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## Camp for Childhood Cancer Survivors and Their Families: A Program Conceptualization

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**CAMP FOR CHILDHOOD CANCER SURVIVORS AND THEIR FAMILIES: A  
PROGRAM CONCEPTUALIZATION**

**PROFESSIONAL DISSERTATION**

**SUBMITTED TO THE FACULTY**

**OF**

**THE SCHOOL OF PROFESSIONAL PSYCHOLOGY  
WRIGHT STATE UNIVERSITY**

**BY**

**CAPRICE S. PARKINSON, M.A.**

**IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE  
OF  
DOCTOR OF PSYCHOLOGY**

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July 13, 2012

I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY **CAPRICE S. PARKINSON** ENTITLED **CAMP FOR CHILDHOOD CANCER SURVIVORS AND THEIR FAMILIES: A PROGRAM CONCEPTUALIZATION** BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

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Martyn Whittingham, Ph.D.  
Dissertation Director

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## **Abstract**

The intent of this program conceptualization is to create a theory-driven residential camp program for child cancer survivors and their families. Although the majority of families appear to adjust to the stressors of the cancer experience, it has been identified that there is a significant portion of the cancer population and their families that are experiencing psychosocial issues and are in need of support (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Levin Newby, Brown, Pawletko, Gold, & Whitt, 2000; Zeltzer et al., 2009). Some typical symptoms noted in this group of pediatric cancer patients and families are depression/anxiety; decreased sense of social support; decreased feelings of self-efficacy and ability to cope; and post-traumatic stress symptoms (Kazak & Christakis, 1996; Shultz et al., 2007). This camp will be grounded in the Adolescent Resilience Model (Haase, 2004), a growth-oriented intervention program that focuses on strength-based factors that promote positive individual and family recovery. Outcome measures will be administered to participants in order to determine the camp's efficacy in future research.

## **Dedication**

This is dedicated to my mother, Carolyn Stearns Parkinson, a 25 year cancer survivor; and my father, David William Parkinson, who lost his battle with cancer in 1997. You made me who I am. Thank you.

## **Acknowledgements**

I would like to thank my friends, family and colleagues for their support and encouragement throughout the dissertation process. In particular, I thank my future husband for the late night encouragement and fresh coffee early in the morning. I wouldn't have made it without you.

My dissertation chair, Dr. Martyn Whittingham, challenged me to learn more about a population I am passionate about and helped create a product that I can use in the future to support these amazing families. He also cheered me on when I was overwhelmed and provided direction when I was lost.

I want to acknowledge the families throughout the world who are championing the diagnosis and treatment of cancer. They are faced with what seems to be an insurmountable challenge with grace and dignity. I look forward to working with you for many years with the hopes of alleviating some of the stress.

Finally, I want to acknowledge my parents. I have grown up in the community of cancer since seventh grade and have experienced joy, heartache, strength through loss and hope. They have taught me how to love life, even in the moments of greatest despair.

## Table of Contents

Chapter 1: Rationale of Study	1
Chapter 2: Pediatric Cancer Patients	4
Chapter 3: Siblings of Pediatric Cancer Patients	14
Chapter 4: Parents of Pediatric Cancer Patients	17
Chapter 5: Diversity Variables	22
Chapter 6: Review of Treatment Options	26
Chapter 7: Theories of Treatment for Children with Cancer and Their Families	31
Chapter 8: Existing Hospital-Based and Residential Camp Programs	43
Chapter 9: Resiliency and Group Work	54
Chapter 10: Camp Safari (Survivors and Families are Resilient)	59
Chapter 11: Manual for Camp Safari	67
Chapter 12: Future Research	74
Appendix: Camp Session Information Sheets	75
References	83

## **List of Figures**

Figure 1: Phases of Traumatic Stress (Kazak, Rourke et al., 2007).	32
Figure 2: Adolescent Resilience Model (Haase, 2004).	37
Figure 3: Modification of the Adolescent Resilience Model (Chou & Hunter, 2009).	42

## **Chapter 1: Rationale of the Study**

Cancer is a traumatic event at any age. When a child is diagnosed, the patient, family and community struggle to make sense of the experience. Most of these children miss school for an extended period of time, are separated from their siblings and other family members and have to endure painful procedures, treatments and surgeries (Askins & Moore, 2008). As traumatic as the cancer experience is, research has identified that, in general, survivors display good adjustment and their scores on self-report measures are not significantly different from those of the norms (Maurice-Stam, Oort, Last, & Grootenhuis, 2008). Although these survivors and families report good adjustment, further research identifies that there is consistently a small but significant group of children and families that do not cope well and may have significant personal, psychosocial and adjustment difficulties (Kazak et al., 2005; Levin Newby et al., 2000; Zeltzer et al., 2009). Some typical symptoms noted in this group of pediatric cancer patients are depression/anxiety, decreased concentration and attention, antisocial behaviors and post-traumatic stress symptoms (Kazak & Christakis 1996; Shultz et al., 2007). Cancer survivors have been found to express poorer self-concepts and had a more external locus of control. These survivors were also less confident about themselves and felt less in control of their lives (Greenburg, Kazak & Meadows, 1988). A substantial group of childhood cancer survivors and their parents report symptoms of Post-Traumatic Symptoms (PTS) up to twelve years after treatment and the impact of PTS on the family may have significant impact on the parent-child relationship, spousal relationship and the

child's adjustment in the long term (Barakat et al., 1997; Stuber, Christakis, Houskamp, & Kazak, 1996). Siblings, often overlooked in families with a cancer patient, can exhibit symptoms that are just as severe as the patient and other members of the family (Tiller, Ekert, & Rickards, 1977).

Current psychological treatment for pediatric cancer survivors and their families address issues such as: understanding procedural pain, realizing long-term consequences, appreciating distress at diagnosis and over time and knowing the importance of social relationships (Kazak, 2005). The types of treatment range from educational support and cognitive-behavioral therapy to expressive therapies and problem solving training (Goodman, 2007; Sahler et al., 2005). Most psychosocial interventions with child cancer survivors and families use a deficit model; which is focused on ameliorating stress and preventing negative psychosocial outcomes (Orbuch, Parry, Chesler, Fritz & Repetto, 2005). Growth-oriented intervention programs, such as the Adolescent Resilience Model (ARM, Haase, 2004), focus on strength-based factors that promote positive individual and family recovery (Orbuch et al., 2005).

An alternate form of providing support and treatment to pediatric cancer patients and survivors are residential camp programs. Residential camps are a way to meet the social needs of the children and families while, at times, addressing symptoms such as self-confidence, independence, behavioral concerns, post-traumatic stress, anxiety, and depression (Carpenter, Sahler, & Davis, 1990; Packman et al., 2004; Shields, Abrams, & Siegel, 1985).

The aim of this dissertation is to incorporate a theory-driven model of treatment into a residential camping program for child cancer survivors and their families. The

program will be grounded in the Adolescent Resiliency Model (ARM, Haase, 2004), a comprehensive, integrative representation of the resilience and quality of life process in adolescents with cancer (Chou & Hunter, 2009). In line with research recommended by Levin Newby et al. (2000), and Kazak (2005), group therapy will be the primary method of intervention. The goals of the camp will be to (1) increase social support; (2) increase adaptive skills; (3) increase positive copings skills, (4) increase family cohesion, communication and support; (5) increase physical and emotional self-confidence, and (6) gain derived meaning from the cancer experience. These goals will be measured before, during, and after the camp through empirically-based assessment measures to evaluate the program's efficacy.

## **Chapter 2: Pediatric Cancer Patients**

Approximately 12,060 children under the age of 15 will be diagnosed with cancer in 2012 (Cancer in Children, 2011). Pediatric cancer survivorship has changed dramatically over the last forty years. According to the American Cancer Society, the 5-year survival rate for the most recent time period (1999-2006) for the more common childhood cancers range from 66% to 95%, whereas the 5-year survival rate was less than 50% in the 1970's. With this burgeoning population of childhood cancer survivors, there is a need for identification of psychosocial problems in the patients and their families and new interventions to help alleviate said problems.

There has been research stating that, in general, school-aged survivors adjusted well to the cancer experience (Maurice-Stam et al., 2008; Zeltzer et al., 2009). One perspective is that the experience with cancer can have changed children's conceptualization of problems, so that fewer problems are being experienced (Maurice-Stam et al., 2008). Although there is little evidence of serious maladjustment in this study, research on more specific pediatric psycho-oncology outcomes demonstrated that there is consistently a group of children and family members who do not cope well with the cancer or who have personal, family and social difficulties (Kazak et al., 2005; Levin Newby et al., 2000; Zeltzer et al., 2009). Areas that have been found to be problematic include academic achievement, employment difficulties, impaired or decreased social relationships, and self-concept, self-esteem or identity (Patanaude & Kupst, 2005). Their social well-being relates not only to their physical condition, but to interruptions in their

development, both psychologically and socially, based on the time of life at which cancer was diagnosed (Zebrack & Chesler, 2002).

### **Types of Pediatric Cancer**

The common types of childhood cancer vary in symptoms, treatment and long-term effects.

1. **Leukemia:** Leukemia is most common type of childhood cancer (about 34% of all cancers). The most common forms are acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML). Leukemia may cause bone and joint pain, weakness, bleeding, fever, weight loss, and other symptoms. The main treatment for childhood leukemia is chemotherapy. One of the most serious side effects of ALL therapy is the possibility of getting acute myelogenous leukemia (AML) at a later time. Survivors of childhood leukemia often suffer from emotional or psychological problems. They also may have some problems with normal functioning and schoolwork (Cancer in Children, 2011). According to Zeltzer et al.'s study (2009), Lymphoma survivors demonstrated higher rates of anxiety and somatization when compared with siblings.
2. **Brain and other nervous system tumors:** These tumors comprise of 27% of all childhood cancers. They can cause headaches, nausea, vomiting, blurred or double vision, dizziness, and trouble walking or handling objects. The main treatments for children with central nervous system tumors are surgery, radiation therapy, and chemotherapy. Children may lose some brain function if large areas of the brain get radiation. Problems can include memory loss, personality changes, and trouble learning at school. These may get better over time, but some

effects may be long-lasting. The possible effects of the tumor and its treatment on physical and mental function can range from very mild to fairly severe (Cancer in Children, 2011). In the Childhood Cancer Survivor Study, it was found that brain tumor survivors had higher rates of impaired physical health compared with siblings, including a lower capacity to fulfill physical roles (Zeltzer et al., 2009).

3. Neuroblastoma: Neuroblastoma accounts for about 7% of childhood cancers. This type of cancer occurs in infants and young children and is rarely found in children older than 10. Neuroblastoma is a form of cancer that starts in certain types of nerve cells found in a developing embryo or fetus. This tumor can start anywhere but is usually in the belly (abdomen) and is noticed as swelling. It can also cause bone pain and fever. The types of treatment used may include: surgery, chemotherapy, retinoid therapy, radiation therapy, high-dose chemotherapy/radiation therapy and stem cell transplant, and immunotherapy. Late effects of cancer treatment can include: heart or lung problems (due to certain chemotherapy drugs or radiation therapy), slowed or decreased growth and development (in the bones or overall), changes in sexual development and ability to have children, changes in intellectual function with learning problems, and development of second cancers later in life (Cancer in Children, 2011). According to the Childhood Cancer Survivor Study, Neuroblastoma survivors demonstrated higher rates of depression, somatization and anxiety when compared to their siblings (Zeltzer et al., 2009).
4. Lymphoma: Lymphoma (including both non-Hodgkin lymphoma [NHL] and Hodgkin disease) is the third most common cancer in children, accounting for

about 8% of childhood cancers. Non-Hodgkin lymphoma usually occurs in younger children, while Hodgkin disease is more likely to affect older children and teens. Even if the disease appears to be localized to a single swollen lymph node, non-Hodgkin lymphoma in a child has often spread by the time it is diagnosed. Lymphoma cells are probably present in other organs, but these are too small to be felt by the doctor or seen on imaging tests. For this reason, all children with non-Hodgkin lymphoma get chemotherapy. Late effects of treatment can include: heart or lung problems after getting certain chemotherapy drugs or getting radiation therapy to the chest, slowed or decreased growth and development, changes in sexual development and ability to have children, changes in intellectual function with learning difficulties, and development of second cancers later in life. Along with physical side effects, survivors of childhood cancer may have emotional or psychological issues that need to be addressed. They also may have some problems with normal functioning and school work (Cancer in Children, 2011). According to the Childhood Cancer Survivor Study, Lymphoma survivors present with higher rates of psychological distress, including anxiety and somatization, compared with siblings and population norms (Zeltzer et al., 2009).

### **Psychosocial Symptoms Associated with Treatment**

During treatment, child cancer survivors (CCS) face multiple challenges both physically and socially. Askins & Moore (2008) describes the social challenges that are inherent in treatment. Time is spent with hospitalizations, doctor visits, chemotherapy and recovery. CCS often miss school for an extended period of time, are separated from

their siblings and other family members and express concerns about body image. These and other changes in well-being may underlie a sense of loss of control for children and teens, which can affect their long-term psychosocial adjustment. Using the data from Childhood Cancer Survivor Study, Shultz et al. studied behavioral and social skills in adolescent cancer survivors (Shultz et al., 2007). They discovered that the adolescent cancer survivors demonstrated more at risk behaviors consistent with difficulties than a comparable sibling group. The primary difficulties noted in the adolescent cancer survivors were symptoms of depression/anxiety, attention deficit, and antisocial behaviors. Because these are primarily internalized behaviors, they are not as apparent to healthcare practitioners and are often overlooked (Shultz et al., 2007).

Woodgate, Denger and Yanofsky (2003) undertook a longitudinal qualitative study addressing cancer symptoms in children. Children with cancer, ages 4 ½ to 18 years, and their families participated in open-ended formal interviews. With the data collected and analyzed, Woodgate et al. were able to establish eight meaning-assigned cancer symptoms:

1. *I have a sick stomach...I feel sick, I feel bad.* These attributes describe the physical feeling of being sick and the feeling that the cancer is real. Although the cancer patients feel bad, it is also a sign that the cancer is being beaten and the feeling sick is accepted by children and their families as a part of getting better.
2. *I feel yucky crappy, shitty...I feel really sick, I feel really bad.* This group describes the experience where children feel “really sick”, and make dying more “real”. This grouping is also a sign of the belief that things may not be going well and the cancer may not be beaten.

3. *I am sore, hurting...Boy, my body hurts.* This grouping describes the experiences where children feel consumed with physical pain and made life “unfair”. It is also a sign that reinforced the suffering nature of cancer.
4. *I am cranky...I am not myself.* This grouping describes the experiences where the children don’t feel like their usual selves. It made life stranger and reinforced the controlling nature of cancer.
5. *I am just experiencing an everyday thing...I am just a little sick.* This grouping describes experiences when certain symptoms become normal feelings. This mindset helped make the cancer easier to deal with and increased the belief that life can go on.
6. *I am wiped out...My body is just too tired for me to care.* This grouping describes experiences that made children feel physically and mentally exhausted.
7. *I am scared...I don’t know what is going to happen to me.* This grouping talks about the experiences that caused uneasy feelings and the uncertainty of life and cancer. The children describe that life was experienced in a state of fear.
8. *I am hurting...My heart is sad.* This grouping describes experiences that caused mental distress and made life more painful. They also describe that life was full of heartache.

In addition to identifying the feeling states of children and their families, Woodgate et al. have findings related to how health professionals can better understand and treat these symptoms when they emerge. They recommend helping the child and families seek out the meanings assigned to their cancer symptoms, promote ongoing communication that supports telling their illness stories in their own words, and accept families as part of the

solution to relieving the children's symptoms.

Kazak and Baxt (2007) address the effects of cancer in an infant or young child and their families. Some of the clinical themes in regard to traumatic stress in an infant and their parents that emerged are as follows: parent's experience of grief and loss of the future for their child and 'loss of innocence' in the face of a life-threatening disease; infants are too young to understand the diagnosis and treatment; parents can feel helplessness in regards to the responsibility of the child's well-being; and parents can experience a range of traumatic stress symptoms, depression and anxiety.

Patterson, Holm and Gurney (2004) also address the impact of childhood cancer on the family. They outlined sources of strain to the family at different system levels: cancer-related, child, family, community and health-care systems. Within the child who has cancer, they identified themes of strong emotions (fears of treatment, nightmares, fears of cancer recurrence), self-conscious about reactions of others and loss of normal life and activities.

### **Psychosocial Symptoms Associated with Remission**

The objective of Reinfjell, Lofstad, Nordahl, Vikan, & Diseth's study (2009) was to explore aspects of mental health and psychosocial adjustment of children in remission from Acute Lymphoblastic Leukemia (ALL) and their parents compared with healthy controls. It was determined that children treated for ALL reported higher levels of depression and anxiety. This study shows that problems can be seen several years after diagnosis and treatment, and demonstrates the need for close awareness of adjustment related to mental health and psychosocial functioning in children in remission from ALL. Greenburg et al. (1989) identified that relative to a matched group of children drawn from

the same hospital, cancer survivors expressed poorer self-concepts and had a more external locus of control. These survivors were also less confident about themselves and were less in control of their lives.

Educational achievement is a good indicator of social adjustment. Gurney et al. (2009) found that the cancer experience can contribute to significant academic disruption. Sloper, Larcombe and Charlton (1994) assessed the psychosocial adjustment of childhood cancer patients five years after diagnosis. Their study found that the child cancer survivors had significantly higher scores of parent- and teacher-rated scales of behavioral problems and significantly lower scores on teacher ratings of concentration, academic progress, and popularity with peers. The children who had high levels of behavioral problems were more likely to view themselves as having lower levels of close, confiding friendships, and lower social acceptance from peers. It was also noted that the children who had more behavioral problems had had more problems with school-work when they first returned to school. Sloper et al. posit that if these children do not receive sufficient support at the time of returning to school, they may become more withdrawn or disruptive and underachieve in schoolwork later, leading to an increase in problems. Patanaude and Kupst (2005) noted that patients with cognitive impairments tend to feel and be perceived as more isolated than peers and to have more behavioral problems that is much higher than that of other cancer survivors. According to Boydell, Stasiulis, Greenberg, Spiegler, and Greenberg (2008), child survivors of brain tumors struggle with the notion of competence in their social and academic/work realms. Competence was recognized in their desire to be normal and to be treated as such by their friends and family. Despite this desire to be normal and perform well, they often resisted seeking

additional support.

**Post-traumatic stress symptomology.** There has been significant research done regarding cancer survivors and posttraumatic stress symptomatology (Barakat, Alderfer, & Kazak, 2006; Kazak, Alderfer, Rourke et al., 2004; Kazak, Barakat et al., 2001; and Stuber et al., 1996). Post-traumatic stress disorder (PTSD) is an anxiety disorder that some people develop after seeing or living through an event that caused or threatened serious harm or death. Symptoms include flashbacks or bad dreams, emotional numbness, intense guilt or worry, angry outbursts, feeling “on edge,” or avoiding thoughts and situations that remind them of the trauma (American Psychiatric Association, 2000). One such study indicated that a substantial group of cancer survivors report symptoms of post-traumatic stress up to 12 years after successful completion of treatment (Stuber et al., 1996). Stuber and her colleagues identified that 12.5% of the survivors in their study reported a level of symptoms that correlate to a clinical diagnosis of PTSD; this is comparable to the prevalence of PTSD in survivors of severe childhood burns and somewhat less than child victims of sexual abuse. Kazak, Alderfer, Rourke et al. (2004) further discusses the effect of PTSD and posttraumatic stress symptoms (PTSS) in her 2004 study. She posits that if a long-term survivor who is expressing PTSS and has reexperiencing or arousal symptoms when reminded of cancer treatment, they may not relay appropriate information to the health care team in their continuing care. Alternatively, if the patient is experiencing symptoms of hypervigilance, it could contribute to higher health care utilization and cost. Brown, Madan-Swain and Lambert (2003) predicted that recent and past stressors, family functioning, and emotional support would account for a significant amount of the variance in PTSD symptomatology for

survivors of cancer and their mothers. Findings revealed that survivors endorsed a greater frequency of stressful life events and PTSD symptoms than did their non-cancer counterparts.

### **Chapter 3: Siblings of Pediatric Cancer Patients**

Interestingly, siblings of cancer patients exhibit symptoms that are just as severe as the patient and other members of the family. Tiller et al. posited in 1977 that school aged siblings had adverse reactions such as feelings of neglect, abandonment, anger, sadness and depression and some exhibited a decline in school performance.

#### **Psychosocial Symptoms Associated with Treatment and Remission**

Patterson et al. (2004) conducted a qualitative study where they identified in one of the sub-sections, family strains, the siblings expressed anger, resentment or jealousy at the amount of attention the child with cancer received. Sloper and While (1996) investigated the psychological adjustment of 99 siblings of children with cancer. Of the 99 siblings six months post-diagnosis, one-quarter of the siblings had experienced problems in behavioral problems both at home and school. Multiple variables were identified; the number of nights the ill child spent in the hospital, lack of a family car, mother's dissatisfaction with social support and sibling's perceptions of interpersonal effects of the illness. The number of nights spent in the hospital is an indicator of the degree of disruption to family life. The longer the sick sibling was in the hospital, the longer the parents were away and the less attention and support the siblings received from the parents. An additional strain that was identified was the families that do not own a car. Often the sick child has to be at a hospital away from the local area, making it difficult to visit the siblings and being present for their special occasions, such as birthdays and graduations. Many parents indicated the importance of support from

family and friends. This social support helps with raising the siblings and providing needed attention. The final variable addressed in this study is the sibling's perception of loss of attention from parents, from others and feelings of neglect. Sloper and While found a link between negative perceptions and an increase in behavioral problems.

Quin (2004) discussed the sibling's changes in fear, resentment, attention-seeking behaviors, guilt, worry and protectiveness of the ill sibling and its relation to their relationship with the parents. In this qualitative study, parents spoke about being focused on the child with cancer at a cost to the other siblings. Some of the parents felt that the siblings had suffered more than the child with cancer. Shifts in family role responsibilities, distress of the sibling undergoing treatment, long parental absences (both physical and emotional), and intense stress of the parents may interfere with successful adaptation of siblings and inhibit a healthy transition once their sibling is in remission (Alderfer, Labay, & Kazak, 2003; Patterson et al., 2004; Tiller et al., 1977). Quin (2004) reported that the parents believed that the siblings coped best if they got as much attention as possible (either by the parents or other family members) and were kept informed about the illness.

**Post-traumatic stress symptomology.** Alderfer et al. (2003) explore post-traumatic symptoms (PTS) in siblings of child cancer survivors. In their study, they found that adolescent siblings of child cancer survivors report symptoms of PTS. Nearly half of the siblings had mild post-traumatic stress reactions and almost a third had moderate to severe reactions. The siblings reported exposure to the physical and emotional suffering of their sibling, some think their sibling will die and many feel fear. This is further supported by a study by Schuler et al. (1985) where it was posited that the

siblings of patients were in the most unfavorable position of all family members. Their contact with their parents became looser, they had problems in the community (adaptation problems, failure to achieve and anxiety) and their relationship with their sibling deteriorated. These symptoms showed little change during the course of their sibling's disease. Tiller et al. (1977) discusses that these symptoms may be a result from a limitation in families on the amount of stress that they can handle. The focus of their attention is on the sick child, therefore they are not able to attend to the siblings, denying or minimizing their experience for the sake of maintaining some semblance of family equilibrium.

## **Chapter 4: Parents of Pediatric Cancer Patients**

Ongoing concerns and fears about the physical and psychosocial well-being of the survivor of childhood cancer appear to be universal among parents and these concerns do not disappear when treatment ends (Leventhal-Belfer, Bakker, & Russo, 1993).

### **Psychosocial Symptoms Associated with Treatment and Remission**

Van Dongen-Melman, Van Zuuren, and Verhulst (1998) conducted a qualitative study exploring the experiences of parents of childhood cancer survivors. In this study, parents discussed that cancer in their child was the most overwhelming experience in their life and that the changes were definitive and long-lasting. Themes of losses emerged; loss of their usual way of life, loss of the ability to cope with new stressors, and loss with respect to the child. After treatment has ended, even 'minor' side effects could function as a reminder. If the aftereffects were more permanent and disabling, the parents had to come to terms that their child may be cured of cancer, but was not the same healthy child as before. Another loss identified was concerning marital relationship. Partners reported to experience the illness differently, therefore coping with it in alternate ways. Van Dongen-Melman et al. discovered two coping behaviors: parents facilitated in each other's strategies that were in line with their own way of coping and partners developed a differentiation in their response to stress. Both variations may cause feelings of loneliness in the other partner, because they both imply that the other partner is restricted in expressing emotions. This can cause isolation, loneliness within the relationship and may cause marital friction. Parents identified different avoidance

strategies, such as: avoidance strategies were drinking alcohol or smoking; distancing oneself; striving toward normalcy and avoiding information about the disease and its long term consequences. Other strategies of coping were observed in supporting the child, talking with other parents of children with cancer, talking with the medical staff and seeking help and assistance. Another theme that was identified in this study was anxious perseveration about a recurrence of the disease. It was indicated that even long after the end of treatment parents were uncertain and anxious about the possibility of recurrence and also about the appearance of physical aftereffects in their child. Due to this uncertainty, Van Dongen-Melman et al. report parents tended to perceive their child as a vulnerable child; in respects to both their physical condition and psychosocial development.

**Post-traumatic stress symptomology.** Post-traumatic stress disorder and symptomatology has been linked to both survivors and family members (Barakat et al., 1997; Kazak, Alderfer, Streisand et al., 2004; Stuber et al., 1996). Stuber et al. (1996) posit that a substantial group of childhood cancer survivors and their parents report symptoms of PTS up to twelve years after treatment. Barakat et al. (1997) compared PTS in survivors of childhood cancer with healthy children and their parents. It was found that the parents of childhood cancer survivors reported greater symptoms, such as intrusive thoughts, hypervigilance, and distress at reminders of treatment at a greater frequency and intensity than their child who had cancer. The authors suggest that the impact of PTS on the family may have significant impact on the parent-child relationship, spousal relationship and the child's adjustment in the long term. Brown et al.'s (2003) study is one of the few late-effect studies in the cancer literature examining adaptation,

operationalized here as PTSD symptomatology in adolescents and their mothers. They predicted that recent and past stressors, family functioning, and emotional support would account for a significant amount of the variance in PTSD symptomatology for survivors of cancer and their mothers. Findings revealed that survivors endorsed a greater frequency of stressful life events and PTSD symptoms than did their counterparts. Mothers of survivors endorsed a higher frequency of stressful life events than did mothers of healthy adolescents, and they received higher PTSD symptom scores than did the healthy comparison group.

Posttraumatic stress symptoms in parents vary amongst each family. Alderfer, Cnaan, Annunziato, & Kazak (2005) used a cluster analysis technique to investigate these patterns in parents of childhood cancer survivors. This study identified five clusters of PTS:

1. The first and largest cluster included mothers and fathers with few PTS symptoms.
2. The second largest cluster was when fathers had few symptoms and mothers had moderate levels of PTS; more specifically, moderate elevations on reexperiencing and arousal symptoms.
3. Parents that presented as disengaged; including symptoms such as loss of interest in things and restricted affect comprise the third cluster.
4. Cluster four included couples with the father exhibiting higher levels of PTS.

Interestingly, these fathers display highly elevated scores, whereas the mothers in cluster two only exhibit moderate symptoms. Cluster three and four, where the father displays more symptoms, had the poorest family coherence, a construct

similar to family-level efficacy. This cluster supports the importance to attend to the reaction of fathers, as well as other family members.

5. The smallest cluster represented couples where the mothers showing high levels of PTS in all areas, with severe reexperiencing symptoms, and the fathers showed elevation on avoidance symptoms. This pattern of symptomatology seen in cluster five may be detrimental to long-term individual functioning.

Since parents have different patterns of PTS and corresponding interaction between the couple, varying interventions will be optimal for each family depending on the family pattern. Alderfer et al. (2005) suggest that family intervention models may be well suited for treatment for most of these families. The majority of families in this study had at least one parent exhibiting PTS symptoms, thus, addressing these issues with the context of the family may be beneficial by helping family members to identify the symptoms of PTS and respond in ways that reduce stress and promote resilience for the individual and family.

**Family strain.** Streisand, Kazak and Tercyak (2003) investigated the relationship between pediatric parenting stress and family functioning. They found that the current treatment status of the child has a direct relationship with whether or not the parents experienced disruptions in family life. They found that parents who report more frequent cancer-related stressors, particularly emotional issues, report poorer family functioning, such as difficulty with behavioral control among their family members. This loss of behavioral control suggests a need for assistance with establishing and maintaining near-normal daily routines during treatment. The researchers indicated that behavioral and psychosocial support is needed throughout the treatment period, not just at time of

diagnosis with the hopes to promote stress resilience in the families.

Patterson et al. (2004) discussed family strains and identified the following: strong parental emotions (feeling numb, devastated, overwhelmed, helpless, loss of control, fear child would die and guilt), balancing multiple family needs, parent-child relationship strains, loss of normal family life, and financial strains. Quin (2004) identified that fathers typically used coping strategies such as avoidance and dependence on their spouses as their sole means of emotional support. She also noted that the parents in her study identified the period immediately following completion of treatment to be particularly stressful. Reinjfell et al. (2009) conducted a study where they explored aspects of mental health and psychosocial adjustment of children in remission from Acute Lymphoblastic Leukemia (ALL) and their parents compared with healthy controls. Fathers of children treated for ALL showed significantly more anxiety and depression compared to the healthy controls (no such differences were found for the mothers). This study shows that problems can be seen several years after diagnosis and treatment, and demonstrate the need for close awareness of adjustment related to mental health and psychosocial functioning in children in remission from ALL.

## **Chapter 5: Diversity Variables**

Cancer impacts families regardless of ethnicity, socioeconomic status, education or disability status. Unfortunately, there is a disparity in representation of ethnic minorities in current and past research (Clay, Mordhorst, & Lehn, 2002; Kazak, 2005; Wells & Zebrack, 2008). Most forms of empirically supported treatments (EST) were developed from the white, middle-class perspective (Clay et al., 2002). Clay and his colleagues examine the extent in which EST's for pediatric health problems address key issues of race, ethnicity and culture. Seventy-one articles were identified as empirically supported treatments for pediatric asthma, cancer, obesity, and diabetes. The articles were examined to determine if they addressed key cultural issues. They were reviewed on the following variables: race/ethnicity, socioeconomic status (SES), moderating cultural variables, EST's cultural bias, larger cultural issues, and measurement/procedure bias. The results reveal that diversity variables in medical conditions are rarely addressed in EST's. Only 27% of the reviewed studies reported the ethnic demographics of the study sample, 11% reported sampling American minority participants, 18% of the studies reported SES (the majority was in the middle-class range), 6% discussed moderating cultural variables, 7% recognized cultural bias of treatments and only 6% addressed larger cultural issues in disease and its treatment. Kazak (2005) discusses the need for focus on cultural variables when developing evidence-based interventions for survivors of childhood cancer. This disparity is a great concern in our increasingly multicultural society, compounded with multiple and complex family configurations. The difficulty of

recruiting ethnic minority participants can be approached. The researchers need to discuss the ethnic disparity amongst research participants, pay attention to the development and evaluation of existing interventions regarding their applicability to ethnic minorities, and consider alternate models of intervention delivery.

One of the few research studies focused on an ethnic minority was conducted by Casillas, Zebrack & Zeltzer (2006). Health-related quality of life (HRQOL) for Latino survivors of childhood cancer was explored by using qualitative measures. Casillas et al. (2006) determined that both Latinos and non-Latinos pediatric cancer survivors overall are experiencing a good HRQOL in their adult life. The majority of the themes that emerged were similar in both the Latino and non-Latino groups, such as chronic pain, concerns of infertility, appreciation for life, fear of passing cancer on to offspring, anxiety associated with attendance of a long-term follow-up clinic, closer family relationships and the medically vulnerable adult. One subtheme that was reported exclusively by the Latino group was impaired sibling relationships that extend into adulthood. This could be due to Latino cultural factors, such as a heightened concern for family which in turn creates an increased bond with all family members. It would be imperative for the clinician to address the strength/resilience of the family connection during treatment, and including family members as often as it is appropriate.

Wells and Zebrack (2008) discuss the psychosocial barriers that are contributing to the under-representation of racial/ethnic minorities in cancer clinical trials. They have categorized these barriers based on the Social Ecological Model, with the assumption that varying levels of influence operate simultaneously within and between levels, and therefore impact individual behavior. Often minorities feel isolated from the dominant

culture. This feeling of isolation influences their health-related attitudes, beliefs, behaviors and access to care. Lack of knowledge and understanding are factors that affect participation in clinical trials. More accurate knowledge may lead to more favorable perceptions about participation, therefore potentially increasing the chance of involvement in studies. Interpersonal barriers to participation in clinical trials can involve the doctor-patient relationship, communication and social networks. Distrust in the medical establishment creates a barrier to involvement in trials. The healthcare system can be daunting, especially if English is not your first language. Health care providers are encouraged to supply forms and paperwork in multiple languages, but it is costly and time-consuming. Socio-cultural barriers include community mistrust and skepticism related to past historical injustices in history. Culturally influenced views on health and disease, low socioeconomic status, inaccessibility, and limited formal education are also factors in reducing participation.

New approaches to health care, illness prevention, and health promotion among ethnic minorities in the United States are needed (Tucker, 2002). The existing formal health care system is not meeting the needs of our children. Many ethnic minorities underutilize formal mental health services; which suggests a need for pediatric psychology in nontraditional settings, such as settings where ethnic minorities seek out other services and social and emotional support. Tucker discusses five different approaches that can be taken to better serve ethnic minorities: informal care, empowerment, culturally sensitive, illness prevention and health promotion approaches. These approaches address the need to provide care that is culturally appropriate, both in location, orientation, evaluation and assessment. It is important to recognize your own

cultural biases and the roles of economic and cultural differences between the majority culture and ethnic minority cultures. Pediatric psychologist can work in schools and community centers to reach this underrepresented clientele, collaborate with community and religious leaders, and advocate for ethnic minority parents.

## **Chapter 6: Review of Treatment Options**

When a child is diagnosed with cancer, the patient, family and community struggle to make sense of the experience (Askins & Moore, 2008). Often, these families require additional support outside of their immediate family. This chapter is a review of the different support teams, key components and therapeutic modalities used in treatment of CCS and their families.

### **Psychosocial Support Teams**

Askins and Moore (2008) reviewed the history and current psychosocial support for children with cancer and their families. She defines modern psychosocial support teams as “multidisciplinary groups of professionals who facilitate positive adjustment and coping of patients and their families in the pediatric cancer setting.” Within these behavioral pediatric teams, there are many different types of professionals. Psychiatry, psychology and neuropsychology contribute specialized clinical interventions to help children and their families and contribute through carefully designed research. Child life specialists recognize the importance of maintaining family ties for the hospitalized child and families and engage them in “medical play” to give them an opportunity to exert some control in their medical environment with the goals of decreasing fear and anxiety. They also play a vital role in emotional preparation for medical tests and procedures. Hospital-based education programs assist in enhancing cognitive functioning and providing educational continuity while the child is absent from traditional education programs. Art and music therapy programs are used as an adjunct to traditional

psychotherapy to help children identify issues of concern and increase insight to facilitate positive coping. Spiritual support is offered to provide support to patients and families during a period when their faith is being tested. Social workers support the multidisciplinary team by working towards making life more manageable for patients and their families. They provide psychosocial support as well as conducting research, facilitate support groups and connecting families with resources.

### **Key Components in Current Treatments**

Kazak's (2005) article on evidence-based interventions for childhood cancer survivors summarizes key components in current treatments and need for future research. She breaks down accomplishments in pediatric oncology research into four subgroups:

1. Understanding procedural pain: The procedural pain literature discusses a range of cognitive and behavioral approaches, including desensitization, imagery, relaxation, modeling and positive reinforcement. These interventions have been found beneficial in the hospital setting but also have been able to be flexible to accommodate change within settings and stressors (Kazak & Kunin-Batson, 2001; Powers, 1999).
2. Realizing long-term consequences: Realizing long-term consequences has come about due to the increased success rate with cancer treatments in the last decades. The development of late-effects of cancer treatment provides opportunities for psychosocial intervention, especially for the subgroup of families that are high risk for persistent difficulties (Friedman & Meadows, 2002).
3. Appreciating distress at diagnosis and over time: The largest group of research has been addressing the psychological reaction of patients and families during

active treatment for cancer (Recklitis, O’Leary & Diller, 2003; Zebrack & Chesler, 2002). It has been posited that the most promising interventions during cancer treatment need to be tailored for specific outcomes and each individual family’s needs (Sahler et al., 2002).

4. Knowing the importance of social relationships: Since cancer affects the whole family, it is imperative to incorporate each member in treatment (Kazak, Rourke & Crump, 2003). Social support has been identified as protective against the development of distress and psychopathology, as well as adjustment to the stressors of cancer (Helgeson & Cohen, 1996).

Kazak (2005) discusses the importance of early intervention with pediatric cancer families. To develop effective interventions, it is important to attend to empirically-supported treatment standards as well as recognizing the pragmatic needs of these families and how they are fundamentally different from the populations in which the empirically-supported standards have been developed.

### **Types of Interventions**

There are different types of interventions for childhood survivors of cancer. They vary in focus, type, timing and format. Goodman (2007) discusses four such intervention models that are clinically based and research informed.

1. Educational support: Education can empower children and their families to become allies with the medical team. The author posits that it is not what to tell the children, but how to tell them. Information should be given in a developmentally appropriate manner, clarifying misinformation, being aware of feelings and fears and responding to said emotions.

2. Cognitive-behavioral therapy: Cognitive-behavioral strategies have been found helpful in addressing the stress from discomforting emotions and situations (Schmidt, Petersen, & Bullinger, 2003). Such strategies as identification of feelings, problem solving, behavior modification and relaxation/imagery help reduce negative symptoms related to pain management, procedure-related distress and psychosocial adjustment.
3. Family systems: Goodman (2007) emphasizes the importance of seeing the child in the context of his/her family system. The author suggests that cancer can be an all-consuming experience, not only for the child but for his/her family and outside systems, such as peers, school and community. It is important to address the family needs due to the direct effect the parents functioning has on the child. When the parents are doing well, they can parent better, manage the child's emotions and model appropriate coping skills for the child and his/her siblings. Peer relationships are also very important for children with cancer. Social interaction via support groups or informal settings such as online chat sites helps reduce the physical and psychological isolation that is so common in this disease.
4. Expressive therapies: Expressive techniques allow the child to express their feelings of anxiety, anger and fear in a non-threatening way that is active and allows for emotional release, reorganization and reexperiencing of problems and anxiety. Art therapy allows the child to be constructive in the middle of an experience where part of their selves is physically being destroyed. Common themes in children with cancer's artwork include drawings of loss of identity, altered self-identity, how they feel about being labeled "sick" and loss of control

(Goodman, 2007). Individual art therapy offer specialized support where the child can express their current difficulties, stressors and needs in a non-threatening environment. Group art therapy adds opportunities for the children to interact and learn to cope, therefore reducing fear and anxiety (Wallace, 2007).

## **Chapter 7: Theories of Treatment for Children with Cancer and Their Families**

Researchers have taken the elements and modalities of treatment discussed in the prior chapter and symptoms expressed by CCS and their families and have created models of treatment specific to the childhood cancer population. The following are three current models that attempt to establish a framework for interventions for CCS and their families.

### **Pediatric Psychological Preventative Health Model (PPPHM) and Medical Traumatic Stress Model (MTSM)**

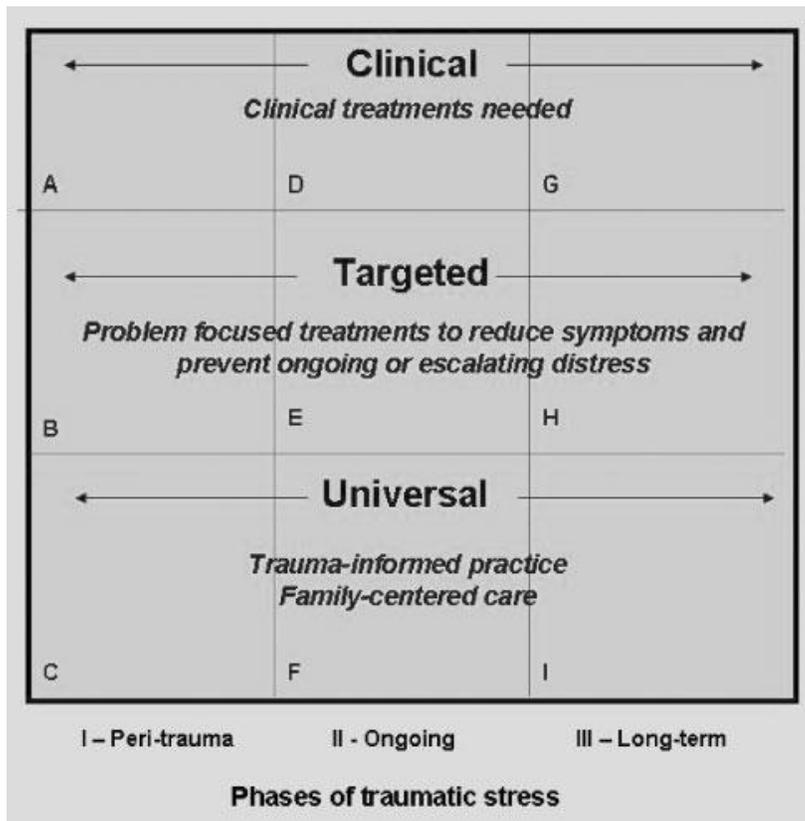
The Division of Oncology at The Children's Hospital of Philadelphia has done extensive research in symptomatology of childhood cancer patients and their families and psychosocial support. Kazak, Rourke, et al. (2007) discuss a way to conceptualize these families and provide a framework for current and future interventions. They have created a competence-based framework, combining two different conceptual models:

**Pediatric Psychological Preventative Health Model (PPPHM).** PPPHM was created on the assumption that most families dealing with pediatric cancer are competent and adaptively organized, without any primary risk factors for mental health interventions. It is divided into three different groups: Universal, Targeted and Clinical/Treatment. *Universal*, the largest group, are the families that are distressed but resilient. *Targeted* are the families in acute distress, present with risk factors (such as pre-existing child problems, psychosocial stressors, family problems and poor coping skills) and are in need of services. *Clinical/Treatment* is the group of families that are at highest

risk, with persistent and/or escalating distress.

**Medical Traumatic Stress Model (MTSM).** The MTSM model is a developmental conceptualization of the cancer experience and is broken down in three phases: peri-trauma, during treatment, and long-term sequelae. *Peri-trauma* is the immediate time period around a traumatic event, such as diagnosis, treatment initiation or waiting for results of diagnostic workups. *During treatment* is variable in length and intensity and continues to expose the patient and families to ongoing traumatic stimuli. *Long-term sequelae* is where the children have completed treatment or for the families of children who have died.

Kazak et al. (2007) have integrated these models as illustrated by the following figure:



*Figure 1: Phases of Traumatic Stress (Kazak, Rourke et al., 2007).*

Since the subject of this report is on cancer survivors and their families, the focus will be on the long-term sequelae. In the Universal Care part of the long-term sequelae (Cell I) the focus is on assessing PTSS in survivors and providing anticipatory guidance on PTSS and other emotional late effects as a standard part of treatment education. It is encouraged to form partnerships with community-based cancer organizations that may reach cancer survivors and their families in order to provide this guidance and assessment. The families in the Targeted Care section of long-term sequelae (Cell H) require interventions that address target symptoms, such as anxiety and/or depression and family stress. The Clinical/Treatment level of the long-term sequelae (Cell G) addresses the need for intensive services for families at the highest risk. These families often have multiple pre-existing difficulties and these needs have to be addressed. Cancer survivors in this group may not associate their ongoing symptomatology to their cancer treatment, and in turn may seek help from health care professionals that are not attuned to the needs of a cancer survivor. The integration of the two models provides a framework to place each family in different arenas in each phase of treatment. Clinicians are given the opportunity to conceptualize the families throughout each phase of treatment and provide the most appropriate and effective method of intervention for that specific family.

### **The Resiliency Model of Family Stress, Adjustment and Adaptation**

Most psychosocial interventions with child cancer survivors and families use a deficit model; which is focused on ameliorating stress and preventing negative psychosocial outcomes (Orbuch et al., 2005). Growth-oriented intervention programs, such as the following resiliency models, focus on strength-based factors that promote

positive family recovery (Orbuch et al., 2005).

The Resiliency Model of Family Stress, Adjustment and Adaptation was created by Marilyn A. McCubbin and Hamilton I. McCubbin (1993). This model posits that families will experience stress and hardship during crises such as childhood cancer, but through their own strengths and relationships, they will adjust and adapt by giving meaning and purpose to their experience (Brody & Simmons, 2007). The Resiliency Model assists health professionals in assessing family functioning and intervening in the family system to facilitate family adjustment and adaptation. It also helps guide professionals in determining what family types, capabilities and strengths are needed, called on and created to manage illness in the family.

Within this model, resiliency is defined as the positive behavioral patterns and competencies that both the individual and family demonstrate under stressful times that in turn help maintain the family system (McCubbin & McCubbin, 1993). The model has two phases, the adjustment phase and the adaptation phase. In the adjustment phase, the family relies on existing patterns of family functioning, coping strategies and problem solving skills with only minor changes being made. If these tools are not adequate to manage a situation, the family is then seen as being in a crisis, and begins the adaptation phase. Crisis is referred to as the family experience of a state of disorganization and the need of change. The adaptation phase is where there is a demand for changes in the family patterns of functioning to restore stability, order and a sense of coherence. Strengths in this phase include newly established patterns of family functioning, obtaining new support resources at the individual, family and community levels, and utilizing new coping skills. The goal of family adaptation in this model is for the

individual members to be functioning well, and the family unit has a sense of balance in carrying out responsibilities within the family and community.

In 2002, McCubbin, Balling, Possin, Frierdich, & Bryne conducted a study to identify family resiliency factors in the management of childhood cancer using the Resiliency Model of Family Stress, Adjustment and Adaptation. They interviewed 26 families and obtained data from 42 parents. It was determined that there was six resiliency factors that helped families manage throughout the phases of treatment.

1. All of the families reported **specific internal family strengths of rapid mobilization and reorganization in response to the crisis** of having a child diagnosed with cancer. It was important to be able to establish new patterns of family functioning as families needed to reallocate roles and responsibilities.
2. The second resiliency factor noted was **support from the oncology health care team**. It was broken down into three components: providing reassurance, accessibility for information, and showing respect for the parents.
3. The third resiliency factor noted was **support from extended family**.
4. The fourth factor was **support from the community**, through financial, home maintenance and emotional support.
5. The fifth factor was noted by approximately one-third of the families; **support from the workplace**.
6. The sixth resiliency factor noted was **changes in family appraisal**.

All the parents provided experiences of recovery through changes in appraisal that occurred at the time of active treatment. This study provided tools to help health professionals support families experiencing childhood cancer. They note that building on

existing resources and helping the family to reorganize their ways of functioning is an essential role for any health care professional.

### **The Adolescent Resilience Model**

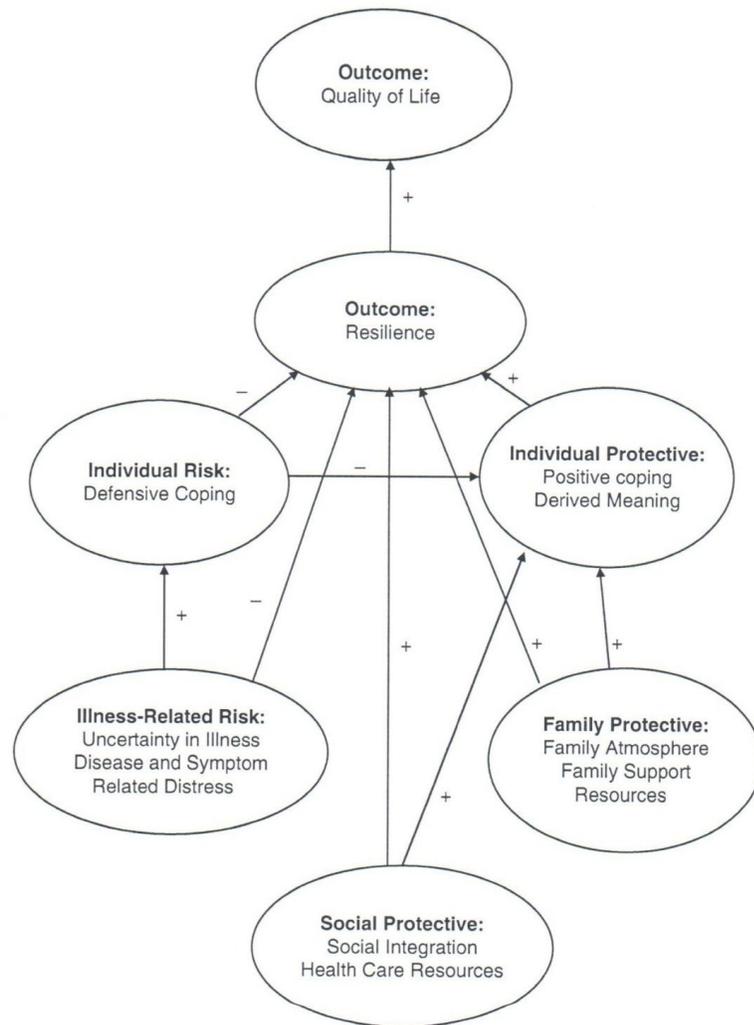
Whereas the Resiliency Model of Family Stress, Adjustment and Adaptation is focused on the family unit, the Adolescent Resilience Model (ARM, Haase, 2004) is a comprehensive and integrative representation of the process of resilience and quality of life in adolescents with cancer.

**Philosophical perspectives.** ARM is grounded in both life-span development and meaning-based models (Haase, 2004). The life-span development perspective seeks to incorporate the historical and contemporary influences as well as the adolescents' response to health and illness development (Weekes, 1991). Developmental variables can be broken down into three different types: normative age-graded (e.g. adolescents typically experience physical changes at time of puberty), normative history-graded (e.g. exposure to a national crisis as an adolescent) and nonnormative universal occurrences (e.g. cancer diagnosis and treatment). The ARM utilizes the developmental stage variables so that any interventions would be grounded in interactions that are developmentally appropriate in regard to meaning of experiences (Haase, 2004).

Meaning-based models emphasize the meanings, patterns and experiences of illness and seek the patients' perception of the experience and relationships with others. In this type of model, data on functional status (e.g. physical, emotional or spiritual) is important, but not sufficient to provide the context of the outcomes. For example, lack of functional ability which impedes the patient attending school should not be assumed to be a negative factor. It could mean for the family that they are looking forward to more time

together and will figure out alternate schooling and social opportunities (Haase, 2004).

**Structure of ARM.** The ARM appears complex but it essentially focuses on concepts that are classified as either protective, risk or outcome factors. Figure 2 illustrates the relationships among each concept.



*Figure 2: Adolescent Resilience Model (Haase, 2004).*

Following is a description of each component:

- 1. Illness-related risk: uncertainty in illness.** Uncertainty has a negative influence of resilience and quality of life. Uncertainty is greatest when the patients and

family do not understand what is happening to them and when treatment-related events are strange or unexpected. Uncertainty negatively influences factors such as hope, social support, and psychological well-being.

2. **Illness-related risk: disease and symptom-related distress.** Pain, anxiety and mood disturbances have been linked to the cancer experience and symptom-related distress. This distress may be amenable to interventions that would improve resilience outcomes.
3. **Family protective: family atmosphere.** This refers to the adaptability, cohesion and perceived support within the family system. These protective factors are used to change family power structure, role relationships and rules in response to stress while still maintaining emotional bonds.
4. **Family protective: family support and resources.** This refers to the qualities and extent of the family system and the resources it possesses. During times of crisis, families tend to rely on their family network for support.
5. **Social protective: social integration.** This refers to the amount of peer and school relationships the adolescent with cancer is able to maintain. These adolescents often require support with maintaining precancer relationships with friends and will need support in how to inform other's about their condition. Adolescents with cancer appear to benefit from knowing others with similar conditions, as they can make comparisons that can help them to place their own disease in context.
6. **Social protective: health care resources.** Health care providers play an important role with the adolescent with cancer and their quality of life.

- 7. Individual risk: defensive coping.** This factor is composed of evasive, fatalistic and emotive coping strategies. They are used as protection in crisis situations, such as in acute, life-threatening events, but create problems when they are sustained and used without development of positive coping skills.
- 8. Individual protective: positive coping.** This is composed of confrontive, optimistic and supportant coping strategies. They have been linked to positive outcomes, such as greater resilience, sense of mastery, confidence and self-esteem, and better quality of life.
- 9. Individual protective: derived meaning.** This factor is composed of hope and spiritual perspective. Hope influences how meaning is derived from events and affects health. Sources of hope can include friends, family, health care providers and religious beliefs. Spirituality is an important aspect of care and is closely related to positive coping and quality of life.
- 10. Outcome: resilience.** Resilience is composed of a sense of confidence, self-transcendence of the cancer experience and self-esteem. Confidence is the perception of control over events in the environment. Self-transcendence refers to the ability to explore inwardly in introspective activities, outwardly through concerns about others and temporally in a way that your past and future enhance the present. For example, this is seen in adolescents with cancer as reaching out to help others who are ill. Self-esteem is referred to as the extent an adolescent has a positive or negative attitude toward themselves. When the survivors have a high level of self-esteem, they appear to feel more knowledgeable about life and have a greater sense of purpose.

**11. Outcome: quality of life.** This refers to a global sense of well-being in the context of the adolescent.

**Use of ARM as a guide for interventions.** The advantage of using a multi dimensional model, such as ARM, is having the opportunity to address one or many of the components of the model, based on the goals and needs of the target population. When using the ARM for interventions, you have the option to target multiple factors or specific concepts in the model (Haase, 2004). When targeting multiple factors, you are likely to be more holistic and increase your outcomes. However, it will be more complex and considerably more costly. If you tackle one or few concepts at a time, you increase your chances of changing the outcome of that specific factor.

**Supporting research.** Chou and Hunter (2009) conducted a study to examine the relationship between risk factors, protective factors, and resilience and quality of life in survivors of childhood cancer as defined by the Adolescent Resilience Model. Chou and Hunter conducted their study in Taiwan and used a mixed method design comprised of Likert-scale questionnaires and semi-structured interviews. Results indicated there was a statistically significant positive correlation between both quality of life and resilience and quality of life and protective factors. Results also indicated a significant negative correlation between quality of life and individual risks and illness-related risks.

Chou and Hunter (2009) were able to generate the following information regarding survivors of childhood cancer:

- Individual risks, illness-related risks and cancer types are important in the explaining the context of quality of life.
- Individual risks and illness-related risks decrease resilience ability, which in turn

negatively impacts quality of life.

- Protective factors were found to be important for resilience and quality of and need to be fostered in treatment.
- Cancer type is an important factor when considering intervention strategies to reduce risk factors and increase quality of life.
- Components critical to achieve optimal quality of life: gaining self-control, promoting resilience skills, reducing chronic fears, preventing loss of self and encouraging development of an integrated self.
- Figure 2 illustrates Haase's (2004) original Adolescent Resilience Model augmented with Chou and Hunter's (2009) findings. These were refined by either further defining the components or by offering a different cultural perspective.

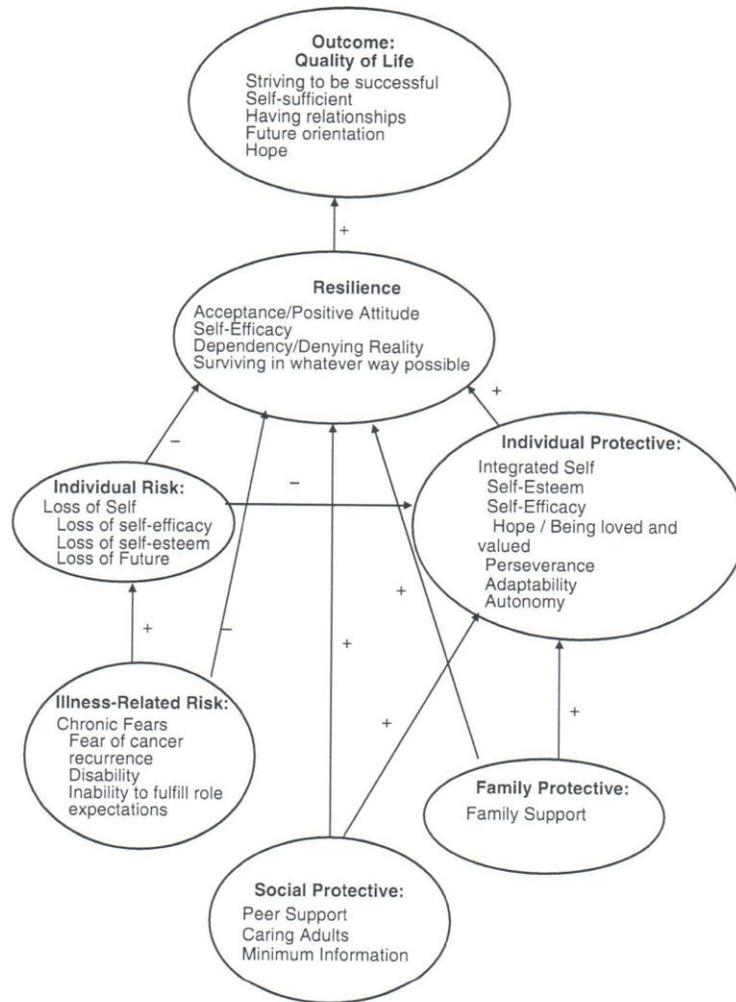


Figure 3: Modification of the Adolescent Resilience Model (Chou & Hunter, 2009).

## **Chapter 8: Existing Clinic-Based and Residential Camp Programs**

When children and families' normal development is disrupted by illness, they are at risk for developing severe, chronic, and/or escalating difficulties that have a sustained impact on the family (Kazak et al., 2006). Concurrently, normal family development is strong and resilient, even in the face of traumatic experiences, such as cancer diagnosis and treatment. Kazak et al. (2006) posits that it is an important contemporary challenge to create systemic approaches of treatment that are supportive of the inherent competencies within the families, meanwhile, providing effective treatment to reduce or prevent distress. The following is a review of recent intervention programs for children with cancer.

### **Clinic Based Programs**

To date, most theory-driven interventions have been carried out through a clinic-based setting. They range in theories and modalities but are all focused on the psychosocial treatment of children with cancer. Following is a review of two current programs.

#### **Problem-solving skills training (PSST)**

Sahler et al. (2005) discuss the distress mothers of children with cancer experience when the child is newly diagnosed. They have examined the use of Problem-solving skills training (PSST) and the efficacy with this population. PSST was developed by applying principles of cognitive-behavioral therapies to individuals who are experiencing distress but do not have a diagnosable psychological condition or require

formal mental health intervention. Mothers of children with cancer generally fit within this population based on the level of trauma experienced with their child's treatment and potential of life-threatening illness. PSST is a program designed to utilize the mother's own experience and knowledge and apply this knowledge to a model of problem-solving techniques to help equip them during the treatment phase of their child's cancer. The materials were provided to the mothers in English, Spanish and Hebrew. After examining this intervention, they determined that administering PSST decreased maternal negative affectivity. This demonstrates the efficacy of this program. Interestingly, they showed that Spanish-speaking mothers exhibited significant benefits over English-speaking mothers, suggesting good cross-cultural generalizability.

**Surviving Cancer Competently Intervention Program (SCCIP).** Surviving Cancer Competently Intervention Program (SCCIP) is a family-systems, cognitive-behavioral theory based program to address the PTSS needs of adolescent cancer survivors and their families (Kazak et al. 1999). It was built by a multidisciplinary team at Children's Hospital of Philadelphia. This one-day, four session program was established to reduce symptoms of PTSS related to cancer and its treatment and to target anxiety, beliefs about cancer and its treatment, social support and family communications. The program has six specific goals: (1) to educate adolescent cancer survivors and families about PTSS; (2) help families identify ways in which cancer and its treatment have affected them; (3) identify PTSS for the survivors and families; (4) teach cognitive-behavioral techniques that can reduce specific PTS symptoms; (5) facilitate discussion about how their beliefs about cancer have affected them; and (6) to practice family discussions about PTS and beliefs about cancer in ways that they can

reproduce at home. The day is split up into four sessions, some dividing into separate sections (survivors, siblings, parents) and some as whole families. These sessions address each of the goals and provide opportunities to discuss concerns and strengths within each family. This pilot program was geared toward adolescent survivors, aged 10-17 years. There were nineteen families, eighteen were Caucasian, and one family was Asian-American. In the preliminary data provided in this study, it was cautioned that this sample was small, nonrandom and predominately Caucasian. Despite these limitations, there appeared to be a positive response. Using pre- and post- questionnaires of PTS and anxiety, decreased symptoms for mothers, fathers, survivors and siblings were found. These effects were seen across the family system, reinforcing the need for family based interventions. As the families reorganize after cancer treatment, the family members may benefit from support in which they can talk about their experience and help to restructure their family system. It was also noted that the families appreciated having the opportunity to share with other cancer survivor families, citing that they have been through similar experiences and it may be easier to share with them.

In a subsequent clinical trial, Kazak, Alderfer, Streisand, Simms, Rourke et al. (2004) noted SCCIP can be successful in decreasing symptoms of arousal in adolescent survivors and may help them be able to soothe themselves when experiencing physiological symptoms. It was also noted that the relevance of PTSS in fathers was evident in this clinical trial. Fathers discussed their fear of sharing their upsetting memories with their families, concerned that it might negatively affect their families.

These clinic-based programs provide beneficial support to cancer survivors and their families. Although not theory driven, another form of treatment and support for

child survivors of cancer and their families are residential camps.

### **Residential Camp Programs**

As cancer treatments improved and pediatric cancer patients lives were extended, more attention was focused on psychosocial and emotional support for the patients and their siblings. Residential camp programs became a way to meet the social needs of these children and their families (Murray, 2001; Shields et al., 1985). Martiniuk (2003) presents the role of camping programs for children with cancer and their families. Therapeutic recreation is defined as purposeful intervention designed to improve the participant's quality of life through recreation and leisure. Basic goals for therapeutic recreation can be developing emotional stability, increasing social skills, decreasing stress, improving self-efficacy, perceived control and pleasure. The evaluations of camping programs for children with cancer and their families appear to demonstrate, at minimum, short-term effects for increases in self-esteem/self-image, friendships, knowledge about cancer, level of activity, positive mood state, locus of control, and improved family function (Conrad & Altmaier, 2009; Packman et al., 2004; Shields et al., 1985; and Zebrack, Oeffinger, Hou, & Kaplan, 2006). The following is a review of different camps that cater to childhood cancer survivors and their families.

**Camp Good Times.** Shields et al. (1985) discuss one of the first residential camp programs operated by the Southern California Children's Cancer Service which, in time, became Camp Good Times. The goals of this camp were to develop self-confidence and independence; create new friendships; build a spirit of group identity and skills; and explore new and existing interests. These goals were established to provide the children with an opportunity to enjoy some of the experiences of normal childhood. One

advantage of the residential camp setting is that the children are away from those who they usually depend on the most. The founders suggest that it provides an opportunity to learn to take care of themselves, but in a setting with support and structure. As independence is gained, self-confidence is thought to grow and allows the children to achieve goals that they never thought they could do. Shields et al. posit that child cancer patients and survivors are able to develop new friendships without feeling ostracized or different while in a camp setting with other children with cancer. Shields et al. also reported that camp allows children with cancer an opportunity to use skills they never thought they could acquire and begin to learn about their own potential. The children are exposed to activities such as boating, fishing, horseback riding, dance, crafts, photography, sports and drama. Shields et al. (1985) note that there are certain precautions that are necessary when developing a camp for children with cancer. Based on these recommendations, physical limitations were taken into consideration, especially when planning physical events such as hiking or active sports. They also provided room for free time, allowing the campers to interact in a non-structured manner, providing space to share their feelings and concerns with one another. Based on the camper's unique medical needs, the camp was fully equipped with a medical staff that can meet the needs of pediatric cancer patients. This article was one of the first to discuss the benefits of a residential camp for children with cancer. Based on feedback from informal discussions with the parents and campers, Shields et al. noted that parents reported the brief separation was a positive experience for both child and parent and the campers have appeared to form a sense of group identity (i.e. wearing the camp shirts to the cancer clinic and one camper requesting his cabin mates to join him at the hospital during a

relapse). Also, 85% of the campers return for subsequent sessions. Shields et al. posit that, based on narratives from the parents and children; the residential camp is a very positive experience and the campers see it as a source of growth and support.

**The Heart Connection.** The Heart Connection's oncology camp was established in 1988 for children with cancer age 5-18 years (Conrad & Altmaier, 2009). Children attending could either be in treatment or in remission. During their week at camp, the children are involved in common camp activities, such as archery, horseback riding and arts and crafts. Different age groups are put together in certain activities with the goal of interacting and team building. There are no organized events directed toward expression of feelings/emotions associated with their cancer experiences. Campers often participated in similar discussions spontaneously with fellow campers and staff throughout the week. Conrad and Altmaier's goal of their study was to understand social support in pediatric oncology patients and the interplay in specialized summer camps. The data was obtained by completion of the Child Behavior Checklist (CBCL; Achenbach, 1991) by the parents and the Survey of Children's Social Support (Dubow & Ulman, 1987) by the campers approximately two weeks after the conclusion of camp. It was noted that female participants reported receiving more emotional/information support than males. The discrepancy may be due to gender differences, where the female campers engaged in more socializing activities. The majority of the campers were white, so ethnic information was not obtained in order to protect the identity of the participants. Based on the information provided by the parents via the checklists; both genders reported receiving more social support than other children who did not attend camp. Conrad and Altmaier (2009) posit that due to the feedback, the camp setting was a highly

supportive environment for children with cancer.

**SIBS Camp.** The Okizu Foundation's SIBS (Special and Important Brothers and Sisters) Camp is a program designed to help with behavioral and psychosocial issues of siblings of pediatric cancer patients (Packman et al., 2004). The camp's goal is to provide the siblings with interaction to validate their experience with cancer and its effects on the family and to bolster self-confidence and esteem. The camp provides traditional recreation activities but adds a therapeutic element with providing a facilitated discussion about their family situations and to share tips on coping. This discussion is done toward the beginning of the week in hopes to establish a bond amongst the campers and continue the conversations throughout the week. The program is also structured to provide positive feedback from the adult counselors. The counselors are trained in techniques for recognition and reinforcement of positive behaviors. Older campers also participate in trust building activities such as a high ropes course. Packman et al. (2004) conducted one of the first empirical investigations into the effects of these types of camps based on PTSD, anxiety, quality of life, and self-esteem:

- 1. PTSD:** The percentage of campers that reported PTS reactions (UCLA PTSD index for DSM-IV; Rodriguez, Steinberg & Pynoos, 1998) reduced from 38% pre-camp to 18% post-camp. There was also a statistically significant decrease noted in the clusters of Re-experiencing, Avoidance, and Increased Arousal.
- 2. Anxiety:** The mean total anxiety sum (Revised Children's Manifest Anxiety Scale; Reynolds & Richmond, 1985) significantly decreased. It was also noted that two subscales (Worry and Social Concerns) contained statistically significant differences pre- to post-camp.

- 3. Quality of Life:** The Pediatric Quality of Life Inventory (PEdsQL; Varni, Seid & Kurtin, 1999) was administered to determine the campers quality of life based on physical and emotional health, social functioning and school functioning. The pre- and post-camp mean scores increased significantly, indicating an improvement in quality of life. In addition, there was a significant increase in the scores of the emotional health, social functioning, school functioning and psychosocial health domains.
- 4. Self-Esteem:** The Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965) was administered to assess for camper's level of self-worth and confidence. The self-esteem scores decreased significantly, indicating improvements in self-esteem.

According to these findings, all siblings attending this camp had decreased PTS, decreased anxiety, improved quality of life, and improved self-esteem when measured three months following camp (Packman et al., 2004).

In a subsequent study, Packman et al. (2005) evaluated the SIBS Camp and the pediatric health-related quality of life (HRQOL) in siblings using the Pediatric Quality of Life Inventory (PedsQL; Varni et al., 1999), parent and child versions; and interviews and satisfaction surveys completed by both child and parents. Results from the PedsQL indicate that the total score decreased significantly pre- to post-camp, indicating an improvement in HRQOL. Also, there was a significant decrease in four of the domains: emotional, social, school and psychosocial. In the qualitative element they discovered that the responses resembled Yalom's (1995) therapeutic factors in group therapy as discussed in Chapter 9. Packman et al. (2005) described six core psychosocial themes, based on Yalom's framework; that emerged from the qualitative data:

1. Group cohesiveness: Described as a sense of trust and belonging and being supported by a group.
2. Development of socializing techniques: Refers to social learning, increase in social skills and peer relationships.
3. Universality: Described as shared personal experiences and the feeling that others understand your experience.
4. Instillation of hope: Refers to a sense of optimism from seeing improvement in others as well as growth, support and confidence.
5. Interpersonal learning: Described as receiving feedback from others and learning healthy ways of relating to peers and adults.

Overall, Packman et al. (2005) posit that the social opportunities and support at SIBS Camp may have accounted for the improvement in social and emotional functioning in the children.

**Camp B&ST.** Camp Brothers and Sisters Together (Camp B&ST) was established in upstate New York in 1982 for siblings of pediatric cancer survivors (Carpenter et al., 1990). While the main focus of this camp was recreation; it was also designed to provide siblings with medical information and peer support. On the second day of the week-long camp, each camper attended a small-group medical information session. The groups were divided into two age groups (6-11 and 12-17 years). The sessions were highly experiential and hands-on. Various medical terms, procedures, and therapies were defined and their function explained. It was determined that the younger group benefit from repeated exposure to the information, whereas the older group appeared to achieve a high degree of understanding and knowledge about cancer-related

information. According to this study, the medical information component appears to help siblings gain a greater understanding of the patient's cancer experience and to decrease some of the common misconceptions regarding the illness.

**Island of Hope.** Maslow (2006) describes a program called Island of Hope, a week-long outdoor-oriented program for teenage survivors of cancer. This program was run out of Boston Harbor by the Robert J. Kennedy Children's Action Corps. This camp provided an opportunity for childhood survivors of cancer to reduce their social isolation by becoming a part of the group, decrease their fears regarding certain physical symptoms by learning to be "comfortable" with discomfort, and can push and challenge themselves physically. Based on pre- and post-camp questionnaires, the teens reported that they learned about how cancer had changed them for the better and were able to recognize the positive aspects of the experience. The families report feeling less alone based on the social support of the other families and reunions offered throughout the year.

**Camp Māk-a-Dream.** The Young Adult Survivor Conference at Camp Māk-a-Dream is a 4-day retreat for off-treatment survivors of cancer (Zebrack et al., 2006). The retreat combined recreation activities and seminars focusing on different topics such as: advocacy, mentorship, public policy, individual survivor needs, late effects and self care, and creating connections amongst fellow cancer survivors. In the post-retreat program evaluation form, participants reported that they most enjoyed meeting and getting to know fellow cancer survivors. By connecting with fellow campers, they stated that if felt like they were a part of a community where everyone seems to have similar emotions, feelings and experiences. The seminars provided information about cancer and its effects, the participants reported that they felt more confident about themselves and how

they wanted to direct their lives.

## **Chapter 9: Resiliency and Group Work**

Woodcock discusses his belief that group work can promote resiliency amongst its group members (2001). He posits that there are three elements of group work that are helpful: the group's capacity to be resilient, its capacity to notice resiliency among group members, and its capacity to know that group members are resilient.

### **What is resiliency?**

Hirayama (2001) posits that there are two approaches to conceptualizing resiliency: protective factors and protective mechanisms or processes. Protective factors are defined as qualities that buffer one from harm or injury, or at minimum, lessen the potential shock associated with an event or crisis. Michael Rutter (1987) posits that resiliency is a result of protective mechanisms or processes rather than protective factors, stating that these traits are not permanent attributes of individuals but healthy responses to stress circumstances at different points in time. Rutter states that resiliency can be enhanced by facilitating four protective mechanisms:

1. Reduction of risk impact.
2. Reduction of negative chain reactions that follow exposure to the threatening event and contribute to long-term effects.
3. Enhancing self-esteem/self-efficacy, developed through personal relationships, new experiences and accomplishing tasks.
4. The opening up of opportunities or completing important life transitions.

Gitterman (2001) discusses that the central element of resilience in children lies in the

power of recovery and sustained adaptive functioning. He defines protective factors as biological, psychological, or environmental components that contribute to preventing a stressor or lessen its impact. Gitterman reports that the following play an important role in resiliency in children: temperament, family patterns, external support and environmental resources.

### **Group Work**

Mutual support groups are comprised of individuals or families who share a similar life problem (Danielson, Hamel-Bissell, & Winstead-Fry, 1993). Part of their success stems from sharing experiences about a problem and discovering a bond with others with similar experiences. According to Yalom (1995), interactional group therapy displays its primary therapeutic power through the following 11 factors:

- Instillation of Hope: encouragement that recovery is possible
- Universality: feeling of having problems similar to others, and that you are not alone.
- Imparting information: teaching about problem and recovery.
- Altruism: helping and supporting others.
- The corrective recapitulation of the primary family group: identifying and changing the dysfunctional patterns or roles one played in primary family.
- Development of socializing techniques: learning new ways to talk about feelings, observations and concerns.
- Imitative behavior: modeling another's manners & recovery skills.
- Interpersonal learning: finding out about themselves & others from the group.
- Group cohesiveness: feeling of belonging to the group, valuing the group.

- Catharsis: release of emotional tension.
- Existential factors: life & death are realities.

When designing a specialized therapy group, such as a cancer support group, Yalom (1995) suggests three steps: (1) assess the clinical situation, (2) formulate appropriate clinical goals, and (3) modify traditional technique in order for it to be responsive to the situation and goals established. He encourages that when creating the goals, they are appropriate to the clinical situation and are achievable in the time frame allotted.

### **Groups and Resiliency**

Hirayama (2001) discusses the nature of group work focusing on the enhancement of resiliency in children. He reports that it is not much different from other groups, except that it is more prevention oriented versus treatment oriented. It is also a growth oriented approach, focusing on the development of strengths rather than reducing deficiencies in children. Hirayama proposes to adopt an eco-systems framework; utilizing family, community and social support networks. He discusses organizing a group focusing on the following 8 protective mechanisms:

1. Develop problem solving skills.
2. Develop a broad range of interests and goals.
3. Develop the ability to attract adults and peers to provide critical support.
4. Develop the ability to nurture others and take responsibility for others.
5. Develop the ability to make some sense out of chaos, assign some purpose or meaning to what is happening, have understanding of interpersonal situations.
6. Develop a child's ability to distance self psychologically from adversity.
7. Develop a range of positive personality traits (e.g. positive outlook on life; being

good natured, affectionate, and curious; sense of humor; and ability to express feelings in a healthy way).

8. Develop a sense of self-esteem, a realistic sense of personal control, and decrease helplessness.

Hirayama (2001) reports that it is important to pay attention to the structure and functioning of the child's family and external support systems. When working with the family, protective mechanisms are established through: instilling positive family values; encouraging positive communication and social interaction; increasing flexibility in family roles; exercising control over children; and providing academic support to their children. Community protective mechanisms relate to the nature of external supports available to children and their families. Hill (1998) posits that informal and formal groups are a good mechanism for resiliency in African-American children and families, as they help mediate the effects of stressful circumstances or negative risk factors.

One aspect of resiliency is the belief that positive changes can result from the negative experience (Lechner, Stoelb & Antoni, 2008). Lechner et al. refer to this belief as benefit finding (BF, 2008). They posit that there are a number of group characteristics that can contribute to the development of BF. Some of these are intrinsic in Yalom's (1998) group work, while others are intra- and inter-personal variables that are often focused on in group-based interventions (e.g. enhancing hope and optimism; and encouraging emotional expression and acceptance). Lechner et al. (2008) argue that the following variables may have the greatest impact on BF in a group setting: supportive environment; social support; cognitive processing; emotional expression and emotional processing; and coping.

Lechner et al. (2008) also explored the relationship between sociodemographic variables and BF. They argue that younger participants in their cancer groups are more prone to growth (in regards to BF) than their elder counterparts, possibly due to a greater openness to learning and change. In their sample of mixed cancer patients, gender did not significantly change the levels of BF. In regards to race/ethnicity, Lechner et al. indicated that there are very few studies that have looked at it in regards to BF in cancer. In their sample of women with early stage breast cancer, non-White ethnicity was associated with higher perceptions of found meaning. In a related study, Kinsinger et al. (2006) identified that Hispanics and non-Hispanic Blacks endorsed higher levels of BF than non-Hispanic Whites in a sample of male prostate cancer patients.

## **Chapter 10: Camp SAFARI**

### **(Survivors and Families are Resilient)**

As discussed earlier, approximately 12,060 children under the age of 15 will be diagnosed with cancer in 2012 (Cancer in Children, 2011). There has been research stating that, in general, school-aged survivors adjusted well to the cancer experience (Maurice-Stam et al., 2008, Zeltzer et al., 2009). Although these studies report healthy adjustment, research on more specific pediatric psycho-oncology outcomes demonstrated that there is consistently a group of children and family members who do not cope well with the cancer or who have personal, social and family difficulties (Kazak et al., 2005; Levin Newby et al., 2000; Zeltzer et al., 2009). As success rates in treatment increase, Friedman and Meadows (2002) identified that the development of late-effects of cancer treatment provides opportunities for psychosocial intervention, especially for the subgroup of families that are high risk for persistent difficulties. The Adolescent Resilience Model (ARM, Haase, 2004) is a comprehensive and integrative representation of the process of resilience and quality of life in adolescents with cancer and has been applied to clinic-based programs to help treat adolescents and their families. Residential camping programs for children with cancer and their families have demonstrated, at minimum, short-term effects for increases in self-esteem/self-image, friendships, knowledge about cancer, level of activity, positive mood state, locus of control, and improved family function (Conrad & Altmaier, 2009; Packman et al., 2004; Shields et al., 1985; and Zebrack et al., 2006). The following is an application of the Adolescent

Resilience Model to a program conceptualization for a residential camp for child cancer survivors and their families.

### **Application of the Adolescent Resilience Model**

The advantage of using ARM (Haase, 2004) in a camp setting is having the opportunity to address one or many of the components of the model, based on the goals and needs of the campers. The following is a breakdown of the ARM components in regards to the survivors and their families.

**Individual risk.** This component is composed of evasive, fatalistic and emotive coping strategies. They are used as protection in crisis situations, but create problems when they are sustained and used without development of positive coping skills (Haase, 2004). CCS are reported to experience a sense of loss of control (over their lives and bodies); decreased sense of self-confidence and self-identity; poorer self-concepts and had a more external locus of control than their healthy counterparts (Askins & Moore, 2008; Greenburg et al., 1989; Reinfjell et al., 2009). Siblings display symptoms of anger, sadness, guilt, worry and feelings of emotional neglect (Patterson et al., 2004; Quin, 2004; Sloper and While, 1996; and Tiller et al., 1977). Parents of CCS often report feelings of helplessness, being numb and overwhelmed, and a loss of ability to cope with stressful events (Van Dongen-Melman et al., 1998).

**Illness-related risk.** CCS often express illness-related psychosocial symptoms, such as feeling physically ill/weak/sick and being self-conscious about people's reactions (Woodgate, 2003). There are chronic fears based on fear of recurrence, disability and inability to fulfill role expectations (Chou & Hunter, 2009). The uncertainty of the disease and related fears increase the probability of pain, anxiety, mood disturbances

(Haase, 2004). CCS, siblings and parents all report more symptoms of depression and anxiety, in relation to the control groups (Reinfjell, 2009; Sloper & While, 1996; and Van Dongen-Melman et al., 1998). Stuber et al. (1996) identified that 12.5% of the survivors in their study reported a level of symptoms that correlate to a clinical diagnosis of PTSD. Alderfer et al. (2003) found that adolescent siblings of child cancer survivors report symptoms of PTS. Nearly half of the siblings had mild post-traumatic stress reactions and almost a third had moderate to severe reactions. Barakat et al. (1997) found that the parents of childhood cancer survivors reported greater symptoms, such as intrusive thoughts, hypervigilance, and distress at reminders of treatment at a greater frequency and intensity than their child who had cancer.

**Social protective.** During treatment, CCS are isolated from their peers (school and social) and perceive a decrease in social support and acceptance (Askins & Moore, 2008). Siblings also experience a decrease in social support, as most of the time and attention has been shifted to CCS and their survival (Sloper and While, 1996). Since cancer affects the whole family, it is imperative to incorporate each member in treatment (Kazak et al., 2003). Social support has been identified as protective against the development of distress and psychopathology, as well as adjustment to the stressors of cancer (Helgeson & Cohen, 1996).

Families benefit from knowing others with the same or similar concerns, because they can then make comparisons that assist them to place their own experience in context or have role models who provide hope (Haase, 2004; McCubbin & McCubbin, 1993). It is important to provide support to the CCS and siblings to maintain peer relationships and

build new ones (Haase, 2004). It is also important to provide support from the oncology team, community and workplace for the entire family (McCubbin & McCubbin, 1993).

**Family protective.** Throughout the treatment process, the family experiences shifts in role responsibilities, outside stressors, and intrapersonal concerns (Patterson et al., 2004). Because of these changes there is a decrease in family support, reports of family members feeling isolated, poor family functioning and difficulty with behavioral control (Streisand et al., 2003). Partners report experiencing the cancer diagnosis and treatment differently; therefore coping with it in alternate ways (Van Dongen-Melman et al., 1996). These differences can cause feelings of loneliness in the other partner, as they both imply that the other partner is restricted in expressing emotions. This can cause isolation, loneliness within the relationship and may cause marital friction (Quin, 2004). The parents reporting marital distress may triangulate with the children as a form of defensive coping (Alderfer et al., 2005). These shifts in role responsibility and parental distress have been reported to negatively impact the siblings (Tiller et al., 1977).

Strengths that have been reported by families are: recognizing support from extended family; changes in family appraisal; and the ability for rapid mobilization and reorganization in response to a crisis (McCubbin et al., 2002). Resilient families appear to be flexible, cohesive, able to find new meaning in life, and communicate and problem-solve effectively (Haase, 2004; McCubbin & McCubbin, 1993).

It is important to address the family needs due to the direct effect the parents functioning has on the child. When the parents are doing well, they can parent better, manage the child's emotions and model appropriate coping skills for the child and his/her siblings (Goodman, 2007). Goals of the Family Support component are to increase

adaptability, cohesion, communication and perceived support within the family system to provide the family with tools to help change family structure, role relationships/responsibilities in response to stressors while still maintaining emotional bonds

**Individual protective.** This component is comprised of confrontive, optimistic and supportant coping strategies, which are linked to positive outcomes such as greater resilience, sense of mastery, confidence, self-esteem and better quality of life (Haase, 2004). Goals of the Individual Protective component are: to increase individual positive coping mechanisms (in relation to individual and illness-related risk symptoms); help gain derived meaning from their cancer experiences; learn adaptive skills; and help gain confidence in self (physically and emotionally) (Chou & Hunter, 2009; Haase, 2004).

**Outcome: Resilience.** Within the Resiliency Model of Family Stress, Adjustment and Adaptation, resiliency is defined as the positive behavioral patterns and competencies that both the individual and family demonstrate under stressful times that in turn help maintain the family system (McCubbin & McCubbin, 1993). The individual aspects are composed of a sense of confidence (perception that you have some control over events in the environment), self-transcendence of the cancer experience and self-esteem (Haase, 2004). Self-transcendence is defined as extending one's self inwardly in introspective activities, outwardly through concerns of others and temporally in a way that the perceptions of your past and future enhance the present (Haase, 2004).

**Final Outcome: Quality of Life.** According to ARM, quality of life is defined by a global sense of well-being (Haase, 2004). Elements of quality of life are as follows: increased sense of self-sufficiency; striving to be successful; having positive

relationships; future orientation; increased hope (Haase, 2004); and individual members functioning well and family unit has a sense of balance in carrying out responsibilities in family and community (McCubbin & McCubbin, 1993).

### **Goals of the Camp**

Based on ARM (Haase, 2004) and research attained about the survivors, siblings and parents, the following are the goals we are trying to achieve at the residential camp with hopes of helping the families become more resilient:

- 1. Provide social support.**
- 2. Increase adaptive skills.**
- 3. Increase positive coping skills.**
- 4. Increase family cohesion, communication and support.**
- 5. Be a witness to the cancer experience.**
- 6. Help gain self-confidence.**
- 7. Gaining meaning: why me?**

### **Rationale for a residential camp setting**

Research indicates that residential camp programs can be an effective way to meet the social needs of CCS and their families (Murray, 2001; Shields et al., 1985). Roberson (2010) conducted a study to determine how campers perceived social support and also understand what processes at camp led the campers to perceive feelings of social support. Roberson identified themes using House's (1981) four categories of social support:

1. Emotional support: Campers reported that they were encouraged to participate by the counselors and other campers but stated that there was no ridicule associated with not participating. They reported that group sessions were a supportive

environment and were able to talk about feelings. The campers also stated that empathy appeared genuine from others who were able to relate to their own lived experience.

2. Informational support: Campers reported receiving clarification about their ill sibling's condition and information that provided an adaptive skill for the camper.
3. Instrumental support: This theme occurred as a result of campers and staff being helpful and thoughtful, which led to the campers feeling like they had gained adaptive coping skills.
4. Appraisal support: Themes in this section indicate that the campers perceived appraisal support by having an ability to relate to others at camp, being in an empathic environment, and being in a safe and supportive environment.

Social support appeared to be an important mechanism for the campers. Roberson's (2010) study suggests that intentionally designed camps have the ability to impact a broad range of attitudes and behaviors.

Wellisch, Crater, Wiley, Belin and Weinstein (2006) conducted an evaluation of pediatric cancer patients and their siblings to assess their experiences and affective changes after a 1-week camp experience. They concluded that both memories and pleasure about camp remain intact and affective improvements were demonstrated and became more pronounced over time. Briery and Rabian (1999) report in their study that specialized camping experiences can improve attitudes toward illness in children with a pediatric illness or disability. The children in their study demonstrated more positive attitudes about their illness at the end of the 1-week camp than at the start. This finding was consistent across all three diagnostic groups evaluated (asthma, diabetes, and spina

bifida), indicating that the observed benefits of camp do not appear specific to one condition or group.

## **Chapter 11: Manual for Camp SAFARI (Survivors and Families Are Resilient)**

### **Mission**

The camp will be a multidisciplinary program, providing clinical interventions to address risk factors such as anxiety, depression, self-confidence, post-traumatic stress symptoms, and family relationships. The program will be grounded in the Adolescent Resilience Model (Haase, 2004), providing a strength-based approach to a comprehensive and integrated model of risks, protective factors, resiliency and quality of life of adolescent cancer survivors and their families. The primary method of intervention will be groups, supporting the research stating the need for social support, group validation and universality (Kazak, 2005; Levin Newby et al., 2000). The aim of this program is to help each camper improve their global sense of well-being, increase self-confidence, develop positive coping skills, and increase family cohesion, communication and support.

### **Participants**

This camp will be open and available to families with a recent survivor of childhood cancer. This includes parents and/or legal guardians and siblings. This is a conceptualization for a pilot camp program for adolescents (both survivors and siblings), ages 11-18, based on the formulation of the ARM (Haase, 2004). The camp is designed to address the needs of the families soon after remission. Based on this, the camp will be offered to each family for one visit up to one year post remission. After the camp weekend, referrals will be given to recurring camping and support programs near each

family's community.

### **Pre-Camp Screening**

Based on the concept that there is a consistent group of children who are in need of services, Kazak, Rourke et al. (2007) created a way to conceptualize these families and provide a framework for current and future interventions. Kazak, Rourke et al. (2007) divided the families into three different groups: Universal, Targeted and Clinical/Treatment. *Universal*, the largest group, are the families that are distressed but resilient. *Targeted* are the families in acute distress, present with risk factors (such as pre-existing child problems, psychosocial stressors, family problems and poor coping skills) and are in need of services. *Clinical/Treatment* is the group of families that are at highest risk, with persistent and/or escalating distress.

Prior to camp each family will be screened for appropriate fit based on time since remission, after-treatment symptoms, and age and size of families. Using the framework described by Kazak, Rourke et al. (2007), we will be focusing on families in the Targeted group. The pre-camp measures (described in next section) will be used to identify the needs of each family and appropriateness for the camp.

Prior to camp each family will complete background information, consisting of family history, illness history, and goals for the camp. We will obtain releases of information and contact the oncology departments in order to assist in continuity of care.

### **Outcome Measures**

Pre-, Post- and Post-Post- camp measures will be administered to: assess for appropriateness for the camp; create a baseline; and be used as an assessment tool to determine the efficacy of the camp. Each parent will complete the Connor-Davidson

Resilience Scale (CD-RISC, Connor & Davidson, 2003), the SF-36v2 (Ware, Kosinski & Dewey, 2000), and the Psychological Assessment Tool (PAT2.0, Pai, Patino-Fernandez et al., 2008). The survivors and siblings will both complete the SF-36v2 (Ware, 2000) and the Resiliency Scale for Children and Adolescents (RSCA, Prince-Embury, 2007).

During the camp, the participants will be given a brief assessment tool to measure the effectiveness of the group after each subgroup session. We will use the Therapeutic Factors Inventory-19 (TFI-19, Joyce, MacNair-Semands, Tasca, and Ogrodniczuk, 2011) throughout the weekend.

**Connor-Davidson Resilience Scale (CD-RISC).** The CD-RISC is a brief self-rated assessment measure used to help quantify resilience and develop treatment goals (Connor & Davidson, 2003). This measure contains 25 items, carrying a 5-point range of responses (0-4), with higher scores reflecting greater resilience. The CD-RISC has been tested in the general population and with clinical samples (psychiatric and primary care), and has demonstrated sound psychometric properties, with good internal consistency and test-retest reliability. It exhibits validity in relationship to other measures of stress and hardiness, and reflects different levels of resilience in differing populations (e.g. general population vs. primary care patients).

**SF-36v2.** The SF-36v2 is a multi-purpose, short-form health survey with 36 questions (Ware et al., 2000). It yields an 8-scale profile of functional health and well-being scores (Physical functioning, Role-physical, Bodily pain, General health, Vitality, Social Functioning, Role-emotional, and Mental health) as well as physical and mental health summary measures. The SF-36 has proven useful in surveys of general and specific populations, comparing the relative distress of diseases, and in differentiating the

health benefits produced by a wide range of different treatments. The SF-36 is available in both standard (4-week) and acute (1-week) recall versions, which will be used in the post-camp and the post-post-camp assessment.

**Psychological Assessment Tool (PAT2.0).** The Psychological Assessment Tool (PAT2.0) is a brief screening instrument used to identify families at risk for preexisting, ongoing and escalating distress (Kazak, Prusak et al., 2001; Pai et al., 2008). The 20-item screener is based on the Pediatric Preventative Psychosocial Health Model (Kazak, Rourke et al., 2007), and is broken into 10 potential predictors of ongoing family distress: (1) family structure, (2) family resources, (3) social support, (4) child knowledge, (5) school attendance, (6) child emotional and behavioral concerns, (7) child maturity for age, (8) marital/family problems, (9) family beliefs, and (10) other stressors. The research reports strong internal consistency and 2-week test-retest for the PAT2.0 (Pai et al., 2008). Validity with standardized measures of child, parent and family function are strong and in the expected directions.

**Resiliency Scale for Children and Adolescents (RSCA).** The RSCA is an assessment tool to identify and quantify core personal qualities of resiliency in youth (Prince-Embury, 2007). The three sections: sense of mastery, sense of relatedness, and emotional reactivity create the 64-item measure designed to identify resiliency factors in children and adolescents aged 9-18. Test-retest reliability correlation coefficients for the three scales ranged from .79 to .95. Further research indicated that race/ethnicity of the child or adolescent did not create unique variance when parent education level was controlled (Prince-Embury, 2009).

**Therapeutic Factors Inventory-19 (TFI-19).** The TFI was created to provide a

comprehensive measure to determine the presence or absence of therapeutic factors in group (Lese & MacNair-Semands, 2000). The TFI-19 was developed to assess therapeutic factors in group in a more efficient manor than that TFI (Joyce et al., 2011). The 19-item inventory has demonstrated good sensitivity to change across time, good discriminant validity, and is significantly predictive of posttreatment levels of depression, anxiety, general symptomatic and interpersonal distress.

### **Staff**

The goal of the staff is to provide social/emotional support while helping the families enjoy their weekend at camp. The staff will consist of an Executive director, senior counselors, junior counselors, buddies/support staff and outside staff.

1. Senior counselors will be licensed clinicians (Psychologists, Marriage and Family Therapists, Professional Counselors, and Psychiatrists) and will be responsible for leading one or more of the group sessions and provide support to family and staff.
2. Junior counselors will be psychology or masters-level interns or trainees. They will be responsible for co-facilitating one or more of the group sessions and provide support to families.
3. Buddies and support staff provide support to families and help with organization and running of the camp. Buddies will be non-clinical volunteers or first year doctoral or master-level students.
4. There will be a physician or nurse practioner on staff in order to provide medical support to the families

Prior to the camp weekend, the staff will meet for training on the mission and goals of the camp. The Senior and Junior Counselors will also receive training on how to facilitate

each group session and how to administer the outcome measures.

### **Schedule**

The following is a proposed template of the schedule for the weekend. This will be adjusted based on location of the camp, the make-up of the families and clients' needs. Handouts describing each group session are attached in the Appendix.

There will be structured group activities, whole camp activities and also ample amount of free time for the families to connect on their own time.

- a) Friday PM:
  - i) Check-in and Introductions
  - ii) Session I:
    - (1) Multi-Family Group: Going on a Safari
  - iii) Family choice of activities: camp fire, board games, etc.
- b) Saturday AM:
  - i) Breakfast and Review of Today's Schedule (9 am)
  - ii) Session II (10-11 am)
    - (1) Parents, survivors, siblings: Introductions and Coping
  - iii) Session III (11-12 pm)
    - (1) Parents: Open Communication
    - (2) Survivors and siblings: Physical challenge
- c) Lunch (12-1 pm)
- d) Saturday PM
  - i) Free Time (1-3 pm)
  - ii) Session IV: (3-4 pm)

- (1) Parents, survivors, siblings: Story Telling
- iii) Session V: (4-5:30 pm)
  - (1) Whole camp group: Story Telling continued.
- iv) Dinner (6-7 pm)
- v) Evening camp event (depending on location of camp...maybe camp fire, dance, etc...)
- e) Sunday AM:
  - i) Breakfast and Review of Today's Schedule (9am)
  - ii) Session VI: (10-11 am)
    - (1) Parents, survivors, siblings: What has changed? What will happen in the future?
  - iii) Closing Ceremony: Revisit the Safari

## **Chapter 12: Future Research**

This program conceptualization is intended to be a template for a pilot program camp. The next step would be to develop a camp curriculum, facilitator manual, research funding and create a business plan.

Upon completion of the first camp, there will be a lot of data available to analyze, with the in-camp measures and the pre-, post- and post-post-camp measures. These measures will assist in understanding the effectiveness of the program and each component. In turn, the manual can be adjusted accordingly.

Additionally, this program conceptualization was set up to evaluate the efficacy of incorporating a theory-based model into a residential camp setting. The outcome measures were intended to evaluate the efficacy in a broad manner. Future research is recommended in evaluating and refining each specific goal and intervention.

Integrating the entire family into a weekend-long camp creates many variables that are difficult to account for. Further research regarding sibling response, parental relationship issues, socio-economic status, and diversity elements are some of the variables that would deserve more attention.

## **Appendix: Camp Session Information Sheets**

### **Session I: I'm going on a safari!**

#### *Facilitator Guide*

##### **Background**

Haase (2004) posits that resilient families have better psychosocial outcomes. Components of a resilient family are: flexibility, cohesion, able to find new meaning in life and able to communicate and problem-solve effectively. The goal of the activity is to establish a baseline in their ability to communicate and problem-solve as a family. It also provides an opportunity to identify each member's role in the family. Creating a family "team name" will also start building family cohesion that will continue throughout the weekend.

##### **Method**

Each family will be grouped individually and will be provided with the "I'm going on a safari" handout, a couple sheets of large paper and markers. Their goal is to complete the prompts on the handout and create their team flag which will then be posted with the other family flags in a common area. Once each family has completed their materials, the lead facilitator will invite each family to present their "team" to the rest of the families.

Facilitators' roles: The lead facilitator will introduce the activity to the group and facilitate the sharing portion of the activity. The counselors and buddies will circulate amongst the families to provide support and encouragement. Counselors will also need to be alert to any issues that may need to be addressed during camp or require additional support; such as family fighting, lack of communication, behavioral concerns, or individual symptoms (e.g. tearfulness, isolation) and report back their concerns to the lead facilitator.

##### **Materials**

- Large sheets of paper
- Colored markers
- Family handouts

##### **Outcome of Activity**

The goal of this activity is to build family cohesion and communication. This goal will be reinforced throughout the weekend and the level of cohesion and communication will be evaluated at the end of the weekend at the Safari revisit session.

# I'm going on a safari!

## *Family Guide*

Imagine that you and your family have been invited to go on a safari in the wild. In any effective exploration, there is a team that works together to make sure everyone gets to where they want to go, are safe from wild animals and have a good time!

Your task is to create your team.

1. What is the name of your Safari Expedition?
2. Where are you going?
3. Who are the players in your team?
  - Leader:
  - Map person:
  - Hunter:
  - Cook:
  - Activities Director:
  - Who else?
4. Please utilize the art supplies and create your team flag.

When you are finished, please share with the other Safari Teams!

## **Session II: Parents, Survivors, Siblings**

### *Facilitators Guide*

#### **Background**

Yalom (1995) argues that many patients enter group therapy feeling like they are alone in their pain, that no one else understands, or will accept, their thoughts or feelings about their experience. Yalom's therapeutic factor of universality addresses this sense of isolation and uniqueness. He posits that the disconfirmation of the patient's feelings of isolation and uniqueness is a powerful source of relief. After hearing other members disclose similar experiences, patients report a decrease in feelings of isolation.

The experience of cancer evokes a wide range of affective responses (e.g. fear, anxiety, confusion, guilt, shame, anger) (Cordova, 2008). Often cancer patients and family members will try to avoid thinking about it in hopes of reducing emotional arousal. This avoidance is further reinforced by pressures to "stay positive" by family and community. According to Cordova (2008), educating the survivors and families about these common reactions, and helping them redefine what "staying positive" means, can increase acceptance of the emotions involved, which can provide them tools to better process and cope with the cancer experience.

#### **Method**

This is the participants first group session of the weekend. In order to start facilitating a sense of universality, start the session with introductions (including role in cancer experience, brief description of experience, and any personal goals for the weekend). After completion of introductions, invite a discussion regarding emotions and how they have managed them throughout the process.

#### **Outcome**

The goals of this first session are to begin instilling a sense of universality in the group members and to increase flexibility and coping in regards to emotions. At the completion of the session, please administer the TFI-19.

## **Session III: Parents**

### *Facilitators Guide*

#### **Background**

Partners report experiencing the cancer diagnosis and treatment differently; therefore coping with it in alternate ways (Van Dongen-Melman et al., 1996). These differences can cause feelings of loneliness in the other partner, as they both imply that the other partner is restricted in expressing emotions. It is common for family members to attempt to conceal emotional reactions to avoid upsetting each other (Cordova, 2008). When someone tries to hide their emotions, it is common that survivors and family members are experiencing similar emotional reactions in isolation and without the support needed. This can cause isolation, loneliness within the relationship and may cause marital friction (Quin, 2004). Orienting parents to these common dynamics and instilling an open line of communication can enhance mutual support and improve relationship satisfaction.

#### **Method**

This group will be a space for the parents to discuss their emotions regarding the cancer experience and what they need in the form of emotional support from their partners (or other support systems). Also, this will be a time to brainstorm with parents on how to encourage these lines of communication with the rest of the family.

#### **Outcome**

The goal of this session is to increase communication amongst the parents and to provide skills that they can instill in their respective families. Again, please have members fill out the TFI-19 in order to properly evaluate the efficacy of this group and topics discussed.

## **Session III: Survivors and Siblings**

### *Facilitators Guide*

#### **Background**

Therapeutic recreation is defined as purposeful intervention designed to improve the participant's quality of life through recreation and leisure. Basic goals for therapeutic recreation can be developing emotional stability; increasing social skills; decreasing stress; and improving self-efficacy, perceived control and pleasure (Conrad & Altmaier, 2009; Packman et al., 2004; Shields et al., 1985). Shields et al. (1985) reported that camp allows children with cancer an opportunity to use skills they never thought they could acquire and begin to learn about their own potential.

#### **Method**

The survivors and siblings will be in their separate groups for this activity. This will adjust based on the location of the camp. The goal is to find an activity that will facilitate group cohesion and support through a physical activity (ropes course, obstacle course, etc.). Shields et al. (1985) note that there are certain precautions that are necessary when developing a camp for children with cancer. Based on these recommendations, physical limitations will be taken into consideration when planning this activity.

#### **Outcome**

The goal of this session is to build group cohesion, increase social and problem solving skills. Please have the campers complete the TFI-19 upon completion of the activity.

## **Session IV: Parent, Survivor and Sibling Groups**

### *Facilitators Guide*

#### **Background**

Often, the cancer experience can be viewed as a “blur”. The process of detection, diagnosis and treatment can be so fast and anxiety provoking; participants often don’t have time (or the correct environment) to process the experience (Cordova, 2008). Helping survivors and family members construct a coherent narrative about what they have been through can help develop a sense of understanding and control. Telling this story can help them access and process strong affective reactions linked to their experience, and emerge feeling stronger (Cordova, 2008).

#### **Method**

Each subgroup will prepare a presentation about their cancer experience. Facilitate discussion on their experience and how they will present it. Encourage groups to be creative (create a play, poem, art work, etc.). Also, encourage them to talk about what you learned about yourself and what good (if any) came out of the experience. A good way to start may be to identify what they want the others to know that they may not know.

#### **Materials**

- Paper
- Colored markers
- Other arts and crafts materials
- Stage props (if available)

#### **Outcome**

The goal of this activity is for the subgroups to work collaboratively to create their shared experience. The TFI-19 will again be administered.

# **Session V: Camp Group Session**

## *Facilitators Guide*

### **Background**

Undergoing a challenging time may disrupt previously held beliefs about one's self and the world, and the revision of these beliefs is argued to be a major component in the development of benefit finding (Lechner et al., 2008). Revision of beliefs, or schemas, can be achieved through cognitive processing. Cognitive processing involves reflecting on the events in a deliberate manner and coming to terms with the changes that have occurred due to the event. Lechner et al. (2008) suggest that group-based interventions may play a critical role in this process for people affected by cancer, as different members of the group may have already completed some of the cognitive processing and can provide support or be a role model for others who are starting their process.

### **Method**

This is a full camp group. Each subgroup will present their cancer experience as a unit to the rest of the camp. Then each family will sit together and there will be a facilitated discussion regarding hearing each experience and what did people learn/already know. Then brainstorming on how we can support each member of our families through the continuing cancer experience.

This group will be led by a Senior Counselor. During the group other counselors are to be distributed amongst the participants, observing and identifying any individuals in need of extra support.

### **Outcome**

The goal of this activity is for the subgroups to be a witness to their family members' cancer experience and help provide family support.

## **Session VI: Parents, Survivors, Siblings**

### *Facilitators Guide*

#### **Background**

There are a lot of losses associated with the cancer experience. Helping participants examine what has and hasn't changed can enable them to identify losses and recognize who they are now (Cordova, 2008). Helping them identify enduring qualities, abilities and roles can help them develop a strengthened sense of identity. It is also important to allow survivors and families to talk about their ultimate worries and concerns. Many believe that if they talk about their greatest concerns it will make them "depressed", cause them to come true, represent a lack of hope or burden others. Cordova (2008) posits that survivors or family members that have difficulty facing their concerns will undermine the goal of focusing on life in the present. Talking openly about these fears can allow them to identify solutions, express emotions, and also reinforce that they are not alone in these worries (Cordova, 2008; Yalom, 1995).

#### **Method**

This is the final individual subgroup session. Allow time for the members to process their experience with cancer and at camp. Discuss the changes associated with the cancer experience and how to incorporate them into their current lives. Facilitate a conversation regarding their current fears (e.g. recurrence, physical effects, family stress, etc.) and the effects they have individually and as a family.

#### **Outcome**

The goals of this group are to provide a space to identify the changes and fears associated with cancer within their subgroups. At the end of this session, the complete TFI will be administered.

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