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The Effects of Summer Camp on the Self Esteem of Children with Cancer and Their Siblings

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**THE EFFECTS OF SUMMER CAMP ON THE SELF-
ESTEEM OF CHILDREN WITH CANCER AND THEIR
SIBLINGS**

**A thesis submitted to
Regis College
The Honors Program
in partial fulfillment of the requirements
for Graduation with Honors**

by

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May 2016

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Part I. Introduction: A Personal Narrative

My interest in the field of pediatric psycho-oncology can be traced back to the first years of my life—when my younger brother was diagnosed with a form of cancer called Rhabdomyosarcoma. This simple diagnosis changed the course of life for our entire family—in my parent’s eyes, their world was put on hold so they could focus on saving their precious son, Liam. I was about two years old at the time of Liam’s diagnosis and eight years old when he eventually lost his battle to cancer. Many of my first memories of life took place in hospitals and overnight stays with friends and relatives. Growing up with a sibling who was slowly losing his battle to a terrible disease was my normal. Nonetheless, the experience is something I hold very near to my heart, as the effects of it are deeply engrained in how I approach life. My motivation for writing this thesis stems from my personal experience of the perils of childhood cancer—I will share some of that story here.

I imagine that my life in February of 1998 was similar to other three year olds—I enjoyed playing in the sandbox, making messes, and riding atop our giant Dalmatian, Otis. My brother, Liam, had been born ten months before, becoming the third child of the McGrane family—my older sister Madeline, myself, and Baby Liam. This sense of ‘normalcy’ in my family quickly diminished after my parents found a small lump on Liam’s bottom. A few weeks later, we discovered it was a rare and aggressive form of cancer called Rhabdomyosarcoma (Rhabdo), found mainly in infants and toddlers. From this point onwards our family had one objective—to get rid of this damn cancer.

The next five years could be best described as a roller coaster ride, which is fitting because Liam sure did love roller coasters. The ride is called “Childhood Cancer”—it is a ride for the whole family and it will take you up and down, and down some more. After a successful surgery and long

bouts of chemotherapy the doctors would say that there was no trace of cancer in his body and he would go into remission. I was very young through most of this process, so I did not quite know what was going on, but I knew when Liam was in remission because he had a full head of hair and my parents seemed more at ease.

As time wore on, I became more aware of the gravity of Liam's sickness. I saw that my parents were always in and out of the hospital, trying to balance being with Liam and raising two healthy kids. My mom and dad did their best to ensure that my brother was never alone at the hospital. My mother would usually be at the hospital and my dad at work—this called for many circumstances in which my sister and I were either with relatives or neighbors. Often times I felt left out and jealous that my brother would get so much attention. To make things worse, I felt guilty for feeling jealous because I knew that he was sick and needed the love and attention more than I did. Still, there are strong feelings of jealousy and isolation associated with watching your one of your siblings constantly being showered with gifts and love. As we will see later, such feelings of isolation and “unwantedness” are common amongst siblings of cancer patients.

Liam's first remission period lasted two years, but came to an immediate halt when we learned that his cancer came back. Within days of relapse, he was back on chemotherapy, radiation and spending his nights at Kaiser Hospital in San Francisco. At the age of four, a 12-hour surgery resulted in a colostomy. I cannot imagine the emotional toll of learning your child has relapsed with cancer, but to me it seems like a parent's worst nightmare. Liam went through three periods of remission in a span of five years and each time the cancer returned it seemed to come back stronger and more destructive than before. Childhood cancer is truly a roller coaster for all members of the family, and while this ride does come to an inevitable end, some families are left with one less rider on board.

In the fall of 2002, Liam had relapsed and this time, the cancer was relentless. As the weeks passed, Liam was becoming more and more sick. He was still on heavy doses of chemotherapy, but the cancer was fighting back. The combination of chemotherapy and rapidly spreading cancer took a heavy toll on his physical and emotional well-being. My mother told me that for Halloween that year, Liam got dressed up as a “scary alien”, but he was too sick to walk so my father carried him to a couple of neighbors’ houses. After only a few minutes Liam asked to go home, as he felt too sick. My mom stayed with him all night, while my dad, sister, and I went out together. In all the years since his diagnosis, we had never seen Liam in this weak of a condition.

Liam was also being treated at UCSF hospital with world-renowned pediatric oncologists—many of whom had been treating Liam since he was first diagnosed. We were confident that he was in the best of hands. Just after Halloween, our family received news from the doctors that the cancer was growing and spreading too rapidly for any available treatment to have an effect. In short, there was nothing they could do. The decision was made to take him off all drugs (except those controlling pain) and bring him back home from the hospital. His first night back from the hospital he slept in my parent’s bed, a place where he was to spend the remainder of his life.

My parents knew that Liam’s time on Earth was quickly coming to an end. I do not remember much in the weeks preceding my brother’s death, but my experience on the night he passed is one that is forever engrained in my memory—one that I will hold dearly for my entire life. Liam had been home, lying in my parent’s bed for three weeks and my whole family, even myself, knew we were waiting for his passing. On November 22, 2002 my mother came into my room before going I fell asleep. I remember very clearly when she asked, “Jack, if Liam dies tonight, do you want me to wake you up.” I replied with a simple, “Yes.”

At midnight my parents entered my room and woke me up. I quietly followed them down the hall to their bedroom. There I saw my brother's body lying still. A being that was once so full of life and laughter was now empty and lifeless. I do not know what I was thinking in that moment. In fact, I was not thinking much at all. It is almost like my brain turned off for a few seconds and allowed for that moment to be etched in my mind forever. Not many words were exchanged between my father, my mother, my sister and I. I do remember my mom saying, "Lili is Heaven now." That night I curled up and slept at the foot of the bed and when I woke up, Liam's body was gone.

The loss of Liam took an emotional toll on my entire family. We all seemed to grieve in different ways. My mother was very outwardly emotional; I remember times when I would walk downstairs in the morning to find her crying in the kitchen. My father was quite the opposite, as he isolated himself and fell deep into alcoholism. My relationship with my sister suffered, as we would talk to each other less and less with each passing day; eventually it reached the point to where several days could go by without us even acknowledging each other. I felt like Liam was the glue that held our family together and after he died, we were being pulled apart. I felt as if I could not express my emotions to anyone in my family, as they seemed to be suffering as much as I was. To be clear, I harbor no resentment towards any of my family members—we all had our own way of coming to terms with Liam's passing. I was fortunate to have a place to go for one week of every summer where I was surrounded by kids who were in my same shoes. Looking back now, I could not have asked for a greater blessing in my life than Camp Okizu.

Camp Okizu is an organization that seeks to provide services to families affected by childhood cancer. For 35 years Okizu has offered week-long summer camps for both children with cancer and their siblings, completely free of charge. My family heard about Okizu from one of

Liam's nurses; I went to camp for the first time when I was six years old and have gone back every summer since. Outside of camp, I felt like none of my friends could truly know what I was going through, but at Okizu, I was surrounded by many kids who shared the same feelings—I felt at home.

The content of this thesis centers around the benefits that summer camp has on the emotional well-being of children with cancer and their siblings. First, I will discuss a history of pediatric psycho-oncology research, as well as a history of research on the effect that childhood cancer can have on the patient's sibling. I will then give a brief history of Camp Okizu: from when they started in 1982 to where they are today. This all is a preface for the research I conducted at Camp Okizu in the summer of 2015; A study that examines how attending summer camp can affect the self-esteem the campers' self-esteem, in both patients and siblings. This project will conclude by exploring the question of how evidence-based research for non-profit organizations fits into Father Gregory Boyle's model of *success*.

Part II. A History of Pediatric Psychosocial Oncology & Siblings Research

CHILDHOOD CANCER'S EFFECT ON THE PATIENT

It is safe to say that children diagnosed with cancer are dealt a rough hand—these kids are faced with extended stays in the hospital, surgeries, social isolation, and even the devastating possibility of not surviving the ordeal. Today, children diagnosed with cancer have a significant chance of beating the disease, as the five-year survival rate is over 80% (National Cancer Institute, 2010). However, our methods of treatment were not always this successful—in the 1960s most children with cancer did not survive, as the 5-year survival rates were 28% (Ries, Harras, Edwards, & Blot 1996; Gurney, Ries, Smith, et al., 1999). Chemotherapy was gaining in popularity in the late 1960s to early 1970s and by 1975 it was a standard treatment for pediatric cancers (DeVita & Chu, 2008). During this time the five-year survival rates of children diagnosed with cancer jumped to 56%; (Ries et al., 1999; Ries et al., 2002). Chemotherapy treatments allowed children diagnosed with cancer to live significantly longer and provided a much higher chance of overcoming the illness.

In the 1960s little attention was paid to the emotional well-being of the patient. This makes sense, as low survival rates called for increased attention to their physical health. The increase in effectiveness for childhood cancer treatments allowed for more attention to be paid towards the child's emotional well-being. Psycho-oncology research ramped up in the mid to late 1970s, around the same time that chemotherapy was implemented as a standard treatment for pediatric cancers (Ries et al., 2002). Now that these kids had a much greater chance of overcoming the illness, more focus could be directed towards taking care of the patients' emotional well-being.

While much of the research focused on the psychological effects of childhood cancer started in the mid to late 1970s, there was some research present in the 1960s to early 1970s. However,

most of this research was predominately geared towards observational recordings of parents' mourning and their psychological reactions to the death of the child (Binger et al., 1969; Chodoff, Friedman, & Hamburg, 1964; Natterson & Knudson, 1960). At the time there was very little open communication with the child with cancer coming from parents and/or medical professionals regarding the name or nature of the disease. Thus, it was thought that the child was essentially oblivious to the nature of the disease and prognosis (Patenaude & Kupst, 2005). It turns out this was not the case, as studies showed that children were not deceived by the avoidance of discussion of their diseases or by false reassurance of their prognosis. These children seemed to understand much more of the situation than originally thought (Spinetta, 1974; Waechter, 1968). The findings of these early studies encouraged a shift in viewing the topic of childhood cancer as something taboo and not to be talked about, to something that should be openly discussed in the family. Pediatric health care professionals now emphasized open communication with the children about their illness and strongly encouraged parents to do the same.

The idea of open communication between doctors and parents to the child was a paramount shift in how we approach the experience of childhood cancer in the family. A topic that was once considered taboo was now on its way becoming more openly-discussed in the hospital and family setting. The process of open communication to the patient called for the inclusion of mental health professionals on treatment teams for children with cancer to assist their emotional needs, as well as for other members of the family (Patenaude & Kupst, 2005). The presence of psychologists, social workers, and psychiatrists helped raise awareness about the behavioral challenges associated with a childhood cancer diagnosis, specifically how to deal with social isolation in the hospital setting and the physical suffering associated with treatments. In addition to these issues, the inclusion of mental health professionals also shed light on cancer's impact on

the whole family, including parents and siblings (Patenaude & Kupst, 2005). This shift in approaching childhood cancer from a purely physical disease to one that can have detrimental emotional effects on the patient and family, sparked years of research into how we can better understand the psychosocial and emotional components of childhood cancer.

In the late 1970s to early 1980s, a significant amount of research began to emerge about the potential emotional effects of childhood cancer on the patient. It was becoming increasingly well-known that cancer may carry detrimental emotional effects on the child, but there was debate as to where the psychological issues manifested. Early research into the psychosocial and emotional effects of cancer showed potential for adjustment problems and mild psychiatric symptomology in a population of patients surviving childhood cancer therapy (O'Malley, Koocher, Foster & Slavin, 1979; Patenaude & Kupst, 2005). However other studies showed that many children did not experience significant emotional and psychosocial problems and that these issues were, in fact, relatively rare (Cella & Tross, 1986; Fritz, Williams, & Amylon, 1988; Greenberg, Kazak & Meadows, 1989; Kupst & Schulman, 1988). These studies suggest that childhood cancer can induce both positive and negative emotional effects on the patient. In the following few paragraphs we will identify the positive and negative emotional consequences associated with childhood cancer. We will then explore the factors involved in predicting why some kids are more negatively emotionally impacted than other.

It is not difficult to imagine that fighting cancer can be a traumatic experience for a child—one that can leave lasting emotional effects. A number of studies have attempted to shed light on where these deficits manifest. In a study of preschool-aged children with cancer, researchers found that the kids faced problems with feelings of isolation, due to the separation from their parents (Hollenbeck, et al., 1980). Other studies showed that roughly 25-30% of children with

cancer did not cope well or had significant family, personal, or social problems (Boman & Bodegard, 1995; Friedman & Meadows, 2002; Koocher & O'Malley, 1981; Kupst et al., 1995). Other areas that have been found to be problematic for childhood cancer survivors include: impaired or decreased social relationships (Boman & Bodegard, 1995; Mackie, Hill & Kiomdryn, 2000; Mulhern et al., 1989); increase in employment difficulties (Hays et al., 1997); decrease in academic achievement (Fritz et al., 1988; Haupt et al., 1992; Hays et al., 1997); deficits in self-concept, self-esteem, or identity (Greenberg et al., 1989; Koocher & O'Malley, 1981; Madan-Swain et al., 2000; Patenaude & Kupst, 2005). Two studies from 2001 showed that moderate to severe posttraumatic stress symptoms are present in 5-20% of survivors (Erickson & Steiner; Kazak et al.). In a study of 115 children who were at least 5 years old and an average of 12 years post-diagnosis, about half of the population of surviving cancer patients were said to be functioning relatively well compared to the controls, while only a quarter of the participants experienced problems in as psychosocial or emotional adjustment (O'Malley, Koocher, Foster & Slavin, 1979). From the findings of this study and others alike, it became known that, while some children with cancer experienced emotional and psychosocial deficits, many of them did not show significant emotional distress. In fact, there is evidence that in some children, the cancer experience may have affected them in a positive way.

Despite life-threatening circumstances and fatal outcomes, significant psychopathology in children with cancer was not always the normative outcome, and many children showed incredible resiliency (Cella & Tross, 1986; Fritz, Williams, & Amylon, 1988; Greenberg, Kazak & Meadows, 1989; Kupst & Schulman, 1988). A literature review of 20 studies of survivors of pediatric cancer found that survivors did not show deficits on measures of anxiety, depression, or self-esteem when compared with matched controls (Eiser, Hill, & Vance, 2000). One study even

showed that childhood cancer survivors tended to have fewer emotional and behavioral problems compared to population norms, based on the report of others (e.g. teachers, parents, and peers; Noll et al., 1997). Though significant psychopathology may not be the norm in children with cancer, studies found that some kids did express negative psychological effects from the experience.

From research over the years, we see that the experience of childhood cancer can have both positive and negative emotional effects on the patient. What are some of the reasons why one child might be more negatively affected than another? Some studies show that psychological adjustment may be linked to socioeconomic status, in that a higher socioeconomic status correlates with better psychological adjustment (Koocher & O'Malley, 1981; Kupst et al., 1995). In terms of family environment, better adjustment correlates with more open family communication (Fritz et al., 1988; Koocher & O'Malley, 1981; Kupst & Schulman, 1988) and greater family and social support (Fritz et al., 1988; Kupst & Schulman, 1988; Trask et al., 2003). Other factors have to do with the disease and treatment: children diagnosed with brain tumors or other central nervous system (CNS) cancers experience lower cognitive and academic functioning (Armstrong & Mulhern, 2000) and greater difficulties in psychosocial functioning (Boman & Bodegard, 2000; Mulhern, 1994; Patenaude & Kupst, 2005; Vannatta et al., 1998). Difficulties in adjustment are also higher in children diagnosed with bone tumors (Eiser et al., 1997; Langveld et al., 2002). Treatment factors include intensity of chemotherapy, in that a more intensive chemotherapy regimen is associated with lower adjustment (Zebrack & Zeltzer, 2002). Better adjustment correlates with a longer period of time since diagnosis (Cella & Tross, 1986; Koocher & O'Malley, 1981; Kupst & Schulman, 1988) and shorter duration of treatment (Koocher & O'Malley, 1981). The results from these studies better explain why significant problems in psychological

adjustment are present in some children with cancer and not others. Clearly, the experience of childhood cancer has a tremendous impact on the patient. We now know that childhood cancer affects more than just the cancer patient—it can have an effect on the family as a whole, especially the siblings of the patient.

CHILDHOOD CANCER’S EFFECT ON THE SIBLING

When thinking about difficulties associated with the childhood cancer experience, one may not immediately think about the effects it has on the sibling of the patient. Although a sibling of a cancer patient may be physically healthy, we now understand that the experience of having a brother or sister with cancer can cause significant psychosocial and emotional problems. Nowadays, hospitals have various programs designed specifically to meet the emotional needs of the siblings of childhood cancer patients, but for many years the emotional effect of childhood cancer on the siblings of the patients was not well understood. The acknowledgement of siblings’ needs in the childhood cancer experience is largely due to the research that illuminated these very needs. The majority of sibling research began in the late 1970s to early 1980s, but we see recognition of this issue as early as 1956 (Cobb). In the following few paragraphs I will mention three of the earliest known studies on the emotional needs of siblings of pediatric cancer patients.

The earliest research that recognizes the emotional needs of siblings, conducted by Cobb, aimed to examine the psychological impact of illness and death in the family (1956). Researchers interviewed a population of parents whose children passed away from cancer. When asked about how the experience may have affected their other children, the parents reported perceived feelings of loneliness, sadness, and loss of parental availability to the siblings. Cobb’s conclusions

reflected the need to consider the psychological impact of disease and death on the entire family (1956).

A later study by Cain, Fast, and Erickson studied children's emotional responses to the death of their sibling (1964). In a sample of 58 children between the ages 2.5 to 14 years, researchers found a prominent immediate reaction of guilt in the siblings' response to the death of their brother or sister, which persisted for five years or more after the sibling's death. Reactions to the guilt included depression, social withdrawal, low school performance, and low self-worth. Researchers in the study also found that the siblings had a heightened fear of death and fear of contracting the same illness that caused their sibling's death (Cain, Fast & Erickson, 1964). This study built upon the Cobb's research by identifying specific emotional responses from the siblings themselves, not from the parents.

A third early study of the emotional impact of having a sibling with cancer came in 1969, where researchers reported that, in approximately half of the 20 families studied, one or more of the siblings showed signs of maladaptive behavioral patterns during the patient's illness that were indicative of difficulties in coping (Binger et al.) These behaviors intensified after death of the sibling. A series of 2-3 hour long interviews with the siblings' parents revealed that the siblings developed headaches, poor school performance, severe separation anxiety, and feelings of rejection, fear, and guilt. Binger et al. studied the emotional effect of child cancer on the sibling from the perspective of the parent *and* sibling. These three studies were paramount for turning the attention towards the well-being of the sibling of the patient, but they have limited applicability due to small sample size, weak research design, and major emphasis on *after* death responses (Murray, 1999). Nonetheless, they paved the way for future studies illuminating the importance of emotional well-being of siblings of children with cancer.

Based on findings from three initial studies, researchers began to examine the psychological impact of having a brother or sister with cancer during the illness—not just after they had passed. One of the first of these studies was performed by Cairns, Clark, Smith, and Lasky (1979), who took a new approach by looking at the emotional state of siblings during the illness. With a population of 71 siblings, researchers used instruments such as the Piers-Harris Children's Self-Concept Scale to assess the children's perception of themselves. Results revealed that these siblings had significant anxiety, long bouts of depression and feelings of social isolation. In 1981, Spinetta conducted a three year longitudinal study of families with a child diagnosed with cancer, including 102 siblings—the largest sample size for a sibling study at the time. Her main focus was to study siblings in the context of the family dynamics. Her results showed that siblings' emotional needs were met at a significantly lower level than those of other family members. Spinetta concluded that sibling adjustment needed to be addressed by professional caregivers (1981). Other studies continued to illuminate some of the negative consequences including: difficulties in relationships (especially with peers), emotional stress, sense of emotional deprivation, anger and guilt, altered peer relationships, and fear of death (Havermans & Eiser 1994; Iles, 1979; Kramer, 1981; Walker 1988). As research on this subject continued to grow, we understood more about effects that childhood cancer had on the siblings of the patient. Like the cancer patients themselves, the not all of the effects contributed to emotional deficits—there were some positive effects, as well.

In addition to the negative consequences of having a brother or sister with cancer, several studies found positive effects. In a 1981 exploratory qualitative study, eleven siblings of children with cancer ages 7 to 11 years were interviewed (Kramer). In addition to finding negative consequences from having a brother or sister with cancer, Kramer also found that the siblings

revealed increased empathy and sensitivity towards the patient and others, enhanced personal maturation, and an increased appreciation for life (Kramer, 1981). Kramer also found that, like the childhood cancer patients themselves, the siblings also wanted to be in the loop in regards to the nature of their sibling's sickness (1981). Another study interviewed siblings aged 7 to 12 years and facilitated discussion with open-ended questions in regards to perception of themselves, family life, and the ill sibling during the experience. Positive responses included increased empathy for parents, respect for the ill child, and improved self-concept (Iles, 1979). A 1994 study revealed that siblings who reported positive effects as a consequence of the illness (increased empathy towards other and/or valued life more) also reported their interpersonal relationships to be more negatively affected (i.e., there were greater difficulties in relationships with others, especially parents; Havermans & Eiser). The data suggested that siblings should have more opportunities for open communication about the disease, especially worries about death.

The data from siblings research suggests that childhood cancer has a significant effect on the emotional well-being of the patient, as well as the siblings. We see that in both siblings and patients, there seem to be positive and negative outcomes derived from the experience. We can conclude that childhood cancer has a tremendous emotional impact on both siblings and patients, as these kids endure an experience that most kids their age know nothing about. That being said, we raise the question: how can we minimize the negative emotional effects of childhood cancer on the patient and sibling and increase the positive effects? Various programs have surfaced over the years to attempt to alleviate the emotional distress caused by the childhood cancer experience. One of the most effective means of intervention is summer camp.

Part III. Summer Camps for Children with Cancer and their Siblings

Summer camps for children with cancer began to emerge in the mid-1970s, not-so-coincidentally around the time that pediatric psycho-oncology research really started to emerge. People around the world began to understand the importance implementing programs to treat the emotional needs of children who have experienced cancer. During the 1970s and '80s, more than 60 camps were established in the US specifically for pediatric cancer patients. Camps continued to sprout around the country and camper attendance increased. Today, there are 92 camps that are part of Children's Oncology Camping Association (COCA-I) and they estimate that more than 38,000 children attended these camps in 2015 (Children's Oncology Camping Association, 2016). Research into these types of camps began in the early 1980s, but most of the studies had qualitative designs. More quantitative research came about in the early 1990s, and has increased since then. Even today, research on oncology summer camps has resorted to older methods of data collection, which can be costly and logistically detrimental. This study aims to implement an online model of data collection, a design that has yet to be explored in research on oncology summer camps. More specific information about previous research on oncology summer camps is present in the following manuscript of my research.

HISTORY OF OKIZU

Okizu (oak-eye-zoo) comes from the Sioux language and means unity, to come together, to heal from hurt, to make whole. Their mission is to provide peer support, respite, mentoring, and recreational programs to meet the needs of all members of the family affected by childhood cancer. They recognize that children who are diagnosed with cancer miss out on a normal childhood, as illness, treatment, and complications can keep them from enjoying activities that are

often taken for granted. Okizu started with the belief that a residential camp can be an ideal setting for children struggling with cancer to explore and enjoy a normal life experience, while interacting with others who truly understand their illness.

They learned that all family members, including the ill child, parents, and siblings are uniquely emotionally impacted by the childhood cancer experience. Interactions with true peers and the sense of community that comes with the residential camping experience provide much-needed emotional and practical support for enduring the cancer journey, while allowing a break from the daily routine to have a great time.

Camp Okizu was founded 35 years ago; two of the founders John Bell and Dr. Michael Amylon, are still directly involved in Okizu's programs today. I had a chance to speak with John Bell about how things got started for Okizu, and how they got to where they are today. He got the idea to start a camp for children with cancer when a close friend of his passed away from the disease. Shortly after, he saw a TV ad about some hospitals in New York State taking the kids in the oncology ward up to the mountains for recreation. He said, "Hey, that sounds like a good idea." Not long after he met up with Dr. Mike and found out he had a similar idea. They teamed up with individuals from University of California San Francisco Hospital (UCSF) and got the ball rolling on starting a summer camp for cancer kids (J. Bell, personal communication, March 6, 2016).

1982 was the first summer of Camp Okizu, with only 28 kids attending. They borrowed space and staff from a Campfire Girls Camp in Grass Valley, CA. While the first few summers were a blast for everyone involved, they quickly learned that they needed to hire their own staff to accommodate the specific needs of kids with cancer (restricted diets, medical personnel at the ready, etc.)—the Campfire Girls' staff was not trained in this area. After three years they ended up renting the space from the Campfire Girls and began to hire their own staff. Recruitment was

difficult at first, as counselors were hired as volunteers, but they managed to pull through.

Amazingly, a few of the volunteers from those early days still attend camp today. In 1985, Okizu recognized the emotional needs of the siblings and created a summer camp programs geared towards the siblings. At the time, they were one of two camps in the United States to do so. In addition, Camp Okizu is the longest running oncology summer camp in America (J. Bell, personal communication, March 6, 2106).

Camp Okizu is lucky to offer programs that many camps across the country do not yet have funding/resources for yet. One of these is their SIBS program, which allows *all* siblings of the patients to attend camp, whereas many oncology camps only allow for one sibling or none at all. Also, these siblings can attend camp even after their brother or sister has passed away—once you are part of the Okizu family, you are in for life. Okizu prides themselves in having never turned a child away, some of this is made possible by offering all of the programs completely free of cost. Bell has a simple motto, “Never turn anybody away; never charge a dime.”

Camp Okizu has increased funding and resources since starting out 35 years ago, which has allowed them to expand their program. In addition to three week-long sessions of camp for oncology patients (ages 6-17), they have four week-long sessions for the patients’ siblings. They also have 9 family camp weekends, 2 weekends for teens who have lost their brother or sister to cancer, and several TNT (Teens and Twenties) weekends—where campers who have exceeded the age limit (17 years) for camp can get together and relive their camp experience.

DESCRIPTION OF OKIZU’S PROGAMS

All summer camp activities are designed to fulfill their mission statement. Surprisingly, the summer camp program for oncology patients and siblings is not much different. On Monday, the

kids arrive, meet their cabin mates, their counselors, and settle into their cabin they will be staying in for the next week. They are then prepared for a whirlwind of fun activities. Some of the activities include, but are not limited to: swimming, boating, archery, capture the flag, night hikes, yoga, themed meals (i.e., Baseball Lunch, Texas BBQ Dinner, etc.), dancing, and most of all—singing dozens of camp songs throughout the week.

Amongst all the fun and laughter, these kids are building relationships with their peers and sharing their experiences with other kids who truly know what it feels like. During siblings camp, campers meet one time throughout the week for a facilitated discussion, led by a social worker. Oncology patients do not have this discussion, as most of them have many opportunities for this in the hospital setting. On Saturday morning, the day before the campers leave, the whole camp gathers for Inspiration—a time when campers are invited to share whatever they would like in front of the whole camp. From personal experience, this is a truly powerful moment. All of the activities at Okizu create a space for joyous moments, bonding experiences, and overall healing. The magic of Okizu inspired me to do a research project on how the camp can affect the self-esteem of its campers.

**Part IV. The Effects of Summer Camp on the Self-Esteem of Children with Cancer and their
Siblings**

Jack McGrane

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ABSTRACT

This research was conducted at a summer camp for children with cancer (ONC) and their siblings (SIBS). The Rosenberg self-esteem measure was used to assess the self-esteem of 36 campers (20 oncology, 16 siblings; ages 12-17). Data was collected before camp, on the last day of camp, and 1-3 months after camp. From pre-camp to 1-3 months post camp, statistically significant increases in self-esteem were found in a sample of combined SIBS and ONC participants. These findings suggest the value of summer camp in the emotional well-being for families affected by childhood cancer.

INTRODUCTION

Approximately 10,700 children are diagnosed with cancer each year in the United States; however, advances in medical treatment have enabled us to better treat these children (National Cancer Institute, 2010). The 5-year survival rates for children diagnosed with cancer have increased from 28% in the 1960s to over 80% today (National Cancer Institute, 2010; Ries, Harras, Edwards, & Blot 1996; Ries, et al., 1999). While we are better able to treat patients' physical needs, numerous studies show that the experience of childhood cancer can have significant emotional and psychosocial effects on the patient (Packman 2004; Packman, 2005; Silberman, Fochtman, et al. 1985; Swensen, 1988). Research also shows that, in addition to the emotional impacts on the patient, childhood cancer affects the emotional well-being of the whole family, particularly the siblings of the patient (Binger et al., 1969; Cairns, Clark, Smith, and Lasky, 1979; Murray, 1999; Spinetta, 1981). In response to this issue, organizations such as Camp Okizu in Berry Creek, CA, aim to provide peer support, mentoring, and respite to all members of the patient's family through a summer camping experience (Camp Okizu, 2015).

Though most children with cancer will not experience lasting adjustment problems, studies suggest that more specific areas of psychological function may be affected (Eiser, Hill, & Vance, 2000). Some of these include: impaired or decreased social relationships (Boman & Bodegard, 1995; Mackie, Hill & Kiomdryn, 2000; Mulhern et al., 1989); employment difficulties (Hays et al., 1997); academic achievement (Fritz et al., 1988; Haupt et al., 1992; Hays et al., 1997); and self-concept, self-esteem, or identity (Greenberg et al., 1989; Koocher & O'Malley, 1981; Madan-Swain et al., 2000; Patenaude & Kupst, 2005). It has also been shown that moderate to severe posttraumatic stress symptoms are present in 5-20% of survivors (Erickson & Steiner, 2001;

Kazak et al., 2001). It is understood that cancer has an emotional impact on children with cancer, but research also suggests it has an effect on their siblings.

Much of the psycho-oncology research focuses on the emotional well-being of the patient; however there is a significant amount of research that suggests the experience can have a detrimental effect on the patients' siblings, as well. Some of the negative consequences found in siblings of cancer patients include: difficulties in relationships (especially with peers), emotional stress, sense of emotional deprivation, anger and guilt, and feelings of isolation and neglect (Havermans & Eiser 1994; Iles, 1979; Kramer, 1981; Packman et al., 2004; Spinetta, 1981; Walker 1988). These emotions and difficulties often translated into lower self-esteem for t (Packman et al., 2004, Packman et al., 2005). Taking this research into account, it becomes clear that the experience of childhood cancer not only affects the patient, but it has a significant emotional impact on the whole family, particularly the siblings.

In response to this phenomenon, summer camp programs were initiated to help alleviate some of the emotional and psychosocial issues surrounding childhood cancer. These types of programs have provided services to cancer patients and their families since the late-1970s, but the research on its potential psychosocial and emotional benefits is relatively scarce during that time. In the 1980s research began to surface about the ways in which a summer camp program can be used to meet the many social needs of children with cancer (Silberman, Fochtman, et al. 1985; Swensen 1988). Increased attention was called to the well-being of siblings of cancer patients, after studies began to demonstrate that the siblings were also at psychological risk (Sahler & Carpenter, 1989; Sahler et al., 1994). More current research has focused on the effect that summer camp has on specific facets of emotional and psychosocial well-being for the cancer patient and their siblings, such as Post-Traumatic Stress Disorder (PTSD), anxiety level, health related quality

of life (HRQOL), and self-esteem. These findings provide evidence for effective camp programming via reduced levels of PTSD and anxiety, and improvements in HRQOL and Self-esteem in siblings of cancer patients (Packman, et al., 2004; Packman et al., 2005).

While research exists that attempts measures aspects of emotional well-being of the cancer patient and their siblings in relation to summer camps, very few studies have implemented a control group, or use of a pre- and post- camp model. In one of these few studies, Packman, et al. used a pre- and post- model (2-4 weeks before camp and 3 months after camp) to demonstrate a significant reduction in levels of PTSD and anxiety, and a significant increase in HRQOL and self-esteem in siblings of cancer patients (2004 & 2005). There is also a need to conduct a longitudinal study of the psychosocial effects of summer camp for children with cancer and their siblings, to see how the possible benefits of camp change over time. To date, only one known study has included a follow-up measure in addition the pre/post model. Researchers at UCLA School of Medicine measured emotional well-being of children with cancer and their siblings before camp, directly after, and 4-6 months after (Wellisch et al., 2006). This study aims to use a similar timeline of survey administration.

To date, no known studies have used an online battery to measure the effects of summer camp on emotional well-being of the pediatric cancer patient or their siblings. One reason for this might be lack of access to an online survey platform. In 2004, when other pre and post models were used to study the effects of summer camp, many of the simple survey platforms did not exist (Packman et al., 2004). Today, websites such as Qualtrics allow researchers to easily design a survey, post it to the site, and allow participants to complete and submit it. Data is kept securely in a personal account which can only be accessed by the researchers (Scott, 2012).

This method of data collection has the potential to be logistically and financially favorable. In previous studies, to get a measure of a test before camp, researchers would drive out to the patient's homes, administer the tests, and then leave. Each participant required gas money and a total of a few hours of work (Packman, 2004). In the proposed model, parents of campers would receive an email with a link to a consent form and the survey. Therefore, the participants still complete it in their own home, without the need to physically drive there.

This experiment aims to implement a longitudinal model to study the effects of summer camp on the perceived self-esteem of children with cancer and their siblings. We are measuring participants' score on the Rosenberg Self-Esteem Scale (RSE), a ten-item survey that measures level of self-esteem (Appendix C; Rosenberg, 1965). One independent variable in this study is time of administration, in which there are three levels—pre-camp test, immediate post-camp test, and one-three months post-camp test (follow-up). A second independent variable is *subject type*—participants will be either patients or siblings. As previously stated, there is evidence for the increase in self-esteem for the sibling after attending camp, however, less is known about the effect on the cancer patient (Packman, et al., 2004; Packman et al., 2005;). This study will analyze the effect that one week of summer camp at Camp Okizu has on the level of perceived self-esteem in both groups: sibling and oncology patient.

Description of Camp Okizu's Program

During the summer, Camp Okizu runs seven individual, week-long camps sessions starting the beginning of June and ending late July. Three of the seven camp sessions are devoted to patients—this includes any children ages 6-17 that are currently battling cancer, or have in the past and are now in remission. The other four summer camp sessions are for the SIBS (**S**pecial and **I**mportant **B**rothers and **S**isters). SIBS are campers that have a brother or sister that is currently

battling cancer, has battled cancer in the past, or has lost their life to cancer. Camp Okizu welcomes SIBS campers back to camp even if they are *bereaved*— if their sibling has passed away.

Camp Okizu seeks to provide peer support, respite, mentoring, and recreational programs to meet the needs of all members of families affected by childhood cancer. Campers can develop skills in activities such as boating, swimming, archery, arts & crafts, and team-building exercises at the ropes course. The programs for SIBS and ONC camp are nearly identical. On the third day of SIBS camp session, campers meet for a facilitated discussion of their family situations, and to share tips on coping (Packman, et al., 2005). Siblings also have the opportunity to attend a bereaved discussion group.

I predict there will be a main effect of summer camp on self-esteem, in that all children (siblings and campers) will, on average, report a higher level of self-esteem after camp has ended. I also predict a main effect of status of participant, in that the siblings will report a lower overall self-esteem, compared to the patients. I predict that participants will report a higher overall level of self-esteem 1-3 months after camp, compared to before camp.

METHODS

A. Design

This was a mixed-subjects study with a 3 x 2 factorial design. The first independent variable (IV1) in the study was time of survey administration, in which there were three levels: pre-camp, post-camp, and follow-up (1-3 months after camp). The second independent variable (IV2) was participant type, in which there were two levels: sibling and patient. The dependent variable measured was the perceived level of self-esteem of the participants through the

Rosenberg Self-Esteem Scale (RSE). The following descriptive statistics were collected: age of participant, gender, and years they have been coming to camp.

For statistical analyses, I computed descriptive statistics and a 3 x 2 design ANOVA in SPSS using Repeated Measures analysis. Fisher's LSD was used for post-hoc pairwise comparisons.

B. Participants

Participants were recruited according to the following data: The child was enrolled in Camp Okizu as either a SIBS or ONC camper for one of the 1-week sessions in 2015; participants were between the ages of 12 and 17 years, and spoke English.

The study was approved by the Regis University Institutional Review Board. Informed written parental consent and assent were obtained (Appendix A, D). The study instruments were administered through written and online platforms. Online measures were administered 1-6 weeks before camp (pre-camp) and 1-3 months after camp ended (follow-up). Written measures were administered to each participant on the last day of camp (post-camp).

Pre-camp participants included 36 campers (ONC= 20; SIBS= 16). Of the 36 that took the pre-camp measure, 24 completed the written post-camp measure. Of the 24 participants that completed the post-camp measure, 9 completed the follow-up. Thus, a total of 9 participants completed measures at all three time points. The 12 participants with missing data from pre-camp to post-camp were lost for the following reasons: did not attend camp, were not administered post-camp surveys at camp, or failed to write name on survey. The 15 participants with missing data from post-camp to follow-up were lost because they did not respond to the email reminder. Two email reminders were sent to the families of the 24 participants who completed pre-camp and post-camp measures, but 15 of them did not respond in the allotted time.

C. Materials

Rosenberg Self-Esteem Scale (RSE). The Rosenberg Self-Esteem Scale measured perceived level of self-worth and confidence in participants. The survey contains 10 items (or statements) and the participant was asked to report the extent to which they agree or disagree with the statement (See Appendix A) (Rosenberg, 1965). This survey was administered to patients 12 and older, as the complexity of the wording may be beyond comprehension for younger children (Packman 2004 & 2005). Convergent validity of the RSE with three other known self-esteem measures were reported to be .67, .83, and .56. Also, it shows good internal consistency, with a Guttman scale coefficient of reproducibility of .92 (Packman, 2004 & Rosenberg, 1965).

D. Procedure

Parental consent letters were emailed out to the families of the children attending camp May 28th, just over a week before the start of the first session of camp and over a month before the start of the last camp session. Multiple email reminders were sent out about the study.

Parents that read the email letter that gave background information on the study and why I chose to research the specific topic had the opportunity to click a link that directed them to the parental consent form. They read the specific methodology of the study and decided from there whether or not they wanted their child to participate. If they chose to allow their child to participate, they (electronically) signed the form, put their child's name at the bottom, and hit 'submit'. From there, they were emailed another link to the actual survey. This was so they had the option to have their child take it at a time later time.

When the time came for the child to take the survey, they clicked on the link and it directed them to the first page of the survey—the page of assent (Appendix B). At this point, both the parent and child were given instructions to encourage parents to allow their child to independently complete the survey. Parents read this in the consent form and participants read it on the page of assent. The parent was also assured that the online measure, the RSE, is a standard survey for measuring self-esteem that has been used for many years. In other words, I assured them it did not contain any inappropriate or unusual words. Finishing the pre-camp survey represented completion of the first part of the experiment and their next step was to spend a week at Camp Okizu.

After a week of fun in the sun, the participants completed the same measure to observe the effect that summer camp had on the child's self-esteem. The entire camp (ages 12 and up) completed the survey—it was attached (on a separate page) to the back of the usual post-camp satisfaction survey. However, only data from those who completed the pre-camp measure was used—the rest was shredded. Each camper filled out their name at the top of the survey to identify their data from the pre-test measure. This written data was de-identified and remained under lock and key in an office at camp.

The final session of camp ended on 8/2/2015. One month after this, (9/2/2015), emails were sent out to the parents of participants who completed the pre- and post- camp measure, asking them to complete the survey a final time. We then had data from pre-camp, immediate post-camp, and 1-3 months post-camp.

RESULTS

Analyses of SIBS + ONC Campers Combined

Analyses For total RSE score across all 36 participants (SIBS + ONC) pre-camp, the mean score was 22.72 (SD = 4.91). Of the 24 campers who completed the post-camp survey, the mean score was 23.71 (SD = 5.65). Of the 9 subjects who took the follow up test, the mean score was 26.78 (SD = 3.27). Using the nine subjects who completed the measure at all three time points (SIBS and ONC campers), there was an overall increase in self-esteem from start to finish (Figure 1). Using analysis of repeated measures ANOVA, correcting for sphericity, there was significant difference in means $F(2, 16) = 4.825, p = .023$. Post-hoc pairwise comparisons, using Fisher's LSD, showed a significant increase in self-esteem from pre-camp to follow-up with a large effect size ($p = .03, d = .91$). Differences in the other times points increased, but did not reach significance (pre-camp to post-camp: $p = .11, d = .18$; post-camp to follow-up: $p = .12, d = .66$).

Self-Esteem of ONC Campers Only

For total RSE score of ONC campers only ($N = 20$) the mean pre-camp score was 22.10 (SD = 5.57). The mean RSE score for participants who completed the post-test ($N = 15$) was 23.60 (SD = 6.15). Of the seven ONC campers who completed the follow-up measure, the mean score was 26.29 (SD = 3.59). Using these seven ONC campers who completed all three measures, a Greenhouse-Geisser analysis of repeated measures ANOVA showed a trend towards a difference, but did not reach significance ($p = .084$). Using means and standard deviations from pre-camp to post-camp ($N = 7$), we observe a medium effect size ($d = .72$). Post-camp to follow-up revealed a small effect size ($d = .24$). Pre-camp to follow-up reveals a large effect size ($d = .87$).

Self-Esteem of SIBS Campers Only

Since only two of the total SIBS campers completed surveys at all three time points, we decided not to run analyses on SIBS campers only.

SIBS vs ONC Campers

We compared the means of pre-camp scores of ONC (N = 20) campers versus SIBS (N = 16). The mean pre-camp self-esteem score for ONC campers was 22.1 (SD = 5.57) and the mean score for SIBS campers was 23.50 (SD = 3.98). An independent samples t-test revealed there was no significant difference in scores between these samples ($p = .386$).

Analysis of Returning Campers

We examined whether the pre-camp measure of self-esteem was related to the number of times the child (ONC or SIB) attended camp. We correlated pre-camp scores with number of years coming to camp of all 36 participants. We found that there was no gradient in the self-esteem scores for how many times the child had gone to camp.

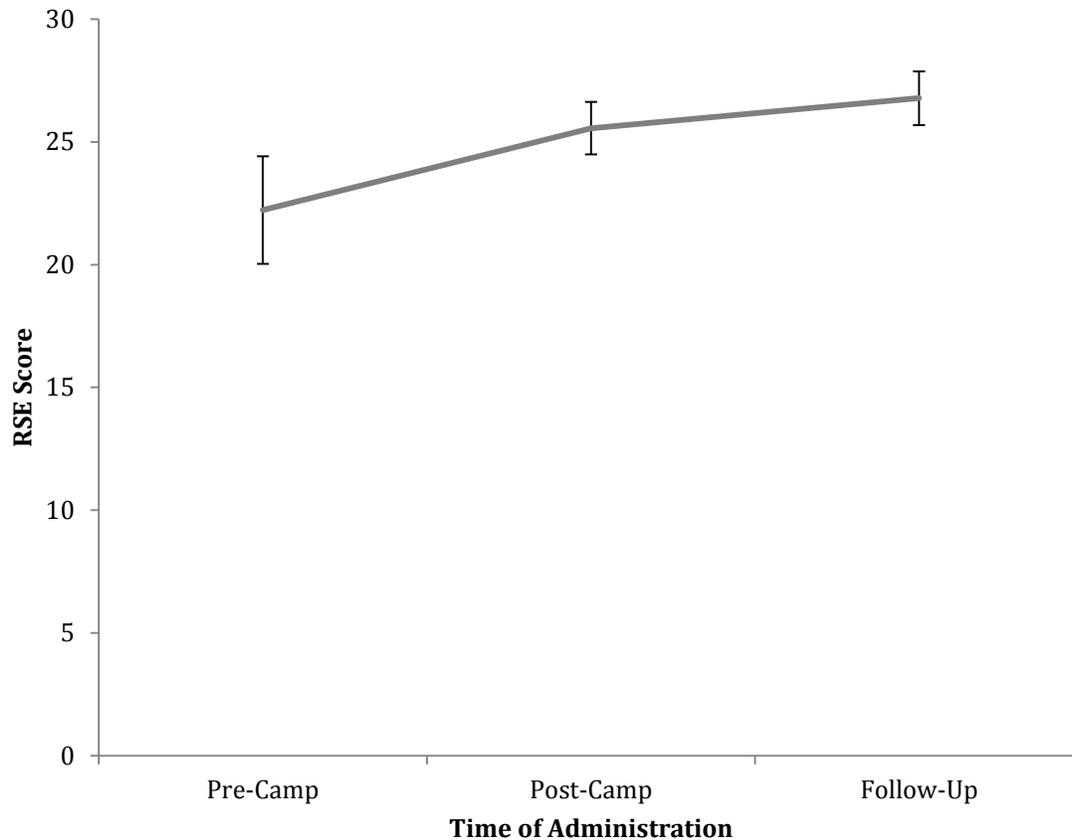


Figure 1. RSE Score in a combined population of SIBS and ONC participants at administration times pre-camp, post-camp, and follow-up. Error bars represent standard errors.

DISCUSSION

Prior to this study, empirical investigations into the psychosocial effects of summer camp for children with cancer and their siblings have been limited to a standard pre/post model of testing. This study is one of the first of its kind to implement a follow-up phase of testing in addition to the pre/post model. In the combined sample of cancer patients and their siblings, statistically significant differences in scores of self-esteem emerged from before camp to the follow-up phase, 1-3 months after camp. These findings are consistent with research of positive

psychological changes in self-esteem before and after a week at Camp Okizu in siblings of cancer patients (Packman et al., 2005).

This study is also the first of its kind to implement an online method of survey administration. There is no evidence of previous psycho-oncology studies relating to summer camps that used online battery. One purpose of this study was to examine the efficacy of such a method. One immediate benefit of the online survey administration was that it was financial favorable to previous studies. In previous studies of this nature, researchers would have to drive to each participant's home, resulting in high travel cost and a large amount of time spent for a single survey. This suggests that with the online method, less time and money is spent per data point.

We had hoped that the online survey would allow for a larger sample size, we did not receive as many participants as we had hoped. We had planned for a minimum of 50 participants, but received 36. One reason for this is that we were short on time for getting the surveys out, as we received IRB approval just a couple weeks before the start of the first camp session. Many parents were very willing to help, but by the time they reached out to us, it was too late for their son/daughter to participate in the study (they had either gone to camp already or they were currently in session). For future studies, if we had 2-3 months to inform parents of the upcoming study via phone and email, we believe sample size would have been much greater. Our retaining rate of participants was also low. Of the 36 participants who completed the pre-camp survey, only 9 had gone on to complete all three time points.

While the online method proved financially and logistically favorable, it is important to note its limitations. To start, there was no researcher present to administer the test, so there is no *absolute* guarantee that the person taking the test was the actual camper. Also, it is possible that

having a parent present while the participant completes the survey would influence their answers. And although we presented parents with instructions to allow their child to take the survey independently, we cannot know for certain that they were not in the room at the time of survey administration. We must also note that the pre-test was online, while the post-camp survey administered on the last day of camp was written. There may be differences in results for an online versus writing testing platform.

Our study design called for administration of the same online survey 1-3 months after the child had attended camp. Although it would have significantly strengthened our statistical analyses to implement a “rolling schedule” so the time of administration for post-camp surveys would be consistent, this was not possible due to lack of funding. We recognize the 1-3 months post-camp administration as a limitation to our study.

In summation, the online method shows promise as an effective means to measure emotional and psychosocial facets of children with cancer and their siblings in a summer camp setting. It shows to be financially and logistically favorable to previous methods of psychological measuring for oncology camps. Also, it has the potential to attract a large population of participants, if ample time is permitted to reach out to the families for consent.

Part V. The Role of Evidence-Based Research in Boyle's Model of Success

The research of this thesis project attempts to show how attending a summer camp can influence the self-esteem of children with cancer and their siblings. In the non-profit world, this research is referred to as evidenced-based research. From the data obtained in the study, we found evidence that camp works to boost self-esteem in some areas, whereas in other areas it seemed not to have a significant effect. In light of the mixed results, I am left with the question: Was this research *successful*? This is a loaded question and largely depends on your individual definition of success. In this final section, we will explore the idea of success in evidence-based research, while drawing from the text of Boyle's *Tattoos on the Heart*. I found that my thesis research, along with other evidence-based research, holds little value from the view of Boyle's model of success. However, judging that Boyle funded an evidence-based research project for his own non-profit, we reason that he must place significant value in the benefits of this research, though it may not be compatible with his definition of success in the text.

Everyone has their own way of judging the success of their actions—that is, asking yourself the question: was I successful/unsuccessful at this? We often do this without realizing. For example, when Regis College Student "X" gets her biology exam back and finds out she received a C-, she may be utterly distraught, as she received A's on her last three exams. On the other hand, Regis College Student "Y" is ecstatic over his C- grade because he had gotten D's on all of his previous exams. Many of us set standards for the outcomes of our life-pursuits, whether it is in the form of test grades, job salary, or followers on our social media page. Whether this philosophy of *outcome-based-success-evaluation* (OBSE) is innate, born from cultural influences, or some combination of both, it seems that most all of us embody this perspective at some point in our

lives. While I am guilty of basing my success on the outcomes of my actions, I argue that this philosophy is problematic, because it is a never-ending chase for ultimate success. Unless you have gotten 100% on every assignment in your college career or have as many Twitter followers as there are humans on this planet, OBSE will leave you always asking for more. We see the limitations of OBSE when we apply it to Father Boyle's work with gang members in Los Angeles.

Boyle has devoted his life to working with gang members, offering them help in forms of employment, spirituality and even tattoo removal to allow them a chance to be peaceful and contributing members of society. Each year, more than 10,000 former gang members ("homies") enter Boyle's program, called Homeboy Industries, hoping to make a positive change in their lives. Homeboy Industries employs over 250 homies every year—these individuals have substituted drug-dealing and gang-banging for embroidery and pastry-making (Boyle, 2010). While Homeboy Industries has allowed for thousands of homies to get off the streets, not all of them turn out to be "success-stories." Boyle has personally attended the funerals of over 168 homies, who were murdered as a result of gang-involvement. In addition to those who were killed, an even greater number of homies have tried Boyle's programs, only to revert back to the gang lifestyle (Boyle, 2010). It is clear that Boyle's programs have helped many gang members, but can we truly say that Boyle is successful in his pursuits when so many homies have either died or returned to the gang-banging lifestyle?

The conceptualization of success becomes cloudy and subjective when we define it in terms of numbers in outcomes. The exact ratio of "success stories" compared to those who have succumbed to the perils of gang life in Boyle's program is unknown, but we can explore several possibilities. If the number of homies that have gone through Homeboy Industries and escaped

gang life exceeds the amount of those who have fallen victim to its tragedies, is Boyle *successful* or not? If so what is the exact ratio that would deem his programs successful? 2 to 1? 5 to 1? On the contrary, if the number of homies who have fallen victim to the tragedies of gang life exceeds the “success stories”, could we consider Boyle successful in his pursuits? The determination of Boyle’s success will inevitably vary from person to person because if you conceptualize success in terms of the outcome, there is no end to how successful you can be. That is, you may never be satisfied with your level of success. If we do not place our success on outcomes, how else can we measure success?

It is possible to measure success in a way that is independent of the outcomes of your actions. Father Gregory Boyle offers his own definition—success, lies not in outcomes, but in the fidelity of your actions. Success is measured by *where* you stand and how much you are willing to fight to stay there (Boyle, 2010). Boyle argues right conduct is not the means to some expected outcome, but it is the end in itself. He discusses success in terms of the life of Jesus. Jesus stood with the outcasts—those who were marginalized by the rest of the world. However, he was not a self-proclaimed leader of a political or social revolution. At the time Jesus was living, one side hated that he associated himself with the unclean—the folks you neither touch nor be near. The other side was annoyed with his “brand” of solidarity—they wanted to see the ten-point plan and the works to overthrow the sinful social structure. They wanted to see Him taking the right stand on issues, not just standing in the right place (Boyle, 2010). However, Jesus simply stood faithfully with the outcasts. Boyle summarizes his views of success with this excerpt from the text, “All Jesus asks is, ‘*Where are you standing?*’ And after chilling defeat and soul-numbing failure, He asks again, ‘*Are you still standing there* (Boyle, 173)?” Boyle does not measure his success or failure in terms of how many gang-members he has transformed, or how many have slipped away. Using his own

definition of success, Boyle is successful because he stands with those who are marginalized and continues to stand strong even after things seem not to succeed. Using the ideas from the text, I will explore how the focus of my thesis interacts with Boyle's view of success.

Before examining my thesis through the lens of Boyle's view of success, I will first explain the reasoning behind the research study I conducted and why I thought it to have beneficial implications. The summer camp I researched in this study is Camp Okizu, a place I have been attending since I was six years old. I realized how much of a positive impact it had on how I dealt with losing my brother to cancer and I wanted to somehow convey to others how important the camp is, not only to me, but to the thousands of others who have passed through its gates. I figured it would be fitting to combine my background in psychology research with my love for Okizu—this led to a research study on the effects of Okizu on the self-esteem of its campers.

After attending a Children's Oncology Camping Association (COCA-I) conference in the Fall of 2014, I realized the importance of researching the emotional effects of summer camp on the campers. One reason camp research is important is to provide empirical evidence of the benefits of camp to reassure donors and parents. Some people will donate to a cause based on what they stand for. Others are pickier and want to make sure the organization they are giving their money to is producing favorable results or outcomes—hence the name—*evidence-based research*. Camp research also benefits parents who are on the fence about whether or not to send their kid away to camp for a week by assuring them of the potential positive effects on the camper. A final reason evidence-based camp research is beneficial is that, by better understanding how camp affects the child, directors can make adjustments to their program to ensure kids get the most out of camp. This is not limited to one camp, but provides information to oncology camps around the world.

Given what I believe to be potential benefits of research on the emotional effects of an oncology summer camp, how might Boyle view the importance my thesis in regards to his idea of success?

Boyle's view of success focuses on right conduct and fidelity, rather than on the outcomes of our actions, so would he place any value on a study that aims to illuminate outcomes via scientific data? Initially it seems that Boyle would place little to no value in a research project such as mine, as a main focus of my study was to search for better outcomes in the campers. Boyle, too, hears what many cancer camp directors hear from donors, "We don't fund efforts; we fund outcomes (179)." He responds to this criticism by arguing that focusing solely on better outcomes will lead us to abandon our work with the marginalized, switching our focus to those who are most likely to succeed (Boyle, 179). Attempting to transform gang members into well-behaved, productive members of society is a difficult task, to say the least. Here, Boyle insists that less favorable results do not stop him from working with those who are marginalized. In 2010 (the same year his book was published), Boyle received a 1.3 million dollar grant from LA county supervisors to help continue their program. According to UCLA Luskin School of Public Affairs, a portion of that grant went to fund the institution's 5-year longitudinal study of the homies of Homeboy Industries (UCLA, 2010). It is clear that Boyle place at least *some* value on evidence-based research, as he spent money to fund his own evidence-based research study. How does this interact with his definition of success in the text, one that places little to no significance on outcomes?

The fact that Boyle invested in evidence-based research indicates that he does place value in identifying successful outcomes. Boyle states, "I'm not opposed to success (in outcomes); I just think we should accept it as a by-product of our fidelity (178)." Again, he asserts that successful

outcomes are not ends in themselves and that, right conduct is of utmost importance. What if successful outcomes act as means to perpetuating fidelity and right conduct? If research showing positive outcomes of an organization can lead to generating more funds from donors, then the positive outcomes hold significance because they contribute to the *continuation* of programs. The ugly truth is that all organizations require money to run their programs, obtain resources, and pay their employees. Using evidence-based research can contribute to continuing the works of Father Boyle or Camp Okizu, which both provide hope and support to suffering populations. To sum it up: evidence-based research can bring in funding, funding allows for continuation of programs, continuing these programs means continuing to stand in the *right place*. Seen in this light, we can understand how evidence based research can indeed fit in with Boyle's model of success.

In *Tattoos on the Heart*, Boyle illuminates a less common perception of success—one that focuses on right action and fidelity, as opposed to outcomes. Initially, it seems that Boyle places little to no emphasis on successful outcomes, but because he funded an evidence-based research project for his organization, we must reason that he does indeed place value in results. That is, we can value positive outcomes, but only if they are a by-product of right action and fidelity. Seen in this light, Boyle would likely not deem the research of this thesis as meaningless or lacking-value, as this study was a by-product of my dedication to a place that is faithful to those who are marginalized by the effects of childhood cancer, being in solidarity with them.

References

- Armstrong, F. D., & Mulhern, R. K. (2000). Acute lymphoblastic leukemia and brain tumors. In R. T. Brown (Ed.), *Cognitive aspects of chronic illness in children* (pp. 47–77). New York: Guilford
- Balen, R., Fielding, D., & Lewis, I. (1996). Activity Camps for Children with Cancer. *Children & Society*, 10(4), 317-323.
- Binger, C. M., Ablin, A. R., Feuerstein, R. C., Kushner, J. H., Zoger, S., & Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on patient and family. *New England Journal of Medicine*, 280, 414–418.
- Bluebond-Langner, M et al. (1991) 'Pediatric cancer patients' peer relationships: the impact of an oncology camp experience'. *Journal of Psychosocial Oncology*, 9(2) 67
- Boman, K., & Bodegard G. (2000). Long-term coping in childhood cancer survivors: influence of illness, treatment and demographic background factors. *Acta Paediatr.*, 89, 105–111.
- Boman, K., & Bodegard, G. (1995). Psychological long-term coping with experiences of disease and treatment in childhood cancer survivors. *Acta Paediatrica*, 84, 1395–1402.
- Boyle, G. (2010). *Tattoos on the heart: The power of boundless compassion*. New York, NY: Free Press.
- Cain, A., Fast, I., & Erickson, M. (1964). Children's disturbed reactions to the death of a sibling. *American Journal of Orthopsychiatry*, 34, 741-752.
- Cairns, N., Clark, G., Smith, S., & Lansky, S. (1979). Adaptation of siblings to childhood malignancy. *Journal of Pediatrics*, 95, 484-487.
- Camp Okizu – About (n.d.). Retrieved March 05, 2016, from <http://okizu.org/about/>

- Cella, D. F., & Tross, S. (1986). Psychological adjustment to survival from Hodgkin's disease. *Journal of Consulting and Clinical Psychology*, 54, 616–622.
- Children's Oncology Camping Association, Intl – About COCA-I (n.d.). Retrieved March 05, 2016, from <http://www.cocai.org/index.php/about-cocai>
- Chodoff, R., Friedman, S. B., & Hamburg, D. A. (1964). Stress, defenses, and coping behavior: Observations in parents of children with malignant disease. *American Journal of Psychiatry*, 120, 743–749.
- Cobb, B. (1956). Psychological impact of long illness and death of a child on the family circle. *Journal of Pediatrics*, 49, 746-751.
- DeVita, V. & Chu, E. (2008). A History of Cancer Chemotherapy. *Cancer Res.* 68, 8643-8652.
doi:10.1093/jpepsy/jsi012
doi:10.1093/jpepsy/jsi012
- Eiser, C., Cool, P., Grimer, R., Carter, S., Cotter, I., Ellis, A., et al. (1997). Quality of life in skeletally immature children following treatment for a malignant primary bone tumor around the knee. *Sarcoma*, 1, 39–45.
- Eiser, C., Hill, J. J., & Vance, Y. H. (2000). Examining the psychological consequences of surviving childhood cancer: Systematic review as a research method in pediatric psychology. *Journal of Pediatric Psychology*, 25(6), 449–460
- Erickson, S. J., & Steiner, H. (2001). Trauma and personality correlates in long-term pediatric cancer survivors. *Child Psychiatry and Human Development*, 31(3), 195–213.
- Friedman, D., & Meadows, A. (2002). Late effects of childhood cancer therapy. In E. Vichinsky, M. Waters, & J. Feusner (Eds.), *Pediatric clinics of North America*. Philadelphia: Saunders.

- Fritz, G. K., Williams, J. R., & Amylon, M. (1988). After treatment ends: Psychosocial sequelae in pediatric cancer survivors. *American Journal of Orthopsychiatry*, 58(4), 552-561
- Greenberg, H., Kazak, A. E., & Meadows, A. (1989). Psychological adjustment in 8–16 year old cancer survivors and their parents. *Journal of Pediatrics*, 114, 488–493.
- Haupt, R., Byrne, J., Connelly, R., Mostow, E., Austin, A. D., Holmes, G., et al. (1992). Smoking habits in survivors of childhood and adolescent cancer. *Medical and Pediatric Oncology*, 20, 301–306.
- Havermans, T., & Eiser, C. (1994). Siblings of a child with cancer. *Child: Care, Health & Development*, 5, 309-322.
- Hays, D. M., Dolgin, M., Steele, L. L., Patenaude, A. F., Hewett, K. D., Ruymann, F., et al. (1997). Educational achievement, employment and workplace experience of adult survivors of childhood cancer. *International Journal of Pediatric Hematology/ Oncology*, 4, 327–337.
- Hollenbeck, A. R., Susman, E. J., Nannis, E. D., Strobe, B. E., Hersh, S. P., Levine, A. S., & Pizzo, P. A. (1980). Children with serious illness: Behavioral correlates of separation and isolation. *Child Psychiatry And Human Development*, 11(1), 3-11. doi:10.1007/BF00705865
- Iles, P. (1979). Children with cancer: Healthy siblings' perception during the illness experience. *Cancer Nursing*, 2,371-379.
- Kazak, A., Barakat, L., Alderfer, M., Rourke, M., Meeske, K., Gallagher, P., et al. (2001). Posttraumatic stress in survivors of childhood cancer and mothers. *Journal of Clinical Psychology in Medical Settings*, 8, 307–323.
- Koocher, G. P., & O'Malley, J. E. (Eds.). (1981). *The Damocles syndrome: Psychological consequences of surviving childhood cancer*. New York: McGraw-Hill

- Kupst, M. J., & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. *Journal of Pediatric Psychology*, 13, 7–22.
- Kupst, M. J., Natta, M. B., Richardson, C. C., Schulman, J. L., Lavigne, J. V., & Das, L. (1995). Family coping with pediatric leukemia: Ten years after treatment. *Journal of Pediatric Psychology*, 20, 601–617
- Langeveld, N. E., Stam, H., Grootenhuis, M. A., & Last, B. F. (2002). Quality of life in young adult survivors of childhood cancer. *Supportive Care in Cancer*, 10, 579–600.
- Mackie, E., Hill, J., Kiomdryn, H., & McNally, R. (2000). Adult psychosocial outcomes in long-term survivors of acute lymphoblastic leukemia and Wilms' tumor: A controlled study. *Lancet*, 355, 1310–1314
- Madan-Swain, A., Brown, R. T., Foster, M. A., Vega, R., Byars, K., Rodenberger, W., et al. (2000). Identity in adolescent survivors of childhood cancer. *Journal of Pediatric Psychology*, 25, 105–115.
- Mulhern, R. K. (1994). Neuropsychological late effects. In D. Bearison & R. K. Mulhern (Eds.), *Pediatric psychooncology* (pp. 99–121). New York: Oxford University Press.
- Mulhern, R. K., Wasserman, A. L., Friedman, A. G., & Fairclough, D. (1989). Social competence and behavioral adjustment of children who are long-term survivors of cancer. *Pediatrics*, 83, 18–25.
- Murray, J. (1999). Siblings of Children With Cancer: A Review of the Literature. *Journal of Pediatric Oncology Nursing*, 16(1), 25-34.
- National Cancer Institute. (2010). A snapshot of pediatric cancers. Retrieved from <http://www.cancer.gov/aboutnci/servingpeople/snapshots/pediatric.pdf>

- Natterson, J. M., & Knudson, A. G. (1960). Observations concerning fear of death in fatally ill children and their mothers. *Psychosomatic Medicine*, 22, 456–465.
- Noll, R. B., MacLean, W. E., Whitt, J. K., Kaleita, T. A., Stehbens, J. A., Waskerwitz, M. J., et al. (1997). Behavioral adjustment and social functioning of long-term survivors of childhood leukemia: Parent and teacher reports. *Journal of Pediatric Psychology*, 22, 827–841.
- Okizu | The mission of Okizu is to provide peer support, respite, mentoring, and recreational programs to meet the needs of all members of families affected by childhood cancer. (n.d.). Retrieved April 3, 2015, from <http://okizu.org/>
- O'Malley, J. E., Koocher, G., Foster, D., & Slavin, L. (1979). Psychiatric sequelae of surviving childhood cancer. *Annual Progress In Child Psychiatry & Child Development*, 543-553.
- Packman W., Fine, J., Chestermn B., et al. (2004). Camp Okizu: preliminary investigation of a psychological intervention for siblings of pediatric cancer patients. *Children's Health Care*, 33: 201-205.
- Packman W., Greenhalgh J., Chesterman, B., et al. (2005). Siblings of pediatric cancer patients: The quantitative and qualitative nature of life. *J Psychosoc Oncol*, 23: 87-108.
- Packman, W., Crittenden, M., Schaffer, E., et al. (1997). Psychosocial consequences of bone marrow transplantation in donor and nondonor siblings. *Journal of Developmental and Behavioral Pediatrics*, 18: 244-253.
- Patenaude, A.F. & Kupst, M.J. (2005). Psychosocial Functioning in Pediatric Cancer. *Journal of Pediatric Psychology*, 30(1), 9-27.
- Ries L.A., Eisner M.P., Kosary C.L., Hankey B.F., Miller B.A., Clegg L., Edwards B.K. (2002). SEER Cancer Statistics Review, 1973-1999. Bethesda, MD: National Cancer Institute.

- Ries L.A., Smith M.A., Gurney J.G., et al. (1999). Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975-1995. *National Cancer Institute, SEER Program*. NIH Pub. No. 99-4649.
- Ries, L. A., HARRAS, A., Edwards, B. K., & Blot, W. J. (1996). Cancer rates and risks (4th ed.). Washington, DC: National Institutes of Health, National Cancer Institute.
- Rosenberg, M. (1965). Society and the adolescent self-image. Princeton, NJ:Princeton University Press.
- Sahler, O. J., & Carpenter, P. J. (1989). Evaluation of a camp program for siblings of children with cancer. *American Journal of Diseases in Children*, 143, 690–696.
- Sahler, O. J., Roghmann, K. J., Mulhern, R. K., Carpenter, P. J., Sargent, J. R., Copeland, D. R., et al. (1994). Sibling adaptation to childhood cancer collaborative study: Prevalence of sibling distress and definition of adaptation levels. *Journal of Developmental and Behavioral Pediatrics*, 15, 353–366.
- Scott, M. (2012). Customer research easier in digital era. *USA Today*. Retrieved April 28, 2015.
- Silber, E., & Tippett, J. (1965). Self-esteem: Clinical assessment and measurement validation. *Psycho-logical Reports*, 16, 1017–1071.
- Silberman, M. A., Fochtman, D, et al. (1985). One step at a time: summer camping for children with cancer. *J Assoc Pediatr Oncol Nurses* 2 (1): 24-30.
- Spinetta, J. (1981). The siblings of the child with cancer. In Spinetta, J. and Spinetta, P. (Eds.), *Living with childhood cancer*. St. Louis: The C.V. Mosby Co.
- Spinetta, J. J. (1974). The dying child's awareness of death. *Psychological Bulletin*, 81, 256–260
- Swensen, T. G. (1988). "A dose of Camp Dost: meeting the psychosocial needs of children with cancer." *Issues Compr Pediatr Nurs* 11(1): 29-32.

- Trask, P. C., Paterson, A. G., Trask, C. L., Bares, C. B., Birt, J., & Maan, C. (2003). Parent and adolescent adjustment to pediatric cancer: Associations with coping, social support, and family function. *Journal of Pediatric Oncology Nursing*, 20(1), 36–47
- UCLA, (2010, September 23). UCLA Partners with Homeboy Industries to Study Program's Effectiveness. Retrieved from: <https://www.youtube.com/watch?v=WSSrIvL-aaA>
- Vannatta, K., Gartstein, M. A., Short, A., & Noll, R. B. (1998). A controlled study of peer relationships of children surviving brain tumors: Teacher, peer, and self-ratings. *Journal of Pediatric Psychology*, 23, 279–287.
- Waechter, E. H. (1968). Death anxiety in children with fatal illness. Unpublished doctoral dissertation, Stanford University, Palo Alto, California
- Walker, C. L. (1988). Stress and coping in siblings and childhood cancer patients. *Nursing Research*, 12, 208- 212.
- Wellisch, D. K., Crater, B., Wiley, F. M., Belin, T. R., & Weinstein, K. (2006). Psychosocial impacts of a camping experience for children with cancer and their siblings. *Psycho-Oncology*, 15(1), 56-65. doi:10.1002/pon.922
- Wylie, R. C. (1974). *The self-concept*. Lincoln: University of Nebraska Press.
- Zebrack, B., & Zeltzer, L. (2002). Quality of life issues and cancer survivorship. Report prepared for the Institute of Medicine. Retrieved September 16, 2004, from <http://www.iom.edu/file.asp?id=15236>

Appendix A:

Name: _____ |

Participant Questionnaire

○ How many years have you been coming to camp? _____

○ How old are you? _____

○ Are you a boy or girl? (Circle one)

Appendix B

Rosenberg Self-Esteem Measure:

Below is a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. On the whole, I am satisfied with myself				
2. At times, I think I am no good at all				
3. I feel that I have a number of good qualities				
4. I am able to do things as well as most other people				
5. I feel that I do not have much to be proud of				
6. I certainly feel useless sometimes				
7. I feel that I'm a person of worth, at least on an equal plane with others.				
8. I wish I could have more respect for myself.				
9. All in all, I am inclined to feel that I am a failure.				
10. I take a positive attitude toward myself.				

