THE EFFECTIVENESS OF CHILDHOOD CANCER SURVIVORSHIP PROGRAMS IN CALIFORNIA

A Project

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by

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Hester Joelson

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Division of Social Work
Abstract

THE EFFECTIVENESS OF CHILDHOOD CANCER SURVIVORSHIP PROGRAMS IN CALIFORNIA

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Hester Joelson

This study evaluated the comprehensive services offered by existing childhood cancer survivorship programs (CCSPs) in California as indicated by professionals and investigated their effectiveness in providing psycho-social-cultural-spiritual support to survivors and their families. Twenty-one licensed medical professionals with either a health or mental health background including medical doctors, registered nurses, licensed social workers and doctors of psychology, who are currently working with survivors and their families within CSSPs in California participated in this study.

All professionals indicated the main focus of CCSPs in California is current and long-term medical follow-up care for the survivor. Most professionals specified that CCSPs in California provide a moderate level of psycho-social support for survivors, families, and caregivers. Most agreed that culture and spirituality could be better integrated. Many expressed that the services offered within these programs would be more comprehensive with increased funding and more acceptance from the insurance companies. Increased funding would allow programs to enhance their current psycho-social-cultural-spiritual
services by incorporating innovative services and hiring more non-medical profession staff, such as social workers, child life specialists, and nutritionists.

Future studies should focus on assessing the non-medical services needed or requested by survivors and their families/caregivers, and the barriers that prevent CCSPs from implementation. Currently, 80% of children, adolescents and young adults diagnosed with cancer are surviving. Further studies need to focus both on services needed and how these services can improve the quality of life of both survivors and their families/caregivers.

_______________________, Committee Chair
Dr. Francis Yuen, DSW, Professor

_______________________
Date
ACKNOWLEDGMENTS

Finishing this project has been the most stressful, challenging, exhausting, and especially rewarding experience we have ever gone through. We have learned about our boundaries and our capabilities and could not be more proud of this accomplishment. We could not have completed this thesis/project without the love and support of our husbands, children, family, friends, and thesis advisor.

I, Hester Joelson, would like to dedicate the completion of this project to my husband, Eddy, who has been my cheerleader through good times and bad, and to my children, Elisheva and Roee, for their understanding and silliness. Additionally, I want to thank my extended family and friends for always listening and believing that I would finish, even when I doubted it, and Sandi who spent hours editing with a fine-tooth comb.

I, Heather Cortez would like to dedicate the completion of this project to my supportive husband, Collin, and loving children, Ashlynn and Isaiah. I would have not been able to do this without their encouraging words, shining smiles, and unconditional love. I also want to thank my parents and extended family for always being available and supportive. I am grateful for their support through the good and bad times and will forever be thankful for their caring words and understanding throughout this challenging experience.

Finally, we have been privileged to work together as partners. We are grateful for all the memories made during this process. We are overwhelmed with gratitude to you all, and we love, respect, appreciate and admire you all more than you will ever know.
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Chapter 1
THE PROBLEM/ THE ISSUE

The number of children, adolescents, and young adults diagnosed with cancer has increased from 58.1 percent in 1975–77 to 79.6 percent in 1996–2003 (National Cancer Institute, 2008). These statistics indicate that currently, one in every 330 children will be diagnosed with cancer annually (Casillas, CCSS Study, 2011). As a result of increased knowledge and research medical professionals have dramatically improved the likelihood of survival. Current research indicates that 80% of children survive a childhood cancer diagnosis. Currently, there are more than 325,000 childhood cancer survivors in the United States (Casillas, CCSS Study, 2011; Buchbinder, et al., 2010). When a family and patient survive cancer, they begin another challenging battle. The survivorship process is a life-altering experience for the child and the entire family unit. The survivor and their family’s life are completely different after experiencing the cancer treatment process. Many aspects of identity shift, such as life views, life concerns, values and fears. Another difficulty families and survivors often face is the change of dynamics within their family structure. Family cohesion, flexibility within the social structure, and communication are often affected. As the population of survivors increases, it is essential to assess the survivors and their family/caregivers quality of life post treatment. Research and studies are necessary to help meet the psycho-social-cultural needs of the survivors and their families.
Once a patient has completed treatment, they are considered a survivor and are referred to a survivorship program to assist with their follow-up care needs. Survivorship programs tend to have a standard form of treatment, with a strong focus on medical and educational services. Although there are direct and clear benefits of Childhood Cancer Survivorship Programs, it is unclear whether the services provided are addressing all of the survivor’s diverse psychosocial needs. After talking with professionals involved with survivorship programs, reviewing previous and current studies, and researching literature it is apparent that Age-appropriate survivorship programs that meet the psychosocial needs of the target population will improve the quality of life and care to the childhood survivors and their families.

The goal of this study is to better understand the needs of the child/adolescent/young adult/family/caregiver during the survivorship process in order to provide more comprehensive psychosocial support. This assessment will allow childhood cancer survivorship programs to better integrate social work support services through an ecological perspective, focusing not only on the cancer survivor, but their support network as well.

**Background of the Problem**

Until recently, much of cancer research and focus has been directly aimed at finding a cure and trying to save the lives of cancer patients. In the 1960s, the five-year cancer survival rate was merely 28 percent. Research has paid off, with survival rates of pediatric cancers increasing each year, so that now three out of four children will survive the disease and treatment (Patenaude & Kupst, 2005). With more children surviving,
there is a need for greater understanding of the implications of survival, leading to improved quality of life for patients and their families/caregivers.

It is imperative that the focus of new research begin to shift. Reintegration can be difficult for the child, adolescent, and young adult survivors and their families/caregivers. It is critical that healthcare and other professionals directly involved begin to understand the true impact cancer has on the survivor and their families in order to provide sufficient and effective services to assist them in living vibrant and productive lives (Zebrack & Zeltzer, n.d). Many programs focus on what is needed for cancer survivors to not only thrive medically, but also psycho-socially so the survivor may reintegrate into their community and social environment.

It is critical that professionals understand the long-term effects that survivors and their families face. Posttraumatic Stress Disorder (PTSD) and Posttraumatic Stress Symptoms (PTSS) are some of the disorders that have been linked to the late effects of cancer and treatments (Kazak, 2005). As these effects have become more visible, the field of psycho-oncology has developed? Psycho-oncology originally focused on observations of mourning families. This focus has shifted to the survivors’ and families’ quality of life. Psycho-oncology has given professionals an ability to learn a great deal about neurocognitive and psychosocial functioning of children, adolescents, and young adults with cancer, as well as their families (Patenaude & Kupst, 2005). Field discussions have now begun to include topics such as the needs of the pediatric cancer survivor and their family.
Patenaude and Kupst (2005) emphasize the need for developing evidence-based clinical practice guidelines for care of survivors, defining a set of standards for comprehensive multidisciplinary care, improving awareness of late effects among children and their families, and increasing support for research regarding survivorship. Implementing these services and program recommendations into survivorship programs will lead to improved quality of care, and in turn create opportunities for improved quality of life for survivors and their families.

Current cancer survivorship research focuses on practical program involvement and the development of clinical guidelines, with a focus on the social, psychological, and economic well-being of the survivor and their families (FDA, 2004). According to one study, young adults age 18-39 who were diagnosed with cancer within the last decade, had completed all treatment, were currently in remission, and spoke English fluently expressed a desire for physical activity within the boundaries of individual capabilities post-treatment. These survivors indicated a specific desire for a “gym-like” program supporting cardiovascular health, as well as holistic physical health (Rabin, Simpson, Morrow, & Phillips, 2010). Other suggestions focused on the need for relaxation tools and techniques, emotional support, nutrition and weight management support, as well as practical life information about insurance issues, fertility, and late-effects possible risks (Rabin, Simpson, Morrow, & Phillips, 2010). Most of the desires of young adult cancer survivors relate to their psychosocial needs. Once these diverse needs are met, survivors may both improve their quality of life and increase their length of time as a survivor.
According to Nathan, et al., transitional resources that should be available to adolescents, young adults, and children throughout survivorship include “health-related education, health surveillance and screening, management of cancer-related complications, and psychosocial support relevant to their development” (2011, p. 2337). It is crucial to make sure the services that are provided are age-appropriate and target evolving developmental stages. Many programs currently offered are not standardized and are structured towards the survivorship population as a whole (Agastino, Penney, & Zebrack, 2011). The adolescent has distinct and different needs. When a person is diagnosed with cancer during the adolescent stage, the experience has been shown to have a major impact on their psychosocial functioning both currently and in the future. As a result of treatment there is a tendency for the survivor to experience increased dependence on caregivers and decreased opportunity for participation in peer activities (Dieluweit, et al, 2010).

Most cancer survivors and their families are resilient and capable of positive life changes, allowing them to healthfully return to their previous environment. Most have the capability to find meaning in life through this battle (Zebrack, et al, 2011). It is essential that survivors and families receive services that specifically address their psychosocial concerns and the many hurdles they face on an ongoing basis. By creating programs and services that help child, adolescent, and young adult survivors and their families, we are ensure a greater chance of improved quality of life and an opportunity for positive outcomes. When survivors and their families find meaning in their recovery and are able to transition to, and excel in, their survivorship and beyond, they are able to thrive.
Statement of the Research Problem

Each year more than 12,000 children and adolescents younger than 20 years old are diagnosed with some form of cancer (American Academy of Pediatrics). Due to advancements in medical treatments, the number of survivors is increasing. Many survivorship programs focus on the medical aspects but do not consider the psycho-social-cultural aspects of the survivorship process. For survivors to truly have a positive quality of life, childhood cancer survivorship programs must appropriately and accurately address their diverse needs.

Purpose of the Study

The purpose of this study is to evaluate the effectiveness of Childhood Cancer Survivorship Programs (CCSP) in meeting the psycho-social-cultural needs of survivors and their families/caregivers. It is our hope to identify the gaps within the services provided, as well as the diverse needs of children, adolescents, young adults, and their families/caregivers. This study will be shared with professionals who are involved with survivorship programs and who completed our survey. By making professionals aware of the gaps in services and the needs of survivors, this study will be of great benefit to the CCSPs to assist in making changes to better meet the needs of survivors and their families/caregivers.
Theoretical Framework

Childhood cancer survivors are unique, and their needs vary. It is important to utilize evidence-based theory knowledge when creating and working with survivors and their families. As in most areas of social work, many theories apply to this specific group of individuals and their families, but there are several theories that have evidence-based support. These theories assist in working with this population, as their framework addresses some of the common issues that survivors and their families face.

The impact that cancer has on the whole family system is profound. The extent of the impact and the success of the transition have much to do with the family system’s ability to remain cohesive and flexible, and to continue with positive communication patterns (Yi, 2009). Family system theory, founded by Dr. Bowen in the 1950s is a significant theoretical framework that assists in understanding the positive and negative family adaptations in the survivorship of childhood cancer (Yi, 2009). It is often the perception of clinicians that the battle with cancer and for survival is a battle fought by the whole family unit. When creating a survivorship program, it is essential that the family system framework be considered and applied. According to the family system theory, professionals must not only study and work with the individual, but must work with the family system as a whole. Systems theory (Karl Ludwig Von Bertalanffy, 1934) looks at the individual and family, as well as how that system fits into the greater system of interconnections among broader systems of work, school, ethnicity, neighborhood, friends, and culture (Yi, 2009).
Yi (2009) reports Olson’s (2000) study and compiled the three most significant concepts of systems theory and how they apply to survivors and their families. These concepts include family cohesion, flexibility, and communication (Yi, 2009). Family cohesion refers to the emotional bond that family members have. Family flexibility refers to a family’s ability to change leadership and relationship roles. Family communication includes listening skills, speaking skills, self-disclosure, clarity, continuity tracking, respect, and regard. Communication is the basis for flexibility and cohesion (Yi, 2009). Given the changes that cancer imposes on the family system, this framework is essential as a basis for survivorship programs, leading to the ultimate goal of improved quality of life.

Family cohesion is the system support that is needed within the family unit, allowing family members to work together throughout the healing process. In looking at family cohesion it has been found that the closer the family was before the diagnosis, the higher their likelihood for cohesiveness and functioning within the family unit (Yi, 2009). Cohesion of the family can also be affected by external systems such as medical staff, friends, and their community. Studies have shown that when the family system is receiving social support from their healthcare team, community, workplace, and neighborhood, they have higher rates of recovery, positive marital outcomes, positive outcomes for adaptation, and improved coping outcomes (Yi, 2009). When families are not receiving this support, they often find themselves feeling isolated and their interactions with the outside world altered (Yi, 2009). This may happen more often in
certain cultures, and can cause a decrease in positive outcomes for reintegration back into their community.

When looking at a family’s ability to be flexible, these researchers are looking at their ability to change roles, assume new roles, and modify daily tasks, all suggesting a lack of rigidity. Studies have shown that flexibility is easiest after diagnosis and during treatments, but more of a struggle throughout survivorship when one is attempting to reintegrate (Yi, 2009). It is often noted that during reintegration, healthy siblings take on adult roles, and it is suggested that more research should be done around the sibling’s ability to assume that role without having feelings of resentment or guilt (Yi, 2009).

Assuming new roles and changing the functioning of one’s system is very difficult. The systems theory framework views reintegration as essential for child, adolescent, and young adult survivors, and their family systems.

The last area that systems theory focuses on is a family’s ability to communicate. When a family is going through the cancer process, as well as the survivorship process, communication is often the main component that is affected. In a study conducted by Yi (2009), two thirds of families experienced issues with communication. Communication is affected for several reasons: avoidance of psychological distress, desire for mutual protection, and belief in positive thinking (Yi, 2009). Communication can affect every relationship within the system and will often cause a “domino effect.” Direct communication is a key concept that needs to be taught to survivors and their families to ensure the cohesiveness and flexibility mentioned previously. With strong communication there is potential for greater success and reintegration resulting in
improved quality of life for the whole family system. It is the clinicians’ responsibility to use this framework to help to ease tension among family members, thus assisting them in maintaining a family bond, as well as connections with their family system and their external supports.

Current research indicates that survivorship treatment needs to be based on the child, adolescent, young adult, and their whole support system. By supporting these relationships, professionals are strengthening the support systems for the survivor, allowing better and more stable long-term care.

In reviewing the many theories that can be applied to childhood cancer survivorship programs, it is crucial to look at theories that support treatment. The cognitive behavior theoretical framework (CBT) supports treatment by addressing thoughts and behaviors, and giving individuals the opportunity to modify their thoughts and behaviors. CBT has been used in many ways to help treat survivors. It is often used to teach survivors desensitization, guided imagery, relaxation, modeling, distraction, and positive reinforcement when dealing with the pain experienced during the treatment process (Kazak, 2005). CBT is a technique used in various capacities to assist in improving survivors’ quality of life.

CBT is used to restructure thinking and promote changes in behaviors. The lasting physical symptoms directly related to cancer treatment can have serious social and emotional consequences for the child, adolescent and young adult. Survivors often develop negative perceptions related to appearance, which often result in academic, social, and psychological impairment, low self-esteem, and symptoms of depression.
Survivors also struggle with negative perceptions of treatment-related pain, visible side effects such as hair loss, weight gain or loss, physical disfigurement, repeated absences from school and a distraction from peers throughout the treatment and survivorship processes. These effects stem from negative thinking. By applying CBT techniques and interventions, survivors learn to modify their thinking and thus change their behaviors.

Survivors face many of the same mental health diagnoses that CBT successfully treats. Survivors of childhood cancer may experience severe anxiety, inhibited and withdrawn behavior, excessive somatic complaints, depression, and post-traumatic stress disorder (PTSD). Research has shown promise in the effectiveness of cognitive-behavioral interventions for children, parents, siblings and the family as a whole, including teaching effective coping strategies for children, targeting social skills development, group therapies alleviating sibling’s emotional and behavioral problems, and improving overall and long-term family functioning via family therapy (Toro, n.d.). Using an evidenced-based practice approach to treat survivors, will open doors to create new innovative programs.

Kazak (2004) introduced an intervention used in a hospital in Canada that reduces Post Traumatic Stress Syndrome (PTSS. The Surviving Cancer Competently Intervention Program (SCCIP) integrates cognitive, behavioral, and family therapy in a one-day program broken down into four sessions involving groups of families of pediatric cancer survivors. The program was tested, and the results suggested a significant decrease in PTSS (Kazak, 2004). We believe that further research needs to be done on what programs
in the U.S. have attempted to integrate this model, a model focusing on survivor families. We also believe further testing should be done to determine whether this model would be more effective as a long-term intervention instead of a one-day workshop.

Research has shown that further testing should be done to assess what models of support would be more effective if their treatment was long-term, lasting for a specified amount of time throughout the first year of survivorship. As we become a society that focuses on evidence-based treatment, it will be essential to dedicate more time to interventions that balance theoretically and clinically grounded approaches with empirical evidence. These interventions must fit with the current programs and be equally deliverable and creative in a brief format that is able to intersect pediatric practice and health care economics (Kazak, 2012). In further creating programs and interventions directed towards this specific population, it is essential to use a combination of systems theory and CBT.

**Definition of Terms**

**Conceptual Definitions**

Childhood Cancer Survivor - persons between the ages of birth and 25 years of age, five years post treatment.

Family/Caregiver- Persons living with the child during treatment.

Childhood Cancer Survivorship Program (CCSP) - Any program connected with a hospital that provides specialized follow-up care for patients who have completed treatment for a cancer that was diagnosed before they were 22 years old.
Psycho-social needs- The interaction between social and psychological factors of childhood cancer survivors.

Quality of life - Personal satisfaction with the cultural or intellectual conditions under which you live; a tool that measures an individual’s sense of well-being and ability to carry out various activities; an overall enjoyment of life.

Operational Definitions

For the purpose of this study, the childhood cancer survivorship programs are programs currently in use in California for the 2012 calendar year.

Childhood Cancer Survivors - The persons enrolled in the above stated programs.

Family/Caregivers- The persons who lived with the enrolled survivors during their treatment.

Childhood Cancer Survivorship Programs - Any programs connected to a hospital in California.

Psycho-social-cultural needs - The needs assessed based on a questionnaire handed out by a Social Worker.

Services – The actual services provided by each program individually.

Quality of Life – Individual opinions of the highest satisfaction of life even with the side effects of their cancer.

Justification

By evaluating childhood cancer survivorship programs as a whole, we hope to make suggestions to restructure current programs. Programs will thus be supported by
data suggesting ways to improve their support for survivors and families, and their quality of care. Cancer survivorship is heavily based on the medical model of care. By incorporating a psycho-social-cultural model of care we will be able to create an improved quality of life for survivors and families/caregivers complimenting the improved quality of care. By making professionals aware of the gaps in services and the needs of survivors, this study will be a great benefit to the childhood cancer survivorship programs, and assist in making changes to better meet the needs of survivors and families/caregivers.

**Statement of Collaboration**

This thesis project is a collaborative effort completed by both Heather Cortez and Hester Joelson. All information gathered, studies completed, and work is agreed upon by both researchers.
Chapter 2

REVIEW OF THE LITERATURE

When a child, adolescent, or young adult is diagnosed with cancer, their life, as well as their family’s lives, will be changed forever. If the child, adolescent, or young adult (AYA) survive the cancer, they are considered to be in survivorship and require various levels of post-treatment support and medical care. Current research shows that 80% of children who have been diagnosed with a pediatric cancer survive, indicating that there are more than 325,000 childhood cancer survivors currently living in the United States (Casillas, 2011; Buchbinder, et al., 2010). Advancements in the quality of medical treatments have increased the likelihood of these children, adolescents, and young adults surviving at least five years post-diagnosis.

Given the excellent survival rates and the increased population of children and AYA cancer survivors, proper follow-up medical care, coupled with psycho-social-cultural services, will greatly improve this population’s quality of life (QOL).

Current Focus and Research of Survivorship Programs

Tesauro, Rowland, and Lustig (2002) argue that survivorship programs should focus on medical and psychosocial services in the hope of enhancing the QOL of survivors. Review of the literature, however, reveals that much of the focus of survivorship care is on educating survivors regarding their specific medical issues relating to their exposure to various toxins and treatments, and making sure the survivor
is receiving appropriate follow-up medical care. Smith (2009) interviewed five different medical professionals on their methods of preparing their patients for survivorship and found that only one professional brought up psychosocial aftercare and discussed making referrals to appropriate professionals for her patients. Limited information exists as to what type of services survivors and families/caregivers need post-treatment (Tesauro, Rowland, & Lustig, 2002). Although follow-up medical care is crucial, the psychosocial-cultural needs of survivors/families/caregivers is often neglected, and studies indicate that a lack of awareness of the needs of both the survivors and their support systems results in a poorer quality of life for survivors.

Physicians report that children, adolescents, and young adults experience grave medical effects known as late effects, due to their treatment regimen (chemotherapy, radiation, scans, etc.). These late effects include cardiac issues and cognitive impairment. Santacroce (2010) defines late effects as persistent adverse outcomes that develop within the five years post-treatment. Numerous physical late effects of treatment have potential psychological effects as well. Santacroce’s definition does not take into account the psychosocial and/or cultural challenges survivors and their families confront as a result of medical late effects.

A multi-institutional study of individuals, who have survived less than five years post treatment, indicates that less than 50% of adult survivors of childhood cancer are receiving cancer-related follow-up care (Nathan, et al., 2011).
Previous Research Findings

In the recent past, research efforts relating to cancer survivorship focused mainly on early detection and awareness and less on the transition from treatment care to survivorship support. Current cancer survivorship studies emphasize practical program involvement, the development of clinical guidelines, and awareness of the psychosocial and economic well-being of the survivor and their families (FDA, 2004). Many programs exist for survivorship, and current research is using these programs to conduct studies. These studies use a variety of methods with the shared hope of discovering new explanations and expectations for survivorship care. In order to bridge the service gap between the child survivor, the adolescent survivor, and the young adult survivor, childhood cancer survivorship programs should include developmentally appropriate services acknowledging the vastly diverse needs of all survivors (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011).

Rabin, Simpson, Morrow, and Phillips (2010) examined the needs for survivorship support of English-speaking young adults ages 18 to 39, who were diagnosed with cancer within the last decade and currently in remission after completing all treatment. Many young adult survivors shared a desire for involvement in physical activity within the boundaries of individual capabilities post-treatment. During the treatment process, many patients lose limbs, physical strength, and physical confidence. Survivors in this study indicated a specific desire for a “gym-like” program supporting cardiovascular health, as well as holistic physical health (Rabin, Simpson, Morrow, &
Phillips, 2010). Other suggestions focused on their need for relaxation tools and techniques, emotional support, nutrition and weight management guidance, as well as practical life information, such as insurance issues, fertility questions, and risks of late effects (Rabin, Simpson, Morrow, & Phillips, 2010). Most of these desires relate to fulfilling their psychosocial needs (Cantrell & Conte, 2009). If these needs are met, survivors may gain an improved quality of life as well as potentially increase their length of survivorship.

Research indicates that survivorship care would be most beneficial to the survivor and their family/caregiver if it were introduced and implemented early in both the treatment and survivorship processes. According to Nathan et al (2011), transition from medical treatment administration care to survivorship care is often discussed during the final medical treatment and with minimal detail. Children, adolescent, and young adult patients often have psycho-social-cultural needs that, if addressed early, would benefit their psychosocial health outcome (Nathan et al., 2011). Current research indicates that more psycho-social and educational support needs to be offered in order to provide a holistic approach to survivorship. Psycho-social and educational support, in order to be most effective, needs to include long-term follow-up care throughout survivorship (Nathan et al., 2011). Transition from cancer treatment care to survivorship care takes planning and awareness by all professionals and can give a child and their family/caregiver a sense of control and understanding, making their life less chaotic.

When a child, adolescent, young adult, and their family are in the treatment phase, they are surrounded by a team of professionals providing attentive and aggressive care to
defeat the cancer. Patients and families are commonly and abruptly moved out of
treatment care and put into transition/survivorship care without warning and are forced to
grieve several losses. They are grieving the loss of their life prior to cancer, the comfort
with treatment established while fighting the disease, and the loss of the interactions.
They also grieve the loss of support from the medical team that followed them during
treatment and gave them a sense of security. According to research conducted by Nathan
et al. (2011), transition from treatment care to survivorship care induces considerable
amounts of anxiety, fear, and vulnerability for patients and their families/caregivers. If
transition details are discussed early and often, and a plan is established before
completing the treatment protocol, a more effective transition will take place, decreasing
anxiety, fear, and vulnerability for survivors and their families/caregivers. Further
research needs to be done to determine the appropriate timing before attempting to make
a transitional care plan.

**Effects of Developmental Stages and Treatment**

Young adults in the oncology world face a number of unique medical and
psychosocial challenges from diagnosis through survivorship and beyond. These
challenges have not yet been addressed by medical and research communities (Rabin,
Simpson, Morrow, & Pinto, 2010). The lack of research surrounding young adult cancer
survivorship suggests that young adult survivors are an anomaly with many unknown
needs. These needs relate to both non-medical psychosocial issues and unique post-
treatment medical follow-up care. Psycho-social-cultural support for children,
adolescents, and young adults needs to be based on appropriate developmental ages and stages. Developmental differences between patients/survivors need to be incorporated into all aspects of survivorship care. In the past, survivorship care has attempted to provide services targeting all developmental ages and stages, but it has been unsuccessful. Currently, survivorship care provides non-developmentally specific support (Agastino, Penney, Zebrack, 2011). According to Nathan et al. (2011), transitional resources that ought to be available for children, adolescents, and young adults throughout survivorship should include “health-related education surveillance and screening, management of cancer related complications, and psychosocial support relevant to their development” (p. 2337). It is essential to confirm that services provided to the survivor are age-appropriate and target their unique developmental stage. Children, adolescents, and young adults present unique psychosocial issues, because they are grappling with immense, constantly evolving, normal developmental changes while simultaneously attempting to understand the cancer process. Zebrack (2011) shares that the psychosocial issues faced by children, adolescent, and young adult survivors include altered interpersonal relationships, issues of dependence/independence, achievement of self-established/family-encouraged life goals, concerns about body-sexual image and integrity, and existential issues. These psychosocial issues support the need for survivorship programs that take into consideration healthy development, despite the disruption brought about by the cancer diagnosis, thus improving their quality of life.

Children, adolescents, and young adults feel vastly different than adults when faced with issues such as mortality, fertility/sterility, their bodies, increased dependence
on others, and disruptions to their social life. Therefore, when attempting to treat a child, adolescent, and young adult survivor, it is important to observe their differences and not treat them the same way one might treat a 60-year-old woman.

A teenager who has survived cancer treatment may appear “typical” in their invincible presentation, but they are very much affected by the cancer experience and its integration into their life and future. It is important to recognize the need for independence desired by adolescents and young adults, while maintaining boundaries for survivorship accountability (Lally, 2007). Adolescents and young adults need to understand the importance of late-effects follow-up care as well as to express their unique psycho-social-cultural needs as evolving survivors.

Research does not clearly define psychosocial and/or cultural issues faced by survivors and their families (Zebrack & Landier, 2011; Hinds, Burghen, Haase, & Phillips, 2006). Many survivors suffer from depression, posttraumatic stress disorder, and anxiety, and note social and behavioral transformations (Santacroce, Asmus, Kadan-Lottick, & Grey, 2010). Psychological distress stems from discrimination, social life disruptions, developmental retardation, stigmatization by society of a childhood cancer diagnosis, and lack of involvement in educational or employment activities (Zebrack & Landier, 2011). The ability to clinically evaluate the quality of life for children and adolescents will allow for a more comprehensive assessment of the immediate and later effects of existing and future anticancer therapies and other therapeutic interventions (Hinds, et al, 2006).
Assessments of quality of life for childhood cancer survivors as well as children, adolescents, and young adults who lost their battle with cancer did not exist before 2000. A shift in the focus of childhood cancer research from simply assessing cancer patient’s quality of life to including survivorship and post-death assessment of caregivers took place in 2000 (Hinds, et al, 2006). This shift allowed for families and caregivers who are survivors of children who have lost their battle with cancer to be included in research, and valued as caregivers.

Although childhood cancer survivorship rates have been progressively increasing over the past 20 years, adolescent and young adult survivorship rates have been stagnant (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011). Young adult cancer patients and survivors are often neglected, as evidenced by the less than one percent of cancer research focusing on their unique survivorship issues. This lack of research is particularly problematic because young adult cancer survivors often face increased long-term physical and psychosocial challenges (Rabin, Simpson, Morrow, & Pinto, 2010). Stagnation of survivorship rates is fundamental to address in survivorship care, because it highlights the limited number of adolescent and young adult survivors thus supporting the need establishing improved peer survivor support/interaction. Inspecting adolescent and young adult cancer diagnoses, as well as survivorship challenges in this population, via a different lens than their child counterparts may enhance their survivorship rates and positively affect their long-term quality of life (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011). Researchers need to develop behavioral and psychosocial programs specifically geared towards young adult cancer survivors because of their vulnerability (Rabin, et al.,
Adolescents and young adults are particularly vulnerable post treatment in the medical setting due to lack of awareness by medical professionals as to how best to treat an individual faced with a cancer diagnosis (Rabin, Simpson, Morrow, & Pinto, 2010). Many adolescents and young adults who survive treatment confront concealed survivorship issues such as fertility, sexual dysfunction, premature menopause (for women), risk of secondary cancer, fatigue, employment, isolation from peers, as well as many other psycho-social issues with lasting effects (Rabin, Simpson, Morrow, & Pinto, 2010; Cantrell & Conte, 2009).

What is most daunting, as stated by Rabin et al (2010), is that despite awareness of their unique and varying needs, there are few organizations that focus directly on the survivorship needs of adolescents and young adults. In order to bridge the service gap between child survivor and adolescent/young adult survivor, childhood cancer survivorship programs should embrace separate services for adolescents and young adults, thus acknowledging their vastly diverse needs.

**Challenges of Childhood Cancer Survivorship Programs**

Although Childhood Cancer Survivorship Programs have had a positive impact on survivors and families/caregivers, challenges remain. According to Schlairet, Heddon, & Griffis (2010) survivorship care is a major component in the continuum of cancer care. Currently, there is no established system to guide patients and/or their families/caregivers through the complexities of transitional care, survivorship care and beyond. Equally important, childhood cancer survivorship must integrate the needs of families and
caregivers who were fighting alongside the survivor throughout the treatment process. 
Although community cancer centers in the United States meet the medical and physical 
needs of patients and their families/caregivers, they inadvertently overlook critical social, 
emotional, cultural, and spiritual needs. Integration, by healthcare professionals, of 
medical, psychosocial, cultural, and spiritual support, as well as a multidisciplinary care 
approach to survivorship would assist in providing comprehensive survivorship care, thus 
improving quality of life.

The challenge that childhood cancer survivorship programs face is to create a new model of care, a model that is more wide-ranging, based on the success of current treatment protocols. A major concern within health care organizations, based on the 80% survival rate, is assisting and managing patients and their families/caregivers through the transition from pediatric care to adult medical care. Health care organizations are struggling to provide appropriate and adequate resources necessary for healthy, successful survivorship (McLaughlin, et al, 2011). At least two-thirds of childhood cancer survivors will have one or more late effects based on their treatment. As a result, clinicians have been forced to focus on survivorship from a medical and educational perspective, leaving little room for understanding and support on the psycho-social-cultural levels (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). A recent survey study of pediatric hematology/oncology training programs was done “to evaluate their resources and capacity for survivorship education and to explore the barriers and opportunities for the optimal provision of survivorship-centered training” (Nathan, et al, 2011, p.1186). This survey focused on available resources for teaching survivorship and
did not assess trainees’ knowledge of survivorship issues or awareness of survivorship programs (Nathan, et al, 2011). It would seem more beneficial for health care professionals, and more specifically medical doctors, to understand survivorship issues as part of their training and how best to support survivors and their families/caregivers. In a survey of 56 institutions by Nathan et al (2011), 46 indicated that they provide follow-up care throughout childhood and adolescence and 36 served post-adolescence. Survivors, families, and caregivers need to be supported throughout their survivorship life span. This includes educational, medical, psychosocial, and cultural support (Santacroce, et al, 2009). Putting an age limit on support appears inappropriate given the current research on the number of survivors and the duration of survivorship.

Applying Systems Theory to Survivorship Care

Another way in which survivorship programs can improve their overall support of survivors and their families/caregivers is to base their program model on a systems theory approach to care. Family systems theory from Dr. Bowen takes into account all individuals within the survivorship family and integrates their needs into program formation and application. Some research has been done, but more research needs to be completed on the social systems of the survivor and the effects that the cancer diagnosis and treatment have on each system and relationship (Kazak, 2004). Child, adolescent, and young adult survivors’ growth and development are not only affected by the lack of psychosocial care, they are also influenced by relationships, or social systems (Kazak,
2004). Social systems include family, school, neighborhood, hospital, subcultures, and the culture a person identifies with.

When a child, adolescent, or young adult goes through treatment, their family/caregiver and surrounding social systems are impacted by both short- and long-term effects. Kazak (2004) introduced the Cancer Competently Intervention Program (CCIP) that has been used in a hospital in Canada to reduce Post Traumatic Stress Syndrome (PTSS). The CCIP program integrates cognitive behavioral and family therapy in a four-session day program involving families of children, adolescents, and young adult survivors. When the CCIP was tested, the results showed a significant decrease in PTSS among participants (Kazak, 2004, p.143). Further research needs to be conducted to determine what programs, if any, in the U.S. have attempted to use the CCIP model, allowing for proper assessment of its effectiveness on long-term and short-term survivorship. Assessment will inform programs whether the CCIP model alleviates possible signs of PTSS.

Current research recommendations specify that childhood cancer survivorship support needs to include the family system as a whole because of the detrimental effects experienced by all. By supporting the family/care giving system as a whole, professionals strengthen support systems for the survivor allowing for enhanced, stable, long-term care/support, and further improve quality of life.
Family Centered Care

Survivorship care, as well as childhood cancer treatment, would benefit the child, adolescent, young adult, and their families/caregiver most if approached from a family-centered care perspective (Buchbinder, et al, 2010; Bowman, Rose, Deiling, 2006; Schwartz, Tuchman, Hobbie, Ginsberg, 2011). Survivorship treatment for a child, adolescent, and young adult must include their family/caregivers as well. Family/caregivers are the individuals who, during the treatment process, administered medications, made appointments, and held the child while he/she was in discomfort (Ryan et al, 2011). It is important to recognize that the cancer diagnosis and treatment affect both the parent and child concurrently, causing a need for post-treatment support services for the survivor and their family/caregivers in the hopes of improving their psychosocial well-being.

It appears negligent to discuss childhood cancer survivorship and not include the uncertainty and fear of families and caregivers who watched their loved one suffer thorough the treatment process and all of its consequences. Uncertainty as to the duration of survivorship is a significant source of parental anxiety that haunts families throughout the survivorship process. Uncertainty can be highly contagious within family systems; therefore, interventions need to target not only parents, but the entire family system (Santacroce, et al, 2009; Bowman, Rose, Deimling, 2006). Uncertainty often felt by parents, caregivers, and survivors can be lessened and/or alleviated if more detailed information is shared regarding their loved one’s medical and psychosocial well-being.
According to Santacorce, et al (2009), the Institute of Medicine recommends that all persons who have been treated for cancer receive a treatment summary plus information about potential medical late effects. As a result of these recommendations, survivorship programs need to implement interventions that will assist survivors and their families/caregivers in better understanding their unique needs, thus empowering them.

The Office of Cancer Survivorship acknowledges and highlights the significant psychological stress placed on those close to the cancer patient during and post treatment. Survivorship programs, especially those related to childhood cancer survivorship, ought therefore to include support services for families/caregivers, thus enhancing their quality of life. Kim and Spillers (2010) indicate that:

[Quality of life] is a multidimensional construct, including mental, social, physical, psychological, and spiritual components. The most studied aspect of [quality of life] is psychological distress. Many studies have documented the negative secondary impact of cancer on the family, such as heightened levels of psychological distress equal to or even greater than those of survivors. (p. 431)

The American Cancer Society created a survey assessing the quality of life for family members and caregivers of long-term cancer survivors, providing a major leap in survivorship awareness and research (Kim & Spillers, 2010). Using the survey results or data collected from these surveys, survivorship programs can support families as a unit to the best of their abilities. Families, if supported psychosocially as a whole, will have better quality of life outcomes over their lifespan (Bowman, Rose, & Deimling, 2006).
Buchbinder, et al. (2010) asserts that little is known about the psychosocial affects experienced by siblings of long-term childhood cancer survivors. As siblings sit in the hospital watching their brother or sister, suffer through treatment, putting their lives on hold, and conjecturing about their parents/caregivers concerns, it is vital that these siblings have an opportunity to express themselves during survivorship. According to Buchbinder, et al. (2010) the younger the sibling is at the time their sister/brother is diagnosed and treated, the greater the effects on their psychosocial success during survivorship. Additionally, the amount of time post completion of treatment, the unfortunate death of a sibling, and socio-demographic status all affect the psychosocial outcome of cancer patients and their siblings. While it is known that siblings are affected by the treatment and survivorship processes, little research has been done to understand the vast needs of siblings, and little support during and after treatment is offered to them to improve their quality of life. A better understanding of the varying needs of siblings would benefit all family members and improve overall quality of life within the family system.

Quality of life is greatly impacted by the prospect of a recurrence of cancer. Vivar, et al. (2009) suggests that facing the reality of having to experience the physical and psychological effects of cancer again is a traumatic experience for families and survivors. Recurrence is most common within the first five years post treatment (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2006). Unfortunately, the treatment for one cancer often leads to a greater risk of secondary cancers. The survivor and their families/caregivers live daily with the knowledge that, at any moment, recurrence, or a
new, secondary cancer may arise. “Fear of recurrence, referring to a perception of serious threat and belief that cancer may return at any time, is one of the greatest psychosocial stressors confronting survivors and families” (Vivar, Canga, Canga & Arantzamendi, 2009, pg. 726). Knowing that recurrence is a grave concern for survivors and their families, it seems critical to incorporate into survivorship care interventions that support healthy psychosocial management of the fears surrounding recurrence.

Care for children, adolescents, and young adults who are facing a recurrent cancer diagnosis should be addressed with a family system approach, taking into account all members and their unique fears, anxiety, and uncertainty. Care needs to include and acknowledge death, as recurrent cancers are more difficult to treat. It is important to be open about the possibility of death for the survivor and their family/caregivers, yet not take away the hope of surviving cancer for the second time. Openness regarding death will allow individuals to have permission to deal with their psychosocial needs more easily and understand the reality of their medical diagnosis.

When a recurrence occurs, the survivor and their family/caregivers are forced back into the treatment phase of a cancer diagnosis, with a strong knowledge and emotional response to the treatment process. Families/caregivers/patients are aware of how they are going to feel, what their bodies are going to experience, and the isolation that goes along with a cancer diagnosis (Vivar, et al, 2009). Patients diagnosed with cancer experience low immunity, causing isolation; hair loss, causing stigmatization; weight loss, causing a person to stand out; and many other physical and emotional effects. Heightened awareness of the reactions to treatments because of prior experience
needs to be integrated into psychosocial support services, allowing programs to support these patients, families, and caregivers as treatment veterans.

Dealing with the reality of recurrence requires ongoing efforts and restructuring of the family environment. The family is forced to adjust to a new reality that includes awareness of hygiene, time for medical appointments, as well as many other daily, weekly, and monthly changes. Family life has to incorporate the family’s commitments to the management of recurrence, highlighting the upheaval a recurrent cancer diagnosis poses for families and their need for additional support (Vivar, et al, 2009).

The reality of recurrence also introduces the possibility of death. Parents/caregivers who are faced with the devastating reality that their child, adolescent, and/or young adult will not survive their cancer treatment are forced to live with that loss for the rest of their lives. Regardless of age, a person is always a child in their parents’ eyes. Healthy bereavement, according to Barrera, et al. (2009), involves the ability to positively appraise the life lost as well as derive meaning from the loss based on the shared experience with the deceased. A positive appraisal of the loss, as well as deriving meaning from the loss, lead to healthy post-traumatic emotional growth allowing for a reestablishment of equilibrium in one’s life. Emotional equilibrium allows a person/parent/caregiver to dissolve assumptions about the world and renew a sense of worth and purpose in life without their child.

It is difficult to lose a child to cancer and maintain a positive outlook on life. Death is difficult, but even more difficult when the deceased is a child. Interventions need to be created within survivorship programs to construct a safe place for family
bereavement (Barrera, et al., 2009). Bereavement is an important process post-death. Parents/caregivers go through the treatment process together with their children and are therefore “secondary survivors,” even if their children do not survive. In assessing the effects of cancer, we need to take into account the difficult treatment courses and how they create distinct post-loss challenges for parent/caregivers (Barrera, et al., 2009). Barrera, et al. (2009) explains that due to medical advances regarding cancer treatment and survivorship improvements, parents who have lost a child to cancer may not be recognized as a group with significant psychosocial needs. These parents have distinctive and significant psychosocial needs, as do their subsequent children. For example, bereaved parents often shift their focus from dealing with the loss of their child to caring for their living children (Alam, Barrera, D’agosino, Nicholas, & Schneiderman, 2012). Therefore, despite the fact that a significant number of children survive a childhood cancer diagnosis, it is important to keep in mind that some do not survive, and the loss to parents deserves attention and support.

In a study done by Barrera, et al. (2009), bereaved parents suggested that an opportunity to talk, share, and discuss the grief related to the loss of their child would be beneficial. Parents also shared the pain, emptiness and yearning that exist on a daily basis. Lastly, parents shared a difficulty in attending events related to milestones their child was unable to reach, such as a bar mitzvah, wedding, baby naming, etc. (Barrera, et al., 2009; Yi, 2009). These challenges suggest that the loss of a child has psychosocial affects that isolate parents/care givers from their social network. Barrera, et al. (2009), found that mothers tend to have greater difficulty than fathers reengaging in and with the
outside world. Reintegration for mothers is especially painful because the treatment process requires intense interaction and devotion to care, forcing the withdrawal from normal social interactions. This devotion, according to Barrera, et al. (2009), includes time and resources requiring mothers, as well as fathers and other care givers, to modify their daily life. The most intense lifestyle modification is required at the end of the child’s life. All of the bereavement challenges that parents/caregivers shared support the need for better survivorship support for parents/families/caregivers, including discussions surrounding death and dying, with the hope of improving their psychosocial quality of life.

Families/caregivers support their child, adolescent and/or young adult throughout the treatment and survivorship process and are therefore affected psychosocially by the traumatic experience (Yi, 2009). Research suggests that survivors improve psychosocially over time; however, their family members actually get worse (Bowman, Rose, & Deimling, 2006). Parents, siblings, extended family, and caregivers all experience psychosocial reactions to supporting a child, adolescent and/or young adult through their treatment and survivorship, but are not directly offered psychological support as an outlet to share their feelings (Kim, & Spillers, 2010). Bowman, Rose, and Deimling (2006) assert that people who are close emotionally to patients during and beyond treatment are often confronted with lasting psychological consequences. “The director of the Office of Cancer Survivorship at the NCI (National Cancer Institute), Julia Rowland, has referred to family members as ‘secondary survivors’ who are often profoundly affected by the cancer diagnosis of a loved one” (Bowman, Rose, &
Deimling, 2006, p. 835). Secondary survivors have a lifelong struggle to comprehend and evaluate the cancer experience for themselves because they have watched their loved one suffer. It is imperative that survivorship programs support first-hand survivors as well as secondary survivors, because, although their experiences are different, both need support.

**Cultural Competence of Survivorship Programs**

Ample research has been done concerning pediatric and adolescent/young adult survivorship programs, allowing for a thorough and effective literature review. This literature review encourages further research regarding how to improve services and patient/family access within survivorship programs. Further studies need to be conducted on delivery of services, implementation of programs, cultural considerations and awareness, integration of models of care that support the family system, developmentally accurate individualized care, and fidelity of treatment across all programs. More in-depth research regarding the best means of program implementation needs to be considered with the goal of increasing quality of life for survivors and their families/caregivers.

Finally, research has focused on delivery and cultural competence of cancer survivorship programs. Methods of delivery of programs offered by survivorship groups are often communicated via telephone interview, face-to-face interaction, or media outlet (i.e. Internet, TV, and Radio). These research approaches do not take into consideration at-risk, underserved populations, populations residing in rural locales, and/or non-English-speaking populations (Meneses, et al., 2007). Ineffective modes of communication about survivorship programs could lead to misrepresentation of needs
within research data, preventing the crafting accurate and appropriate programs. Current survivorship programs may be underutilized and therefore ineffective in improving quality of life of all survivors and families/caregivers.

Childhood cancer diagnoses do not differentiate between cultural and economic background. Children, adolescents, and young adults within all races, ethnicities and socioeconomic backgrounds are affected by childhood cancers (Yi, 2009). Despite the fact that some are more affected than others, all deserve to be supported in their unique needs from diagnosis through survivorship and beyond. “African-Americans were found to have a more despairing view of health in general and a more negative appraisal of cancer in particular compared to whites” (Bowman, Rose, Deimling, 2006, pg. 836). Incorporating the unique worldviews, beliefs, spiritual practices, and health views into survivorship support would create a comprehensive, culturally competent program. Yi (2009) shares that “[f]amily systems theories emphasize that families exist within a larger social context and highlight the importance of exploring the cultural and social aspects in which families with diverse ethnic and cultural backgrounds are embedded” (pg. 234). Emotional and spiritual beliefs and practices may shift during the cancer experience, but cultural and ethnic backgrounds remain the same.

Because of the vast cultural and ethnic ties survivors/families/caregivers bring, survivorship programs need to employ culturally/ethnically competent professionals. These professionals can best support families with their unique psychosocial needs and improve their quality of life (Kim & Spillers, 2010). Professionals need to focus on
medical follow-up care with an awareness of the psychosocial issues of survivors and their families/caregivers.

**Peer Mentorship**

Current research suggests that peer support has strong implications for improving quality of life for survivors, especially adolescent/young adult survivors. A critical need shared by young adult cancer survivors, as well as their families/caregivers, is the need for peer support and interaction. Survivorship programs with participants of similar age, diagnosis, time since diagnosis, gender, treatment history, and life situation will be most helpful (Rabin, Simpson, Morrow, & Phillips, 2010; McLaughlin, et al., 2011). The desire for similarity suggests a need for peer mentorship. Mentorship has the potential to benefit both the survivor and their family/caregivers. A recent study using a mobile social network to build relations and social support amongst community members indicates that virtual environments that support peer mentors with similar medical experiences assisted adolescents and young adults in making a smooth transition into survivorship (McLaughlin, et al., 2011). Adolescents and young adults within the research study had better compliance with survivorship guidelines, improving their quality of life. Research indicates that peer mentorship at a distance (online, not face-to-face) or up close (face-to-face) has many benefits and implications for improved quality of life (McLaughlin, et al., 2011).

Peer interaction for all people is beneficial, and it is especially beneficial for cancer survivors, their families and caregivers because it normalizes their experience.
Cancer is an isolating disease. A network of supportive and empathetic peers is particularly important to encourage survivors to engage in healthy behaviors that promote successful survivorship (McLaughlin, et al., 2011). Support from family is not the same as support from a peer who has had a similar experience and is willing to share and support. Only someone who has experienced and survived cancer treatment can understand the treatment and survivorship processes. McLaughlin, et al. (2011) attempted to tackle the need for peer support by young adult childhood cancer survivors by creating a mobile social networking program. Topics discussed in these sessions were depression, quality of life, self-efficacy, and family support.

Unfortunately, the better a survivor feels, physically and emotionally, the less likely they are to participate in a peer mentorship program (McLaughlin, et al., 2011). This is that it indicates that there is a negative relationship with involvement in a mentorship program. The goal of peer mentorship should be to reach out to those surviving and thriving while simultaneously supporting those who are struggling in their survivorship process.

It is critical that a bio-psycho-social-cultural understanding of cancer, survivorship, and recurrence exists for families/caregivers and survivors. From diagnosis to treatment on through “hopeful” survivorship and beyond, survivors and their families need support and guidance with the primary goal of improving quality of life medically and psycho-social-culturally.
Chapter 3

METHODOLOGY

The purpose of this study is to explore the psycho-social-cultural services provided to children, adolescents, young adults and families/caregivers within childhood cancer survivorship programs (CCSP) in California from doctors, nurses, social workers, and other non-medical specialists. This is a survey study using a mixed method design to collect both qualitative and quantitative data to better understand the unique psycho-social-cultural needs of children, adolescents, young adults, and families/caregivers. It also aims to suggest further service elements to integrate into current childhood cancer survivorship programs with the goal of improving quality of life. This chapter describes the methodology of the study, including the study design, sampling, data collection and analysis, instruments, and the protection of human subjects.

Study Design

This questionnaire survey study employs a descriptive design to collect both qualitative and quantitative data via Survey Monkey to assess the childhood cancer survivorship programs in California and to identify room for improvement. Rather than gathering data from survivors and families/caregivers, and thus further disrupting their healing process, information was collected from professionals who work directly with patients and families/caregivers, on-line and anonymously. Individuals surveyed were asked to respond based on their knowledge of the survivorship program and their interactions with survivors and their families or caregivers. Using this approach, the
researchers were able to gather information on the detrimental effects of cancer and how professionals would like to best support survivors and their families/caregivers.

**Population and Sampling**

A total of five hospitals in California that are linked to the Children’s Oncology Group (COG), the world’s largest organization focused on childhood and adolescent cancer research and treatment, were included in this study. The study aimed to recruit at least 20 professional staff, including pediatric oncologists, nurses, social workers, child life specialists, and other specialists who were working with childhood cancer survivorship programs at the time of this study.

Professionals were selected through a purposive convenient sampling with the goal of obtaining at least five professionals from each of the above categories. The researchers began by requesting via email (see Appendices A) the names and email addresses of professionals currently working in CCSPs in California. The COG Clinical Director, Dr. Landier, agreed to assist with recruitment efforts (see Appendices B). Contacting the associate chair allowed the researchers to gain official access to professional staff within CCSPs in California. Upon receipt of names and email addresses, the researchers sent an e-mail to each professional requesting their voluntarily participation in this study (see Appendix C). The email included a brief explanation of the purpose of this study, the researchers’ personal connection to the topic, and how the findings may improve the quality of life for both the survivors and families/caregivers. Participants were informed that their participation in the study was confidential and voluntary, and that they would not receive any compensation for completing this survey.
Professionals who voluntarily agreed to participate could click on a hyperlink included in the e-mail to access the survey questionnaire administered through Survey Monkey. All data was gathered from professionals with no personal or professional connections with either researcher to avoid any conflicts of interest.

The sample collected was not as planned. These researchers were able to obtain more than 20 survey questionnaires but were unable to obtain an equal number of surveys from each professional category due to CCPS staffing issues. The information gathered indicates that further support with a psycho-social-cultural focus would benefit these programs and their patients, families, and caregivers.

**Instrumentation**

In this research study, the researchers utilized an online survey via Survey Monkey. The online survey assessed the diverse programs provided by CCSPs and how these programs are attempting to meet the psycho-social-cultural needs of survivors and families/caregivers through professional opinions. Current literature and the purpose of this study guided the development of the survey questionnaire (see Appendices D). The questionnaire consisted of 20 open-ended and closed-ended questions. Open-ended questions were unstructured questions to which respondents could provide any answer suggesting an opinion or definition related to survivorship support and psychosocial needs. Closed-ended questions gave respondents fixed responses from which to choose, relating to their professional knowledge of survivorship program services. The survey also collected basic demographic information such as gender and ethnic background, as well as professional information such as title, duration of professional affiliation with
CCSP, and awareness of services provided and who the services target. The survey also asked professionals to indicate areas that would benefit from modification and included four open-ended questions specifically related to assessing awareness and necessity of providing services that support the psychosocial needs of survivors and families/caregivers. A “miracle question” was also incorporated, addressing how professions would improve their programs if no barriers existed. The online survey took approximately 30 to 45 minutes to complete.

**Data Collection and Analysis**

The questionnaire survey is the most widely used data-gathering technique in social work and many other social science disciplines. Survey questionnaires are appropriate for research questions about opinions, behavior, attitudes, characteristics, expectations, self-classification or knowledge. The researchers chose to use an online secured survey questionnaire because of the practical limitations of this research study. An email was sent to professionals through their professional email address with a link to the online survey questionnaire. The email explained that participation in this study was voluntary and should the professional choose to complete the online survey questionnaire, their consent was implied.

Descriptive statistics were used to analyze quantitative data obtained from closed-ended questions. Content analysis was used to analyze the definitions and personal opinions provided in the open-ended questions. Content analysis allowed the researchers to uncover emergent themes, patterns and associations. Higher levels of analysis, such as the Pearsons correlation and the one-way t-test, were used to identify any correlations.
among interval level variables such as the hours per week/month/year the professional
spends with a child, adolescent, young adult survivor and families/caregivers and the type
of services the professional finds useful or necessary within CCSPs. Frequency
distributions and cross-tabulations were also used to look for associations between
nominal and interval level data, such as awareness of the need for improved psychosocial
support services within CCSPs and the professionals’ number of years working within
these programs.

Protection of Human Subjects

The Protocol for the Protection of Human Subjects was submitted and approved
by the Committee for the Protection of Human Subjects from the Division of Social
Work as exempt risk based upon federal guidelines (Appendices F). Based upon the fact
that professional opinions were obtained and there was no direct contact with survivors
and/or their families/caregivers, the research is considered to be an exempt risk research
project. On September 26th, 2012, this research study was approved by the Committee
for the Protection of Human Subjects from the Division of Social Work as an “exempt”
risk research study.

Participation in the study was voluntary. All information was confidential. An
informed consent form was used to explain the voluntary and confidential nature of the
questionnaire. The participants were informed of their right to decline participation or
any questions. No names or other identifying information were used. The implied
consent and questionnaires were stored in an online secure location. Only the researchers
had access to the data. Upon the completion of this thesis research project, all data was destroyed.
Chapter 4
FINDINGS

This chapter analyzes responses from surveys that were provided to professionals in the Childhood Cancer Survivorship Programs (CCSPs) in California. This study examined demographics of professionals working in these programs, the professionals’ opinions of the strengths and weakness of the programs, barriers faced by programs and suggestions for improvements. The survey also focused on how well CCSPs are meeting the needs of survivors and their families/caregivers.

Demographics

Twenty-two professionals from multiple disciplines responded to this survey through Survey Monkey. One survey was not used because it was incomplete. The survey identified the professional’s gender, ethnicity, employment title, and number of years of involvement in CCSPs. As demonstrated in Table 1, the greatest percentage of responses came from medical doctors, and the least from social workers and child life specialists. Results verified the difficulty locating non-medical staff working in these programs. Analysis of gender indicated that a majority of the participants were female. As seen in Table 2, 72.7% (n=16) were females, compared to 27.3% (n=6) males. An overwhelming percentage of participants, as seen in Table 3, identified as 61.9% Caucasian (n=13), while the remaining participants identified as 19% Hispanic (n=4), 4.8% African American (n=1), 9.5% Asian or Pacific Islander (n=2), or 4.8% multiple races (n=1). The mean number of years respondents had been involved in the CCSPs was 7.67 years. The greatest number of years involved was 27 years, and the least was one year. Fifty percent
of respondents had been involved with the program five or more years. Three respondents did not indicate the number of years they had been involved with CCSPs.

Table 1 – Which of the following categories best describes your employment title?

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<th>Answer Options</th>
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Table 2 – Are you male or female?

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Table 3 – Which race do you identify with?

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<td>Black or African American</td>
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<td>American Indian or Alaskan Native</td>
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</table>
Overall Findings

This section will analyze participants’ answers regarding the services that are offered and how well programs are meeting the needs of the survivors and their families/caregivers. This section also looks at common themes noted by participants in their suggestions for program improvement and their perceptions of program strengths. Results regarding how well the CCSPs are meeting the cultural needs of the survivors and their families/caregivers will also be examined.

When participants were asked to indicate the survivorship services of which they were aware they indicated medical follow-up care as the most common (95.5%, n=21), followed by support groups and health and wellness (72.2%, n=16), psycho-social educational activities (68.2%, n=15), family counseling (45.5%, n=10), and illness education workshops (8%).

Each participant was asked what they believed should be the most important focus of CCSPs, as displayed in Table 4. Among the responses (n=21), medical follow-up was ranked most important (n=16, 76%), survivorship care education programs ranked second (n=12, 57%), followed by psycho-social support to survivors (n=9, 42%), survivorship education to families/caregivers (n=7, 33%), and survivorship psycho-social support to families/caregivers (n=5, 24%). It is interesting to note that medical follow-up had extreme responses on both ends of the scale. In contrast, psychosocial support to survivors and their families/caregivers appears to be widely distributed along the spectrum.
Looking at participants’ overall satisfaction with the CCSPs, 28.6% (n=6) were extremely satisfied, 42.9% (n=9) were satisfied, 14.3% (n=14.3) were neither satisfied nor dissatisfied, and 14.3% (n=3) were dissatisfied. None of the participants reported to be extremely dissatisfied. Figure 1, below shows a pie chart comparing participant’s satisfaction levels. All of the participants who stated they were dissatisfied with the program were medical doctors. A majority of the participants satisfied with the CCSPs services were nurses. Social worker responses were evenly distributed among the responses extremely satisfied, satisfied, and neither satisfied nor dissatisfied. The two child-life specialists both indicated they were satisfied with current CCSPs services.

When participants were asked to further explain their level of satisfaction, the overwhelming response was that CSSPs are a great program and resource for survivors and their families/caregivers. Common positive themes indicated by participants included the increase in resources, various programs’ abilities to meet the psychosocial needs of survivors and families/caregivers, quality medical follow-up care, great patient and caregiver education, and an overall comprehensive program. Some of the areas of dissatisfaction included lack of funding to meet the needs of all survivors and their families, the medical focus of programs, lack of a standard system of care, lack of consistency, fragmentation of programs, and lack of communication fostering smooth transitions between pediatric and adult care.

Due to financial constraints of CCSPs, participants were generally involved with CCSPs for an unspecified amount of time. Respondents were generally dissatisfied with the length of time participants were involved in their programs, due to either personal
choice or program limitations. When asked about how long CCSPs should offer services, 53.8% (n=7) of participants felt that CCSPs should be offered as a lifetime program, 30.8% (n=4) felt it should available from diagnosis to five years, and 15.4% (n=2) felt 10 to 15 years was an appropriate duration. The remaining participants did not specify an exact amount of time but felt the time should be determined by the needs of the specific survivor and their family/caregiver.

Analyzing the vast differences in the level of program satisfaction, it appears that CCSPs lack consistency across regions, which results in an inconsistent level of care. This information further implies and validates the participants’ overwhelming responses regarding their concerns about inconsistencies within the programs. Overall, it appears that program evaluations are conducted annually. This self-evaluation process can assist in creating consistency among like programs within all regions.

Table 4 –

In your opinion, on a scale of 1 to 6, 1 being MOST important, what should be the main focus of pediatric cancer survivorship programs?

<table>
<thead>
<tr>
<th>Answer Options</th>
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<th>2</th>
<th>3</th>
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<th>5</th>
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<td>2</td>
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</table>
Participants from this study agreed (88.9%) that psycho-social-cultural support services are essential services provided by CCSPs. Because participants reported that psycho-social-cultural services are so essential, it is important to look at each participant’s definition of psycho-social-cultural support. Analyzing these definitions will assist in understanding how well the psycho-social-cultural needs of survivors and families/caregivers are being met.

Participants seemed to agree that psychosocial support included the mental, social and emotional needs of survivors and their families/caregivers. When considering the survivors’ psychosocial needs, participants also mentioned emotional needs, with a focus on the impact that the cancer diagnosis and treatment process has on the survivors’ support systems. These systems included school, family, friends, and medical professionals. Respondents suggested that psychosocial support should focus on the
lifelong impact cancer has on the survivors’ self-image, stages of development, and level of physical and cognitive functioning. Meeting the mental needs of survivors included evaluating survivors for depression and PTSD. Participants’ definitions of psychosocial support for family/caregivers had some similar responses, including addressing the impact of the survivor’s journey on the family/caregiver and issues of transitioning from being the caretaker of a “sick” child to supporting a “survivor.” Participants also noted the struggle balancing the different roles family/caregivers play while supporting the survivor. Several participants mentioned that psychosocial support is not one-size-fits-all: They suggested that each survivor and family/caregiver has different needs, concerns, and questions that should be specifically addressed and the psychosocial support should be adjusted to fit these individual needs. This was noted in many responses to the definition of psychosocial support.

To determine how well CCSPs meet the psychosocial needs of the survivors, participants were asked to rank several common themes of psychosocial support (Figure 2). Participants (n=17) ranked them as follows: reintegration support, ranked moderate (n=9, 53%); identity reformation, ranked well (n=6, 35%); independence, ranked well (n=6, 35%); physical body changes, ranked equally well and moderate (n=7, 41%); maintenance treatment, ranked well (n=7, 41%); social isolation, ranked equally well and moderate (n=6, 35%); and fear of reoccurrence, ranked well (n=7, 41%). The two categories with the highest median of poor rankings were identity formation (n=4, 23%) and social isolation (n=3, 18%).
Families and caregivers were also asked to rank several common types of psychosocial support in order to determine how well CCSPs meet their psychosocial needs (Figure 3). The categories participants (n=17) ranked were: reintegration support, ranked moderate (n=11, 68%); issues surrounding loss, ranked equally well and moderate (n=6, 35%); financial stress, ranked moderate (n=8, 47%); maintenance treatment, ranked well (n=7, 41%), social isolation, ranked moderate (n=9, 53%); and fear of reoccurrence, ranked moderate (n=8, 47%). The three categories with the highest median of poor rankings were financial stress (n=3, 18%), social isolation (n=4, 24%), and reintegration support (n=3, 18%). Analysis indicated that participants feel CCSPs better meet the psychosocial needs of the survivors than the family/caregivers.

Many diverse cultural needs exist among CCSPs. Participants (n=18) were asked to rank how well CCSPs meet the cultural needs of survivors and their families/caregiver based upon several preselected categories. Participants ranked interpreter services as well (n=9, 50%); religious/spiritual support as moderate (n=7, 39%); nutrition/diet awareness as well (n=7, 39%); socioeconomic barriers to access support as moderate (n=6, 33%); care giving strategies as well (n=6, 33%); and help seeking behaviors as well (n=8, 44%). The category with the highest median of poor ranking was religious support (n=4, 22%). Overall participants’ responses indicate that some categories would benefit from improvement, but overall CCSPs do a good job of meeting the diverse cultural needs of survivors and their families/caregivers (Figure 4).
Figure 2 – *How well do you feel the pediatric survivorship programs meet the psycho-social needs of survivors?*

![Figure 2](image1)

Figure 3 – *How well do you feel the pediatric survivorship programs meet the psycho-social needs of families/caregivers of survivors?*

![Figure 3](image2)
Figure 4 -

*How well do the pediatric cancer survivorship programs meet the diverse cultural needs of the patients and their families?*

CCSPs are a great resource for survivors and family/caregivers. Overall participants felt these programs are successful and important but that there is room for improvement. Participants were asked to identify the strengths and weakness of the programs. Some of the common strengths were continuity and security for survivors and their family/caregivers, individualized plans, coordination of care, multidisciplinary care, education, resources, connections, medical follow-up, and empowerment. Common suggestions for improvement included increased funding and additional support from health insurance providers. Participants suggested that more funding would allow programs to implement additional clinical hours with survivors, staff more social workers, and provide individual counseling. Other suggestions surrounded the issue of continuity of care and regionalizing care. Participants expressed concerns about the treatment survivors and families receive when transitioned to adult care. Participants also
indicated concern that programs are not regionalized and therefore do not provide consistent care region-wide.

Finally, participants were asked what programs they would like to see added to CCSPs if they had one million dollars (Figure 5). Participant’s ranked family support groups highest (93.8%, n=15) and yearly playgroups lowest (31.3%, n=5). Other suggestions included regular neuropsychological evaluations provided by psychologists, cancer survivorship camps, educational specialists, social support groups, and patient support groups.

Figure 5 -
Summary and Prevailing Themes

Overall, it appears that survivors and their families believe survivorships programs are essential. It appears that these programs have many strengths and are moderately meeting survivors’ psycho-social-cultural needs. Participants overwhelmingly agreed that there is a need for improvement within these programs. Funding and communication between programs appear to be the strongest greatest issues. Participants believed that if CCSPs had more funding, more cooperation from insurance companies, more consistent care, better transition programs, and consistency among programs, they would be able to better impact the lives of survivors and their families/caregivers. The survey clearly indicated that CCSPs’ success rates vary depending on location and funding available to specific programs.
Chapter 5

DISCUSSION

Data and results from the study were presented in the previous chapter. Major findings, as well as the related implications, recommendations, and limitations, will be presented in this chapter.

Summary of Study

The study sought to explore and describe the depth and breadth of psycho-social-cultural-spiritual services provided by Childhood Cancer Survivorship Programs (CCSPs) throughout California. Participants from five prominent hospitals participated. Given the current 80% survivorship rate for childhood cancer, the researchers felt that it was important to investigate the current psycho-social-cultural-spiritual services provided by CCSPs in order to enhance future support for survivors and their families/caregivers. The participating hospitals were either academic, community-based, or non-profit institutions. Participants were asked to identify their professional title, the provided services of which they are aware, whom these services target, and how programs can be improved. Participants included social workers, child life specialists, pediatric psychologists, clinical researchers, doctors and nurses. Data suggested that programs provide a moderate level of cultural diversity based on participants’ overall demographic information.

Although participants suggested and supported a major need for psychosocial support for children, adolescents, young adults, and their families/caregivers, the data
indicated that comprehensive services currently offered by CCSPs are not adequately meeting this need. A majority of participants indicated that CCSPs provide psychosocial support on a limited base with a lack of breadth. Data indicated that programs currently focus heavily on medical follow-up care. Participants felt there was a moderate level of psychosocial support and indicated multiple areas where improvement is needed. Specific areas of improvement indicated by professionals include a standardized base for CCSPs that can be implemented and utilized across all regions, better transitional care for survivors, communication and collaboration between programs, and greater continuity of care. Many of the comments indicated that CCSPs do not adequately staff their programs with social workers, child-life specialists, psychologists and other non-medical professionals. Significantly, the data indicated that families/caregivers are an afterthought in childhood cancer survivorship aftercare. All participants indicated that limited support is provided to families/caregivers. Participants also suggested that support provided to families/caregivers focus on supporting the child throughout their survivorship process. Overall data suggests that although CCSPs provide moderate support to children and families, there is much room for improvement.

**Implications for Social Work**

The researchers found that the literature reviewed, combined with their research, could influence all levels of social work practice, on micro-, meso-, and macro-levels. On the micro-level, CCSP professionals can integrate psychosocial support into all areas of care of the survivor and their support network. This integration may prevent medical
follow-up care complications, as well as allow professionals to collaborate with others outside their scope of practice and approach individuals as a whole in their advocacy for more appropriate care interventions. Treating the whole individual, professionals can empower survivors and their support network to make choices that maintain both their physical well-being and their psycho-social-cultural-spiritual wellness. Implications on the meso-level include professional advocacy for the implementation of additional psychosocial services within CCSPs. Professionals know the psycho-social-cultural-spiritual needs of survivors and their support networks, and can therefore encourage implementation of appropriate comprehensive services. Implementation of more comprehensive services within CCSPs may promote a stronger relationship between professionals, the larger community, the survivor, and their family, allowing survivors and their families/caregiver to feel better supported over a longer period of time. Finally, implications on the macro-level include the need for additional staff so that the number of survivors better correlates with the professional staff available for a better survivor-staff correlation/ratio. Inadequate staffing leads to gaps in care simply because there is not enough clinical time for one professional to complete all necessary work. Hiring additional staff, whose primary focus is the psycho-social-cultural-spiritual needs of survivors and their support network, will allow CCSPs to appropriately support survivors and create a more effective program.

Given the findings of this research and the diverse psycho-social-cultural-spiritual needs of survivors and their support network, the researchers feel further studies should explore more specifically the needs of survivors and their support networks and adjust the
services provided to better meet their needs. Appropriate service modifications can improve the quality of life of current and future survivors and their support networks. Additionally, professionals within CCSPs will be able to provide care in a more accurate, efficient, and appropriate manner, leading to improved professional well-being.

**Recommendations**

It is the recommendation of the researchers that CCSPs commit to conducting on-going professional and program evaluations to assess how they are meeting the psycho-social-cultural-spiritual needs of survivors and their support networks. Because research shows that cancer patients are resilient and reintegrate more easily than their families/caregivers, the researchers also recommend expanding support to include families/caregivers on a more direct level. It is the researchers’ recommendation that support focused on the family/caregiver be implemented from diagnosis and beyond, and that further research be conducted to determine what that support should look like. Participants’ call for improved psycho-social-cultural-spiritual support suggests the need for the integration of additional professional disciplines, such as registered dieticians and chaplains. Participants also recommended additional time for individual counseling, professional training opportunities, increased staff ratios, and long-term opportunities to interact with survivors for better continuity of care. All of these recommendations suggest that current CCSPs have room for improvement.

Specific areas of improvement indicated by professionals include a standardized base for CCSPs that can be implemented and utilized across all regions, better transitional
care for survivors, communication and collaboration between programs, and greater continuity of care. These recommendations cannot be implemented appropriately without the support of health insurance companies. Insurance companies must see the value of services beyond medical follow-up care in order to create a comprehensive program that supports the physical, emotional, financial, cultural and spiritual needs of survivors and their families/caregivers, therefore improving quality of life.

**Limitations**

Although significant findings were derived from this study, there were also certain limitations. With more than 50% of participants being medical professionals, one of the main limitations of this study was the lack of professionals with a discipline focused on psycho-social-spiritual-cultural needs. The participants’ experiences and perceptions may therefore not represent the experiences and perceptions of all CCSP professionals. Further research directly targeting professional opinions of social workers, child-life specialists, and psychologists working within CCSPs throughout the United States would be beneficial and provide a more accurate evaluation of psycho-social-cultural-spiritual services provided.

Finally, to minimize the time asked of participants to complete the survey/questionnaire, the researchers did not include questions regarding the ages and stages of survivors. Further research directly related to the age and developmental stage of childhood cancer survivors and their specific needs would assist in creating more
accurate and appropriate services within current CCSPs throughout the United States under the umbrella of the Children’s Oncology Group (COG).

Conclusion

The researchers were able to obtain opinions from prominent professionals because one of the researchers is a childhood cancer survivor. Hearing from a survivor who wants to assist in creating more comprehensive and supportive CCSPs was extremely appealing to medical doctors and their multidisciplinary professional teams. Inspired by the researcher’s passion, these professionals enthusiastically participated in this study. Childhood cancer survivors are anomalies to medical professionals working outside of the cancer-surviving community, yet research indicates most children diagnosed with cancer survive their treatment and beyond. The researchers feel this study was a gift to future childhood cancer survivors and their support systems.

Children are resilient, often going through their treatment process without many noticeable emotional side effects. Children, families, and their external support network are all affected by the experience. This study brought into light the positive aspects of current CCSPs in California. CCSPs in California provide excellent medical follow-up care. But there are areas in need of improvement. CCSPs would greatly benefit survivors and their families/caregivers by expanding the depth and breadth of psychosocial support services they provide. The areas of improvement noted in this study suggest that further research is needed to assess the overall needs of childhood cancer survivors and their support systems.
Within the past 25 years, medicine has focused on curing childhood cancer. Science has been extremely successful, creating a need for increased psycho-social-cultural-spiritual support for survivors and their caregivers. Social work researchers have identified a need for programs to evaluate their practice and knowledge in a changing health care environment. The ideal CCSP would include support services for the child, adolescent, young adult, and their support system. These services would include psychological support, spiritual support, health education, nutrition advocacy, financial guidance, collaborative transitional care, as well as other services based on individual needs. The researchers would be remiss if the reality that, without proper funding, CCSPs cannot provide the services necessary for comprehensive support was not acknowledged. Further research and knowledge can lead to greater integration of services and support in CCSPs and other health care settings, encouraging the financial support necessary for additional professional staff and services.
Appendix A
Organization Request Letter

Dear Gina,

My name is Hester Joelson and I am a current Sacramento State University MSW Student. In 1997 I was diagnosed with Ewing's Sarcoma and was treated with a protocol that was created by Dr. Meiser at City of Hope. As a result, I am a 13 year survivor who wants to give back to childhood cancer survivors and their families/caregivers. Together with a fellow MSW student, Heather Cortez, we are putting together a "Program Assessment of Childhood Cancer Survivorship Programs". The thesis will be conducted under the supervision of Dr. Francis Yuen.

We are looking to get professional opinions from doctors, nurses, social workers, and child life specialists about what childhood cancer survivorship programs provide and how these programs are incorporating psycho-social-cultural support for survivors and their families/caregivers. It is our hope that you can assist us in locating the above named professionals and their email addresses. The researchers will obtain the California State University of Sacramento, Division of Social Work, human subject’s approval before accessing professionals. Professionals will be asked to complete an anonymous survey via Survey Monkey with all safety measures in place to ensure confidentiality.

Current research indicates that 80% of children diagnosed with a pediatric cancer are surviving. What we hope to find in our research is that these survivors and families/caregivers are not only surviving but they are thriving. With the help of Dr. Bhatia (Smita) and the names of professionals working within Childhood Cancer
Survivorship Programs in California we can help assist in creating a thriving surviving community.

Thank You For Your Time,

Hester Joelson & Heather Cortez
Appendix B
Letter of Participation

Human Subjects Review Committee
Division of Social Work
California State University, Sacramento

TO WHOM IT MAY CONCERN:

This letter is to confirm that I have provided Heather Cortez and Hester Joe/son, Master of Social Work Students at California State University, Sacramento, with the URL to the publicly available database of Childhood Cancer Survivorship Programs maintained by the Children's Oncology Group, containing the names and telephone numbers for the long-term follow-up programs at Children's Oncology institutions, as follows:


Sincerely,

Wendy Landier, PhD, RN
Clinical Director, Center for Cancer Survivorship
Assistant Professor, Department of Population Sciences
City of Hope Comprehensive Cancer Center
Chair, Children's Oncology Group Nursing Discipline

1500 E. Duarte Rd., DPS 173, Room 153
Duarte, CA 91010-3000
Phone: 626-471-7320
Fax: 626-301-8983
Email: wlandier@coh.org
Appendix C
Participant Request Letter

Dear Participant,

My name is Hester Joelson and I am a current California State University, Sacramento, Master of Social Work Student. In 1997 I was diagnosed with Ewing's Sarcoma and was treated with a protocol that was created by Dr. Meiser at City of Hope. As a result, I am a 13 year survivor who wants to give back to childhood cancer survivors and their families/caregivers. Together with Heather Cortez, we are conducting a "Program Assessment of Childhood Cancer Survivorship Programs" under the supervision of Dr. Francis Yuen.

Your participation will allow us to obtain professional opinions from doctors, nurses, social workers, and child life specialists about what childhood cancer survivorship programs provide and how these programs are incorporating psycho-social-cultural support for survivors and their families/caregivers. Current research indicates that 80% of children diagnosed with a pediatric cancer are surviving. What we hope to find in our research is that these survivors and families/caregivers are not only surviving but they are thriving.

Attached you will find our implied consent form providing further details regarding this thesis research project. Below you will find the link that will allow you to access the survey via Survey Monkey’s secure online database.

https://www.surveymonkey.com/s/ChildhoodCancerSurvivorshipProgramStudy

Thank You,
Hester Joelson and Heather Cortez,
California State University, Sacramento MSW Students
Appendix D
Survey

Assessment of Pediatric Cancer Survivorship Programs

The final questionnaire is in Survey Monkey format

1. Please describe the pediatric cancer survivorship programs you are aware of:

   (Check all that apply)
   
   ___ Support Groups
   ___ Medical Follow-up Care
   ___ Psycho-social educational activities
   ___ Illness education workshops
   ___ Family counseling
   ___ Health and Wellness

   Demographic Information

2. Are you male or female?

   ____ Male   ____ Female

3. Which of the following categories best describes your employment title?

   ____ Doctor
   ____ Nurse
   ____ Child Life Specialist
   ____ Social Worker
   ____ Specialist
   ____ Other (please specify) __________________________
4. **Which race do you identify with?**

   ___ White
   ___ Black or African American
   ___ American Indian or Alaskan Native
   ___ Hispanic
   ___ Asian or Pacific Islander
   ___ From Multiple Races
   ___ Other (Please Specify) ___________________________

5. **How long have you been directly involved with pediatric cancer survivorship programs?**

   ________ Years

6. **How often do you interact with pediatric/AYA cancer survivors and their families/caregivers?**

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<th>At least Bi-Weekly</th>
<th>At least Monthly</th>
<th>At least Quarterly</th>
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<tr>
<td>Families/Caregivers</td>
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</table>
7. How satisfied are you with the overall care patients receive in pediatric survivorship programs?

___ Extremely Satisfied
___ Satisfied
___ Neither Satisfied nor Dissatisfied
___ Dissatisfied
___ Very Dissatisfied

8. Please explain your level of satisfaction.

________________________________________________________________________

________________________________________________________________________

9. How often does your childhood cancer survivorship program conduct evaluations on comprehensive services provided to survivors and families/caregivers.

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<tr>
<td>Families/caregivers</td>
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10. In your opinion, what should be the main focus of Pediatric cancer survivorship programs? (Rank 1-5 in order of importance, 1 being high and 5 being low)

<table>
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</table>
11. Define in your own words psychosocial support for survivors?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

12. Define in your own words psychosocial support for caregivers/families?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

13. How well do you feel the pediatric survivorship programs meet the psycho-social needs of survivors?

<table>
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<th>Poor</th>
<th>Very Poor</th>
<th>Not Applicable</th>
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<tr>
<td>Reintegration Support</td>
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<tr>
<td>Identity Reformation</td>
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## Independence

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<tr>
<th>Physical Body Changes</th>
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<tr>
<td>Maintenance Treatment</td>
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<tr>
<td>Social Isolation</td>
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<tr>
<td>Fear of Recurrence</td>
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14. How well do you feel the pediatric survivorship programs meet the psycho-social needs of families/caregivers of survivors?

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<tr>
<th></th>
<th>Very Well</th>
<th>Well</th>
<th>Moderate</th>
<th>Poor</th>
<th>Very Poor</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>Reintegration Support</td>
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<td>Issues Surrounding Loss</td>
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<td>Financial Stress</td>
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<td>Ongoing Maintenance Treatment</td>
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<td>Social Isolation</td>
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<td>Fear of Recurrence</td>
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</table>
15. How well do the pediatric cancer survivorship programs meet the diverse cultural needs of the patients and their families?

<table>
<thead>
<tr>
<th>Service</th>
<th>Very Well</th>
<th>Well</th>
<th>Moderate</th>
<th>Poor</th>
<th>Very Poor</th>
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<tr>
<td>Interpreter Services</td>
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<td>Religious/Spiritual Support</td>
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<td>Nutrition/Diet Awareness</td>
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<td>Socioeconomic Barriers to access support</td>
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<td>Caregiving Strategies</td>
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<td>Help Seeking Behaviors</td>
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</table>

16. In your professional opinion how essential are psycho-social-cultural support services in Pediatric Cancer Survivorship Programs?

   ___ Very Essential
   ___ Essential
   ___ Neither Essential nor Unnecessary
   ___ Somewhat Essential
   ___ Not Essential

17. In your professional opinion, how long should a survivor and/or family/caregiver be involved in a peer mentorship programs (programs matching survivors and families/caregivers with people who have had similar experiences).

   _____ Diagnosis to 5 years
   _____ 5 to 10 years post treatment
   _____ 10 to 15 years post treatment
18. What are the strengths of the pediatric cancer survivorship programs?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

19. What suggestions do you have to further improve the pediatric cancer survivorship program?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

20. If given $1 million, what programs would you incorporate to further enhance current Childhood Cancer Survivorship Programs (please distribute the funds among the programs listed)?

___ Nutrition Guidance

___ Spiritual/Religious support

___ Family Support Groups

___ Yearly playgroups

___ Professional training opportunities

___ Other (please specify)
Hello,

You are invited to complete an online survey conducted by Hester Joelson and Heather Cortez. We are Master of Social Work students at California State University Sacramento conducting our thesis research under the supervision of Dr. Francis Yuen. The purpose of this study is to get professional opinions from doctors, nurses, social workers, and child life specialists on how well childhood cancer survivorship programs are meeting the psycho-social-cultural needs of families/caregivers and survivors. This study will also explore the feasibility and utilities of a peer mentorship program.

Your participation is highly appreciated and needed. It will contribute to the better understanding of the diverse needs of the cancer surviving community and the development of appropriate services in the future. Your participation is completely voluntary and consent is implied if the survey is completed. This study involves the following:

**Why is this study being conducted?**

This thesis research is being conducted to get the professional opinion of doctors, nurses, social workers, and child life specialists on how best childhood cancer survivorship programs are meeting the psycho-social-cultural needs of families/caregivers and survivors. The items on this survey pertain to your experiences and opinions of the survivorship programs you are aware of. This survey should take no longer than 30 minutes to complete.
What am I being asked to do?

You are being asked to complete this 20 question survey. These questions relate to basic demographic information, effects of the program, and suggestions for improvement.

Is this voluntary?

Yes. This study is completely voluntary and professionals are under no obligation to participate. There will be no consequences should you choose not to participate. Your participation, however, is extremely valuable as the study findings will help identify ways to further improve childhood cancer survivorship programs. Participants have the right not to answer any question that they do not want to answer.

Is this study confidential and anonymous?

The data for this study will be collected through www.surveymonkey.com and will be transmitted in an encrypted format. This helps to ensure that any data intercepted during transmission cannot be decoded and that individual responses cannot be traced back to an individual respondent. The highest level of data encryption will be used, within the limits of availability and feasibility. Your responses will be kept confidential to the degree permitted by the technology used. However, no absolute guarantees can be given for the confidentiality of electronic data. The information you provide within the questionnaire will be kept confidential and all data obtained over the course of this study will be kept in a locked location, except when being used for the purpose of this study. At the end of the study, all data, and records will be immediately and appropriately disposed of by June of 2013.
Any publications based on this study will contain condensed analytical accounts of responses without any identifying information about the respondents. No identifying information is sought from the respondents other than minimal demographic questions.

What are the benefits of participation?

There are no direct monetary benefits related to completing this survey. However completing this survey may be beneficial for childhood cancer survivorship groups, clients, and family/caregivers.

What risks do I face if I participate?

This study has been approved as “exempt” by the Human Subjects Review Committee of the Division of Social Work at California State University, Sacramento. There may be minor personal discomfort when evaluating gaps in the CCSP programs. The researcher is trained to ask the questions in a way that ensures participants’ dignity and privacy.

Whom do I contact if I have questions about this research?

If you have any further questions, please contact Hester Joelson at moteckhes@aol.com, 916-710-1518, Heather Cortez at heatherays@yahoo.com, or 916-216-6510. This study is being conducted under the supervision of Dr. Francis Yuen, Professor of Social Work. He can be contacted at fyuen@csus.edu or 916-278-7182. By completing and returning this survey, you are consenting to participate in the research.

Thank you
TO: Heather Cortez & Hester Joelson

FROM: Committee for the Protection of Human Subjects

RE: YOUR RECENT HUMAN SUBJECTS APPLICATION

We are writing on behalf of the Committee for the Protection of Human Subjects from the Division of Social Work. Your proposed study, “Needs Assessment of Survivorship Programs for Children and Families.”

__X__ approved as __X____EXEMPT      ____ NO RISK     ____ MINIMAL RISK.

Your human subjects approval number is: 12-13-005. Please use this number in all official correspondence and written materials relative to your study. Your approval expires one year from this date. Approval carries with it that you will inform the Committee promptly should an adverse reaction occur, and that you will make no modification in the protocol without prior approval of the Committee.

The committee wishes you the best in your research.

Professors: Maria Dinis, Jude Antonyappan, Teiahsha Bankhead, Serge Lee, Kisun Nam, Maura O’Keefe, Dale Russell, Francis Yuen.

cc: Yuen
References


Adolescent Young Adult Survivors of Childhood Cancer and Their Parents.


