quality of life**

- a. Correlational analyses between pain ratings, quality of life and hope
  - **Significant results**
    - **Physical QoL and pain ratings= S (inverse)**

- **Psychosocial QoL and pain ratings = S (inverse)**
- **Total QoL and pain ratings = S inverse**
- **Hope Agency and pain ratings = S inverse**
- **Hope Total and pain pain ratings = S inverse**
- **Hope Agency and Total QoL = S positive**
- **Hope Total and Total QoL = S positive**
- **Hope Agency and Psychosocial QoL= S positive**
- **Hope Total and Psychosocial QoL = S positive**
- **Hope Agency and Physical QoL = S positive**

Hypothesis 8a: Pain will predict QoL and the two will have an inverse relationship- Hypothesis not supported

Hypothesis 8b: The relationship will be moderated by hope. Having higher levels of hope will buffer (moderate) the detrimental effects of pain on QoL- hypothesis not supported, no interaction effect

Hypothesis 8c: It is expected that those with high hope will have higher QoL despite pain, while those with low hope will have poorer quality of life- **Hypothesis partially supported. Regression analyses concluded that:**

1. **even after controlling for QoL domains (physical, psychosocial and total) at time 1, agency and total hope predicted physical, psychosocial and overall QoL**
  2. **pathways predicted physical QoL, but it did not predict psychosocial and overall QoL**
- h. Moderation: Hierarchical Multiple Regression Analyses (Answers hypotheses 8a-c)
- DV: 3-month QoL total score  
Step 1: QoL total score T1  
Step 2: centered pain T1, centered GS Total T1:  
Step 3: centeredpainXtotalhope interaction variable = NS
  - DV: 3-month QoL total score:  
Step 1: QoL total score T1:  
Step 2: centered pain T1, centered agency T1= **Agency S when looking at the coefficients**

- Step 3: centeredpainXagency interaction variable
- DV: 3-month QoL total score:
    - Step 1: QoL total score T1:
    - Step 2: centered pain T1, centered pathways T1:
    - Step 3: centeredpainXpathway interaction variable = NS
  - DV: 3-month QoL physical total
    - Step 1: QoL physical total T1
    - Step 2: centered pain T1, centered GS Total T1 = **S Total**

**Hope when looking at the coefficients**

    - Step 3: centeredpainXtotalhope interaction variable
  - DV: 3-month QoL physical total:
    - Step 1: QoL physical total T1
    - Step 2: centered pain T1, centered GS agency T1= **S**

**Agency when looking at the coefficients**

    - Step 3: centeredpainXagency interaction variable
  - DV: 3-month QoL physical total
    - Step 1: QoL physical total T1
    - Step 2: centered pain T1, centered GS pathway T1
    - Step 3: centeredpainXpathway interaction variable = NS
  - DV: 3-month QoL psychosocial total
    - Step 1: QoL psychosocial total T1
    - Step 2: centered pain T1, centered GS Total T1
    - Step 3: centeredpainXtotalhope interaction variable=NS
  - DV: 3-month QoL psychosocial total
    - Step 1: QoL psychosocial total T1:
    - Step 2: centered pain T1, centered GS agency T1= **S**

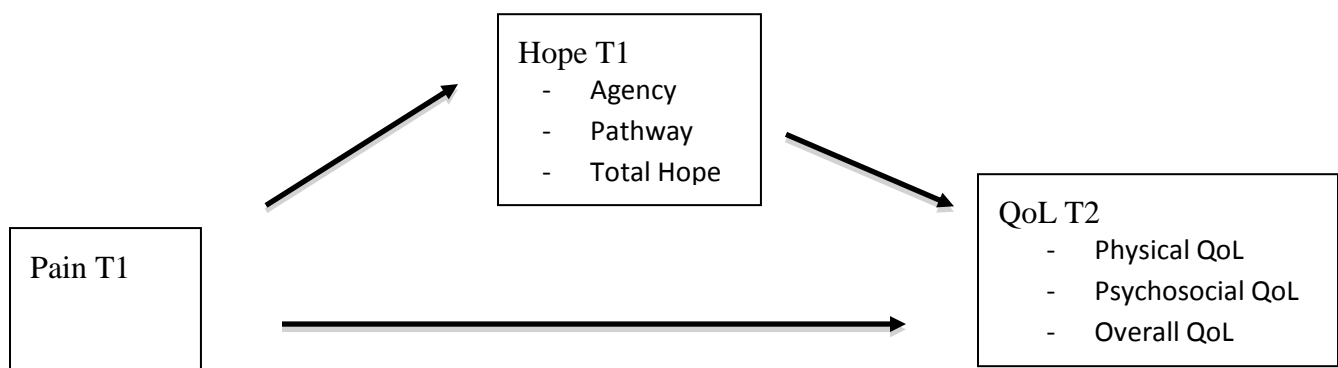
**Agency when looking at the coefficients**

    - Step 3: centeredpainXagency interaction variable
  - DV: 3-month QoL psychosocial total
    - Step 1: QoL psychosocial total T1
    - Step 2: centered pain T1, centered GS pathway T1
    - Step 3: centeredpainXpathway interaction variable =NS

Note: Moderation was also looked at without controlling for Time 1 quality of life- findings did not result in significant interactions

\*\*\*Looking at hope as a mediator was also considered following the correlational analyses as pain was inversely related to quality of life, pain was inversely related to hope and hope was positively related to QoL. Do individuals who have higher pain, but higher hope, specifically more agency, have higher QoL? Does hope provide an explanation for the relationship between pain and QoL

The following model was explored:



- i. Mediation Multiple Regression Analyses: To calculate whether hope mediates the relationship between pain and QoL, four separate equations were entered into the regression:
- Equation 1: Calculating the relationship between the IV (pain) and DV (QoL)
  - Equation 2: Calculating the relationship between the IV (pain) and Mediator (hope)
  - Equation 3: Calculating the relationship between the Mediator (hope) and the DV (QoL)
  - Equation 4: Calculating the relationship between the IV (pain) and DV (hope) via the Mediator (hope)

As entered into the regression analysis

- i. DV: Total QoL at 3-months (also entered Physical and Psychosocial QoL domains separately)  
Step 2: Pain ratings at T1
- ii. DV: Hope Total Score (also entered Agency and Pathways separately)  
Step 2: Pain Ratings at T1
- iii. DV: Total QoL at 3-months  
Step 2: Hope Total
- iv. DV: Total QoL at 3-months at T1  
Step 2: Pain ratings at T1, Hope Total Score

Note: Regression analyses were run both with QoL at T1 as a covariate and without QoL as a covariate. Although a slight change in the relationship between pain and QoL was observed, the regression analyses did not indicate that hope significantly reduced this relationship.

- j. Bootstrap Analyses
  - The Bootstrap method of analysis (Preacher and Hays) is a more robust measurement of mediation that was used to calculate whether hope mediates the relationship between pain a quality of life.

The following variables were entered into the Bootstrap macro:

DV: QoL at 3-months (also entered Physical and Psychosocial QoL)

IV: Pain ratings at T1

Mediator: Hope total score at T1 (also entered Agency and Pathways)

Covariates: age

**Significant results from Bootstrap analyses: significant mediation is concluded if the confidence interval for the indirect effect does not cross zero**

- i. **Indirect effect between pain and total QoL via hope total score (CI: -.79 to -.07)**
- j. **Indirect effect between pain and total QoL via agency score (CI: -.97 to -.03)**



- k. **Indirect effect between pain and physical QoL via total hope score (CI: -.78 to -.03)**
- l. **Indirect effect between pain and physical QoL via agency score (CI: -.92 to -.04)**
- m. **Indirect effect between pain and psychosocial QoL via total hope score (CI: -.79 to -.06)**
- n. **Indirect effect between pain and psychosocial QoL via agency score (CI: -.99 to -.04)**

#### V. AIM 4

**Examine whether pain and neuroticism influence or predict hope. These relationships will be analyzed in both bivariate and multivariate analyses**

Hypothesis 9: Both pain and neuroticism will have an inverse relationship with hope when measured longitudinally – Hypothesis not supported by results. Although pain and neuroticism have an inverse relationship with hope, they did not predict hope longitudinally when controlling for Hope at T1\*

**Significant predictors of hope when Hope at T1 is not a covariate**

1. **Neuroticism and Total Hope**
2. **Neuroticism and Agency**
3. **Neuroticism and Pathway**

- k. Regression Analyses (Do pain and neuroticism predict hope)?
  - DV: 3 month total hope:  
Step 1: hope total at time 1:  
Step2: pain ratings = NS
  - DV: 3 month agency:  
Step 1: agency at time 1:  
Step 2: pain ratings =NS
  - DV: 3 month pathways:  
Step 1: pathways at time 1:  
Step 2: pain ratings =NS
  - DV: 3 month total hope:

Step 1: hope total at time 1:

Step 2: EPQ =NS

- DV: 3 month agency:  
Step 1: agency at time 1:  
Step 2: EPQ =NS
- DV: 3 month pathways:  
Step 1: pathways at time 1:  
Step 2: EPQ =NS

\*Most variance was accounted for by hope at time 1

**Aim 4b: The study will also examine the differences in these relationships for survivors versus controls-**

Hypothesis 10: When examining interaction effects of survivor status on the relationship between pain and hope, there will be a weaker relationship between pain and hope for survivors only- Hypothesis not supported; interaction between survivorship status and pain/neuroticism were not significant

1. Hierarchical Multiple Regression Analyses

DV: Hope

IV: Pain or Neuroticism

Moderator: IV by survivorship status interaction

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