

THE IMPACT OF SPECIALIZED FAMILY CAMPS ON QUALITY OF LIFE AND HOPE IN  
FAMILIES WHO ARE COPING WITH PEDIATRIC CANCER

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## DEDICATION

I would like to thank Dr. Julie Germann and the members of my Graduate Committee for their constant support and guidance throughout the development of this project. I would also like to thank those involved in the planning of family camp programs for providing the opportunity for this study to move forward, especially Dr. Lisa Bashore. This project is dedicated to all the participating families whose lives have been impacted by their experiences at camp.

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by

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THESIS

Presented to the Faculty of the School of Health Professions

The University of Texas Southwestern Medical Center

Dallas, Texas

In Partial Fulfillment of the Requirements

For the Degree of

MASTER OF REHABILITATION COUNSELING

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## Abstract

**BACKGROUND:** Over the past several decades, specialized summer camps for children with cancer have been shown to have various positive results in those who attend. Family camps have become increasingly popular over the past few years, but the efficacy of family camps for specialized populations has not been well established through research. In addition, few studies have addressed the benefits of the camp experience over time, especially in regard to its impact on quality of life. The aim of this study was to learn whether or not the family camp experience increases the quality of life of families with a child with cancer, and whether or not these changes are maintained after the camp experience ends. In addition, this study examined the impact of camp on levels of hope, and analyzed how hope and social support contribute to the quality of life of those who attend camp.

**SUBJECTS:** A total of 66 families participated in this study. Participants include parents, cancer patients or survivors, and siblings. Thirty-nine families who attended a specialized weekend camp participated in the study, and a control sample of 27 families who did not attend camp was recruited as well.

**METHOD:** Questionnaire data was collected at three time points: pre-camp, post-camp, and a three-month follow up. Measures included a demographic questionnaire, age appropriate versions of the PedsQL™ 4.0 Generic Core Scales, the PedsQL™ 2.0 PedsQLTM 2.0 Family Impact Module, the Hope Scale (Adult and Child versions), the Young Children's Hope Scale, and a brief follow-up questionnaire.

**RESULTS:** Quality of life did not significantly increase in the camp group in the overall family unit. However, quality of life was shown to be significantly higher in the camp group than the

control group at the beginning and end of camp. Siblings demonstrated a significant increase in quality of life when examined separately from the family unit. No significant changes in hope or differences in hope between groups were observed.

DISCUSSION: Though this study did not demonstrate the efficacy of family camp as predicted, it did show that individual family members are impacted by camp in different ways. Camp has been shown to benefit siblings in particular, which is indicated by improvement in quality of life, hope, and social support in this population. This study also shows that different results may be found using different measures of the same variables.

*Keywords:* camp, quality of life, hope, family, cancer

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## CHAPTER ONE

### Introduction

While camps designed for special needs populations have been the subject of research for some years now, studies on family camps have only recently begun to emerge in the literature. Even within the realm of family camp research, the efficacy of these camps is an area that is seriously lacking in empirical data (Martiniuk, 2003).

In addition, although improved quality of life is often expressed as an ultimate outcome of therapeutic recreation interventions, such as camps, studies of the effect of camp experiences on quality of life of individuals with chronic illnesses has thus far been inconclusive (Martiniuk, 2003). According to a review by Epstein, Stinson, and Stevens (2005) regarding this issue, most studies on camp and quality of life in chronically ill patients have either lacked a control group for comparison or left out a measurement of at least one of the crucial areas of quality of life, which is generally understood to include physical, psychological, social, and cognitive aspects, resulting in an incomplete evaluation.

In addition, social support, one construct of quality of life which is shown to increase through camp experience (Conrad & Altmaier, 2009; Smith, 1987), is also known to be connected to hope in patients with cancer (Snyder, 2000). Patients with cancer who have high levels of hope are more likely to look for and obtain social support from their families and peers. However, the impact of camp on hope in particular has not been addressed in research. One challenge to conducting research on the impact of camp on outcomes such as quality of life and hope is that sample populations “cannot be randomized not to attend camp” (Barr et al., 2010),

and that inherent differences in personality and values often may exist between groups who choose to attend camp versus those who do not (Balen, Fielding, & Lewis, 1998).

This study adds to the current body of knowledge regarding the efficacy of family camps for specialized populations in a number of ways. First, the aim of this study is to determine whether or not family camp impacts the quality of life of all family members who attend camp, and whether or not changes are maintained over time. Quality of life is measured by constructs that address physical, psychological, social, and cognitive factors, and a control group of families who do not attend camp is compared. Secondly, this study helps to clarify the factors that contribute to positive outcomes of camp by measuring whether or not the family camp experience is correlated to an increase in hope and social support in families who attend. Furthermore, this study examines the relationship among factors that contribute to quality of life in the context of camp experience.

## CHAPTER TWO

### Review of the Literature

#### Impact of Camp

The value of camping experience in general has been well established in literature. While the latter half of the twentieth century saw the publication of various bibliographies and compilations of camping information, more recently outcome research has become common (Henderson, Bialeschki, & James, 2007). In 2007, a national project conducted by the American Camp Association provided scientific evidence of the benefits of camp to the children who attend. This project included participants from nearly 100 camps across the United States and was conducted over the span of two summers. The results of this study suggest that camp helps children become more confident, experience higher levels of self-esteem, and develop social skills that help them make new friends. Camp also helps children become more independent, develop leadership qualities, become more adventurous, and grow spiritually (American Camp Association, 2007). While their source may be somewhat subjective, the results of this study provide empirical data to support an idea that is promoted by most people involved in camping – that camp is a uniquely beneficial and valuable experience. Still, there is much to be learned about how camp influences lives, and this type of general research is a platform for further exploration into more specific camp populations.

Camp experience has also been shown to benefit children with special needs. In one quantitative study (Briery & Rabian, 1999), a one-week pediatric camp experience was correlated with a more positive attitude toward illness and decreased levels of trait anxiety

among patients with asthma, diabetes, and spina bifida, according to the Child Attitude Toward Illness Scale and the State-Trait Anxiety Inventory for Children. A more qualitative study done on youth with HIV/AIDS (Gillard, Witt, & Watts, 2011) found that positive outcomes associated with the camp experience include benefits such as the formation of caring connections through an increased awareness of commonality and a lack of isolation, the feeling of “reprieve and recreation,” as well as an increase in knowledge of illness, an improvement in attitude, and the development of skills relating to anger management, disclosure, and medication adherence.

### **Impact of camp on cancer patients.**

For the past several years, the efficacy of specialized camping experiences for children with cancer in particular has been a subject of interest to researchers. In one study, a week-long summer camp experience for patients and their siblings resulted in a significantly lowered score for depression among patients over time (Wellisch, Crater, Wiley, Belin, & Weinstein, 2006). In addition, this study also demonstrated, through significantly lowered scores on the Child Depression Inventory, that the camp experience is correlated to an improvement in affect in patient campers, and that this improvement is not only maintained but also increased 4-6 months after camp. Interestingly, the significant improvement in patient affect that became evident 4-6 months after camp was not notable immediately following the camp experience, demonstrating the importance of follow-up data for future research. In addition, because this study lacked a control group for comparison, it is impossible to know whether the passage of time could account for these changes.

Studies have addressed not only beneficial outcomes associated with camp experience, but also factors that might influence these outcomes. Social support in particular has been

addressed (Conrad & Altmaier, 2009), because it is not only intuitively associated with the camp experience, but also known to contribute to the adjustment of children with cancer (Houtzager, Grootenhuis, & Last, 2001). According to Conrad and Altmaier (2009), in a study involving a post-camp sample and a control group, children who attended camp reported more social support within the camp setting than children in the control group reported in their everyday lives. While the lack of a pre-camp measurement was a limitation of this study, social support was analyzed in terms of three categories; these include emotional/informational support, emotional/esteem-enhancing support, and tangible support. However, as Martiniuk (2003) pointed out, while it seems logical that the benefits of camp are largely a result of its impact on social support, it has not been determined through research which, if any, other mechanisms may contribute to this correlation.

Furthermore, the impact of camp on social support is demonstrated by a recent analysis of how adolescents who have had cancer benefit from the social comparisons that camp provides (Meltzer, 2005). In this study, it was hypothesized that adolescent survivors of cancer who attend an oncology camp would feel more similar to other campers than to peers at home, and as a result would report more positive self-competence and decreased levels of loneliness as a result of their camp experience. These hypotheses were indeed supported by the results of the study, furthering the idea that specialized camps play a unique role in the construct of social support, not only for young cancer patients, but survivors as well. However, because the measures used in this study were only examined pre- and post-camp without a follow-up, the possible maintenance of these benefits after camp is unknown.

The influence of camp on social interaction is further supported by research which demonstrates that children with cancer who attend a week long summer camp engage in more social activities after camp than before, and that these increases in social activity are maintained over time as well (Smith, 1987). Interestingly, this study also determined that the patient's camp experience may also contribute to a positive shift in family functioning; results indicated that siblings and parents of patients spent more time participating in family activities after the patient's camp experience than before. It is hypothesized that this result may have occurred simply due to the fact that having the ill child out of the household for a week allowed the other family members to reestablish a sense of normalcy that was then continued upon the sick child's return. However, this result also highlights the need for future research to further explore the impact of camp experience on families.

#### **Impact of camp on families.**

The popularity of camping experience has extended in recent years to include the whole family, and as a result, research in family camps has begun to appear. In 2011, a study submitted to the American Camp Association explored factors that motivated families as a whole to attend camp, and the benefits they attribute to their attendance (Baughman, 2011). Most families reported that their reasons for attending camp were that they wanted a fun and relaxing experience, a peaceful outdoor atmosphere, and an opportunity to spend quality time with their families. After camp, quality time with family was rated as the most positive memory by most families, and 86% said that their family relationships were reinforced by the camp experience.

These positive results provide an analysis of the people who attend camps for the purpose of vacation, but as an overview of family camps explained, vacationers make up only one

category of those who attend camp as a family (Agate, 2007). The other most popular reasons for attending family camp include maintaining and enriching family relationships and therapeutic or interventional purposes. While family camps can vary widely in their structure as well as the philosophy on which they are based, most have one important feature in common: their main purpose is to strengthen families. And, despite structural and philosophical differences, most of them fulfill this purpose. According to Agate (2007), the benefits that most people experience from family camp, regardless of their reason for attending, can be sorted into four areas: improving family interaction, nurturing relationships, providing social benefits - both among family members and among other families in attendance, and addressing specific issues. Specific issues may include gaining knowledge about a chronic illness or learning how to adhere to treatment regimens. Still, while it is clear that family camp is largely beneficial because of its effects on interpersonal relationships, there is still much to be learned about how exactly this observation affects camp outcomes in specialized populations.

One would assume that the positive experiences of vacationing family campers would also extend to those at specialized family camps as well, and some research has shown this to be true. At one family camp for families with a child with visual impairments, parent surveys provided information about how strongly parents supported the goals of the camp and how well they felt these goals were met (Day & Kleinschmidt, 2005). According to the results of this study, 89% of parents believed that camp goals that revolved around increasing communication and support were especially important. These goals included providing the children with opportunities to interact with other children with similar impairments, and providing parents the opportunity to talk and share with other parents and families. Likewise, 86% of parents agreed

that these and similar goals were met. These parents reported that they shared and talked with their own families and other parents, their children had opportunities to interact with other children with similar impairments, their children had opportunities to interact with siblings of other children with visual impairments, and their children seemed to enjoy these interactions. The positive effects of this camp were seen in a follow up six months after camp as well, although the sample size from which the follow up result was drawn was significantly small.

Another study based on the outcomes of camp experience for siblings of cancer patients reported a significant improvement in sibling's health related quality of life after a week at a camp designed specifically for siblings (Packman et al., 2005). In this study, based on a pre- and post-camp sample, siblings' quality of life scores, which initially fell approximately halfway between mean scores of the patient and healthy child samples, shifted much closer to the healthy sample mean immediately after camp. Another study of siblings who attended summer camp demonstrated that siblings who attended camp had higher scores on the Personal Attribute Inventory for Children, a self-concept measure (Murray, 2001). This is not surprising, because self-concept has also been closely linked to social support in research.

While these studies support the notion that family camp is likely just as, if not more, valuable for specialized groups than the general population, research regarding outcomes for the whole family is very limited. The research on benefits of the family camp experience for specific groups, such as families with a child with cancer, is inconclusive. It is important to note that while studies like Packman's 2005 quality of life study support the idea that a camp experience known to benefit patients with cancer would similarly benefit their siblings and parents, it is unwise to take this belief for granted. Results from a study by Wellisch et al. (2006) concluded

that the correlation between camp and depression and affect is indeed different between patient and sibling populations. While no significant differences were found between these groups on measures of activities remembered from camp or pleasure in activities, patients were found to have more significant changes in depression scores and greater increase in affect after the camp experience than siblings. This evidence supports the notion that the family's experience of both cancer and camp is different from that of the patient, and thus warrants further exploration.

Another recent study by Barr et al. (2010) was conducted in an effort to measure the effect of an entire family's camp experience on all family members, including issues such as family functioning, parental social support, and utilization of health and social services. Parents in camp-attending families indicated higher levels of family functioning and social support than parents in non-attending families. Parents in attending families also had children who exhibited more anxiety, emotional issues, and hyperactivity, and generally spent more money on health and social services annually than parents in non-attending families. On one hand, it can be argued that this result indicates that families who attend camp are those with the greatest need, but also it is important to recognize the key question that is left unanswered: does camp actually improve the welfare of families who attend, or are more highly functioning families naturally inclined to attend camp?

### **Family Adjustment to Critical Illness**

One reason that the efficacy of specialized family camp is an area that requires future research is that it is generally known that pediatric critical illness is stressful for the entire family (Shudy et al., 2006). This stress comes from a variety of sources depending on the illness of the child, and different family members are impacted by different factors. For example, one study on

the parents of adolescents with congenital heart disease identified several themes that are of concern for parents: dilemmas of normality, disclosure dilemmas, the challenge of uncertainty, illness management, social integration or isolation of the child, the impact of illness on the family, and coping (Sparacino et al., 1997). These parents reported that patterns of family activities were changed in response to the child's illness, and alterations in lifestyles were made in order to incorporate the child's illness into the family dynamic. Another study done on the impact of pediatric traumatic brain injury on families found that behavior changes occurred in siblings in 55% of families studied (Montgomery, Oliver, Reisner, & Fallat, 2002). This study reported that siblings often exhibited increased fear, difficult behavior at home, decreased school performance, and difficulty with peer relationships after one child experienced a traumatic brain injury.

It is clear that pediatric illness has serious implications for the family as a whole and that each member may be affected differently by the illness, but it is also important to consider that the way family members interact with each other also plays a role in their adjustment and coping. Family stress has predicted perceived social support in mothers of children with congenital heart disease in one study, and perceived social support was found to be an important factor in the prediction of maternal coping (Tak & McCubbin, 2002). Furthermore, the mother's coping patterns play a role in the adjustment of other family members, by encouraging them to be supportive of each other (Tak & McCubbin, 2002). Another study of siblings of children with sickle cell disease demonstrated that family adaptation processes could predict up to 21% of the variance in sibling adjustment; families who reported high levels of coping and low levels of

conflict were correlated with positive sibling adjustment (Gold, Treadwell, Weissman, & Vichinsky, 2008).

### **Family adjustment to cancer.**

It is a well known fact that a diagnosis of cancer in particular presents unique challenges to adjustment. Anxiety and depression disorders have been found to be twice as common in hospitalized adult cancer patients as the general population (Hinz et al., 2010). Research in pediatric adjustment to cancer has led to more inconclusive results, and while some studies have shown adjustment of patient populations to be comparable to normative groups (Chao, Chen, Wang, Wu, & Yeh, 2003; Matziou, Perdikaris, Galanis, Dousis, & Tzoumakas, 2008), others have suggested that a child's risk for adjustment problems is predicted by their coping style and social competence (Frank, Blount, & Brown, 1997). Additionally, survivors of childhood cancer are at risk for some psychosocial and adjustment problems, such as difficulty in social relationships, posttraumatic stress, and issues with self-concept and identity (Patenaude & Kupst, 2005). Another study showed that parents of children with brain tumors have significantly lower quality of life than other healthy adults, especially in the domains of physical and psychological health (Chien et al., 2003), and other research has shown that child cancer has been found to be a leading cause of post traumatic stress for parents in comparison to accidents or a child's diagnosis of diabetes (Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003).

Over the past few decades, the adjustment of siblings of cancer patients has been widely researched as well. Various studies have focused on the negative aspects of sibling adjustment, emphasizing issues such as anxiety, feelings of isolation, negative behavior changes, social withdrawal, depression, etc. (Houtzager, Grootenhuis, & Last, 1999; Murray, 2000) Other

studies have found positive aspects of sibling adjustment, and have highlighted areas such as increased sensitivity and maturation as a result of their sibling's diagnosis (Houtzager et al., 1999). Several characteristics are directly related to how well siblings adjust; these include the sibling's functioning before the diagnosis, the way the sibling perceives the illness, coping resources and strategies, and sociodemographic factors (Houtzager et al., 1999).

While some factors related to adjustment may be influenced by the illness itself, one of the most important realizations about both sibling and pediatric patient adjustment research is that adjustment of these individuals is very closely connected to the adjustment process of the entire family (Houtzager, et al., 1999; Varni, Katz, Colegrove, & Dolgin, 1996). Various studies have demonstrated this relationship by explaining that parental coping can affect family relationships, and the quality of family relationships both directly and indirectly affects sibling adjustment. For example, sibling distress could be caused by tension between parents, or the level of parents' social support could impact the way they relate to the children (Houtzager et al., 1999). In addition, Murray (2000) hypothesized that attachment theory could be used to explain some sibling adjustment difficulties; perhaps sibling symptoms of anxiety or depression and displays of anger, blaming, etc. could be routed in excessive separation from the mother, who is usually the primary attachment figure and often the one who accompanies the sick child when a family must be separated for treatment.

Social support is a factor that plays a key role in both sibling and patient adjustment. A study of newly diagnosed pediatric cancer patients indicated that more perceived social support was predictive of lower negative emotion both concurrently and over time (Varni & Katz, 1997). A comparison study between a group of siblings referred for behavior problems and a group of

non-referred siblings showed that siblings who reported more social support also reported fewer symptoms of depression and anxiety than those who reported less social support (Barrera, Fleming, & Khan, 2004). In addition, siblings with more social support exhibited less behavior problems than those with less social support. A study using the open-ended questions of the Nurse-Sibling Social Support Questionnaire determined that most siblings find interventions aimed at meeting their emotional needs most helpful (Murray, 2002). For the sake of this study, emotional support included provisions of empathy, encouragement, understanding, love, and trust. This type of support is precisely the type that families are most likely to experience in a camp setting, providing further support for the idea that the type of social support provided at camp is especially helpful to families, and likely to impact their overall quality of life.

### **Hope**

The role of hope in the adjustment and quality of life of those dealing with cancer is one that has not been addressed in the context of camping research, but is very closely connected to both social support and adjustment in both general and special populations. Not only is hope predictive of parental coping factors in families dealing with pediatric illness, but children's hope is impacted by parental coping (Snyder, 2000). In adult cancer patients, high hope patients are more likely to not only seek and receive more social support, but also provide more social support to their loved ones, thereby impacting family adjustment (Snyder, 2000).

This theme of the interrelationship between hope and social support has been consistent throughout research, despite the fact that the definition of hope has been less clear. One study involving interviews of caregivers of family members with cancer presented definitions of hope involving themes of looking ahead and having faith in God, and reported that hope is fostered by

relationships – with God, faith, church, self, family and others (Borneman, 2002). In interviews of several adolescents with cancer, hope was explained through three categories: inner resources, social network, and factors that fall between these two categories, such as information and perceptions (Juvakka & Kylma, 2009). The importance of a social network that provided emotional support, a positive attitude, and room for expression of feeling was a common theme across all interviews, and was considered a hope engendering factor in this study.

A metasynthesis conducted in order to describe the hope experiences of family caregivers of those suffering from chronic illness found additional themes among recent hope studies (Duggleby et al., 2010). First of all, one theme that resulted from this analysis was that hope is generally comprised of a shifting focus from the difficulty of the present situation to a more positive future. The positive future is generally based in possibilities, which can be either situational or personal. Personal factors shown to influence hope include not only internal factors such as positive outlook, spirituality, and well-being, but also external factors such as level of support, events, illness of the family member, relationship with the family member, and information about the patient's condition. As these conditions change, an individual's focus of hope may change as well, and the individual's degree of uncertainty about achieving their goals will also affect what avenues they may pursue to strengthen their hope (Duggleby et al., 2010).

While it has been determined that several factors contribute a person's level of hope, there is an overriding theme among past research that hope is impacted by external influences on some level. The value of positive relationships and a supportive social network have been cited by patient and caregiver populations alike, implying that hope is not an inert trait, but rather one that can be influenced by these factors. In fact, interventions designed to increase hope have

been successful in decreasing hopelessness and anxiety in depressed patients and improving psychological welfare of community mental health center clients (Snyder, 2000). These interventions have been based on the increase of pathways and agency through discussion of goals and the use of therapeutic tools that increase interpersonal support. These interventions further support the idea that external factors can increase hope, thereby providing a foundation for the prediction that camp experience will also increase hope.

Snyder's definition of hope as "the sum of perceived capabilities to produce routes to desired goals, along with the perceived motivation to use those routes" (Snyder, 2000) is perhaps the most inclusive and quantifiable definition of hope to date. According to Snyder, hope is goal-directed, and determined by the constructs of agency and pathways. In other words, a person's level of hope is determined by their ability to imagine routes to their goals, or pathways, and their motivation to pursue these routes, or agency. Therefore, if social support is a goal because of its positive relationship to adjustment, and an experience such as camp provides an opportunity for this goal to be reached, then according to this model, camp could increase hope by providing a pathway to the goal of social support.

Other recent research has focused less on what fosters hope and more on why exactly hope is important. In a study of primarily women with breast cancer, hope was shown to play a mediating role between the health status of the patients and psychological distress (Rustoen, Cooper, & Miaskowski, 2010). That is to say, in this study, a poor health status was less distressing for those with high hope, and more distressing for those with low hope. Hope is an important resource for cancer patients, and also plays a mediating role in the link between psychological distress and life satisfaction as well (Rustoen et al., 2010). In another study of

mothers with children with chronic physical conditions, hope was examined in conjunction with social support as a resilience factor against psychological distress (Horton, 2001). In this study, hope was found to be a moderator of distress, especially in situations where mothers perceived high levels of caregiver-disability-related stress. In high stress conditions, mothers with higher levels of hope were less distressed than those with low levels of hope.

One study of children with juvenile rheumatoid arthritis examined the relationship between family functioning, hope and quality of life. In this study, while family functioning and quality of life were not significantly correlated, family functioning was related to hope. Children expressed lower hope in situations of greater family dysfunction (Connelly, 2005).

### **Hypotheses**

From the literature, it is clear that there are benefits found in the camping experience, not only in general populations, but also in specialized groups and families. Social support is one such benefit that could be especially valuable to families dealing with cancer, because social support is an important component of adjustment to the cancer experience. Not only does family camp put families in contact with other families in the same situation, it also allows the family to enjoy meaningful and positive experiences together among themselves. This is especially important for strengthening family relationships, because often having a child with cancer lessens the time that siblings are able to spend together and the time that parents are able to spend with their well children (Hamama, 2010). Because of these findings, it is reasonable to predict that the family camp experience will increase the quality of life of families with a child with cancer, primarily through the construct of social support.

However, hope is another construct that is closely related to adjustment and social support, but has not been measured in camping populations. It is reasonable to expect that hope will also increase as a result of camp, because camp itself could be viewed as a pathway to the goal of increased social support. Since, according to Snyder (2000), hope is partially made up of pathways, or a person's ability to find routes to reach their goals, then by increasing a person's pathways to the goal of social support and thereby bolstering a person's perception of their ability to find routes to goals, hope has the potential to increase. Additionally, delineating the relationship between hope and quality of life will help to further clarify the factors that are most closely associated with camp's impact on quality of life.

The aim of this study was to demonstrate the efficacy of family camp for families coping with the experience of pediatric cancer by demonstrating its impact on quality of life, and to further clarify the modes by which camp provides benefits. This study builds upon the current body of literature by comparing results between families who attend camp and a control group. Results were analyzed from both a pre-post camp perspective for camp-attending families, as well as a follow up to determine whether or not the benefits of camp were maintained over time. Results for the control group were analyzed at the pre-camp ( $T_1$ ) and follow up ( $T_3$ ) time points. It is important to compare differences at baseline between camp-attending and control groups, but the control group was not measured at  $T_2$ , the post-camp time point. Since the camps attended by participants in this study were only one weekend long, and because the control group did not attend camp, few changes were expected to occur in the two day span between  $T_1$  and  $T_2$  for the control group. However, comparisons were made between groups at  $T_3$ , to determine the

long-term impact of camp and any naturally occurring changes in the control group. The following hypotheses were addressed in this study:

H<sub>1</sub>: Family camp increases quality of life. A series of *t* tests and a repeated measures analysis of variance (ANOVA) were used to compare differences in quality of life between groups (camp and control) and changes over time (pre-camp, post-camp, three-month follow-up).

H<sub>1A</sub>: Families who attend camp will show significant increases in quality of life at T<sub>2</sub> (post-camp). Specifically, camp-attending families will show an increase in scores from T<sub>1</sub> to T<sub>2</sub> on the PedsQL™ 4.0 Generic Core Scales and PedsQL™ 2.0 Family Impact Module.

H<sub>1B</sub>: Increased quality of life observed in camp-attending families will be maintained at a 3 month follow up. Specifically, scores on the PedsQL™ 4.0 Generic Core Scales and PedsQL™ 2.0 Family Impact Module will remain consistent between T<sub>2</sub> and T<sub>3</sub> for families who attend camp.

H<sub>1C</sub>: Families who do not attend camp (control group) will not show significant increases in quality of life. Scores on the PedsQL™ 4.0 Generic Core and PedsQL™ 2.0 Family Impact Module will remain consistent between T<sub>1</sub> and T<sub>3</sub> for the control group.

H<sub>1D</sub>: Families who attend camp will have significantly better quality of life compared to the control group. Families who attend camp will have greater scores at T<sub>3</sub> on the PedsQL™ 4.0 Generic Core Scales and PedsQL™ 2.0 Family Impact Module than control families.

H<sub>2</sub>: Family camp increases hope. Differences in hope will be compared between groups (camp and control) and changes over time (pre-camp, post-camp, three-month follow-up).

H<sub>2A</sub>: Families who attend camp will show significant increases in hope at T<sub>2</sub> (post-camp).

Camp-attending families will show an increase in scores from T<sub>1</sub> to T<sub>2</sub> on the Hope Scales.

H<sub>2B</sub>: Increased hope observed in camp-attending families will be maintained at a 3 month follow up. Scores on the Hope Scales will remain consistent between T<sub>2</sub> and T<sub>3</sub> for families who attend camp.

H<sub>2C</sub>: Families who do not attend camp (control group) will not show significant increases in hope. No significant changes in scores on the Hope Scales between T<sub>1</sub> and T<sub>3</sub> will be evident in the control group.

H<sub>2D</sub>: Families who attend camp will have significantly higher hope compared to the control group. Families who attend camp will have greater scores at T<sub>3</sub> on the Hope Scales than control families.

H<sub>3</sub>: There is a positive correlation between hope and quality of life. Specifically, mean family scores on the PedsQL<sup>TM</sup> measures will be positively correlated with mean family scores on the Hope Scales as measured by a Pearson correlation in both camp-attending (T<sub>1</sub>, T<sub>2</sub>, T<sub>3</sub>) and control groups (T<sub>1</sub>, T<sub>3</sub>).

H<sub>4</sub>: Social support contributes to the relationship between hope and quality of life. Specifically, a linear regression analysis will demonstrate that changes in social support, measured by scores on the social functioning subscale of the PedsQL<sup>TM</sup> measures, and changes in hope, measured by the Hope Scales, account for a significant portion of the variance in quality of life, measured by scores on the physical and emotional subscales of the PedsQL<sup>TM</sup> in both the camp-attending (T<sub>1</sub>, T<sub>2</sub>, T<sub>3</sub>) and control groups (T<sub>1</sub>, T<sub>3</sub>).

## CHAPTER THREE

### Method

#### Participants

Participants in the camp-attending group of this study were all family members, including parents, siblings, and patients/survivors, who attended weekend family camps specifically designed for families coping with pediatric cancer. The sample includes families who have a child currently in treatment, as well as families with a childhood cancer survivor. These families were recruited from three weekend camps. Two of the camps took place at Camp John Marc in Meridian, TX, and were attended by families who have a patient at the Center for Cancer and Blood Disorders at Children's Medical Center in Dallas, TX or Cook Children's Medical Center in Fort Worth, TX, respectively. Another camp took place at Camp For All in Burton, TX, and was attended by families who are members of the Candlelighters Childhood Cancer Family Alliance in Houston, TX. A total of 50 camp-attending families were recruited for the study; of those, 39 completed measurements for at least two time points and were included in the final data set.

Although the schedules, activities, atmosphere, and purpose of each camp were very similar, there were differences in location, camp staff members, season, and other uncontrollable factors. However, ANOVAs confirmed that there were not significant differences in quality of life or hope at any time among members who attended each of the three different camps.

Participants in the control group were recruited from the Center for Cancer and Blood Disorders at Children's Medical Center. The control group consisted of families who did not attend camp this year and have not attended an oncology family camp within the past two years.

Any control family who voiced interest in future family camp attendance was provided contact information for those involved in camp registration. The control sample was determined on the basis of convenience according to the times a researcher was available to approach a family during a regularly scheduled clinic appointment. A total of 78 families were initially recruited for participation in the control group. Of those, 27 families completed the follow-up measure and were included in the final sample.

The majority of participants were English speaking families; however, a few families (4 in the camp group and 3 in the control group) spoke Spanish only. These families were given Spanish translations of all recruitment materials and surveys. The Spanish speaking families who attended camp participated in camp activities with the help of on-site translators.

### **Procedure**

This study was approved by Children's Medical Center and the Institutional Review Boards of UT Southwestern Medical Center and Cook Children's Medical Center before families were approached for participation in this study. The camp-attending families were approached for participation upon their arrival at camp. Each family was given a packet of questionnaires with a cover letter explaining the study and inviting the family to participate, with the stipulation that filling out the questionnaires and returning them would be considered voluntary consent to participate in the study. See Appendix A for examples of these letters; multiple versions of some recruitment materials are included to accommodate confidentiality requirements of different groups. The packet also included a demographic questionnaire (Appendix B), as well as the age-appropriate hope and quality of life measures included in the study for each family member.

Camp-attending families were asked to complete the questionnaires and return them prior to beginning their camp activities, either immediately upon arrival or before breakfast of the first morning for those who arrived late the first night. Another set of the same questionnaires were distributed and collected at the end of the camp weekend before each family left the campsite. Prior to the three month follow-up date, families received either a phone call, email, or letter reminding them that their follow-up date was approaching and that the questionnaires would soon follow (Appendix D). After three months, a third set of questionnaires was mailed or emailed to each participating family with the request that they be either mailed back or completed online at the links provided. The 3-month follow up also included a brief questionnaire for the parents, which assessed any significant medical changes or other stressors that potentially occurred in the family since the camp weekend and could impact follow up results (Appendix E).

Families in the control group were approached in clinic for participation. They received an equivalent packet including an information letter (Appendix A), demographic form (Appendix B), and the quality of life and hope measures. Any parents, patients, or siblings who attended the clinic appointment were asked to complete the questionnaires before they left, and they were given questionnaires to take home for their siblings who were not present in clinic. Siblings were instructed to complete and mail back the surveys in a pre-stamped envelope as soon as possible; they also had the option of completing the questionnaires online, and instructions were provided. Most control families only provided responses from family members present in clinic, and very few additional family members agreed to participate. After 3 months, the third set of questionnaires and a brief follow up survey were mailed/emailed to each participating family

with the request that they be either mailed back or completed online. Control families were also approached in clinic at regularly scheduled appointments that coincided with their follow-up time frame, and many completed the follow-up measures in clinic.

### **Measures**

**Quality of Life.** Health-related quality of life is an important end point to clinical trials because it increases understanding of how treatment impacts patient functioning and provides an indicator of the treatment's effectiveness, among other things (Trask, Hsu, & McQuellon, 2009). While family camp is not a clinical trial, it is an intervention that has the potential to impact patient functioning. It is valuable to know whether or not camp is effective at improving quality of life because this will provide accountability for those who create the programs, as well as provide empirical support for the promotion of camp to more families.

Because the goal of this study is to assess the impact of camp on the family unit as a whole, through the perspective of all family members, family unit quality of life is computed by a composite score of the child and parent scores on the quality of life measures. The composite score was computed by averaging the total scores on the child measures and the parent health-related quality of life scores on the parent measures.

The quality of life study described here was carried out using the PedsQL™, developed by Dr. James W. Varni. This measure was chosen because it provides measurements of the health related quality of life constructs of physical, emotional, and social issues, as well as school issues for children. The appropriate self-report forms were assigned to each child according to their age, but all were versions of the PedsQL™ 4.0 Generic Core Scales. The reliability and

validity of these scales have been empirically demonstrated in past research (Varni, Seid, & Kurtin, 2001).

While parent proxy forms are available for the child and young adult versions of the PedsQL™ 4.0 Generic Core Scales in addition to self-reports and have the potential to provide useful information, they were omitted for the purpose of this study. Because self-reports should be considered the standard measurement for quality of life (Varni & Limbers, 2009), and because the parents' perception of the child's quality of life should not directly impact the way the child experiences camp in this study, parent proxy reports would be superfluous for this study. Also, research has shown that while child self-report ratings are predicted by their psychological and physical symptoms, parent proxy reports could be additionally related to parent symptoms of anxiety, depression, or parenting stress according to some testing measures (Roddenberry, 2008). For the purpose of this study, quality of life measurements were based solely on self-report, not only in an effort to avoid potential confounding factors, but also to minimize the amount of paperwork that parents were asked to complete, in order to minimize interference with camp activities.

Parent quality of life was measured by the PedsQL™ 2.0 Family Impact Module. This measure was chosen for its specific relevance to the families in this study, because it is intended to measure “the impact of pediatric chronic health conditions on parents and the family” (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). However, this measure includes questions for parents about the quality of life constructs of physical, emotional, social, and cognitive functioning, along with questions on worry, communication, daily family activities, and family relationships. Therefore, the PedsQL™ 2.0 Family Impact Module sufficiently measures parental

quality of life, and also provides more detailed information on family functioning and interaction that is especially relevant to this study. For the purpose of this study, the parent health-related quality of life summary scores of the PedsQL™ 2.0 Family Impact Module, which includes subscales that are equivalent to those found on the Generic Core Scales used for children, is used to determine parent quality of life. The total score on the PedsQL™ 2.0 Family Impact Module, which includes the additional family functioning components, is used in exploratory analyses. Reliability and validity of this measure have been demonstrated in research (Varni et al., 2004).

**Hope.** The instruments used to measure hope in this study were the Hope Scale and Children's Hope Scale, developed by C.R. Snyder, as well as the Young Children's Hope Scale, developed by McDermott, Hastings, Gariglietti, and Callahan and referenced by Snyder (2000). These scales are presented in Appendix C. The Hope Scale targets adult populations age 15-100 (Snyder, 2000) and has been shown to be psychometrically sound, reliable, and valid. The Children's Hope Scale targets children age 8-16 and is also reliable and valid (Snyder et al., 1997). The Young Children's Hope Scale is essentially a simplified version of the Children's Hope Scale and is appropriate for children age 5-7. While the psychometric testing of this scale has not yet been finalized, it has been administered to over 1,000 children and is both internally reliable and validated by significant correlation with concurrent constructs (Snyder, 2000).

According to Snyder, hope is a goal-directed construct, and as such can be understood and analyzed in the context of the concepts of agency and pathways (Snyder, 1994). As Snyder explains, pathways are essentially the routes that people imagine and believe can lead to a certain goal, while agency is the motivational component, or a person's belief that they have the ability and strength to move toward these goals (Snyder, 2000). Both agency and pathways are essential

components of hope, and the Hope Scales are designed to address both of these components and provide a numerical value for each person's level of hope. For the purpose of this study, composite family unit hope scores were computed using an average of family members' total scores on the age appropriate hope measures.

## CHAPTER FOUR

### Results

#### Preliminary Results

##### Demographics.

*Characteristics of total population.* A total of 135 families were initially recruited for this study. Fifty-seven camp-attending families and 78 control families participated during at least one time point. However, only those families who completed measures for at least two time points were included in the final sample. The numbers of participants in the final sample who completed each measure are further delineated in Table 1.

Because the sample is not consistent across time, differences between responders and non-responders on all measured demographic factors were assessed in both the camp and control group. In the camp group, non-responders were those included in the final sample who omitted any one of the three sets of measures. In the control group, non-responders were those from the total sample who initially consented to the study and completed T<sub>1</sub> measures, but did not complete T<sub>3</sub>. A few significant trends were found. In the camp group, those who did not complete T<sub>1</sub> were likely to have been off treatment for longer than those who did complete T<sub>1</sub>,  $t(43) = 2.374, p < .05, r = .340$ . Those who did not complete T<sub>2</sub> for the camp sample were likely to be further from their diagnosis date ( $t(32) = 4.515, p < .01, r = .624$ ) and younger ( $t(47) = 2.453, p < .05, r = .337$ ) than those who did respond. Those who did not respond to T<sub>3</sub> in the camp group were likely to be off treatment longer than those who did respond, ( $t(43) = 3.565, p < .05, r = .478$ ). Consistently, current treatment status also appeared to be significantly different between responders and non-responders in the T<sub>3</sub> camp group,  $X^2(1,48) = 4.623, p < .05$ . Of the camp

families who did not respond at T<sub>3</sub>, 95% had a patient who was off treatment, compared to only 69% of the responders. . Family income level also appeared to be significantly different between responders and non-responders across T<sub>1</sub> ( $X^2(3,48) = 8.527, p <.05$ ), T<sub>2</sub> ( $X^2(3,48) = 9.331, p <.05$ ), and T<sub>3</sub> ( $X^2(3,44) = 14.631, p <.01$ ) in the camp group; however, the results of these Chi square analyses should be interpreted cautiously due to the fact that many cells had especially low counts.

In the control group, current treatment status and mother education level appeared to be different among those who responded to T<sub>3</sub> and those who did not,  $X^2(1,78) = 11.752, p <.01$  and  $X^2(3,73) = 9.487, p <.05$ , respectively. It appeared that those who did not respond to T<sub>3</sub> were more likely to be off treatment than those who did respond; this result is not surprising given that patients on treatment were more likely to be approached in clinic for follow up than those who visit clinic on rare occasions. The education level of most mothers who did not respond at T<sub>3</sub> was either some college or a bachelor's degree , while the education level of mothers who did respond was more evenly distributed among categories. Of the non-responders, eight mothers reported having a high school level education, 25 reported having some college experience, 12 reported having a bachelor's degree, and 3 reported having a postgraduate degree. In the responding group, 7 mothers reported a high school level education, 7 reported some college experience, 4 reported having a bachelor's degree, and 7 reported having a postgraduate degree.

***Characteristics of analyzed population.*** The sample for this study consisted of 66 families, 39 of whom attended camp and 27 of whom participated in the control group. The demographic information of each family is provided in Table 2. Additionally, it is important to note that due to the nature of recruitment opportunities for this study, many control families

provided data for only one parent and the patient, while more family members participated in the camp-attending group. The family composition of each sample is further explained in Table 3. Because control families could not be purposefully matched with camp-attending families on demographic factors that could potentially impact participants' initial levels of hope and quality of life, analyses were conducted to evaluate demographic differences between the camp and control group on several factors.

First, a chi-square analysis was conducted to evaluate differences on the following factors: gender, ethnicity, parent marital status, diagnosis, current treatment status, father education level, mother education level, and family income level. These analyses showed that there were no significant differences between camp families and control families on the variables of gender, ethnicity, parent marital status, mother education level, or family income level. Likewise, chi-square analyses also showed no differences between groups on the variables of diagnosis and father education level; however, these results must be interpreted cautiously because the sample sizes of each category within these variables were smaller than ideal. In these cases, greater than 20% of the cells had expected frequencies that were less than 5 (33.3% for diagnosis and 37.5% for father education). A significant difference was found between groups according to patients' current treatment status, Pearson  $\chi^2$  (1, N=66) = 15.095,  $p < .01$ , with the camp group consisting mostly of off treatment patients and the control group consisting of mostly on treatment patients (Table 2). Differences in patients' relapse history were also considered between groups. However, because the number of families who reported a cancer relapse was very small (1 family in the camp group and 4 families in the control group), it is unlikely that this variable significantly influences subsequent analyses.

Additionally, independent - samples *t* tests were conducted to evaluate the differences between the camp group and control group on the variables of patient age, time since diagnosis, and time elapsed since the end of treatment. No differences were found between groups on the variable of patient age. However, time since diagnosis appeared to be significantly different between groups,  $t(54) = -2.969, p < .01, r = .375$ . Time elapsed since the end of treatment appeared to be significantly different between groups as well,  $t(62) = -2.389, p < .01, r = .29$ . The camp sample mean for time since diagnosis was 40.79 months ( $sd = 40.449$ ), while the control sample mean for time since diagnosis was 14.78 months ( $sd = 21.643$ ). The camp sample mean for time since end of treatment was 31.410 months ( $sd = 38.397$ ), while the control sample mean for time since end of treatment was 10.440 months ( $sd = 27.763$ ). It should be noted that the standard deviations were greater than the means calculated in these analyses. It is possible that this occurred because most of the data points in each sample are at the extreme ends of the range; that is, some participants were fairly recently diagnosed and ended treatment, while others have been off treatment for many years. Few participants' time since diagnosis value and end of treatment value actually fall near the mean for these variables.

Because demographic differences were found between the camp and control group on the variables of current treatment status, time since diagnosis, and time since end of treatment, follow-up analyses were conducted to address the influence of these differences on subsequent analyses. Results of these follow-up analyses are presented in conjunction with the significant primary results discussed later in this section.

**Past camp experiences.** Based on the hypotheses that camp does improve quality of life and hope, it was possible that families who attended camp prior to this study may have had

higher baseline scores on quality of life and hope measures. It is logical to assume that those who start with higher baseline scores will have less room for improvement in scores than those who start with lower baseline scores. However, it was anticipated that very few families would have previously attended a family camp. The past camp experiences of participants are demonstrated in Tables 4 and 5. To rule-out possible differences in camping experiences, independent-samples  $t$  tests were employed to compare baseline scores on the quality of life and hope measures between families who have prior camp experience and those who do not.

***Past family camp experiences.*** Independent-samples  $t$  tests were conducted to determine differences in baseline family unit quality of life and hope scores between families with past family camp experience and those without. No significant differences were found.

***Past medical camp experiences.*** Independent-samples  $t$  tests were also conducted to determine differences in child participants' individual baseline levels of quality of life and hope scores based on previous medical camp experience. Significant differences were found between groups on the quality of life variable,  $t(93) = 3.293$ ,  $p < .01$ ,  $r = .323$ . Contrary to expectation, the mean baseline quality of life score for those who had no prior medical camp experience was 82.79 ( $sd = 12.34$ ), while the mean baseline quality of life score for those who did have medical camp experience was lower, 73.81 ( $sd = 14.11$ ). No significant differences were found between groups on baseline hope.

***Past other camp experiences.*** Independent-samples  $t$  tests were also conducted to determine differences in child participants' individual baseline levels of quality of life and hope scores based on non-medical, or "other," previous camp experiences. Results indicated that differences in baseline individual child scores for quality of life between groups based on past

other camp experience were significant,  $t(95) = .207, p < .05, r = .021$ . Children with no prior other camp experience demonstrated mean baseline quality of life scores of 80.479 ( $sd = 14.031$ ), while children with some prior camp experience demonstrated baseline quality of life scores of 73.971 ( $sd = 12.096$ ). This result demonstrates that those with more other camp experiences tended to have lower baseline quality of life than those with fewer or no other camp experiences. No differences were found in individual baseline hope scores between groups based on past other camp experiences.

**Baseline differences based on interest in camp.** Past research has shown that there may be inherent personality differences in people who attend camp in comparison to those who choose not to attend camp. While potential issues such as separation from parents are not relevant to family camp, it must be considered that those who attend camp may be more open to new experiences and simply more likely to enjoy group activities than those who do not attend camp (Balen, Fielding, & Lewis, 1998). In order to address this potential problem within the control group, an independent-samples  $t$  test was conducted to determine the differences in baseline family unit levels of quality of life and hope scores based on whether the family had any interest in attending camp or not. No significant differences were found between groups based on interest in camp.

**Baseline differences between camp and control group.** Finally, independent samples  $t$  tests were conducted to evaluate baseline differences in mean scores on quality of life and hope measures between the camp and control group. Results indicated that camp families had significantly higher quality of life than control families at  $T_1, t(61) = -2.233, p < .05, r = .27$ . The mean baseline quality of life score for camp families was 77.478 ( $sd = 10.375$ ), while the

mean baseline score for control families was 71.208 ( $sd = 11.848$ ). An independent-samples  $t$  test conducted between groups based on baseline hope scores did not yield significant results.

### **Primary Results**

The original analysis plan for this study was to examine differences between camp and control group quality of life and hope over time through the use of repeated-measures ANOVAs. The ANOVA allows for the same scores to be compared within each group: between  $T_1$  and  $T_2$  and between  $T_2$  and  $T_3$  for the camp group, and between  $T_1$  and  $T_3$  for the control group. However, because the sample sizes in each group were smaller than expected, repeated-measure ANOVA results must be examined cautiously. Paired-sample  $t$  tests were also conducted to address the same questions. While the  $t$  tests allow assessment of more participants because they can include those who responded at only two time points, they also create a greater risk of type 1 error and must be interpreted cautiously for this reason. Both paired sample  $t$  tests and repeated measure ANOVA results are reported in the following sections. Graphs pertaining to the primary analyses can be found in Appendix F.

**Hypothesis 1: Quality of life.** A series of paired-samples  $t$  tests were conducted to evaluate whether or not there were differences in mean family unit quality of life scores within each group across time (see Figure F1 for trends and mean values). Results indicated that there were not significant differences in mean family quality of life scores within the camp group from  $T_1$ - $T_2$  or from  $T_2$ - $T_3$ . However, a  $t$  test indicated that the change in mean family unit quality of life scores in the camp group from  $T_1$ - $T_3$  demonstrated a trend toward significance,  $t(26) = -2.038$ ,  $p = .052$ ,  $r = .37$ . This trend demonstrated that family unit quality of life scores decreased over time. In the control group, no significant changes were found from  $T_1$ - $T_3$ .

Independent-samples  $t$  tests were also conducted to determine differences in quality of life between the camp and control group at each time point. As previously mentioned, baseline tests indicated that quality of life scores were significantly higher in the camp group than the control group. This trend continued to be true at  $T_2$ ,  $t(55) = -2.585$ ,  $p < .05$ ,  $r = .329$ . In the camp group, the mean quality of life score at  $T_2$  was 78.675 ( $sd = 9.949$ ), while in the control group the mean quality of life score was 71.21 ( $sd = 11.848$ ). However, an independent-samples  $t$  test determined that there were not significant differences in mean family unit quality of life between the camp and control group at  $T_3$ . This result indicates that while quality of life scores in the camp group continue to be higher than quality of life scores in the control group, the difference is no longer significant at  $T_3$ .

A repeated measure ANOVA was also conducted to examine differences in family unit quality of life among  $T_1$ ,  $T_2$ , and  $T_3$  for each group as well. The results of this repeated measure ANOVA was not significant overall, indicating no significant differences in quality of life over time or between camp and control groups (see Figure F2 for trends and mean values).

***Possible contributors to quality of life differences.*** Because preliminary results indicated that treatment status was significantly different between the camp and control groups, 2-way ANOVAs were employed at each time point to determine whether there were differences in quality of life based on treatment status that may have contributed to quality of life differences between camp and control groups. No significant interactions were found; however, at  $T_1$  and  $T_2$ , main effects were found for the camp or control group status ( $F(1,59) = 8.375$ ,  $p < .01$  and  $F(1,53) = 10.258$ ,  $p < .01$  respectively), with camp group having higher quality of life than the control group. These findings are consistent with the results of the  $t$  tests previously reported and

confirm that quality of life differences are due to differences in group status rather than treatment status. No main effects or interactions were found in 2-way ANOVAs conducted using  $T_3$  quality of life scores or the change scores in each group from  $T_1 - T_3$ .

Additionally, because time since diagnosis and time post-treatment were also significantly different between camp and control groups, correlation coefficients were calculated between these scores in each group and baseline family unit quality of life. The results were insignificant, indicating that time since diagnosis and time post-treatment were not linearly related to baseline scores on quality of life measures. Furthermore, correlations also indicated that there was no significant linear relationship between time since diagnosis and end of treatment and change in family unit quality of life from  $T_1 - T_3$ .

Finally, independent-samples  $t$  tests were conducted to determine whether or not there were significant differences in family unit quality of life scores at  $T_3$  between families who reported significant health concerns or significant stressors during the interim period between  $T_2$  and  $T_3$  and those who reported no significantly stressful events. Results were not significant. In order to document a more comprehensive view of potential differences due to  $T_3$  health concerns and stress, similar  $t$  tests were calculated using these variables along with  $T_1$  family unit quality of life and  $T_2$  family unit quality of life. The results were also insignificant.

**Hypothesis 2: Hope.** A series of paired-samples  $t$  tests were also conducted to evaluate whether or not there were differences in mean family unit hope scores within each group across time (see Figure F3 for trends and mean values). Results indicated that there were not significant differences in mean family hope scores within the camp group from  $T_1-T_2$  or from  $T_2-T_3$ , which parallel results of quality of life measures. A  $t$  test also indicated that there were not significant

differences in mean family unit hope within the control group from T<sub>1</sub>-T<sub>3</sub> or within the camp group from T<sub>1</sub>-T<sub>3</sub>. An independent samples *t* test was conducted to determine whether or not there were differences in mean family unit hope between the camp and control group at T<sub>2</sub> or T<sub>3</sub>. These results were also not significant, which was consistent with baseline findings.

A repeated measures ANOVA was also used to examine differences between groups in family unit hope scores over time. It is important to note that the assumption of sphericity was violated in this equation; Maunchly's  $W = .508, p < .01$ . Although significant results were initially found, the result was no longer significant when the degrees of freedom were adjusted using the Greenhouse-Geisser test. Using this test, the degrees of freedom are adjusted to 1.341, and  $F = 1.381, p > .05$ . ANOVA results for the hope scores for each group are demonstrated in Figure F4.

**Hypothesis 3: Correlations between change scores.** Correlation coefficients were computed between changes in family unit quality of life and changes in family unit hope within the camp group at all time points in order to examine the interrelationships between hope and quality of life in an exploratory manner. The results indicated that there was not a significant correlation between change in quality of life and change in hope in the camp group from T<sub>1</sub>-T<sub>2</sub> or T<sub>2</sub>-T<sub>3</sub>. However, results indicate that there was a significant correlation between change in quality of life and change in hope from T<sub>1</sub>-T<sub>3</sub>,  $r(24) = .477, p < .05$ . The mean change in quality of life within the camp group at T<sub>1</sub>-T<sub>3</sub> was  $-5.470 (sd=10.554)$  and the mean change in hope within the camp group at T<sub>1</sub>-T<sub>3</sub> was  $.002 (sd=.097)$ . Because these correlations were calculated between change scores, the correlation was positive even though the mean change score in quality of life was negative and the mean change score in hope was positive. This result implies

that even though quality of life and hope changed in opposite directions, the magnitude of the change moved in the same direction. Thus, in cases where a greater change is seen in one variable, a greater change in the other was also likely. Similarly, where there is little change in one variable, there was likely to be less change in the other.

A correlation coefficient was also computed between changes in family unit quality of life and family unit hope within the control group from T<sub>1</sub>-T<sub>3</sub>. The result was significant,  $r(25) = .674, p = <.01$ , indicating that there was a significant correlation between the change in hope and change in quality of life in control families from T<sub>1</sub>-T<sub>3</sub>. The nature of this correlation mirrors that of the camp group; changes occurred in opposite directions, yet the magnitude of change was positively correlated.

**Hypothesis 4: Impact of social support.** Initially, a path analysis was proposed to examine the interrelationships between changes in quality of life, hope, and social support. However, because the sample size available was smaller than anticipated, these relationships were more accurately examined through correlations and linear regression.

*Correlations of social support.* A set of correlation coefficients were computed to determine the interrelationship between changes in quality of life, hope, and social support in both the camp and control groups from T<sub>1</sub> – T<sub>3</sub>. For these analyses, quality of life was measured by a composite of the physical functioning and emotional functioning subscales on the PedsQL™ measures, while social support was measured by the social functioning subscale on the PedsQL™ measures. The quality of life measurement was altered for this analysis in order to avoid problems of collinearity with the social support subscale. The changes in these variables over time in each group were examined through both *t* tests and ANOVA in order to compare

results of these scales to the total quality of life measure originally used in H<sub>1</sub> (See Figures F5-8). According to the *t* test, family unit social support decreased at a trending level from T<sub>1</sub> – T<sub>3</sub> ( $t(26) = -1.814, p = .081$ ). No other significant changes were seen in either group over time according to the adjusted quality of life measure or the social support scale. No changes were made in the method of measuring hope.

Several significant correlations were found among quality of life, hope, and social support using these measures. In the camp group, the relationship between change in quality of life and change in hope was significant,  $r(24) = .476, p < .05$ . However, similar to the relationship between hope and total quality of life, this relationship was also inverse in the camp group. The magnitude of change was positively correlated, although the change in quality of life increased where change in hope decreased and vice versa. The relationship between change in quality of life and change in social functioning was significant at a trending level ( $r(24) = .381, p = .055$ ), but not inversely related. The mean change scores were negative for both variables in this group. The relationship between change in hope and change in social functioning was not significant. In the control group, change in quality of life and change in hope were significantly related,  $r(25) = .656, p < .01$ . However, in the control group, the relationship was not inverse. The mean change scores were positive for both variables in this group. Change in quality of life and change in social support were inverse, but also significantly linearly related,  $r(25) = .654, p < .01$ . In the control group, change in hope and change in social functioning were also significantly linearly related,  $r(25) = .581, p < .01$ , and also inverse.

These results show that as quality of life changes, social functioning also changes in the same direction in both groups. They also show that as hope changes, social functioning also

changes in the control group. For this reason, a linear regression analysis was conducted to evaluate whether a change in social support and/or change in hope predicts change in quality of life. Additionally, because the variables of time since diagnosis and time since end of treatment were also significantly different between groups, they were included in the regression analysis as well. Although some demographic variables, such as income and parent education levels, were considered for inclusion in the regression because of their possible association with quality of life, they were omitted because they are not significantly different between the groups in this study.

*Social support as a predictor of quality of life.* An initial regression analysis was conducted using hope and social support scores at each time point as well as change scores over time to determine which scores best predicted quality of life. A VIF index was used to determine collinearity issues among predictor variables, and redundant variables were omitted from the final analysis to create a more parsimonious method of measurement. The social support predictor in the final regression model consisted of T<sub>1</sub> social functioning and change in social functioning from T<sub>1</sub> to T<sub>2</sub>. The hope predictor in the final model consisted of T<sub>1</sub> hope and change in hope from T<sub>1</sub> to T<sub>2</sub>. The final model also included T<sub>1</sub> physical-emotional quality of life and camp attendance as predictors. Parallel regression analyses were conducted to determine predictors of family unit quality of life at T<sub>2</sub> and predictors of family unit quality of life at T<sub>3</sub>. The results of these analyses are presented in Tables 6-8.

Several significant results were found in the regression analysis. First of all, T<sub>1</sub> quality of life was a significant predictor of quality of life at both T<sub>2</sub> and T<sub>3</sub>. At T<sub>2</sub>, after accounting for baseline quality of life ( $R^2$  change = .601,  $F(3,43) = 20.267$ ,  $p < .01$ ), the social support variables

significantly predicted quality of life 10% over and above the total predicted by other variables ( $R^2$  change = .101,  $F(6,43) = 17.590$ ,  $p < .01$ ); examination of beta weights indicated that a decrease in family unit social functioning from  $T_1$ - $T_2$  accounted for this change. At  $T_2$ , the hope variables significantly predicted an additional 7.5% of the variance in quality of life, over and above the total predicted by social support and other variables ( $R^2$  change = .075,  $F(8,43) = 19.283$ ,  $p < .01$ ): examination of beta weights indicates that an increase in family unit hope from  $T_1$ - $T_2$  accounted for this change. At  $T_3$ , after accounting for baseline quality of life ( $R^2$  change = .296,  $F(3,40) = 6.365$ ,  $p < .01$ ), social support and hope did not account for a significant portion of the variance in quality of life. Interestingly, attendance at camp did not appear to be a significant predictor of quality of life.

### **Exploratory Results**

*Alternative quality of life analysis.* For exploratory purposes, the primary analyses regarding quality of life were conducted a second time using the PedsQL™ Family Impact Module total score in place of the calculated family unit quality of life score. Results were slightly different using this method. Paired-sample  $t$  tests yielded significant results, indicating that there are significant differences in mean PedsQL™ Family Impact total scores from  $T_1$ - $T_2$  ( $t(46) = -2.941$ ,  $p < .01$ ,  $r = .398$ ) and  $T_1$ - $T_3$  ( $t(35) = -3.130$ ,  $p < .01$ ,  $r = .468$ ) within the camp parent group, whereas nearly significant results were only found between  $T_1$ - $T_3$  using the calculated family unit scores. Results indicated that there were not significant differences in mean family quality of life scores within the camp group from  $T_2$ - $T_3$ . Likewise, a paired sample  $t$  test indicated that there were not significant differences in mean PedsQL™ Family Impact scores within the control group from  $T_1$ - $T_3$ , which is consistent with the results of the tests using the

calculated family unit scores. (See Figure G1.) An independent samples  $t$  test indicated that differences in  $T_1$ ,  $T_2$ , and  $T_3$  scores between the camp and control group were not significant, whereas calculated family unit scores were significantly different at  $T_1$  and  $T_2$ .

A repeated measures ANOVA was also used to analyze differences between groups in PedsQL™ Family Impact scores over time (Figure G2). The assumption of sphericity was violated in this equation; Maunchly's  $W = .423$ ,  $p < .01$ . The degrees of freedom were adjusted to 1.269 using the Greenhouse-Geisser test, and subsequently  $F = 1.689$ ,  $p > .05$ , indicating that the result was not significant.

Correlation coefficients were computed between changes in PedsQL™ Family Impact scores and changes in family unit hope within the camp group at all time points. The results indicated that there was not a significant correlation between change in PedsQL™ Family Impact scores and change in hope in the camp group from  $T_1$ - $T_2$  or  $T_2$ - $T_3$ . From  $T_1$ - $T_3$ , a trend toward significance was found in the camp group,  $r(33) = .322$ ,  $p = .059$ . Additionally, results indicated that there was a trend toward a significant correlation between change in PedsQL™ Family Impact scores and change in hope in the control group from  $T_1$ - $T_3$ ,  $r(30) = .336$ ,  $p = .060$ . These results coincide with those found using the family unit quality of life scores.

***Differences among specific family members.*** Additionally, exploratory analyses were conducted to determine differences in the way hope and quality of life changed among individual family members in the context of camp experience. ANOVAs and  $t$  tests were used to examine changes in quality of life (Figures G3-8) and hope (Figures G9-14) among parents, patients, and siblings individually. On the quality of life variable, camp parents showed a trend toward a significant decrease from  $T_1$ - $T_2$ ,  $t(46) = -1.852$ ,  $p = .07$ ,  $r = .263$ , while both camp patients and

siblings showed an increase in quality of life from  $T_1 - T_2$ . The change in camp patients was trending toward significant,  $t(32) = 1.255, p = .076, r = .217$ , and the change in camp sibling quality of life was significant,  $t(28) = 3.385, p < .01, r = .539$ . However, camp patients also demonstrated a significant decrease in quality of life from  $T_2 - T_3$  and  $T_1 - T_3, t(26) = -2.903, p < .01, r = .495$ , and  $t(27) = -2.722, p < .05, r = .464$ , respectively. No significant changes were seen among the control samples. An ANOVA showed a general decrease in patient quality of life,  $F(2,23) = 4.600, p < .05$ , and no significant results for other family members.

Changes in hope among individual family members were examined. While no significant changes were present in the patient group, there were significant changes in the camp parent and camp sibling groups. Camp parents exhibited a significant decrease in hope from  $T_1 - T_3, t(34) = -2.175, p < .05, r = .349$ . Camp siblings exhibited an increase in hope from  $T_1 - T_2$  and  $T_1 - T_3, t(28) = 3.320, p < .01, r = .531$  and  $t(21) = 2.099, p < .05, r = .416$  respectively. No significant changes in hope were seen in the control group, and no significant results were demonstrated by the ANOVAs.

In order to maintain consistency with the primary analyses, individual trends in physical-emotional quality of life were examined as well (Figures G15-20). No significant changes were evident in any specific subgroups of the camp or control sample according to  $t$  tests or ANOVAs.

Because primary results indicated that social support was an important component of quality of life, especially in the context of camp, individual changes in social support were examined as well (Figures G21-26). The results were generally consistent with the changes seen in total quality of life among individual groups. Camp parents demonstrated a significant decrease in social support from  $T_1 - T_2, t(46) = -2.156, p < .05, r = .302$ , whereas siblings

demonstrated a significant increase in social support from  $T_1-T_2$ ,  $t(27) = 2.109$ ,  $p < .05$ ,  $r = .376$ .

Patient social support increased from  $T_1-T_2$  at an insignificant level. Both camp parents and patients demonstrated a decrease in social support from  $T_1-T_3$ . Parent social support decreased at a trending level,  $t(35) = -2.203$ ,  $p = .053$ ,  $r = .345$  and the patient decrease was significant,  $t(27) = -2.784$ ,  $p = .01$ ,  $r = .472$ . No significant changes were seen in the control group, and no significant results were seen in the repeated measures ANOVAs.

## CHAPTER FIVE

### Discussion

The intent of this study was to learn whether or not family camp experience increases the quality of life of families who are coping with pediatric cancer. Furthermore, the aim was to determine whether or not changes in quality of life were maintained after the camp experience ended, and to determine how hope and social support contribute to the quality of life of those who attend camp. The specific changes in individual family members were assessed in addition to the changes in the family unit as a whole.

#### Quality of Life

The basic premise for this study was that family unit quality of life would increase following camp experience. It was predicted that this would occur because the social experience of camp would particularly bolster the social functioning aspect of quality of life. This hypothesis is generally not supported by the results of this study. While results did indicate a slight increase in quality of life during camp as measured by the composite family unit scores, the change was insignificant. Contrary to expectation, results also demonstrated a significant overall decrease in quality of life from the beginning of camp to the follow-up period. Significant decreases were also found during and after camp when quality of life was measured by the PedsQL<sup>TM</sup> Family Impact Module. Overall, H<sub>1</sub> was not supported.

There are several possible explanations for why these results were found. Firstly, the opposing scores from the beginning to the end of camp depending on the measure used could mean that parent scores decreased on subscales of the PedsQL<sup>TM</sup> Family Impact Module that were not included in the composite family unit score. These subscales include communication,

worry, daily activities, and family relationships. It is counterintuitive that parents would endorse these items more so after camp than before, but because of this, parents' test-taking approach should be considered. For example, if they approached the end of camp measurement prospectively and considered worries and problems that could potentially arise when they leave camp, their scores may represent this viewpoint. As this same concern could be applied to all end of camp measurements, future research should monitor test-taking approach more directly.

Additionally, past research has demonstrated that people often report more intense emotion during anticipation of an event than they do in retrospection of an event (Van Boven & Ashworth, 2007). This could be related to the notion that future events are more uncertain and therefore evoke stronger emotion, or it could be related to the concept that people expect the best of future events while remembering past events more moderately (Van Boven & Ashworth, 2007). If lower scores on quality of life measures in this study are interpreted as a less dramatic emotional response, this idea could help explain the differences found between pre- and post-camp scores.

The slight decrease in quality of life from the end of camp to follow-up in the camp group is also possibly related to outside stressors that occurred in the interim period between these measurements. It should be noted that out of the 28 camp families who completed the follow-up measurement, 13 of them reported outside stressors related to health, finances, parent relationship issues, and combinations of these factors. Although significantly different follow-up scores were not found between families who endorsed outside stressors as compared to those who did not, there were also several families who did not provide responses to the follow-up questionnaire regarding these events. Additionally, the window of time in which follow-up

surveys were recruited was extended because of an initial lack of participation. Therefore, while some families responded to the survey 3 months post camp, other responses were obtained 4-5 months post camp. This variability could also contribute to the accuracy of outside stressors reported.

An important finding of this study indicates that camp impacts individual family members in different ways. Where a significant decrease in parent quality of life was seen during camp, a significant increase in quality of life was seen in patient and sibling populations. These results are more consistent with past research; Packman et al. (2005) reported significant increases in quality of life post-camp in sibling populations using the same measure.

The differences in parent and child scores presented here also helps to explain the opposing results that are found in camp family unit quality of life during camp depending on which measurement is used to assess the change: family unit composite scores increased, while PedsQL™ Family Impact scores decreased. Because parent reports are the only information source for the PedsQL™ Family Impact Module, and because parent health-related quality of life significantly decreased, it is likely that this factor contributed to the overall negative trend indicated by the PedsQL™ Family Impact Module.

The third part of H<sub>1</sub> was that families who did not attend camp would show no significant changes in quality of life over time. This hypothesis is supported by the results, which indicate that although follow-up quality of life slightly decreased according to both the composite family unit scores and the PedsQL™ Family Impact Module scores, the change is not significant in the control group. This result is consistent between *t* tests and repeated-measures ANOVA.

Finally, it was expected that the camp group would demonstrate higher levels of quality of life than the control group at follow-up. While differences between groups were not evident at follow-up, the camp sample did demonstrate consistently higher quality of life than the control group at both beginning and end of camp. From this result, it can be inferred that there are inherent initial differences between those who attend camp and those who do not, which is an idea that has been supported by earlier research; however, these differences were not maintained over time following camp. Considering the fact that the majority of past research does not include follow-up data for comparison, this lack of maintenance of differences is especially interesting. For example, Balen et al. (1998) noted that expectations for camp, parent wishes for their children, and fears and concerns are often factors that contribute to the decision to attend camp. However, other differences unrelated to the decision to attend camp may impact quality of life and have not been specifically addressed. Because the only baseline factors tested here that appeared different between groups did not appear to be significantly related to differences in quality of life, it must be inferred that other untested factors contribute to this difference.

The linear regression employed in this study partially explains some factors that contribute to quality of life regardless of having attended camp or not (as camp was not a significant predictor of quality of life). According to the regression, changes in both hope and social support over a short period of time better predict quality of life immediately following that same time period. They are less likely to predict quality of life further in the future. These results provide evidence to support the idea that hope and social support may provide momentary or short-term contributions to quality of life, but do not necessarily predict the maintenance of quality of life for longer periods of time.

**Hope**

The second aim of this study was to explore the role of hope in regard to family camp experience. Family unit hope did increase slightly from the beginning to the end of camp in this study, although this change was not significant. There was no significant change in family unit hope and no significant differences between camp and control groups on the variable of hope at any time point.

The results regarding hope in this study are largely counterintuitive as well, not only regarding the lack of change, but also the correlation between hope and quality of life. In both groups, changes in hope and quality of life were positively correlated from the baseline to the follow-up period. However, this means that a greater magnitude of change in quality of life is correlated to a greater magnitude of change in hope, and, in this case, those who show a greater decrease in quality of life were likely to also exhibit a greater increase in hope and vice versa. The same is true for correlations between change in hope and quality of life measured by the PedsQL™ Family Impact Module. It is not surprising that these two variables were significantly linked, but the inverse relationship between the two is puzzling. Further research is necessary to explain the nature of the relationship between quality of life and hope in regard to camp experience.

Additionally, individual differences among family members were once again apparent in regard to hope. Where camp parents demonstrated an overall decrease in hope, camp siblings demonstrated a significant increase in hope both immediately following camp and at follow-up. No significant changes were seen in patients, which is surprising, given that interventions targeting hope have been shown to be successful in past research (Snyder, 2000). Specifically, if

camp is perceived as a pathway to reach to the goal of social support, and hope increases with the increase of perceived pathways, one would expect that hope would have increased in this sample.

### **Role of Social Support**

Because the expected changes in quality of life and hope were largely not seen in this study, and because those expectations were closely tied to expectations of increased social support, it is important to take a closer look at the changes in social support in these samples. Taken as a family unit, no significant changes were seen in social support. This is contradictory to past research, which historically shows that social support has increased as a result of camp in parent and patient populations (Meltzer & Rourke, 2005, Day & Kleinschmidt, 2005).

When measured individually, decreases in social support were seen in parent and patient groups. Because this result is so counterintuitive, the same expectation effects and outside stressors considered previously must be taken into account here as well. It is also possible that because camp is by nature a very social experience, it may have provided opportunity for self-comparison to peers that many of these children do not often get. For example, a child may not have observed difficulty keeping up with peers until they were in an environment where this became apparent. More specifically, patients who spend time with healthier peers may have difficulty keeping up with them, but they may attribute their difficulties to their illness in this context. If they also notice that they have more limitations than other peers who are in similar health, their difficulty may become more upsetting. Another explanation is that because camp activities are very physical in nature, participants may have endorsed feelings of tiredness and lack of energy more so at the end of camp than the beginning, which could have been reflected in

their social functioning scores. Another consideration is the test-taking approach to these items, as mentioned previously. If participants were looking ahead to future problems or responding in consideration of a broader time frame than intended, their responses may reflect that attitude. In future research, social support measures should be designed to directly target areas that are expected to be impacted by camp, and test-taking approach should be monitored. The results of this study should not be generalized to imply that social support decreases as a result of camp experience.

In fact, it should also be noted that siblings reported an increase in social support after camp, which is consistent with positive sibling results found overall. Generally, this study demonstrates that while camp may not positively impact the family unit as expected, it is related to increased quality of life, hope, and social support in the sibling population specifically. This is a very important finding, especially considering that siblings have historically been provided with less psychosocial support than other family members in adjusting to having a family member with cancer (Murray, 2000). Research has shown that family dynamics are often shifted drastically when one child is diagnosed with cancer; routines are disrupted, healthy children receive less parent attention, and families spend less time together overall (Hamama, 2010). Research has also shown that siblings can be negatively impacted by these changes (Houtzager et al., 1999), yet they often show fewer symptoms of adjustment difficulty when they feel socially supported (Barrera, et al, 2003).

Because siblings likely come into contact with other siblings of cancer patients less often in their daily environment than parents and patients who spend significant amounts of time in clinics and hospitals, it could be that camp provides a unique and beneficial opportunity for

them. Likewise, they are less likely than their sick counterpart to come into contact with healthcare professionals who routinely monitor psychosocial adjustment and focus on building skills. For these reasons, it is helpful to know that family camp can provide a means for meeting psychosocial needs of often overlooked family members and has been shown to be successful with this population.

### **Limitations and Suggestions for Future Research**

Several limitations of this study must be acknowledged. Firstly, the ability to generalize these results is limited due to the small sample size available. More robust results can be obtained and questions can be more thoroughly answered by analyses that require a larger sample size. Secondly, it would be preferable to collect data at a pre-camp time point, before those planning to attend camp have arrived at the camp site. Because factors of anticipation and expectation are likely already in effect and cannot be controlled when the participants are already at camp at  $T_1$ , it would be ideal to collect initial baseline data at an earlier time. This was not logistically possible for this study, although it could provide valuable information for future research. On a similar note, the follow-up data in this study is limited by fact that the follow-up window is longer than preferred. It would be much more ideal for the follow-up window to be limited to one month to improve accuracy, but follow-up data for this study was collected over a 3 month period because of the slow response time of many participants. Additionally, it is important to recognize that the follow-up data for the control sample is somewhat more randomized than the camp sample, because while control families were approached in clinic for follow-up as they were available, the camp follow-up data is more dependent on the willingness of families to participate without being directly approached. Therefore, those who contributed

follow-up data for the camp sample are more likely to be characteristically different from those who chose not to follow-up.

Finally, it would be ideal for the camp and control groups to be more evenly matched on demographic factors to limit differences that could potentially interfere with the variables measured. By nature of recruitment opportunities for this study, families in the control group were much more likely to have a child who is currently on treatment, more recently diagnosed, and/or more recently post-treatment than families who attend camp. This is not surprising given that families on treatment are those most often found in clinic. Yet, it can also be inferred that these families will be more likely to be interested in camp and have opportunities to attend when they are further along in treatment. It would be interesting for future research to follow participants who are all at the same point in treatment to determine what factors best predict camp attendance. Additionally, by nature of the sample available, many of the camp family units in this study consist of multiple family members, including both parents and siblings along with the patient; the majority of control family units consist of one parent and the patient only. Unfortunately, sibling participation in the control group was very low, primarily because siblings were rarely present in clinic and therefore difficult to reach directly for participation. Therefore an important component of control family unit hope and quality of life is not represented as fully as desired.

## **Conclusion**

Although the results of this study were generally contrary to expectation, they provide important contributions to the existing body of literature on the impact of camp. These results indicate that family camp impacts different family members in different ways, and can be

especially beneficial to siblings in particular. It also demonstrates that results seen immediately after camp do not necessarily remain consistent long-term. Additionally, this study demonstrates that there are inherent differences between those who choose to attend camp and those who do not. This study shows that different impressions of changes in quality of life can be drawn depending on the measure used, indicating a need for a careful examination of assessment tools in future studies.

Because the outcomes of this study do not generally support the efficacy of the family camp experience overall, it is likely that those involved in camp programming will find them disappointing. However, it is important to recognize that while it could be concluded that these hypotheses were incorrect, it is more likely that complications in method, sample size, and other uncontrollable factors discussed previously contribute significantly to the results found. Therefore, it should not be determined from this study that family camp is not beneficial, but rather that different methods should be used in the future to examine it more closely.

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Table 1

*Number of Participants of Final Sample at Each Time Point*

	Camp				Control			
	Parent	Patient	Sibling	Family Unit	Parent	Patient	Sibling	Family Unit
T1	57	37	35	37	38	29	3	27
T2	51	36	35	30	-	-	-	-
T3	38	30	25	28	36	29	3	27
T1-T2 only	21	9	13	11	-	-	-	-
T2-T3 only	2	2	3	2	-	-	-	-
T1 & T3 only	8	3	3	9	36	29	3	27
T1, T2, T3	28	25	19	17	-	-	-	-

Table 2

*Demographic Differences Between Camp and Control Groups (Percentage in Parentheses)*

Variable	Camp (n = 39)	Control (n = 27)	Total (n = 66)
<b>Diagnosis<sup>a</sup></b>			
Leukemia	25 (64.1)	13 (48.1)	38 (57.6)
Solid Tumor	12 (30.8)	8 (29.6)	20 (30.3)
Other	2 (5.2)	6 (22.2)	8 (12.1)
<b>Current Treatment Status<sup>ab</sup></b>			
Off Treatment	29 (74.4)	7 (25.9)	36 (54.5)
On Treatment	10 (25.6)	20 (74.1)	30 (45.4)
<b>Time Since Diagnosis<sup>ab</sup></b>			
< 1 year	7 (24.1)	18 (66.7)	25 (44.6)
1-2 years	7 (24.1)	5 (18.5)	12 (21.4)
2-3 years	2 (6.9)	2 (7.4)	4 (7.1)
3-4 years	4 (13.8)	0 (0)	4 (7.1)
> 4 years	9 (31.0)	2 (7.4)	11 (19.6)
<b>Time Since End of Treatment<sup>ab</sup></b>			
Does Not Apply	10 (27.0)	20 (74.1)	30 (46.9)
< 1 year	9 (24.3)	3 (11.1)	12 (18.8)
1-2 years	5 (13.5)	1 (3.7)	6 (9.3)
2-3 years	0 (0.0)	0 (0)	0 (0.0)
3-4 years	3 (8.1)	0 (0)	3 (4.7)
> 4 years	10 (27.0)	3 (11.1)	13 (20.3)
<b>Gender<sup>a</sup></b>			
Male	21 (53.8)	17 (63.0)	38 (57.6)
Female	18 (46.2)	10 (37.0)	28 (42.4)

Variable	Camp (n = 39)	Control (n = 27)	Total (n = 66)
<b>Age<sup>a</sup></b>			
5-7	8 (21.0)	11 (40.7)	19 (29.2)
8-12	18 (47.4)	5 (18.5)	23 (35.5)
13-15	10 (26.3)	5 (18.5)	15 (23.1)
16-19	2 (5.2)	6 (22.2)	8 (12.3)
<b>Parent Marital Status</b>			
Dual Parent Household	29 (76.3)	20 (76.9)	49 (76.6)
Single Parent Household	9 (23.7)	6 (23.1)	15 (22.7)
<b>Father Education Level</b>			
High School / GED	7 (23.3)	8 (38.1)	15 (29.4)
Some College / 2 Year Associate Degree	8 (26.7)	2 (9.6)	10 (19.6)
4 Year Bachelor's Degree	10 (33.3)	8 (38.1)	18 (35.3)
Postgraduate Degree	5 (16.7)	3 (14.3)	8 (15.7)
<b>Mother Education Level</b>			
High School / GED	9 (25.0)	7 (28.0)	16 (26.2)
Some College / 2 Year Associate Degree	12 (33.4)	7 (28.0)	19 (31.2)
4 Year Bachelor's Degree	9 (25.0)	4 (16.0)	13 (21.3)
Postgraduate Degree	6 (16.7)	7 (28.0)	13 (21.3)
<b>Family Income Level</b>			
<20,000 per year	6 (16.2)	6 (25.0)	12 (19.7)
20,000-50,000	11 (29.7)	7 (29.1)	18 (29.5)
50,000-100,000	12 (32.4)	4 (16.7)	16 (26.3)
>100,000	8 (21.6)	7 (29.2)	15 (24.6)
<b>Ethnicity</b>			
White/Caucasian	19 (48.7)	15 (55.6)	34 (51.5)
Latino	12 (30.8)	10 (37.0)	22 (33.3)
Other	8 (20.5)	2 (7.4)	10 (15.1)

*Note.* Percentages reported are based on valid percentages, not including missing variables  
a: Values in these categories are based on the family member who is identified as the patient.  
b: There are significant differences between the camp and control group on these variables.

Table 3

*Family Unit Composition*

<u>Family Unit Composition:</u>	<u>camp (n = 39)</u>	<u>control (n= 27)</u>
one parent and patient only	13	20
both parents and patient only	2	5
one parent, patient, siblings	11	1
both parents, patient, siblings	13	1

Table 4

*Past Camp Experiences*

		Camp Attending Group(n)	Control Group(n)
	Total	39	27
	Yes	17	1
	No	16	26
Family Camp	No response	6	0
	Total	77	32
	Yes	32	5
	No	36	23
Medical Camp	No response	9	4
	Total	77	32
	Yes	17	4
	No	51	25
Other Camp	No response	9	3

Table 5

*Number of Past Camp Experiences*

		Camp Attending Group(n)	Control Group(n)
Family Camp	Total	17	1
	1	5	1
	2	2	0
	3-5	7	0
	>5	3	0
		Total	32
Medical Camp	1	17	5
	2	8	0
	3-5	7	0
	>5	0	0
		Total	17
Other Camp	1	13	2
	2	4	2
	3-5	0	0
	>5	0	0
		Total	17

Table 6

*Multiple Regression Analysis*

Variable	T <sub>2</sub> Family Unit Physical- Emotional Quality of Life		T <sub>3</sub> Family Unit Physical-Emotional Quality of Life	
	$\Delta R^2$	$\beta$	$\Delta R^2$	$\beta$
Step 1	0.002		0.05	
Time Since Diagnosis		0.07		0.34
Time Since End of Treatment		-0.05		-0.22
Step 2	0.60**		0.30**	
T <sub>1</sub> Family Unit Physical-Emotional Quality of Life		.78**		.54**
Step 3	0.04		0.01	
Camp Attendance		0.22		0.11
Step 4	0.10**		0.03	
T <sub>1</sub> Family Unit Social Functioning		0.1		0.1
$\Delta$ Family Unit Social Functioning T <sub>1</sub> - T <sub>2</sub>		.34**		-1.57
Step 5	0.08**		0.02	
T1 Family Unit Hope		0.04		0.06
$\Delta$ Family Unit Hope T <sub>1</sub> - T <sub>2</sub>		.30**		0.12
Total R <sup>2</sup>	0.82**		0.4	
adjusted R <sup>2</sup>	0.77**		0.25	
N	44		41	

\* p &lt; .05

\*\*p&lt;.01

Table 7

*Correlation Matrix for T<sub>2</sub> Family Unit Physical-Emotional Quality of Life*

	1	2	3	4	5	6	7	8
1 T <sub>2</sub> Family Unit Physical-Emotional Quality of Life								
2 Time Since Diagnosis	0.03							
3 Time Since End of Treatment	0.002	0.76**						
4 T <sub>1</sub> Family Unit Physical-Emotional Quality of Life	0.78**	0.01	0					
5 Camp Attendance	0.45**	0.23	0	0.36**				
6 T <sub>1</sub> Family Unit Social Functioning	0.38*	-0.07	-0.1	0.32*	0.29*			
7 ΔFamily Unit Social Functioning T <sub>1</sub> - T <sub>2</sub>	0.09	0.13	-0.1	-0.26	-0.03	-0.2		
8 T <sub>1</sub> Family Unit Hope	0.17	-0.17	0.06	0.30*	-0.12	0.1	-0.26*	
9 ΔFamily Unit Hope T <sub>1</sub> - T <sub>2</sub>	0.40**	-0.11	-0.1	0.11	0.34*	0.2	-0.08	-0.1

\* =  $p < .05$

\*\* =  $p < .01$

Table 8

*Correlation Matrix for T<sub>3</sub> Family Unit Physical-Emotional Quality of Life*

	1	2	3	4	5	6	7	8
1 <u>T<sub>3</sub> Family Unit Physical-Emotional Quality of Life</u>								
2 <u>Time Since Diagnosis</u>	0.16							
3 <u>Time Since End of Treatment</u>	0.05	0.79**						
4 <u>T<sub>1</sub> Family Unit Physical-Emotional Quality of Life</u>	0.54**	-0.03	-0.03					
5 <u>Camp Attendance</u>	0.34*	0.18	0	0.35*				
6 <u>T<sub>1</sub> Family Unit Social Functioning</u>	0.29*	-0.05	-0.06	0.33*	0.32*			
7 <u>ΔFamily Unit Social Functioning T<sub>1</sub> - T<sub>2</sub></u>	-0.31*	0.05	-0.07	0.3**	-0.07	-0.21		
8 <u>T<sub>1</sub> Family Unit Hope</u>	0.17	-0.12	0.07	0.35*	-0.03	0.1	0.28*	
9 <u>ΔFamily Unit Hope T<sub>1</sub> - T<sub>2</sub></u>	0.21	-0.07	-0.09	0.21	0.38**	0.16	0.15	-0.12

\* =  $p < .05$

\*\* =  $p < .01$

## Appendix A

*Cover Letters***A1: Camp-attending group T<sub>1</sub> letter**

Dear Family,

Welcome to camp! As you settle in, we'd like to invite you to take a few minutes to participate in a short survey. This survey is part of a research study that is designed to learn about family experiences at camp. This information will help camp programs best meet the needs of families like you in the future, but also to help make camp opportunities more easily available to more people.

In this packet, you will find a demographic sheet for a parent to fill out, as well as a questionnaire sheet for each parent and each child in your family who is here at camp this weekend. Please have all of your family members complete these questionnaires tonight and return them as soon as possible. If your child is age 5-7 and needs their questionnaire read aloud in order to respond, please read them the questions and allow their response to reflect their own opinion as much as possible. Additionally, you will be asked to complete the survey a second time at the end of your retreat weekend. Your family will also receive a third set of the same questionnaires through a follow-up survey by mail or email 3 months after your retreat weekend. Each survey should not take more than a few minutes to complete, and your participation is greatly appreciated!

This research study has been reviewed and approved by the Institutional Review Board of the University of Texas Southwestern Medical Center and Cook Children's Health Care System. All responses to this survey will be kept strictly confidential. Your patient's medical record may be reviewed to collect data about continuing treatment. Your participation is voluntary, and you may withdraw from this study at any time by contacting me at the e-mail or phone number below. By completing this survey, you will be consenting to a research study. However, any publications that result from this study will not identify any member of your family.

If you have any comments or questions about this survey in the future, please do not hesitate to contact me by e-mail at \_ or by phone at \_ (faculty sponsor office).

Thank you very much,

**A2: Control group T<sub>1</sub> letter**

Dear Family,

You are eligible to be part of a control group for a research study designed to learn about family experiences at camp. Participation in this study will only require that you take a few short minutes to complete a few questionnaires, and your involvement would be greatly appreciated! In this study, “family camp” refers to a weekend retreat program such as Children’s Oncology Family Retreat. We are asking you to participate because you are not planning to attend the retreat, and your participation will provide the unique perspective of people who do not attend camp. The goal of this project is to best meet the needs of families like you in the future, and to help make camp opportunities more easily available to more people.

In this packet, you will find a demographic questionnaire for a parent to complete, as well as questionnaire sheets for each parent and each child in your household. We would like any family member who is in the clinic with you today to complete these questionnaires before you leave. If there are other members of your household who are not here today, we ask that you bring their questionnaires home. These questionnaires can be completed and mailed back in the provided envelope as soon as possible, or completed online at the following links. Please be sure to have each child complete the questionnaire that is marked for their age level. If your child is age 5-7 and needs their questionnaire read aloud in order to respond, please read them the questions and allow their response to reflect their own opinion as much as possible. If you need more forms for a particular age level, please feel free to make copies or email\_. A follow up set of questionnaires will be mailed or emailed to you in 3 months as well.

- For children age 5-7: [https://www.surveymonkey.com/s/Child\\_5-7](https://www.surveymonkey.com/s/Child_5-7)
- For children age 8-12: [https://www.surveymonkey.com/s/Child\\_8-12](https://www.surveymonkey.com/s/Child_8-12)
- For teens age 13-15: [https://www.surveymonkey.com/s/Teen\\_13-15](https://www.surveymonkey.com/s/Teen_13-15)
- For teens age 16-18: [https://www.surveymonkey.com/s/Teen\\_16-18](https://www.surveymonkey.com/s/Teen_16-18)
- For parents: [https://www.surveymonkey.com/s/Initial\\_\\_Parent](https://www.surveymonkey.com/s/Initial__Parent)

This research study has been reviewed and approved by the Institutional Review Board of the University of Texas Southwestern Medical Center and Cook Children’s Healthcare System. All responses to this survey will be kept strictly confidential. Your patient’s medical records may be reviewed to collect data about continuing treatment. Your participation is voluntary, and you may withdraw from this study at any time by contacting me at the e-mail or phone number below. By completing this survey, you will be consenting to a research study. However, any publications that result from this study will not identify any member of your family.

If you have any comments or questions about this survey in the future, please do not hesitate to contact me by e-mail at \_ or by phone at \_(faculty sponsor office).

Thank you very much,

**A3: Camp-attending group T<sub>3</sub> letter (Version 1)**

Dear Family,

Thank you very much for your participation in the research study of family camp experiences during your family camp weekend in \*. Your involvement in this research effort is very much appreciated!

Enclosed is the 3-month follow up questionnaires for your family to complete. They are the same surveys that you completed at your retreat, and we are requesting that all members of your family who attended camp fill them out one last time. Please be sure to have each child complete the questionnaire that is marked for their age level. If your child is age 5-7 and needs their questionnaire read aloud in order to respond, please read them the questions and allow their response to reflect their own opinion as much as possible. Please return the completed questionnaires in the pre-addressed envelope provided as soon as possible. For your convenience, the questionnaires are also available online at the following links. If your family prefers to submit the questionnaires electronically instead of by mail, please feel free to do so following the instructions on the website.

- For children age 5-7: [https://www.surveymonkey.com/s/Child\\_5-7](https://www.surveymonkey.com/s/Child_5-7)
- For children age 8-12: [https://www.surveymonkey.com/s/Child\\_8-12](https://www.surveymonkey.com/s/Child_8-12)
- For teens age 13-15: [https://www.surveymonkey.com/s/Teen\\_13-15](https://www.surveymonkey.com/s/Teen_13-15)
- For teens age 16-18: [https://www.surveymonkey.com/s/Teen\\_16-18](https://www.surveymonkey.com/s/Teen_16-18)
- For parents: [https://www.surveymonkey.com/s/FollowUp\\_Parent\\_Camp](https://www.surveymonkey.com/s/FollowUp_Parent_Camp)

This research study has been reviewed and approved by the Institutional Review Board of the University of Texas Southwestern Medical Center and Cook Children's Health Care System. All responses to this survey will be kept strictly confidential. Your participation is voluntary, and you may withdraw from this study at any time by contacting me at the e-mail or phone number below. By completing this survey, you will be consenting to a research study. However, any publications that result from this study will not identify any member of your family.

If you have any comments or questions about this survey in the future, please do not hesitate to contact me by e-mail at\_ or by phone at \_(faculty sponsor office).

Thank you very much,

\*insert camp name and date

**A4: Camp-attending group T<sub>3</sub> letter (Version 2)**

Dear Family,

Thank you very much for your participation in the research study of family camp experiences during your weekend at camp. Your involvement in this research effort is very much appreciated! Provided here are links to the 3-month follow up questionnaires for your family to complete. They are the same surveys that you completed at camp, and we are requesting that all members of your family who attended camp fill them out one last time. Please be sure to have each family member enter their individual ID number (provided below) at the beginning of the survey.

Family Member	Survey ID number
Dad:	1D
Mom:	1M
Girl, age 12	1C1
Boy, age 10	1C2

If your child is age 5-7 and needs their questionnaire read aloud in order to respond, please read them the questions and allow their response to reflect their own opinion as much as possible. Please complete the questionnaires online as soon as possible, or complete and return the paper copies you received in the mail.

- For children age 5-7: <https://www.surveymonkey.com/s/...>
- For children age 8-12: <https://www.surveymonkey.com/s/...>
- For teens age 13-15: <https://www.surveymonkey.com/s/...>
- For teens age 16-18: <https://www.surveymonkey.com/s/...>
- For parents: <https://www.surveymonkey.com/s/...>

This research study has been reviewed and approved by the Institutional Review Boards of the University of Texas Southwestern Medical Center and Cook Children’s Medical Center. An Institutional Review Board is made up of a group of people that review research studies to make sure that the rights of research participants are protected. All responses to this survey will be kept strictly confidential. Your participation is voluntary, and you may withdraw from this study at any time by contacting me at the e-mail or phone number below. By completing this survey, you will be consenting to a research study. However, any publications that result from this study will not identify any member of your family. There is a slight possibility you may experience emotional discomfort or anxiety related to completion of these surveys. If you are interested in receiving psychological assistance, referrals within the community will be made available to you.

If you have any comments or questions about this research study now or in the future, you may contact (insert name) by email at \_ or by telephone at \_. If you have any questions about your rights as a research participant, you may contact the Cook Children’s Health Care System Institutional Review Board \_

Thank you very much,

**A5: Control group T<sub>3</sub> letter**

Dear Family,

Thank you very much for your continued participation in the research study on family camp experience. Enclosed is the final round of questionnaires. Please have all family members complete these questionnaires as soon as possible and mail them back in the pre-addressed envelope provided, or complete them online at the following links. Remember to have each child complete the questionnaire that is marked for their age level. If your child is age 5-7 and needs their questionnaire read aloud in order to respond, please read them the questions and allow their response to reflect their own opinion as much as possible. . Your continued participation in this study is very much appreciated!

- For children age 5-7: [https://www.surveymonkey.com/s/Child\\_5-7](https://www.surveymonkey.com/s/Child_5-7)
- For children age 8-12: [https://www.surveymonkey.com/s/Child\\_8-12](https://www.surveymonkey.com/s/Child_8-12)
- For teens age 13-15: [https://www.surveymonkey.com/s/Teen\\_13-15](https://www.surveymonkey.com/s/Teen_13-15)
- For teens age 16-18: [https://www.surveymonkey.com/s/Teen\\_16-18](https://www.surveymonkey.com/s/Teen_16-18)
- For parents: [https://www.surveymonkey.com/s/FollowUp\\_Parent\\_Control](https://www.surveymonkey.com/s/FollowUp_Parent_Control)

This research study has been reviewed and approved by the Institutional Review Board of the University of Texas Southwestern Medical Center and Cook Children's Health Care System. All responses to this survey will be kept strictly confidential. Your participation is voluntary, and you may withdraw from this study at any time by contacting me at the e-mail or phone number below. By completing this survey, you will be consenting to a research study. However, any publications that result from this study will not identify any member of your family.

If you have any comments or questions about this survey in the future, please do not hesitate to contact me by e-mail at \_ or by phone at \_ (faculty sponsor office).

Thank you very much,

Appendix B

*Demographic Forms*

**B1: Camp-attending group demographic form (version 1)**

Please provide the following information for **all family members attending camp**:

Name:	Gender:	Age:	Date of birth:	Ethnicity:

Parent marital status: \_\_\_\_\_

Has one of your children at camp this weekend been diagnosed with cancer? YES      NO

If yes, please complete the following:

Please indicate which child has/had a cancer diagnosis: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Stage/type: \_\_\_\_\_

Date of diagnosis: \_\_\_\_\_

Time elapsed since end of treatment (if applicable): \_\_\_\_\_

Has your family ever attended a **family camp** before? YES      NO

(Ex: oncology camp, vacation camp, church camp)

If yes, what type and how many prior camp experiences has your family had?:

Have any of your children individually attended a **medically-related camp** before? YES      NO

(Ex: oncology summer camp, sibling camp, etc.)

If yes, please indicate which child and the number of prior camp experiences:

Have any of your children individually attended a **non-specialized summer camp**? YES      NO

(Ex: church camp, recreational camp)

If so, please indicate which child and the number of prior camp experiences:

What is your family's average annual income? (Circle the correct range.)

< 20,000    20,000 – 30,000    30,000-50,000    50,000-75,000    75,000-100,000    >100,000

What is the highest level of education of each parent in the household? (Circle the correct range.)

Mom: HS/GED    some college    2yr. associate degree    4yr. bachelor's degree    postgraduate degree

Dad: HS/GED    some college    2yr. associate degree    4yr. bachelor's degree    postgraduate degree

Current address: \_\_\_\_\_

Phone number: \_\_\_\_\_

If you prefer to receive follow-up questionnaires via email instead of mail, please provide your email address: \_\_\_\_\_

**B2: Camp group demographic form (version 2)**

Please provide the following information for **all family members attending camp**, in order to distinguish which family member has completed each survey.

\*Survey ID numbers are labeled on the survey packet.

Survey ID number:	Gender:	Age:	Ethnicity:

Parent marital status: \_\_\_\_\_

Has one of your children at camp this weekend been diagnosed with cancer? YES NO

If yes, please complete the following:

Survey ID number of child who has had a cancer diagnosis: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Stage/type: \_\_\_\_\_

Date of diagnosis: \_\_\_\_\_

Time elapsed since end of treatment (if applicable): \_\_\_\_\_

Has your family ever attended a **family camp** before? YES NO

(Ex: oncology camp, vacation camp, church camp)

If yes, what type and how many prior camp experiences has your family had?:

Have any of your children individually attended a **medically-related camp** before? YES NO

(Ex: oncology summer camp, sibling camp, etc.)

If yes, please indicate which child (by Survey ID number) and the number of prior camp experiences:

Have any of your children individually attended a **non-specialized summer camp**? YES NO

(Ex: church camp, recreational camp)

If so, please indicate which child (by Survey ID number) and the number of prior camp experiences:

What is your family’s average annual income? (Circle the correct range.)

< 20,000    20,000 – 30,000    30,000-50,000    50,000-75,000    75,000-100,000    >100,000

What is the highest level of education of each parent in the household? (Circle the correct range.)

Mom: HS/GED    some college    2yr. associate degree    4yr. bachelor’s degree    postgraduate degree

Dad: HS/GED    some college    2yr. associate degree    4yr. bachelor’s degree    postgraduate degree

**B3: Control group demographic form**

Please provide the following information for **all family members in your household**:

Name:	Gender:	Age:	Date of birth:	Ethnicity:

Parent marital status: \_\_\_\_\_

Please indicate which child has/ had a cancer diagnosis: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Stage/type: \_\_\_\_\_

Date of diagnosis: \_\_\_\_\_

Time elapsed since end of treatment (if applicable): \_\_\_\_\_

Has your family ever attended a **family camp** before? YES      NO  
 (Ex: oncology camp, vacation camp, church camp)

If yes, what type and how many prior camp experiences has your family had?:

Have any of your children individually attended a **medically-related camp** before? YES      NO  
 (Ex: oncology summer camp, sibling camp, etc.)

If yes, please indicate which child and the number of prior camp experiences:

Have any of your children individually attended a **non-specialized summer camp**? YES      NO  
 (Ex: church camp, recreational camp)

If so, please indicate which child and the number of prior camp experiences:

If no one in your family has attended camp, please mark one of the following:

My family/child is:

- interested in camp, but has not yet had an opportunity to attend. \_\_\_\_\_
- interested in camp, but opportunities have been at inconvenient times. \_\_\_\_\_
- not interested in attending camp. \_\_\_\_\_
- Other (please explain here: \_\_\_\_\_) \_\_\_\_\_

What is your family's average annual income? (Circle the correct range.)

< 20,000    20,000 – 30,000    30,000-50,000    50,000-75,000    75,000-100,000    >100,000

What is the highest level of education of each parent in the household? (Circle the correct range.)

Mom: HS/GED    some college    2yr. associate degree    4yr. bachelor's degree    postgraduate degree

Dad: HS/GED    some college    2yr. associate degree    4yr. bachelor's degree    postgraduate degree

phone number: \_\_\_\_\_

If you prefer to receive follow up questionnaires via email instead of mail, please provide your email address: \_\_\_\_\_

## Appendix C

*Hope Scales***C1: Adult Hope Scale**

## The Goals Scale

*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

5 = Slightly True

2 = Mostly False

6 = Somewhat True

3 = Somewhat False

7 = Mostly True

4 = Slightly False

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.

**C2: Children’s Hope Scale**

Questions About Your Goals

Directions: The six sentences below describe how children think about themselves and how they do things in general. Read each sentence carefully. For each sentence, please think about how you are in most situations. Place a check inside the circle that describes YOU THE BEST. For example, place a check (✓) in the circle (○) above “None of the time,” if this describes you. Or, if you are this way “All of the time,” check this circle. Please answer every question by putting a check in one of the circles. There are no right or wrong answers.

1. I think I am doing pretty well.

- |                     |                         |                     |                      |                     |                    |
|---------------------|-------------------------|---------------------|----------------------|---------------------|--------------------|
| ○                   | ○                       | ○                   | ○                    | ○                   | ○                  |
| None of<br>the time | A little of<br>the time | Some of<br>the time | A lot of<br>the time | Most of<br>the time | All of<br>the time |

2. I can think of many ways to get the things in life that are most important to me.

- |                     |                         |                     |                      |                     |                    |
|---------------------|-------------------------|---------------------|----------------------|---------------------|--------------------|
| ○                   | ○                       | ○                   | ○                    | ○                   | ○                  |
| None of<br>the time | A little of<br>the time | Some of<br>the time | A lot of<br>the time | Most of<br>the time | All of<br>the time |

3. I am doing just as well as other kids my age.

- |                     |                         |                     |                      |                     |                    |
|---------------------|-------------------------|---------------------|----------------------|---------------------|--------------------|
| ○                   | ○                       | ○                   | ○                    | ○                   | ○                  |
| None of<br>the time | A little of<br>the time | Some of<br>the time | A lot of<br>the time | Most of<br>the time | All of<br>the time |

4. When I have a problem, I can come up with lots of ways to solve it.

- |                     |                         |                     |                      |                     |                    |
|---------------------|-------------------------|---------------------|----------------------|---------------------|--------------------|
| ○                   | ○                       | ○                   | ○                    | ○                   | ○                  |
| None of<br>the time | A little of<br>the time | Some of<br>the time | A lot of<br>the time | Most of<br>the time | All of<br>the time |

5. I think the things I have done in the past will help me in the future.

- |                     |                         |                     |                      |                     |                    |
|---------------------|-------------------------|---------------------|----------------------|---------------------|--------------------|
| ○                   | ○                       | ○                   | ○                    | ○                   | ○                  |
| None of<br>the time | A little of<br>the time | Some of<br>the time | A lot of<br>the time | Most of<br>the time | All of<br>the time |

6. Even when others want to quit, I know that I can find ways to solve the problem.

- |                     |                         |                     |                      |                     |                    |
|---------------------|-------------------------|---------------------|----------------------|---------------------|--------------------|
| ○                   | ○                       | ○                   | ○                    | ○                   | ○                  |
| None of<br>the time | A little of<br>the time | Some of<br>the time | A lot of<br>the time | Most of<br>the time | All of<br>the time |

**C3: Young Children's Hope Scale**

## Questions about Your Goals

Directions: The six sentences below describe how children think about themselves and how they do things in general. Read each sentence carefully. For each sentence, please think about how you are in most situations. Place a check inside the circle that describes YOU the best. For example, place a check (✓) in the smallest circle (○) beside "Never" if you don't ever think this way. If you think this way "Sometimes," check the middle-sized circle. If you "Always" think this way, place a check in the biggest circle. Please answer every question. There are no right or wrong answers.

1. I think I am doing pretty well.

- Never       Sometimes       Always

2. I can think of many ways to get the things I want.

- Never       Sometimes       Always

3. I am doing just as well as other kids in my class.

- Never       Sometimes       Always

4. When I have a problem, I can come up with lots of ways to solve it.

- Never       Sometimes       Always

5. I think the things I have done before will help me when I do new things.

- Never       Sometimes       Always

6. I can find ways to solve a problem even when other kids give up.

- Never       Sometimes       Always

## Appendix D

*Pre –T<sub>3</sub> Reminders (letter or email):***D1: Camp-attending group Pre-T<sub>3</sub> Reminder**

Dear Family,

Thank you so much for your continued participation in the Family Camp Project. Your contribution during your family camp weekend was extremely helpful in allowing us to understand family experiences at camp, and your involvement in the follow-up portion of this study is equally important. This message is just a reminder that your 3 month follow up questionnaires will be arriving shortly. Please have your family complete and return them as soon as possible.

Thank you very much!

**D2: Control group Pre-T<sub>3</sub> Reminder**

Dear Family,

Thank you so much for participating in the Family Camp Project. Your contribution during your clinic visit 3 months ago was extremely helpful in allowing us to best meet the needs of families like you in the future, and your involvement in the follow-up portion of this study is equally important. This message is just a reminder that your 3 month follow up questionnaires will be arriving shortly. Please have your family complete and return them as soon as possible.

Thank you very much!

**D3: Phone Call Script**

Hello, I am calling about the Family Camp research project that your family participated in (during your weekend at camp / 3 months ago during your clinic visit at Children's Medical Center.) I just wanted to thank you for participating in the project and let you know that your 3 month follow up questionnaires will be arriving shortly. If you could have all members of your household complete the questionnaires online or return them by mail as soon as possible, it would be greatly appreciated. Thank you very much!

## Appendix E

*Follow Up Questionnaire***E1: Camp-Attending Group T<sub>3</sub> Questionnaire:**

Has anyone in your family experienced any significant changes in health since your weekend at camp on \*? (Ex: cancer relapse, surgery, etc.)

If yes, please indicate which family member and briefly specify what happened:

Has your family experienced any significant stresses or changes since your weekend at camp? (Ex: parental separation, divorce, job loss, increased financial difficulties, etc.)

If yes, please briefly explain:

\*insert date

**E2: Control Group T<sub>3</sub> Questionnaire:**

Has anyone in your family experienced any significant changes in health in the past three months? (Ex: cancer relapse, surgery, etc.)

If yes, please indicate which family member and briefly specify what happened:

Has your family experienced any significant stresses or changes in the past three months? (Ex: parental separation, divorce, job loss, increased financial difficulties, etc.)

If yes, please briefly explain:

Appendix F

Primary Analysis Graphs

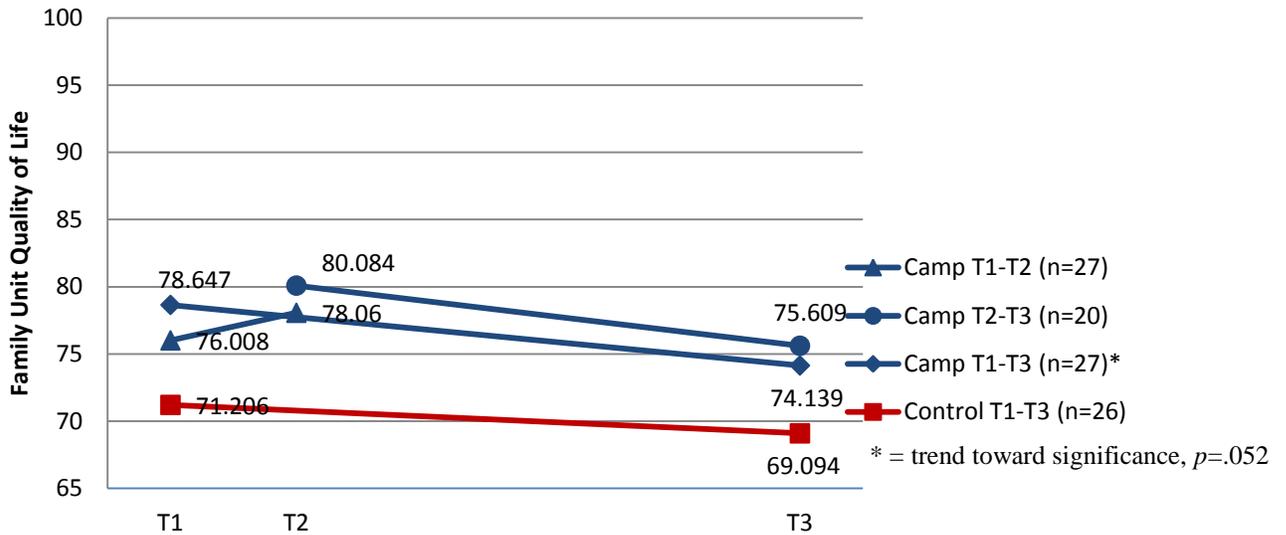


Figure F1. Family Unit Quality of Life Across Time: Paired Sample *t* Test Results

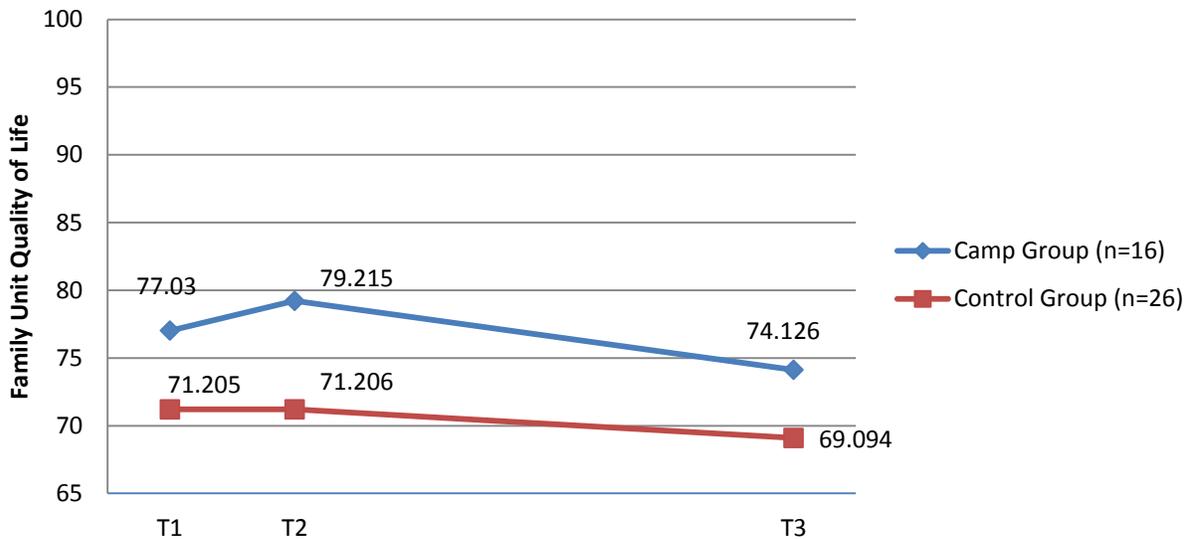


Figure F2. Family Unit Quality of Life Across Time: Repeated Measures ANOVA Results

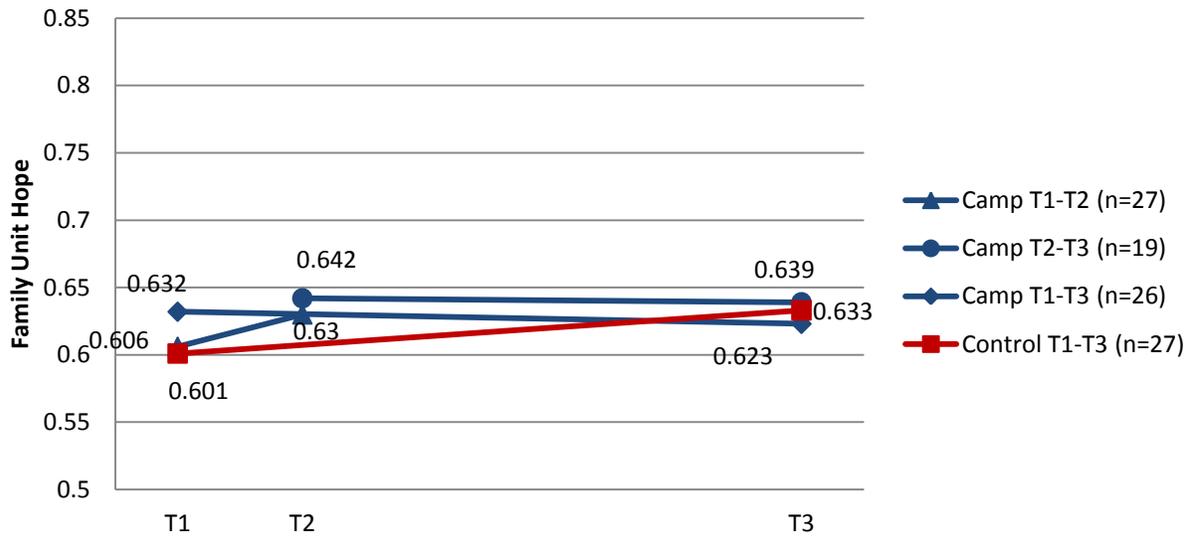


Figure F3. Family Unit Hope Across Time: Paired Sample *t* Test Results

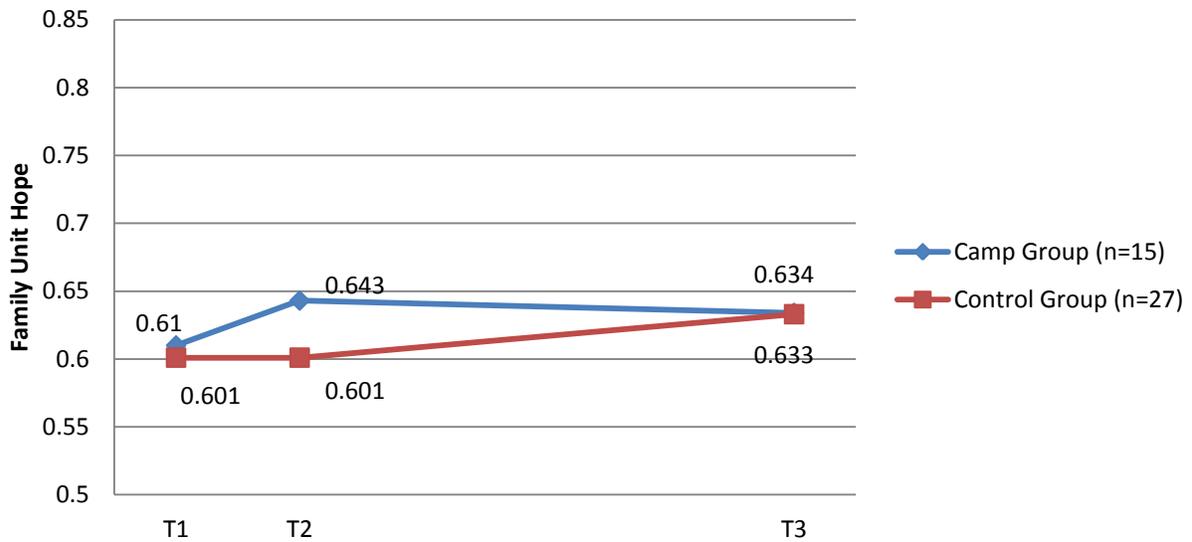


Figure F4. Family Unit Hope Across Time: Repeated Measures ANOVA Results

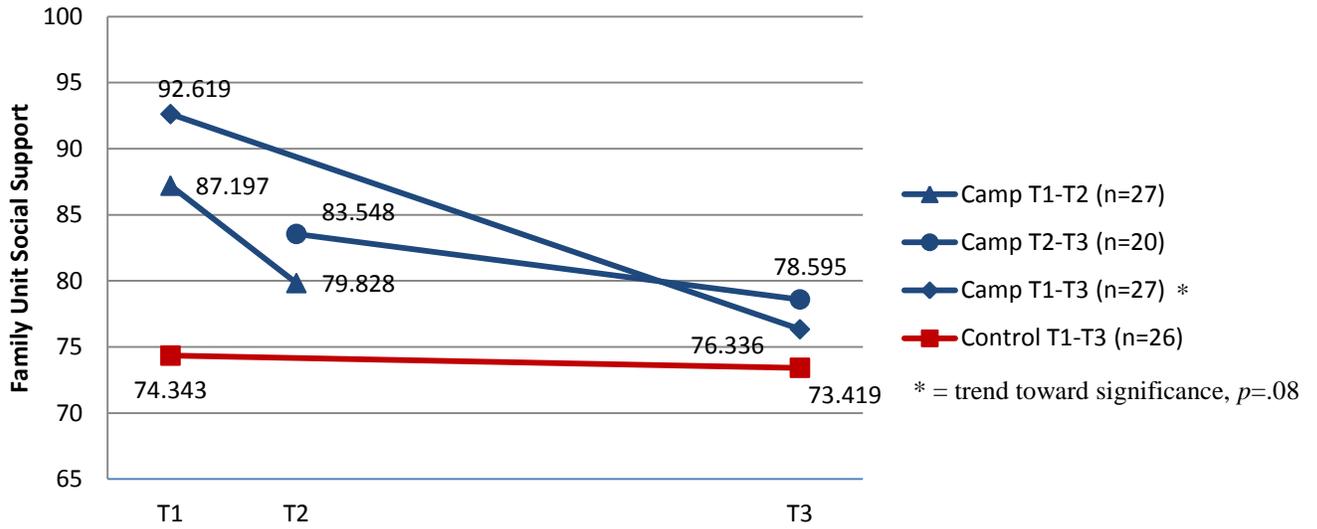


Figure F5. Family Unit Social Support Across Time: Paired Samples  $t$  Test Results

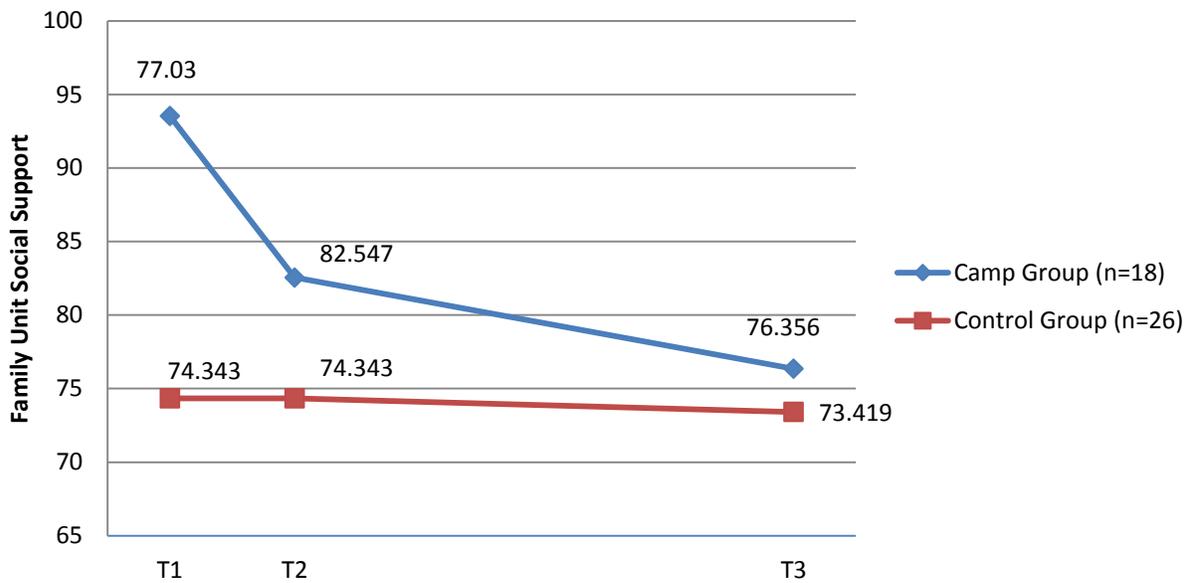


Figure F6. Family Unit Social Support Across Time: Repeated Measures ANOVA Results

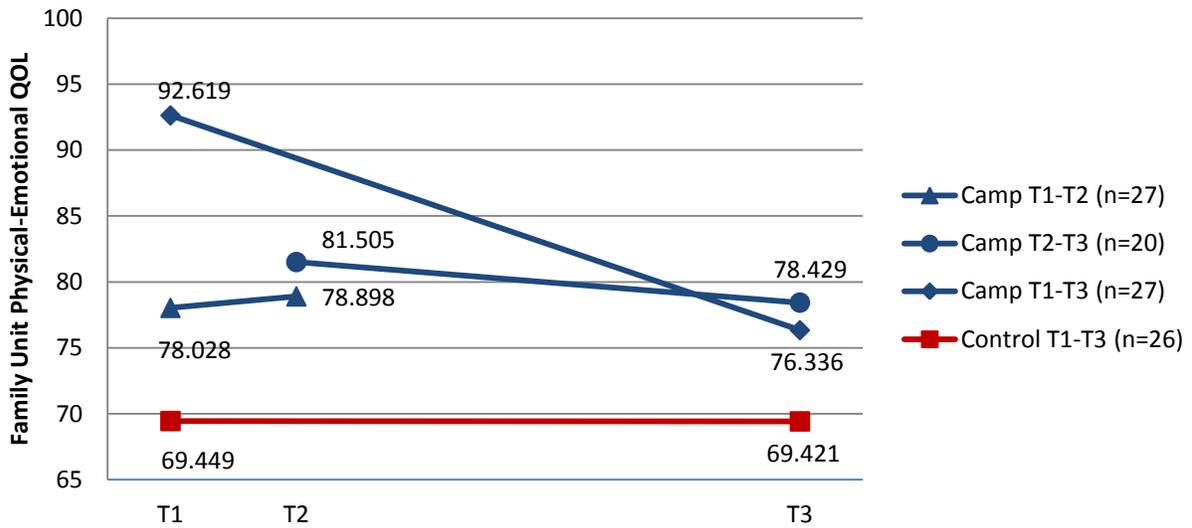


Figure F7. Family Unit Physical-Emotional Quality of Life Across Time: Paired Sample t Test Results

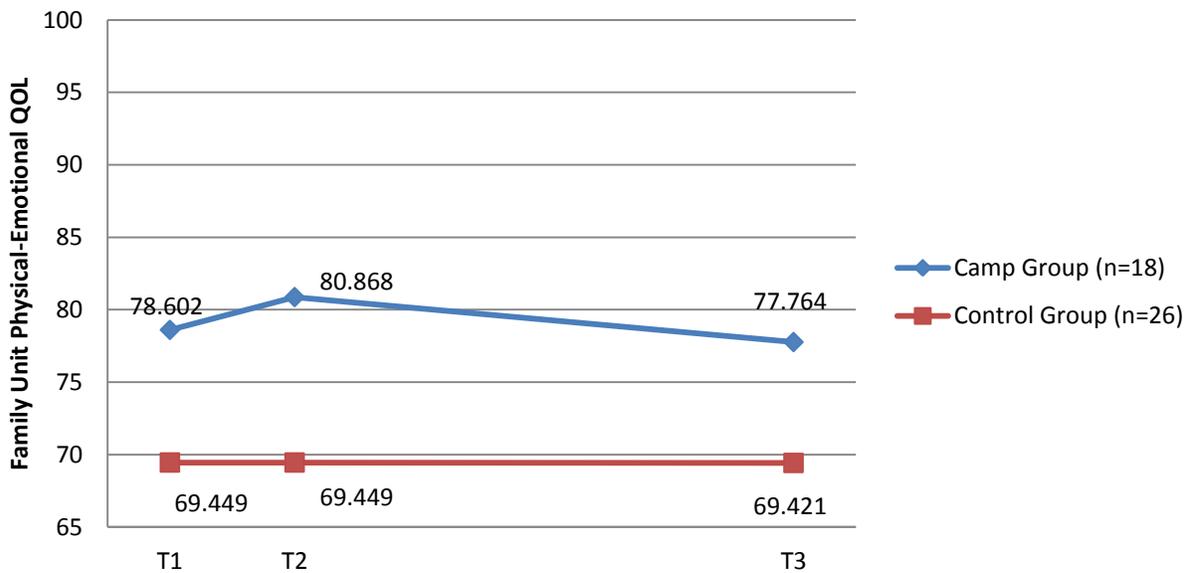


Figure F8. Family Unit Physical-Emotional Quality of Life Across Time: Repeated Measures ANOVA Result

Appendix G

Exploratory Analysis Graphs

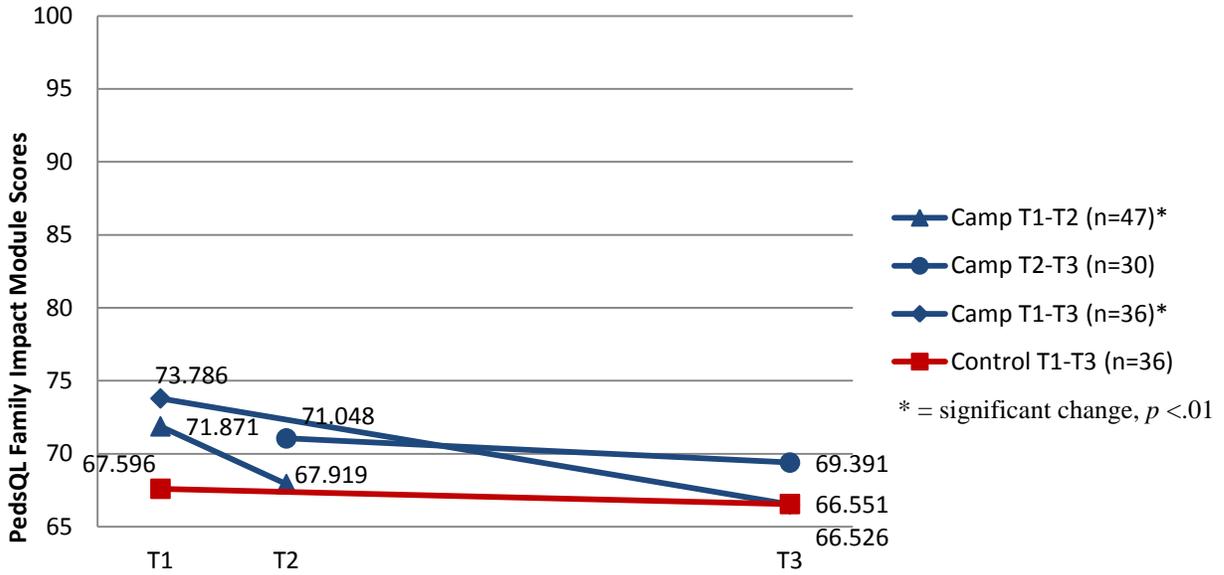


Figure G1. PedsQL™ 2.0 Family Impact Module Scores Across Time: Paired Sample *t* Test Results

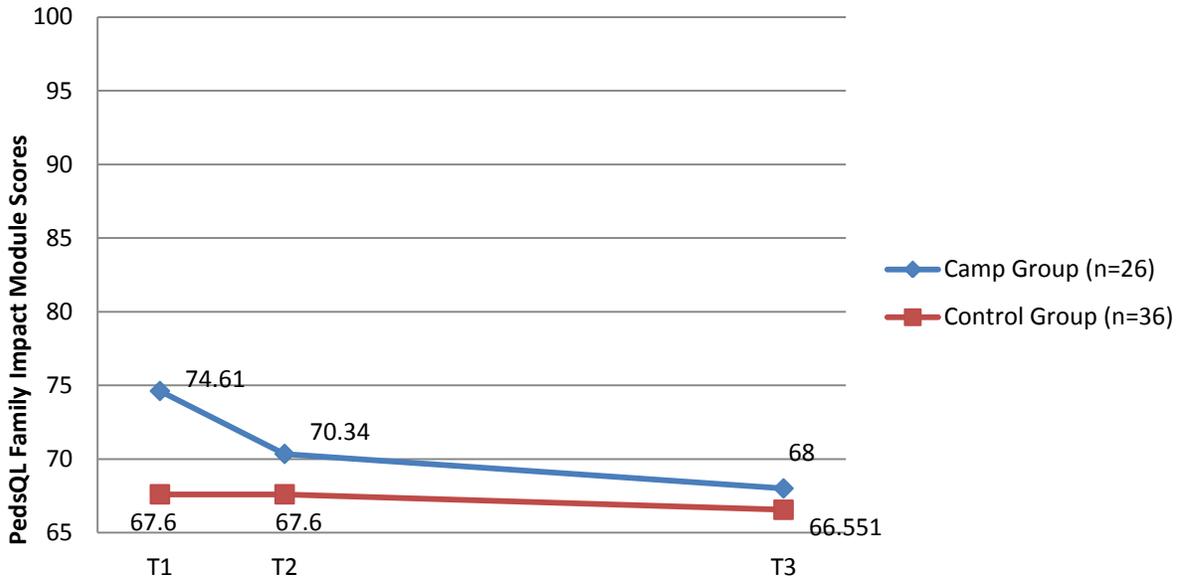


Figure G2. PedsQL™ 2.0 Family Impact Module Scores Across Time: Repeated Measures ANOVA Results

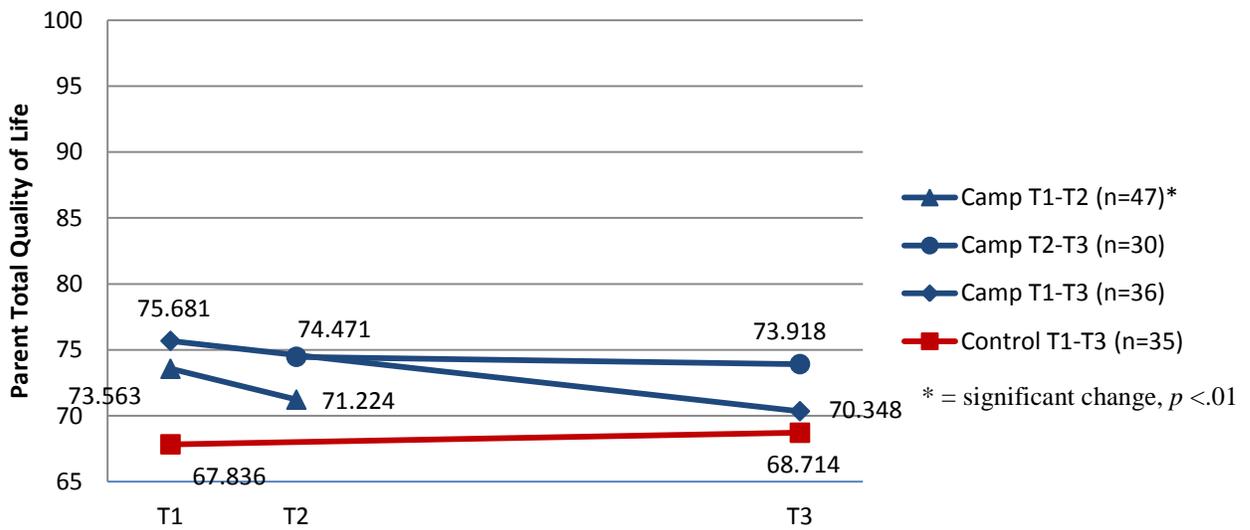


Figure G3: Parent Quality of Life: Paired Sample *t* Test Results

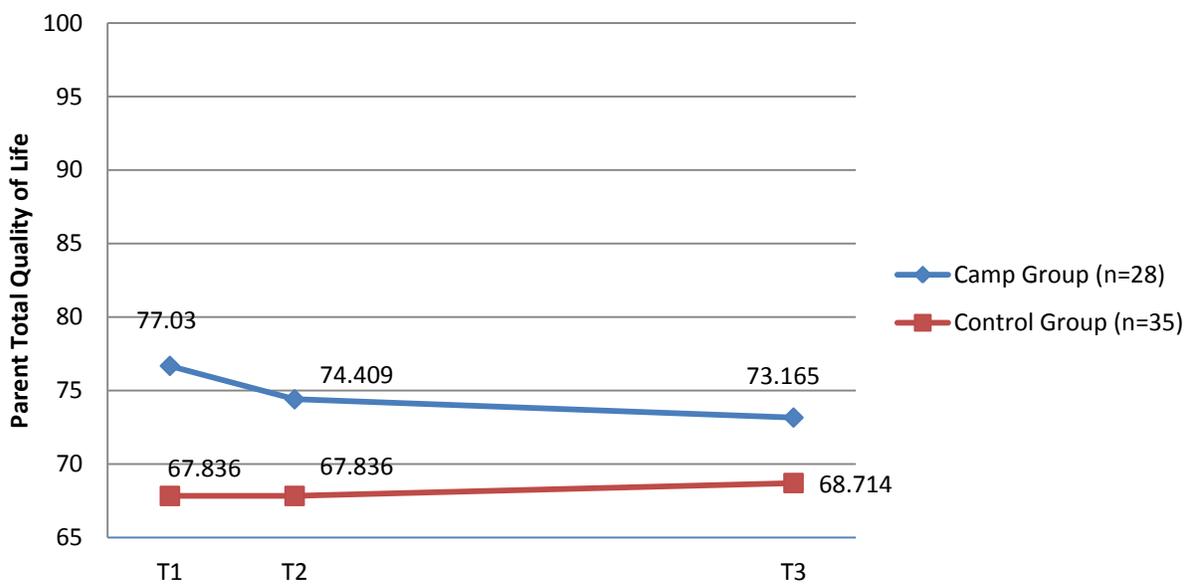


Figure G4: Parent Quality of Life: Repeated Measures ANOVA Results

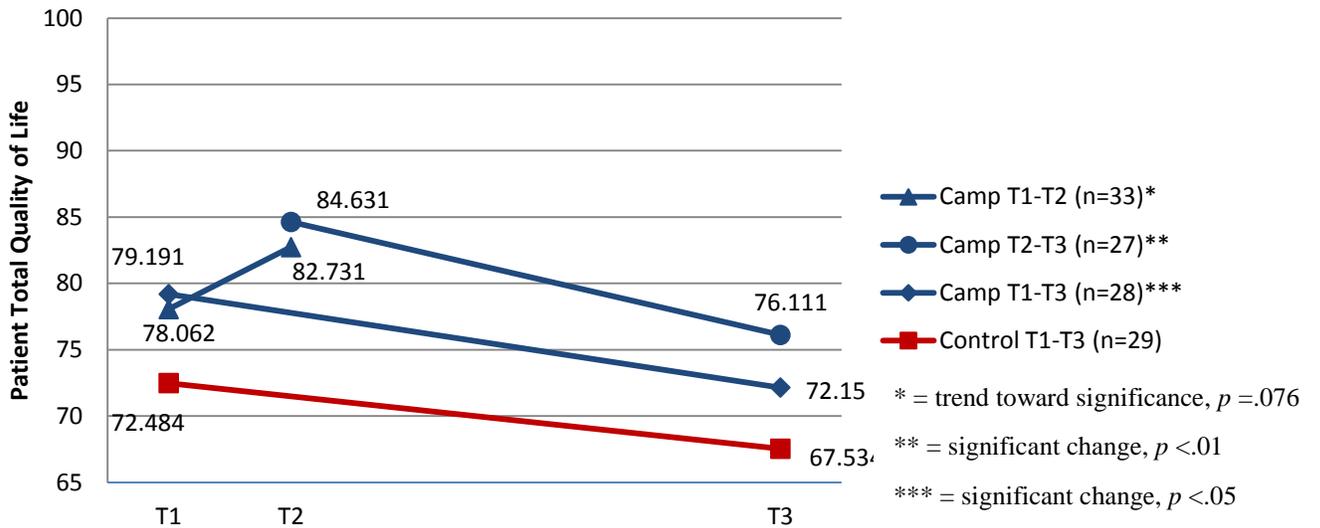


Figure G5: Patient Quality of Life: Paired Sample t Test Results

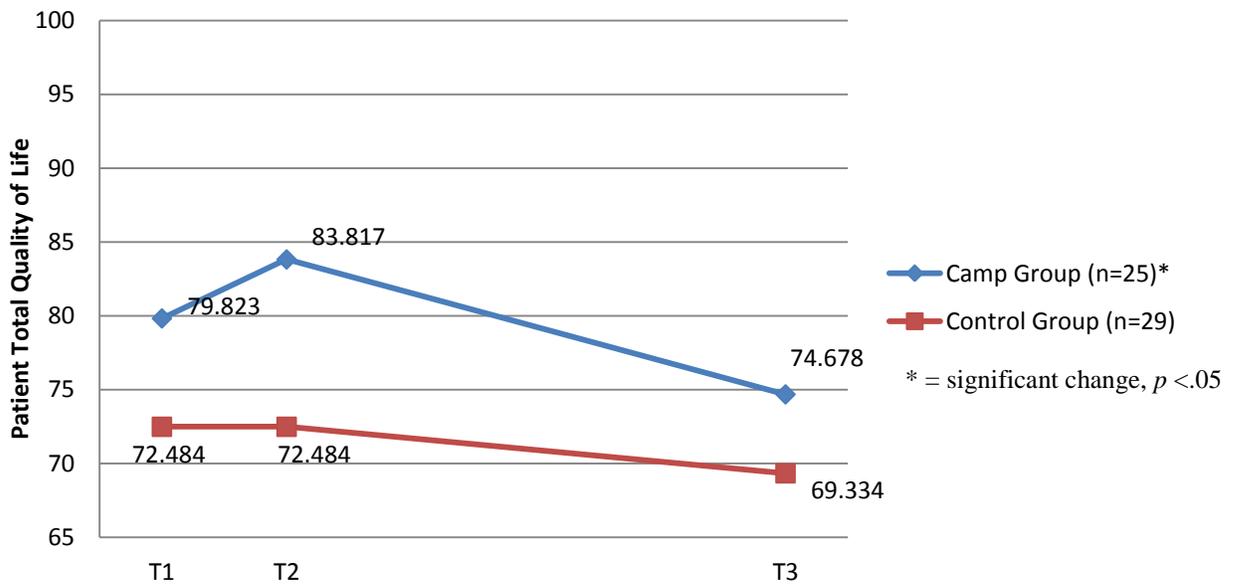


Figure G6: Patient Quality of Life: Repeated Measures ANOVA Results

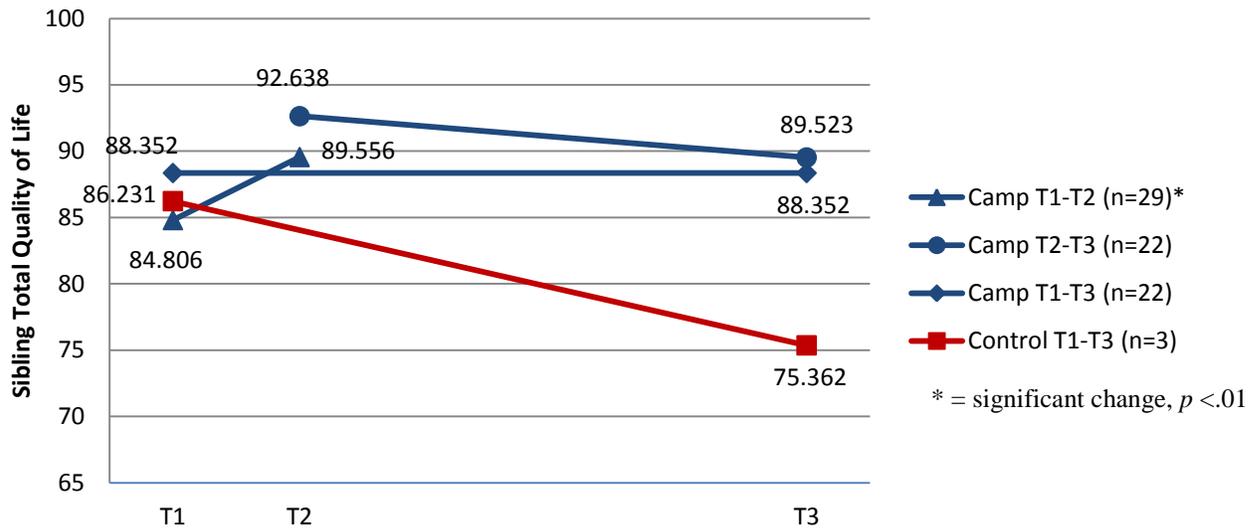


Figure G7: Sibling Quality of Life: Paired Sample *t* Test Results

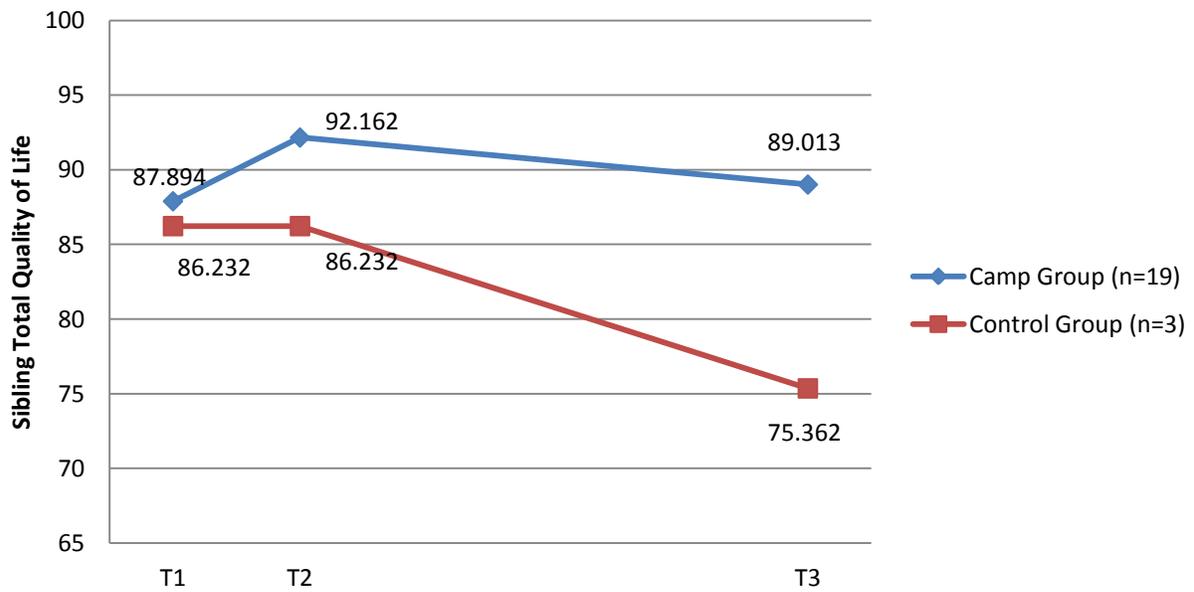


Figure G8: Sibling Quality of Life: Repeated Measures ANOVA Results

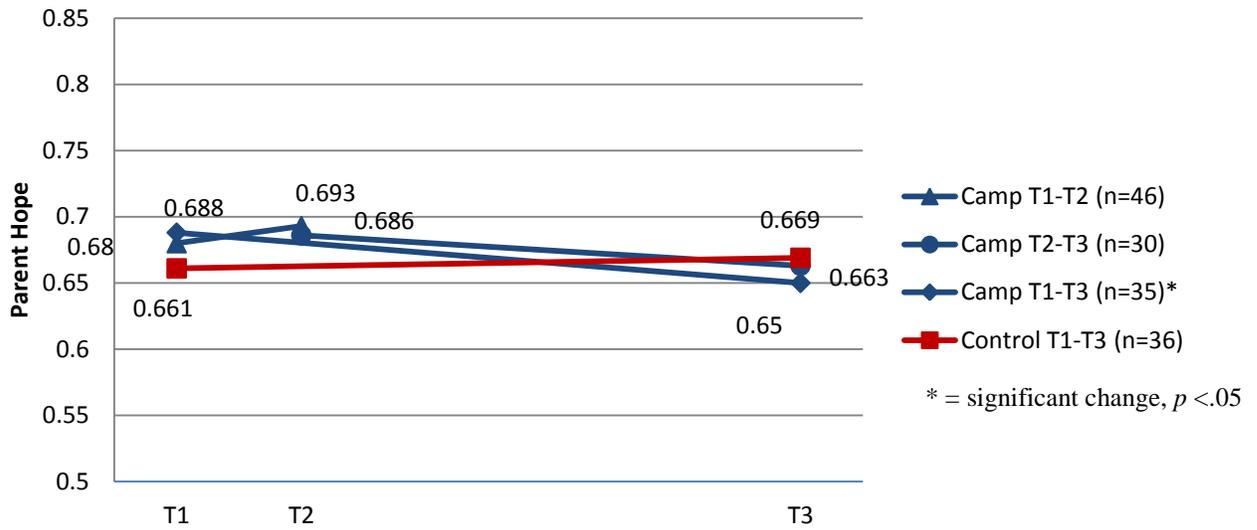


Figure G9: Parent Hope: Paired Sample *t* Test Results

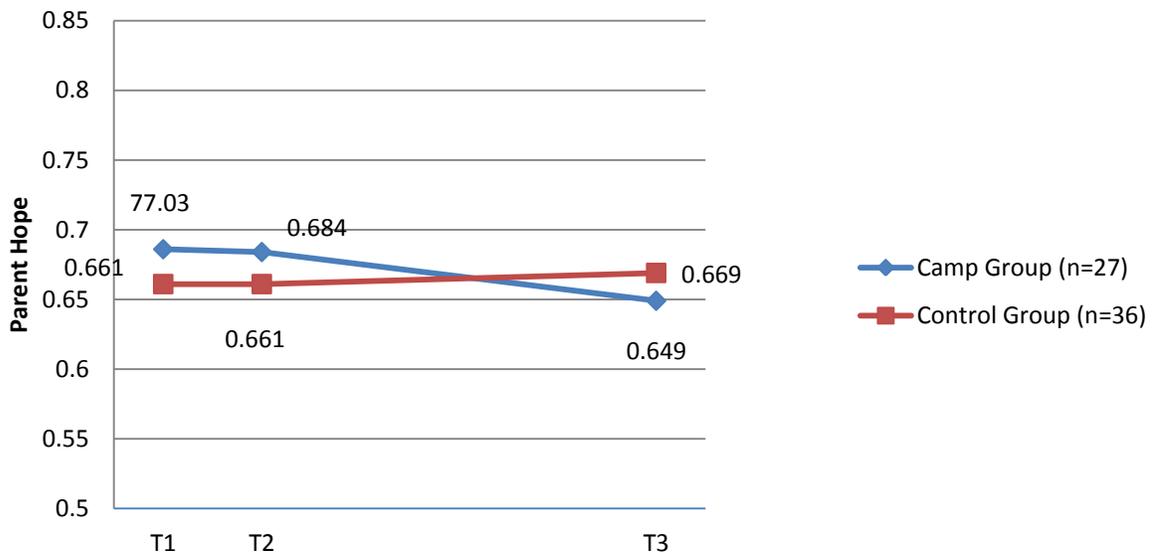


Figure G10: Parent Hope: Repeated Measures ANOVA Results

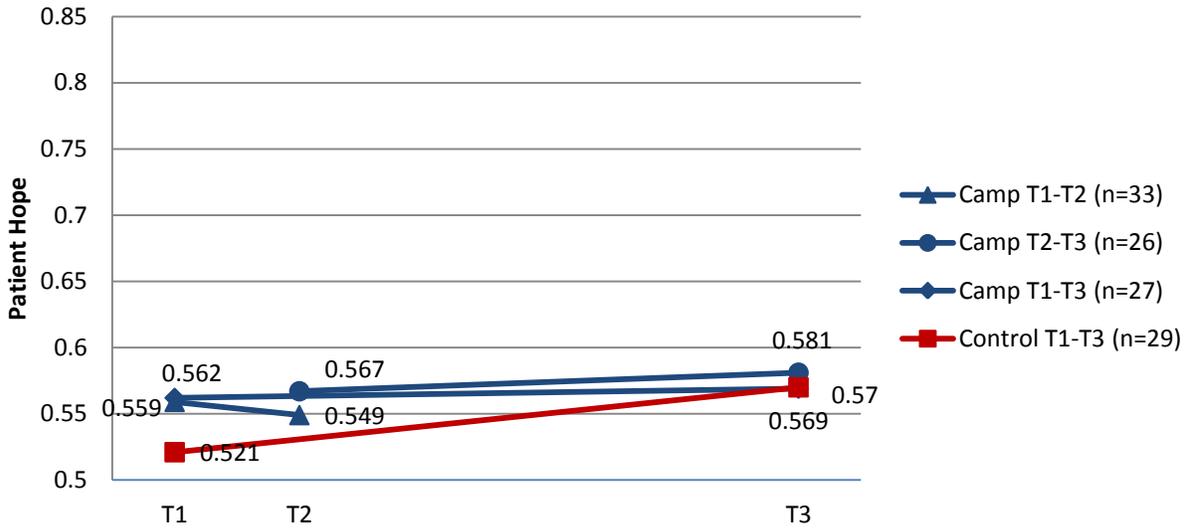


Figure G11: Patient Hope: Paired Sample *t* Test Results

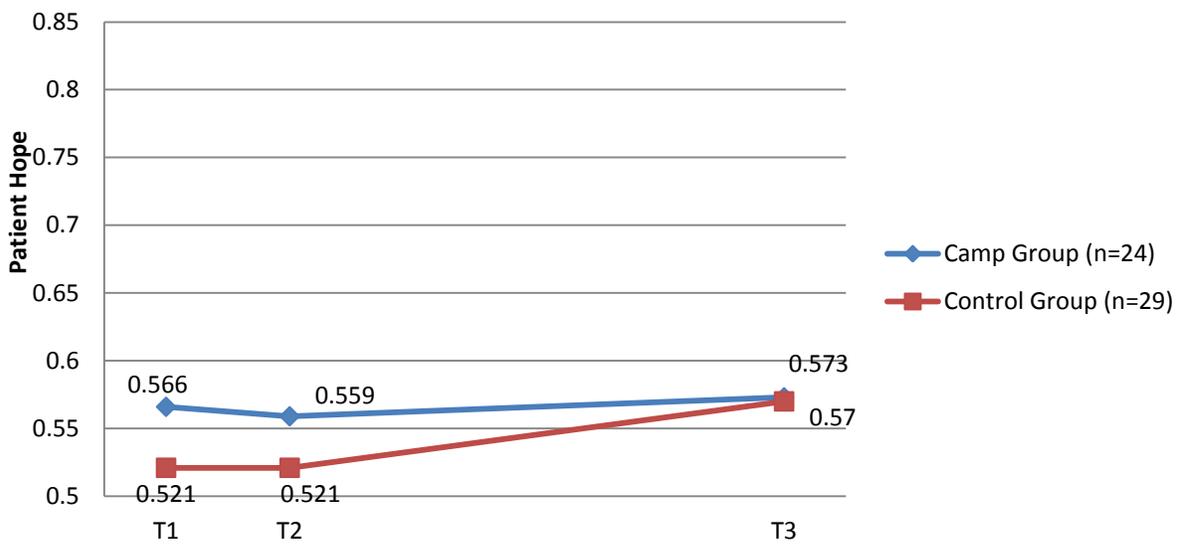


Figure G12: Patient Hope: Repeated Measures ANOVA Results

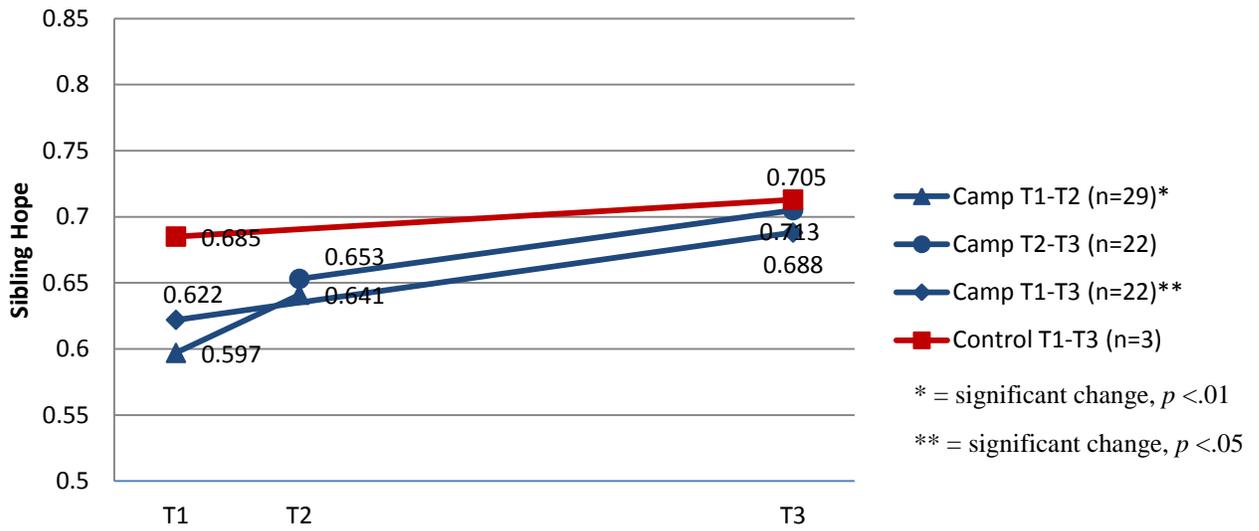


Figure G13: Sibling Hope: Paired Sample *t* Test Results

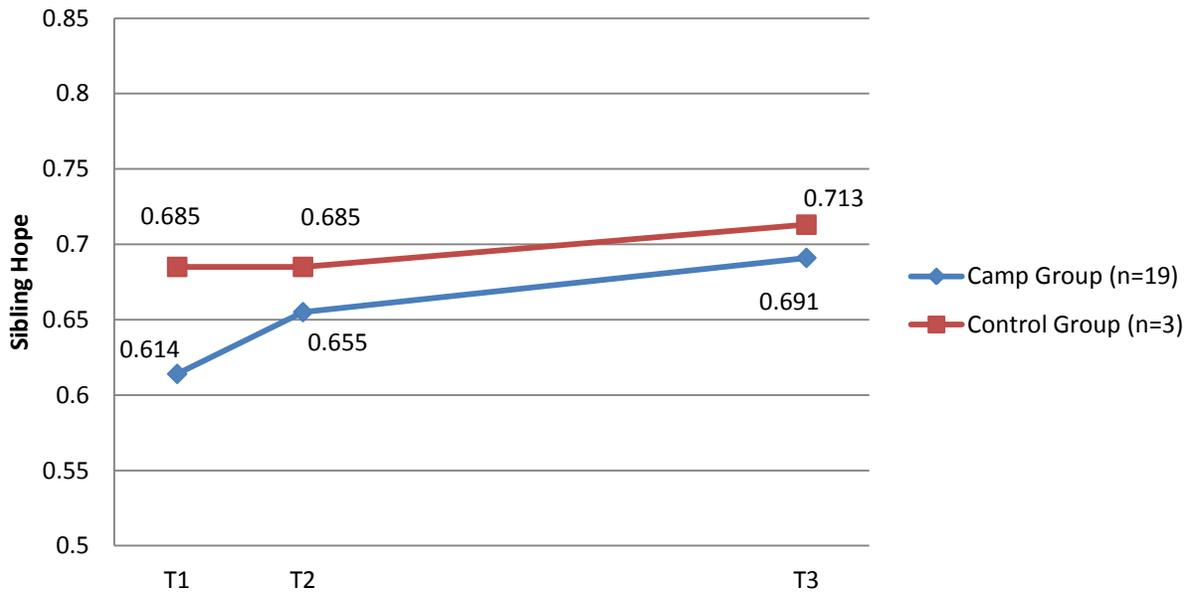


Figure G14: Sibling Hope: Repeated Measures ANOVA Results

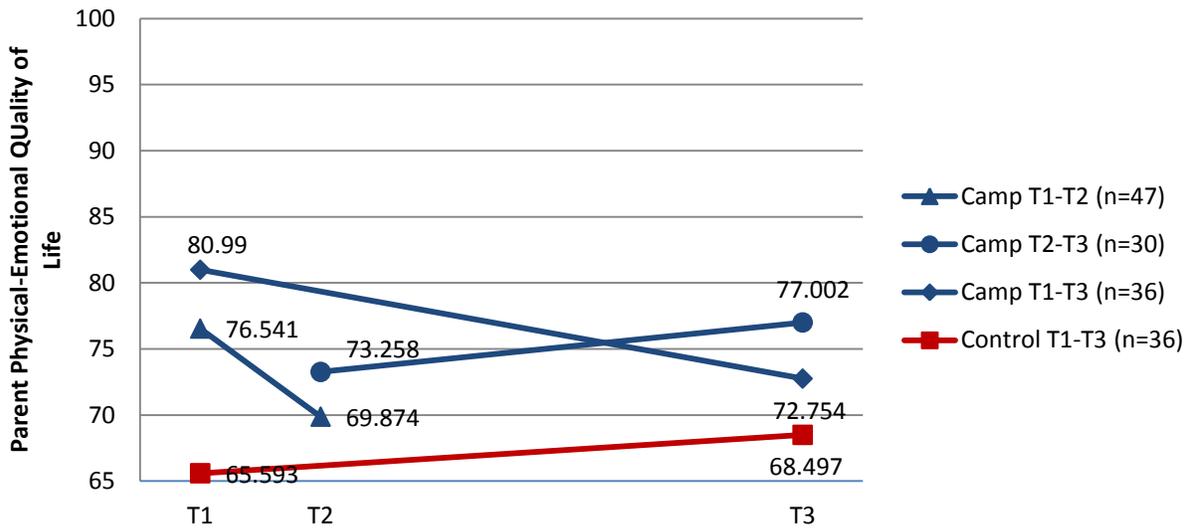


Figure G15: Parent Physical-Emotional Quality of Life: Paired Sample *t* Test Results

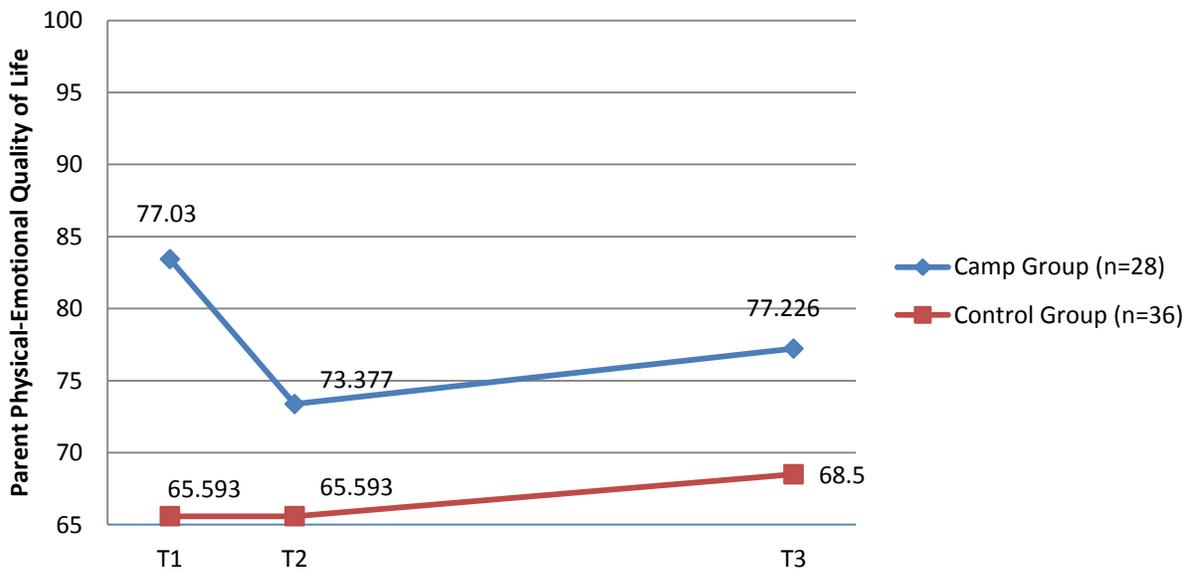


Figure G16: Parent Physical-Emotional Quality of Life: Repeated Measures ANOVA Results

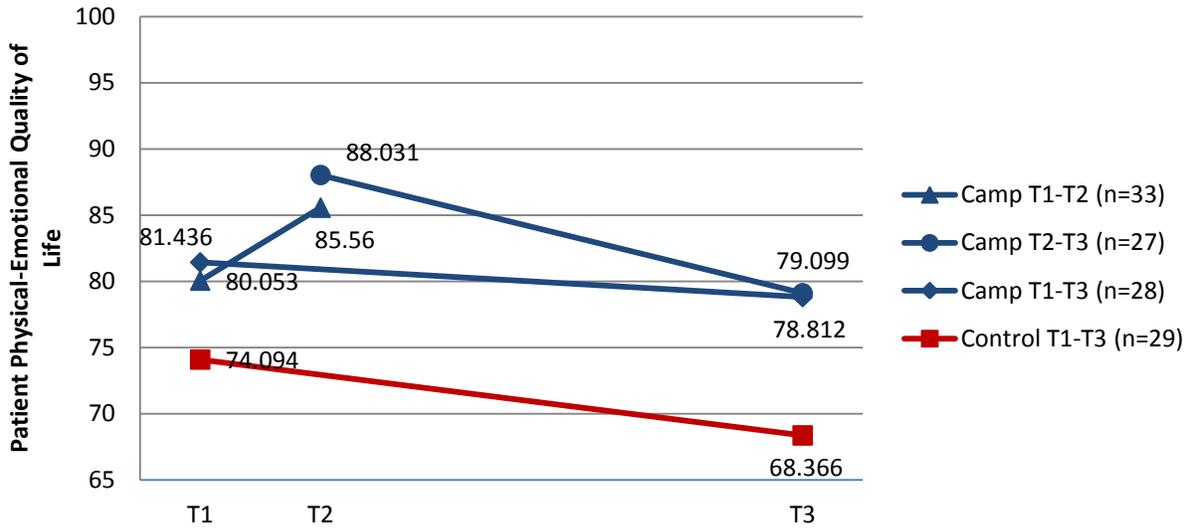


Figure G17: Patient Physical-Emotional Quality of Life: Paired Sample *t* Test Results

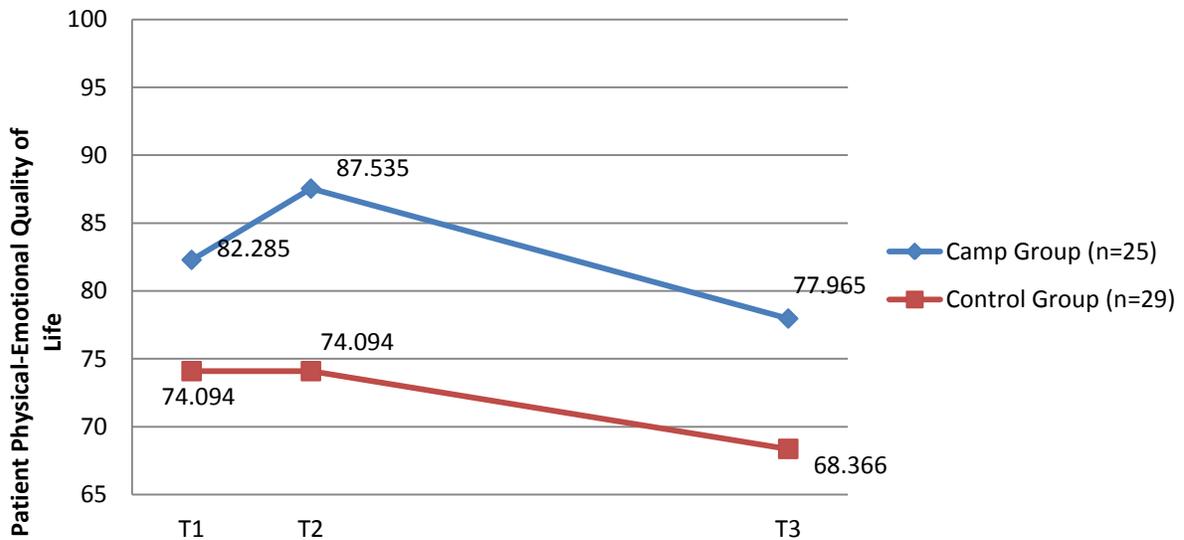


Figure G18: Patient Physical-Emotional Quality of Life: Repeated Measures ANOVA Results

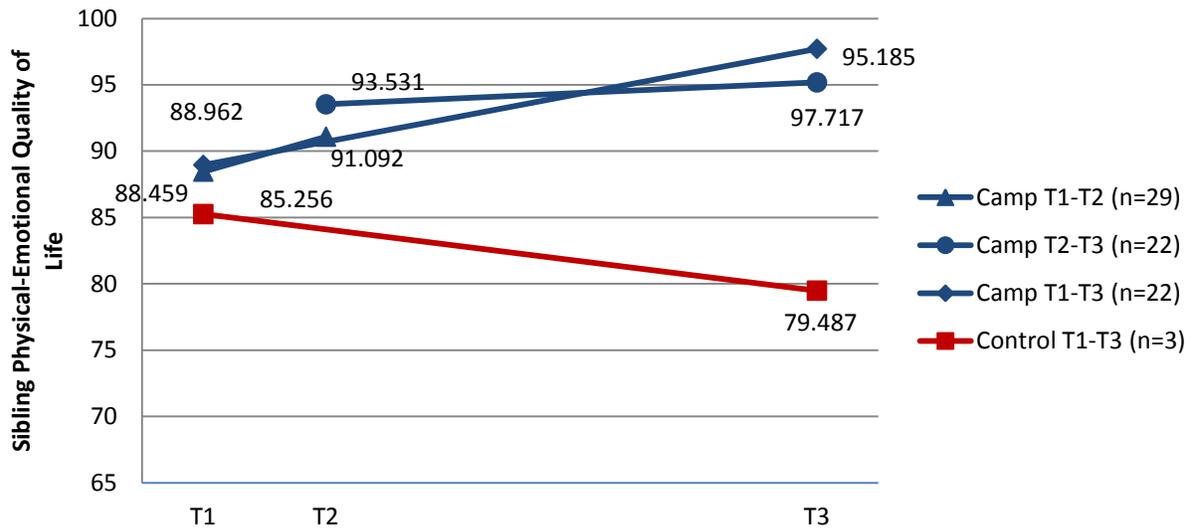


Figure G19: Sibling Physical-Emotional Quality of Life: Paired Sample *t* Test Results

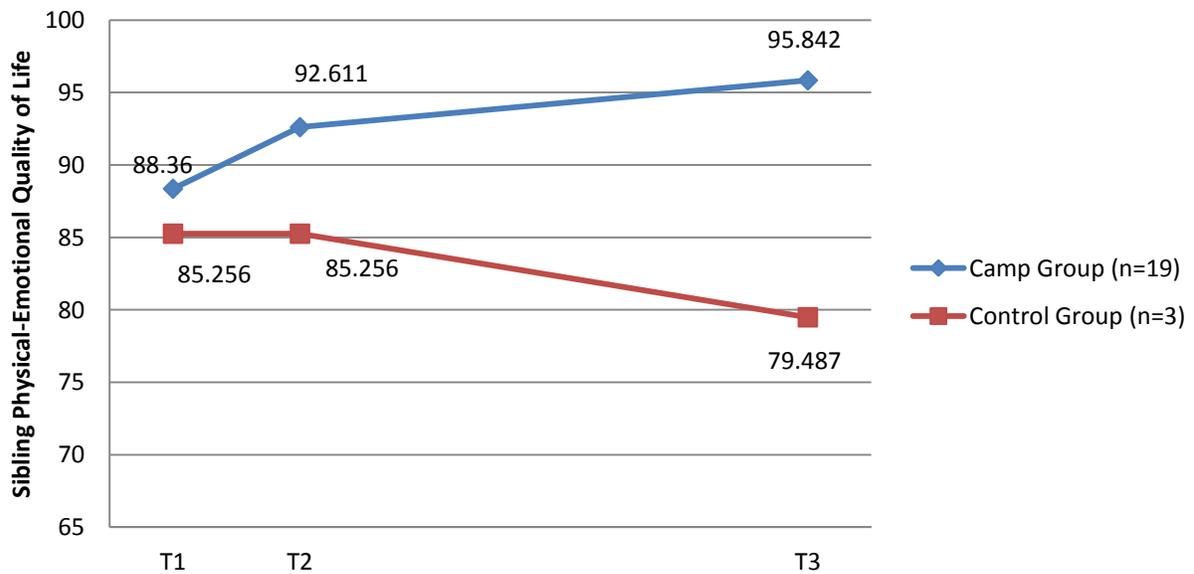


Figure G20: Sibling Physical-Emotional Quality of Life: Repeated Measures ANOVA Results

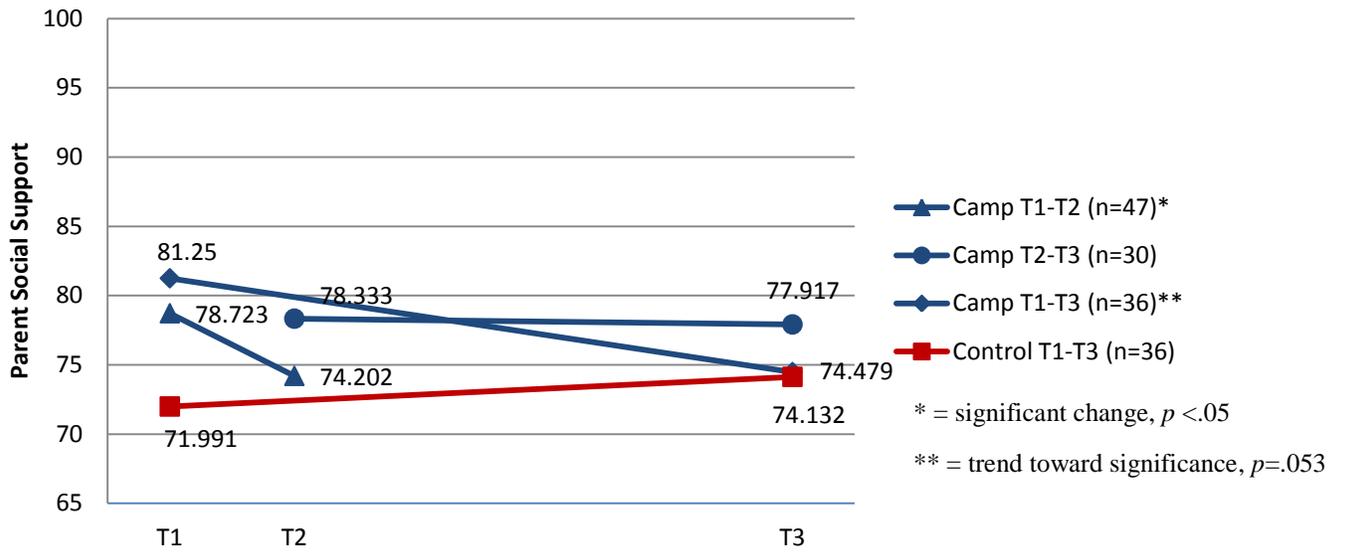


Figure G21: Parent Social Support: Paired Sample *t* Test Results

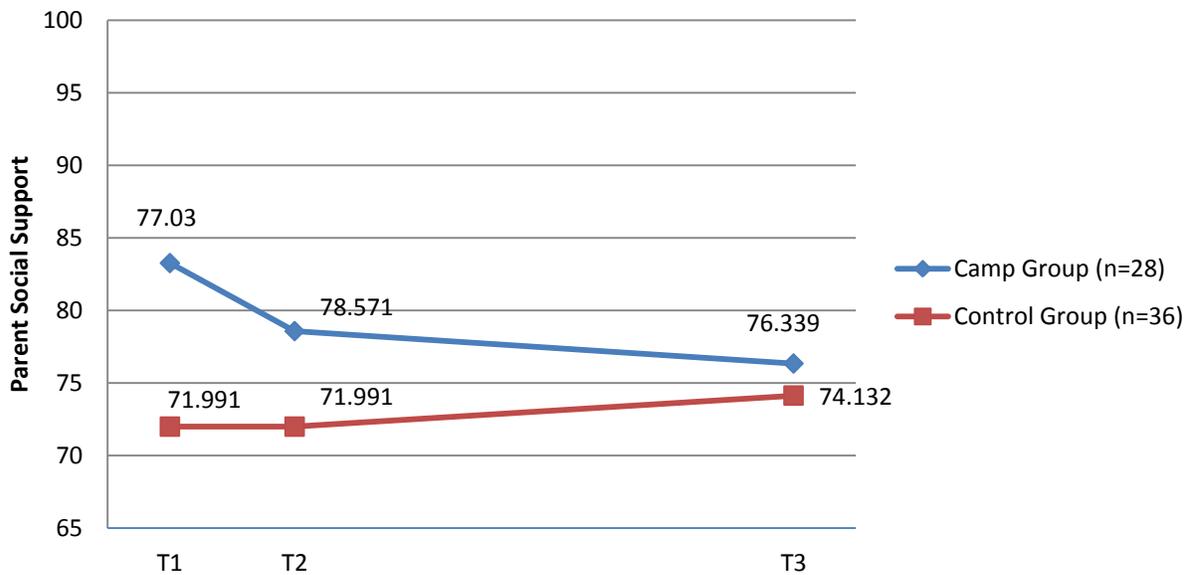


Figure G22: Parent Social Support: Repeated Measures ANOVA Results

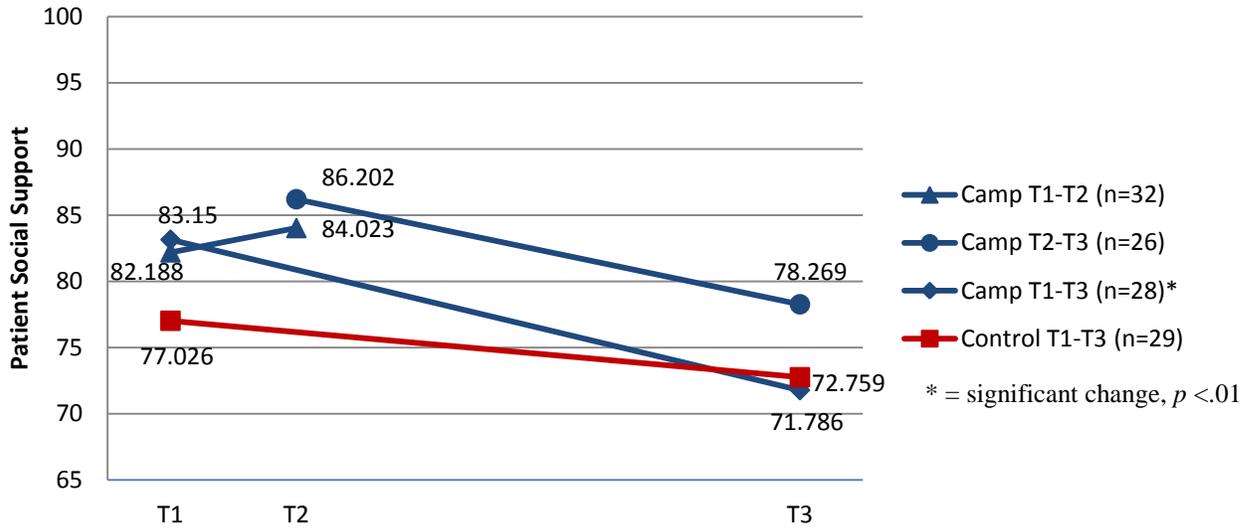


Figure G23: Patient Social Support: Paired Sample *t* Test Results

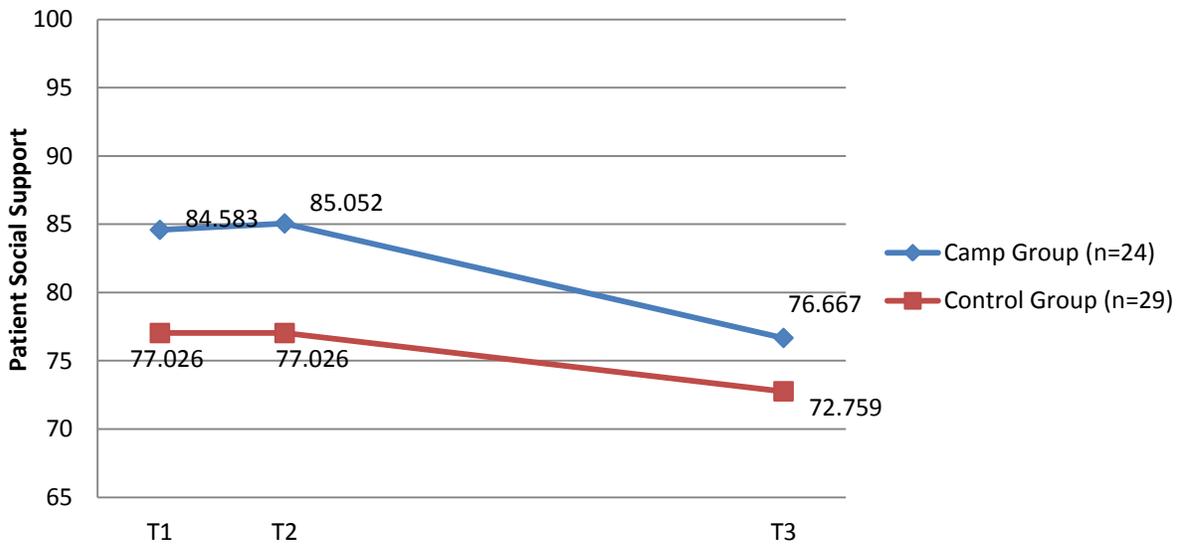


Figure G24: Patient Social Support: Repeated Measures ANOVA Results

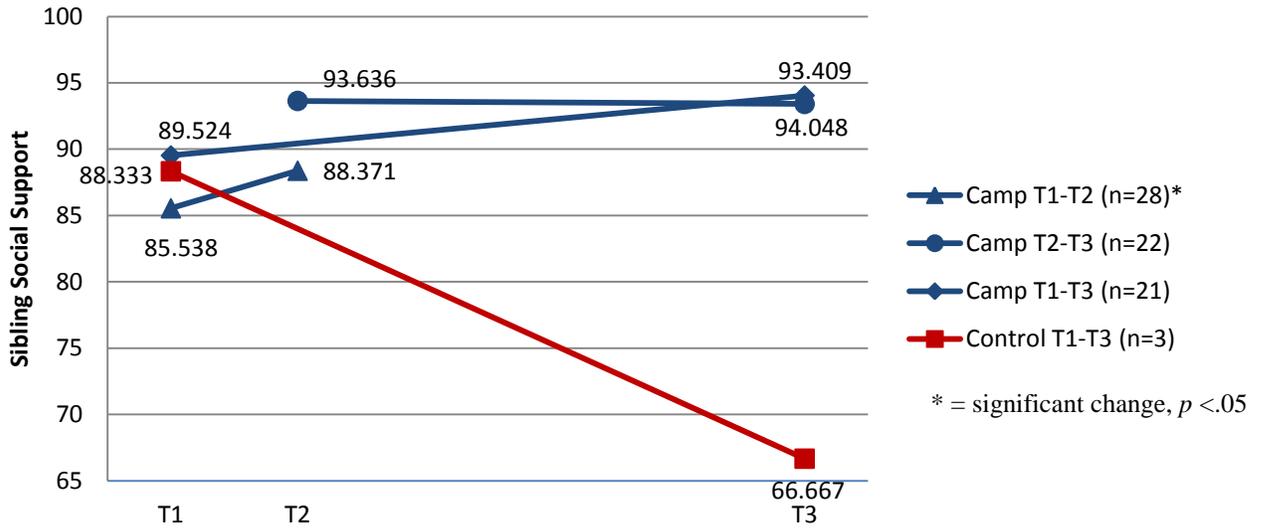


Figure G25: Sibling Social Support: Paired Sample *t* Test Results

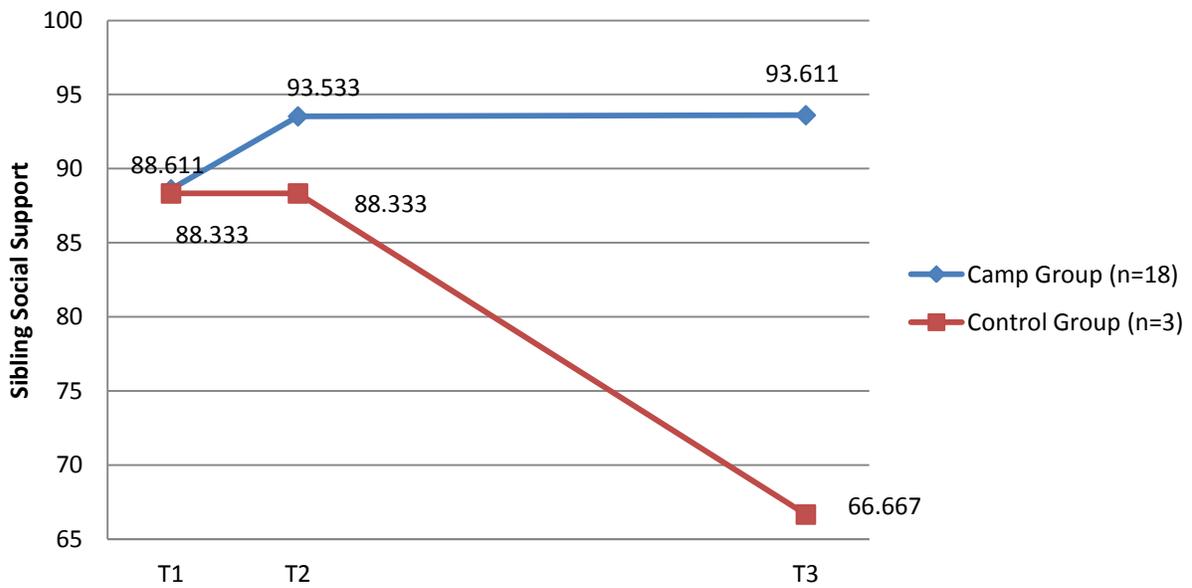


Figure G26: Sibling Social Support: Repeated Measures ANOVA Results

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**BIOGRAPHICAL SKETCH**

Ellen Cook  
Ellencook09@gmail.com

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**EDUCATION/TRAINING**


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Texas A&M University	B.A.	2009	Psychology
The University of Texas Southwestern School of Health Professions	M.R.C.	2012	Rehabilitation Counseling

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**Clinical Experience**

2011-2012 UT Southwestern University Rehabilitation Services – intern  
 2011-2012 Children’s Medical Center – Psychological Services intern  
 2012 UT Southwestern Bariatric Surgery Clinic – Psychological Services intern