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Building Stories of Resilience in the Face of Childhood Cancer:

Exploring the experiences of childhood cancer survivors

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A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Bachelor of Arts in Social Work  
2011

### **Abstract**

This qualitative study addressed the personal stories, characteristics, influences, and factors which assisted childhood survivors of cancer to be resilient and thrive. Six childhood cancer survivors told stories of coping with the hardships of a cancer diagnosis and eight common themes uniquely experienced by each survivor were revealed. Results of this study indicated that professionals should address a cancer diagnosis as a family diagnosis, constantly facilitating communication within the family system. Health promotion should also be a common professional practice, supporting the individual in self-advocacy. Professionals should also support survivors in the process of making meaning out of his/her cancer experience and accepting the survivor identity. Finally, this study found that professional collaboration utilizing aspects of narrative therapy is an ideal vehicle towards supporting survivors in building stories of resilience.

## Building Stories of Resilience in the Face of Childhood Cancer

Childhood cancer and other critical illnesses are in many ways a life-long diagnosis. Unfortunately, the current health care and social service system do not always acknowledge this. The child patient not only needs physical and medical attention, but he or she also faces a series of long-term medical, psychological, social, and advocacy needs (Chesler & Zebrack, 2000). Once treatment is complete and the child re-enters mainstream society, one is labeled as “in remission” or “cured.” The child experiences a series of adjustments and is prone to many problems if these new set of needs are not addressed. Childhood cancer survival rates are on the rise, with an 80% five -year survival rate. In comparison to a rate of less than 50% in the 1970’s, the childhood cancer survivor population is growing (American Cancer Society, 2010). In 2010, there were approximately 270,000 childhood cancer survivors in the United States (Jones, 2010). This is a population that is continuously growing. The transition period from cancer patient to survivor is knowledge that social workers and professionals that work in the medical field need to have.

Once a child or adolescent experiences the physical and psychological trauma of cancer treatment, that child is not the same. The entire family system is forced to adjust to these new needs of the sick child and the new roles they have taken on in the family system. Research continues to reveal long-term effects of treatments, both physical and psychological. These effects include secondary cancers, heart damage, lung damage, infertility, chronic hepatitis, alterations in growth and development, impaired cognitive abilities, and psychosocial effects (American Cancer Society, 2010). As awareness of these effects increase, the growing range of needs of this population should be addressed.

Re-adjusting to life in school and in the social atmosphere can be overwhelming when the relationships and friendships the child or teenager had previously relied upon are different or even cease to exist. It has been previously found that all childhood cancer survivors have problems in adjusting socially and hold continuous fears and concerns about their medical and social futures (Chesler & Zebrack, 2001). The psychological stress these survivors are subject to consist of worries about relapse, the need for future treatment, general health, late effects of treatment, academic and/or scholarly achievement, changes in relationships, and much more. These worries and concerns can ultimately affect their self-image and general life outlook. Such stress has the potential to negatively impact the survivor's quality of life and ability to achieve the developmental milestones that every healthy individual should have the opportunity to experience. The opportunity to achieve these life events and experiences such as dating, entering the job market, and marriage are essential in leading a fully rounded socially and economically rich lifestyle.

The psychological stress and worries that these survivors face have the power and potential to negatively affect the transition process into mainstream society and their overall quality of life. The presence and intensity of these stressors is crucial for social workers and other health care providers to be aware of if they are going to provide their clients with the psychosocial support and services they need from diagnosis into remission (Chesler & Zebrack, 2001).

However, there is a promising starting point for these providers. Human beings, especially children, are resilient. People have the potential to grow and to thrive in the face of hardship and trauma. In reference to the strengths perspective, emphasizing and looking for one's strengths and accomplishments as opposed to one's weaknesses and failures, it is not

necessarily required for helping professionals to look at childhood cancer solely as a trauma but also as a “potential catalyst for growth” (Chesler & Parry, 2005).

People have the potential to thrive, become resilient in the face of trauma, develop improved coping skills, and ultimately transform the meaning of their illness from a series of threatening experiences into challenges they can overcome. It has been found that in order to thrive in the face of trauma, one must partake in two activities, meaning making and coping. The way an individual perceives his/her illness and the ways that he/she chooses to cope with the hardships that accompany it greatly affect his/her well-being from diagnosis through remission (Chesler & Parry, 2005).

Research has found that experiences with cancer change the way that people view themselves in relation to the world around them. These perceptions can be positive, negative, or a combination of both. In a narrative study of three hundred childhood cancer survivors by Chesler and Parry (2005), many of the subjects reported positive factors that have pushed them to appreciate their experiences with cancer. These factors include psychological maturity, increased empathy and compassion for others, reassessed values and priorities, an enhanced sense of strength, and a deeper appreciation for life (Chesler & Parry, 2005).

According to this study, thriving is an active and continuous process of empowerment. It includes meaning making, coping, and integrating the experienced gains and losses into these life meanings in ways that help to promote growth. A thriving narrative has been previously defined as “a narrative of how some survivors experience tremendous pain and loss but embrace themselves in the experience, finding strength, courage, and, ultimately, wholeness” (Chesler & Parry, 2005 p. 1068 ).

No matter how positive and optimistic an individual is, there is inevitably going to be an excessive amount of pain and hardship while enduring cancer for both the child and the family. The core of the “thriving” cancer survivor is the ability to embrace life and their sense of self. It is important to acknowledge that this thriving process needs to begin at diagnosis and continue throughout treatment and remission. Helping professionals need to learn what it is exactly that help to make these individuals “thrive” (Chesler & Parry, 2005).

Childhood cancer is a diagnosis that forever changes the child and the family system as a whole. More effort and resources need to be put towards enrichment of support and services even when the patient is considered to be “in remission.” Social Workers need to gain an understanding as to what it is that contributes to these meaning making processes that lead to positive perceptions and ultimately a story of both thriving and resilience. In order for these survivors to have the opportunity to become resilient and lead self-sufficient and fulfilling lives, social workers need to advocate for the long-term needs and services for such clients and their families. What are those needs and what are the influences and services that best address those needs? This study will aim to find the personal characteristics, influences, factors, circumstances, and services that help childhood cancer survivors find their resilience and thrive. Furthermore, this study will attempt to explore what social workers and other helping professionals can do to help these individuals find that resilience within them to create their “thriving narrative.”

### **Literature review**

#### **Childhood cancer challenges on the individual and family system**

To most individuals, cancer diagnosis represents a series of traumatic and stressful life events. These events affect the entire family system. It has been classified as a “family disease” that is composed of a multitude of stressors and hardships (Chesler, Fritz, Parry, Repetto, &

Orbuch, 2005). A childhood cancer diagnosis places the family system under a unique set of stressors. When a child is diagnosed with cancer, the entire family system is strained and the relationships within this system are forced to change in terms of what the sick child needs from his/her primary support system. As the sick child has a new and demanding set of needs, a process of adjustment in family relations is crucial for the well being of its members and the system as a whole (Gerhardt, Noll, Robinson, & Vannatta, 2009). All members of the family explore ways to manage their feelings and make the necessary adjustments. As each member has lost a sense of control, safety, and predictability as a result of their experience with cancer, they are forced to redefine their familial relationships as well as their relationship with the external world (National Association of Social Workers, n.d.).

According to family systems theory, adjustment of family members and resources are primary influencing factors for the adjustment of the child patient (Chesler et al., 2005). In most cases, the family system is the child's primary source of care, support, and rehabilitation (Chesler et al., 2005). Taking the means necessary towards stabilizing and maintaining the continuity of that support system is important for the well being of the sick child and the family as a whole.

Unfortunately, cancer diagnosis is the first step in a series of stressful and traumatic experiences. Even in the face of survival, there are long-lasting physical, psychological, social, and emotional challenges that the individual endures. Some of these challenges include physical impairment, infertility, uncertainty, fears about recurrence and mortality, reinterpretation of life goals, and discrimination in employment and insurance (Chesler & Parry, 2005).

Furthermore, childhood cancer, in comparison to adulthood cancer, has its own specialized set of hardships, challenges, and adjustments that the child and the family are forced



to experience. Survival rates are continuously on the rise, with 80% of childhood cancer patients exceeding the five-year survival rate (Eiser, Jenney, Morse, & Vance, 2001). This population is increasing along with their unique set of needs. These short term and long term side effects and life challenges interrupt the normative development of the child and create a set of “non-normative” needs (Chesler & Parry, 2005).

Communication is a primary means of maintaining a healthy and stable family system. Unfortunately, this is not always accomplished in times of high stress. When a family is in distress, communication tends to diminish or take on a superficial form. It takes work to keep those doors of genuine communication open. According to a study that measured the quality of life in childhood cancer survivors, they found there was poor agreement in terms of the interpretation of the survivor’s quality of life on three subscales, comparing the parent’s interpretation against those of their own child (Eiser et al, 2001).

Results of this study indicated that these parents perceived their child’s physical, cognitive, and disease/treatment functioning at a much lower level than their child reported their own functioning. Parents also rated their child as having a poorer quality of life than the child perceived it. Furthermore, it was also found that parents who are more depressed have a higher risk of having children who perceive their own quality of life as being poor (Eiser et al, 2001). Also, parents tend to be naturally inclined to shelter and protect their child for as long as possible. Unfortunately, when the child is fighting for his/her life, this is not always a realistic approach. Cancer is full of uncertainties and challenges from which parents cannot protect their children. The third finding of this study showed that even in their attempts to hide their own feelings and fears about these uncertainties, parents are less likely to hide feelings of pervasive depression from their children. As a result, the child’s recognition of their parent’s depressive

feelings ultimately affects their own quality of life (Eiser et al, 2001). These findings foster the need for more open, honest, and direct communication of such feelings to potentially contribute to higher quality of life for the sick child (Eiser et al, 2001).

From a developmental perspective, childhood cancer is an “off-time” life event that is neither planned for nor predicted (Costanzo, Ryff, & Singer, 2009). As the child is developing and learning how to establish his/her place in the world, this diagnosis has changed how this developmental process will evolve. Furthermore, as the child has not acquired a level of maturity and stability in his place in the world, the experience is even more traumatic and distressing (Costanzo et al, 2009).

Age has a significant impact on the level of distress experienced, with younger individuals at a higher risk for heightened distress and trauma. One study on the psychosocial adjustment among cancer survivors found that the lack of preparation of these cancer-related challenges and limited availability of social support from peers dealing with similar problems is what contributes to this age factor (Costanzo et al, 2009). Children, adolescents, and even young adults are typically not developmentally prepared to handle the unforeseen experiences and hardships of cancer. This study found that younger individuals are more vulnerable, have poorer emotional well-being, greater depressive symptoms, and greater anxiety once treatment comes to an end (Costanzo et al, 2009). Furthermore, the cancer experience itself can affect the typical age-related experiences of dealing with anxiety and depression, subjecting the individual to extreme emotions he/she is developmentally not equipped to handle.

### **Long term and short term side effects**

The increased survival rate for children diagnosed with cancer is a direct result of the creation and advancements of the three primary treatments of cancer. Treatments include

chemotherapy, radiation, and surgery (Eiser, 1998). Progression in technology has led to advances in these treatment options. However, these invasive methods and procedures also come with an array of disadvantages and potential side effects. These side effects range from physical, psychosocial, cognitive, and emotional disadvantages (Eiser, 1998).

Physically, there is an array of negative side effects that result from treatment. Childhood cancer survivors are at increased risk for damage to heart, kidney, thyroid, hearing, dental, growth, and fertility functioning. The presence and intensity of these side effects are largely dependent on the degree of chemotherapy and radiation treatment, as each individual's dosage varies. Depending on where on the body the person receives radiation treatment will affect what areas are at highest risk for damage or decreased functioning. For example, radiation to areas on the head and neck can lead to decreased functioning of the thyroid gland and even hypothyroidism. This will ultimately decrease growth and metabolism. Also, treatments before or during times of development and puberty have more profound effects on the individual, and can ultimately stunt growth (National Association of Social Workers, nd). As a whole, abnormal growth and hindered endocrine function is a potential side effect of all forms of radiation and chemotherapy. More specifically, radiation of the pituitary, thyroid, or gonads most strongly stunt growth and development. Also, compromised fertility, as a result of radiation in the abdominal area or certain levels of chemotherapy, can also result from treatment (Costanzo et al, 2009).

Also, specific drugs such as anthracyclines can lead to cardiac damage. Chemotherapy inevitably leads to hair loss (alopecia), which is usually a distressing experience, especially for the adolescent/young adult population. Nausea is a direct side effect of the chemotherapy. Mouth ulcers, rashes/allergic reactions, changes in food preferences, disturbance in taste buds and eating

habits, mood alterations, changes in behavior, and sleep disturbance can also result from chemotherapy. Also, childhood cancer survivors are at an increased risk for secondary malignancies, most commonly leukemia, breast cancer, or skin cancer (National Association of Social Workers, n.d.). According to Costanzo (2009), survivors are six times more likely than the general population to experience relapse and/or a second cancer type.

Psychologically, experiences with childhood cancer require an adjustment on an emotional, social, and psychological level. The survivor has a new sense of control over his/her life. The survivor's social life is also disrupted and they may experience the loss of some friends. The style and dynamic of the survivor's social life is largely impacted by his/her cancer experience. It affects their body image, self-perception, ability to fit in with peers, and confidence. Survivors also may not feel "in sync" with their peers, as their experience with cancer has exposed them to the reality of death early in development, leading to increased maturity. However, this can be frustrating as their peers are not necessarily developmentally capable of grasping these concepts to the extent of the survivor. On the other hand, the lack of exposure to socialization experiences as a result of long hospital stays, treatment, and school absences can lead to a sense of immaturity in terms of how to socialize appropriately with peers (National Association of Social Workers, n.d.).

Survivors can experience excessive feelings of anxiety in terms of health and safety. Fear of recurrence and the intensity of long-term side effects can be overwhelming to manage if the survivor does not possess effective coping skills. As a whole, dealing with the presence of intense feelings and reactions to these feelings can be very difficult and exhausting. These feelings can range from anger, sadness, depression, anxiety, hope, joy, happiness, and gratitude. Also, feelings of grief over loss can be overwhelming. Childhood cancer patients have described

they feel as though there are only a select few people who can understand what they are going through and experiencing. This can lead to a feeling of loneliness (National Association of Social Workers, n.d.). Furthermore, this population is forced to deal with the concepts of death and loss of loved ones on a regular basis, through the loss of friends they have met throughout treatment. The reality is that not every child survives. Even though many of these children have a sense of enhanced maturity, an overwhelming fear of the possibility of their own death or their loved ones is almost inevitable even throughout survivorship (National Association of Social Workers, nd).

Individuals can develop a form of conditioned nausea following extensive periods of chemotherapy treatment, experiencing feelings of nausea in response to triggers of the chemotherapy experience (i.e. hospital visits, doctor appointments). Specific phobias, like needle phobia, can also result (Costanzo et al, 2009). Also, posttraumatic stress disorder (PTSD) is a common side effect that surfaces as a result of the continuous life threatening experiences and many painful and invasive procedures and treatments. PTSD typically stunts an individual's level of social functioning and/or development since they usually cannot engage in the social activities they used to be able to experience (Costantzo et al, 2009). Unfortunately, approximately 25% of childhood cancer survivors experience PTSD, which can ultimately have detrimental effects on their social and psychological development (Chesler & Parry, 2005).

Individuals also often experience decreases in cognitive functioning. With a combination of factors such as accumulated school absences, the effects treatment has on learning, and social pressures; children and adolescents usually struggle to keep up with their peers. Sometimes, individuals experience effects on specific neuropsychological functioning (like the attention

processes) which can result in lower performance with activities that require higher levels of attention (Costanzo et al, 2009).

Survivor's guilt is an experience that each survivor will most likely experience at some point in time to a certain degree. As they are most likely going to form bonds and friendships with children and individuals they receive treatment with, they will inevitably come in contact with people who are either suffering more extreme side effects from treatment or do not survive their disease (National Association of Social Workers, n.d.). In the event that they are exposed to an excessive amount of loss and grief, the survivor will most likely experience feelings of sadness, guilt, loss of hope, and even question the meaning behind their own survival.

### **Qualitative narratives of life experiences with cancer**

Cancer is a constant battle of the human race that alters the individual's life experience(s) and changes his/her life story in very drastic ways. Each child cancer patient has a unique story full of different experiences, people, circumstances, and influences. The child comes from a unique family system surrounded by various influencing systems and resources, and is subject to different degrees of pain, oppression, and prestige. Cancer is an evil that has the power to destroy one's assumed reality, the image of his/her life so far and how it will be in the future (Chesler & Parry, 2005). Developmentally, children and adolescents are still working to grasp the concepts of vulnerability and mortality, a concept that the realities of cancer will force them to face sooner rather than later.

Once diagnosed, the individual is forced to cope and rebuild his/her understanding of life and relation to the world. This rebuilding of one's understanding of life and life story has been previously termed as the building of a "quest narrative." Fortunately, even when dealing with an enemy like cancer, there is room in the creation of this narrative for positive growth and changes.

These positive changes most importantly include changes in life outlook, personal identity, a sense of self, and sense of meaning in the world (Chesler & Parry, 2005).

According to this perspective, these positive changes most strongly depend on one's approach towards making meaning out of his/her experience, their relationships with others, their relationship with them self, and their relationship with the external world. It is a life-long process in which survivors continuously alter their ways of coping and looking at life (Chesler & Parry, 2005). It is a skill one can develop through experience(s) with cancer, beginning with diagnosis and persevering through survivorship, becoming a part of the survivor's way of interacting in and looking at the world (Chesler & Parry, 2005).

The telling and re-telling of these narratives provides other people with insight into the survivor's process of meaning making and coping with his/her cancer experience (Chesler & Parry, 2005). People are resilient and others can better understand this resiliency through the stories these survivors share. The purpose of this meaning making process and creation of these narratives is not to deny the continuous hardships of child hood cancer (Chesler & Parry, 2005). After all, physical and psychological difficulties and stress are inevitable in cancer treatment. The point is to have a firmer grasp on how resilience and thriving can also be a part of survivorship. Resilience and thriving is largely dependent on how one can balance losses and gains, make meaning out of them so that they can make the necessary changes to live a fulfilling life with a cancer diagnosis. In turn, this process will ideally lead to positive experiences and a positive life outlook (Chesler & Parry, 2005).

There is further research that indicates how there are two levels of the meaning making process. Situational meaning making is the ability of the individual to cope with the specific experiences of cancer treatment while global meaning making is the deeper changes in identity

and life outlook (Chesler & Parry, 2005). As human beings, we are constantly trying to make sense out of what happens to us. In the face of an overwhelming and life-threatening obstacle such as cancer, the meaning making process is even more complex. In order to understand how an individual truly sees himself in relation to this disease and the world around him, persistent telling and re-telling of these stories is important, as things are constantly changing for that person and his/her family.

The most significant changes one can experience during the meaning making process are psycho-spiritual changes. These changes represent big shifts in how one perceives the meaning of events. These changes are made through the global meaning making process (Chesler & Parry, 2005). This aspect of the process includes the integration of gains and losses, ultimately finding the positive in the midst of all the negatives. It resembles the individual's willingness and ability to embrace the experienced losses and vulnerability and finding the strength to grow from it (Chesler & Parry, 2005). Chesler and Zebrack (2001) found that the individual's subjective understanding of his/her experience with cancer has an even more powerful influence over self-image and life outlook than the objective and physical experiences of cancer treatment. It can be argued that self-image and life outlook are secondary concerns to the physical health of the individual. However, it does acknowledge that how one makes sense out of what is happening to him/her can ultimately determine their wellbeing and general life outlook (Chesler & Zebrack, 2001).

In sum, the goal of the meaning making process is to formulate the "thriving narrative," a narrative of how survivors who experience great pain and loss can still embrace themselves in the experience. They find strength, courage, and ultimately wholeness in doing so (Chesler &



Parry, 2005). The means towards achieving this end, however, is through the frequent telling of their unique stories.

### **Narrative Therapy**

From a professional perspective, sharing survival narratives can be utilized in a therapeutic approach, allowing the individual to say his/her story out loud while the professional is empathically and actively listening. Ideally, in the scenario of a cancer patient or survivor telling their story, the receiving and listening aspect should be a multidisciplinary technique. With a cancer diagnosis comes the involvement of an array of different professionals, including but not limited to oncologists, surgeons, nurses, social workers, psychologists, and more. The involvement of these professionals in the story telling and retelling process would be most beneficial.

Realistically, it is not possible for every professional to be completely knowledgeable of the detailed stories of every patient and survivor. However, the involvement and recognition of those who are involved in the content of the child's story should be involved to a certain extent. It is very important for all individuals involved in the healing process to help and actively participate in the telling and retelling of these stories over time. These narratives are evolving stories that change as new things are experienced, circumstances change, and different people enter the individual's life (Chesler & Parry, 2005).

Narrative story telling is a means of communication between the patient, professionals, and family members. It is a way to create the whole-hearted dedication among those involved in the child's survival. Capriono, Massimo, and Wiley (2004) explored the use of narratives with childhood cancer survivors and found that the distressing situations and experiences of these cancer patients might have been avoided if there had been more open communication. In order

for the doctor and other professionals involved in the child's care to be fully aware of the experience of the child, careful listening and evaluation of the child's way of expressing his/her story is crucial (Capriono, Massimo, & Wiley, 2004).

Capriono et. al (2004) studied the accounts of four young adult child hood cancer survivors. He found that their stories revealed anxiety about things that they had not been able to express as a child during treatment or information they had not been provided. A combination of the lack of information and opportunity to express their fears and experience as a child prevented them from internalizing the experience and making sense of it. Their accounts showed distress resulting from a lack of knowledge concerning what had happened to them as a child and relational problems that developed within the family system. The findings of this study indicate that it is better to speak as directly and honestly with children as possible concerning their illness, allowing them to express themselves fully in return. This communication process can lead to internal reconciliation of feelings within the child patient concerning his/her experiences with cancer. The researchers emphasized how the involvement of parents and the family system are crucial in this process and should work collaboratively in order to encourage the child's self-expression (Capriono, Massimo, & Wiley, 2004). These researchers, whom are also pediatric hemato-oncologists, claim that listening to a patient tell his/her story is the first necessary step towards building that doctor-patient relationship. They emphasize how it is important for doctors to communicate medical information in a way that is in accordance to their personal needs, circumstance, and communication style (Capriono, Massimo, & Wiley, 2003).

Qualitative story telling is also a way that individuals can contribute to their getting well process and it provides opportunity for the individual to relate to others through the content and dynamic of their story (Chesler & Parry, 2005). In narrative therapy, the individual actively faces

the suffering and accepts their illness, demonstrating their acceptance through words (Chesler & Parry, 2005). According to one study by Chesler and Parry (2005) on psychosocial thriving in childhood cancer survivors, the narrative stories are made up of the experiences of these survivors and the reactions they receive from others through these experiences and sharing of their stories. For example, many of the survivors reported receiving feedback and encouragement from their doctors and family members complimenting them on their bravery and courageousness after hearing their story. These appraisals played a role in the story telling process, as these encouraging words affected their outlook, attitude, and identity.

Narrative therapy is an empowering approach. It allows the individual to be actively involved in the healing process by giving the client a form of control as opposed to being a victim of things that are simply happening to him/her (Chesler & Parry, 2005). It is a continuous and active process, requiring the individual to accept and verbally describe these experiences to others. It is an approach that needs to start at diagnosis and continue through termination of treatment and survivorship (Chesler & Parry, 2005).

The telling of their stories is how these patients are able to come to a “meaning” of their cancer experience(s), verbally recognizing and integrating the gains and the losses, and hopefully embracing the experience for what it is and growing from it. Ideally, the individual will not only prove to be resilient and persevere despite the hardships, but also embrace these hardships and grow as a result of it. This is the thriving narrative. The ability to thrive is the ability to embrace the life experiences, events, and a sense of self. It is a way for the individual to live “fully, consciously, and richly, embracing the struggle and developing a story” (Chesler & Parry, 2005). Narrating these stories is a means towards achieving this “thriving narrative” and living as fully and completely while also living with cancer.

## **Resiliency, Thriving, and Survivorship**

Even though cancer is treated in accordance to the medical model that strives to treat the symptoms of a disease, it does not mean that the patients cannot overcome challenges, find the positive in them, and grow from these experiences. People are resilient. Children are even more resilient. Shielded by their innocence, children can fight and live in the moment. Resilience is often defined as one's ability to return to their normal level of functioning, equal to those of their age-related peers who are not undergoing such challenges and hardships (Costanzo et al, 2009). Not only can people show resilience, they can show the ability to thrive, going beyond that normal level of functioning to a level of superiority in comparison to their age-related peers. Not only can these individuals function and participate in society at the same levels that their peers can, but they have grown through enhanced spirituality, a sense of strength and appreciation for life, and closer intimate relationships (Costanzo et al, 2009).

Looking for and finding the strengths of these individuals can lead to stories of resilience and thriving, not just impairment and decreased levels of functioning (Costanzo, et al, 2009). Unfortunately, there is little research that has been geared towards finding out what factors and influences work to foster the inspirational stories of resilience and thriving in the fight against cancer. On the other hand, there is much research based on the stories of distress and impairment (Costanzo, et al, 2009).

The impairment model used by experts looks at the illness and the individual in terms of higher psychological distress, poorer mental health, higher role impairment, emotional problems, poorer social well being, and decreased functioning (Carver, 1988). From this standpoint, the professionals are pushed to simply treat the symptoms of the disease, not the emotional needs. With the approach that works towards fostering resilience and thriving, the professionals are

pushed to find the strengths in these individual's stories that ultimately lead to resilience and thriving.

According to family systems theory, the relationships within the family are a primary source of strength that fosters more positive outcomes for children and young adults (Chesler et al, 2005). According to a study by Chesler (2005) on parent-child relationships and quality of life focusing on the Resiliency Model of Family Stress, Adjustment, and Adaptation, the strengths of the family can enhance the positive outcomes for children undergoing stressful circumstances. According to this theory, it is clear that there is a need for parent and family focused treatment and intervention in childhood cancer patients and survivors (Chesler, et al, 2005).

One of the biggest strengths a family can possess in a circumstance like childhood cancer is high quality parent-child relationships. A study by Chesler, et al. (2005) correlated better parent relationships with higher quality of life, especially in a child's relationship with the mother figure early in life, largely influencing adjustment and success in the world around him/her (Chesler, et al, 2005). Typically, parents are the ones who provide their children with the social support and capital necessary to succeed in goals, establish relationships, and maintain social support and understanding (Chesler, et al, 2005). Therefore, taking the means necessary to foster these parent-child relationships (beginning from birth through the rest of the developmental process) is crucial for the success and well being of childhood cancer patients and survivors.

The dynamic of the parent-child relationship has a significant impact on the spiritual and psychological domains and quality of life; they reflect how an individual thinks about and approaches life (Chesler, et al, 2005). Ironically, Chesler et. al (2005) found that the child's

overall quality of life was more closely correlated with the relationship the survivor had with their father as opposed to their mother. The relationship the child had with his/her mother at the time of illness more strongly affected his/her psychological well being. Simultaneously, the relationship between the father and child strongly affected the child's psychological, spiritual, and social wellbeing as well as his/her overall quality of life. Unfortunately, Chesler et al (2005) also found that most survivors report having more open and supportive relationships with their mothers than they do with their fathers. Despite the evidence that shows the significance of the support and involvement of a father figure, individuals tend to primarily rely on their mother figure in times of distress (Chesler, 2005). With this evidence, the authors found that fathers should work to enhance their relationships with their ill child. The willingness of the father to engage in caretaking and supportive behavior that may not be in compliance with his gender role is encouraged, for it could potentially have a great impact on their child's quality of life (Chesler et al, 2005). The professional should work with the family to more actively involve the father in the child's adjustment to the illness and new lifestyle.

Identifying the strengths and resources within a family system is a beneficial starting point. Also, using other survivors and their families who have experienced such hardships and proved to be resilient as "role models" for the possibility of a positive and satisfactory future is a good approach. The primary objective in such approaches is the avoidance of obsession over the deficit model and focusing on the growth model working towards stories of resilience (Chesler et al, 2005).

In accordance to the Resiliency Model of Family Stress, Adjustment, and Adaptation, resiliency is defined as the ability and competency of families to show positive adjustments under the given stress and hardship that develops from distressing situations. This concept of

resiliency infers that the positive parent-child relationships could promote family coping strategies and recovery. More specifically, one study found that warm and supportive child relationships give children the means to develop positive self-esteem and increase social competence and life satisfaction (Chesler, et al, 2005).

According to a study by Chesler and Parry (2005) on psychosocial thriving in childhood cancer survivors, there has been much research that does not show increased anxiety, depression, and self-esteem in cancer patients. In fact, many report positive outcomes from their experiences with cancer like an enhanced life outlook, better relationships, and enhanced psycho-spiritual development. These individuals do not just survive the stress and hardships, but they actually experience a higher quality of life than they reported before being diagnosed with cancer (Chesler & Parry 2005). The key towards this thriving experience is one of transformation. Through cancer, they become resilient, transform their coping skills, grow in the face of trauma, and ultimately transform the perceived threats into challenges they are meant to overcome (Chesler & Parry 2005). According to this study, the concept of thriving is defined through the changes in identity from a victim to a survivor, greater self-reliance, an enhanced appreciation for life, interpersonal growth, greater emotional openness and compassion for others, philosophical changes, new priorities, a new sense of meaning, spiritual development, and wisdom. As addressed previously, thriving is primarily based on the meaning survivors make out of their experiences with cancer and the potential psycho-spiritual growth they experience as a result (Chesler & Parry, 2005). More specifically, they found 65% to report increased psychological maturity, 61% reporting increased compassion and empathy, 57% reporting new values and priorities, 48% reporting new strengths, and 44% reporting increased recognition of their vulnerability and struggle (Chesler & Parry, 2005).

Their perceived growth in psychological maturity (65%) had to do with the fact that they felt more mature than peers and the challenges they were forced to face at such a young age subjected them to this progression. They were able to develop coping skills by ridding themselves of a level of childhood denial (Chesler & Parry, 2005). Their life experiences were not in coordination with that degree of childhood innocence, and they were forced to overcome this innocence to a certain extent. These survivors described how they had to “grow up fast” if they wanted to overcome the challenges they had to face. One subject reported, “It just made me grow up. I had to deal with things that other people didn’t”(Chesler & Parry, 2005, pg. 1061).

Many reported greater compassion and empathy for others. Mostly as a result of feeling “different” as a child, they developed deeper empathy for others who may have feelings of being “different.” These individuals also reported having experienced better relationships (Chesler & Parry, 2005). For example, one subject reported feeling being more receptive towards people with special needs. These individuals were able to transform the painful feelings of being “different” into sensitivity, empathy, and even a sense of altruism. These altruistic feelings were associated with their desire to be of service, share experiences, and provide hope for children with cancer and their families. As quoted by one respondent, “I don’t necessarily look at someone and see ‘different’ anymore. Because I know how that felt. And I just think I have a greater capacity to understand now, and I would not trade that in for anything” (Chesler & Parry, 2005, p.1062). Not only do these individuals experience positive growth in their own lives, but they want to share those experiences of positive growth with others. This sense of selflessness that comes with the concept of altruism is something that not every individual grows to achieve in a lifetime.



According to Chesler and Parry (2005), the process of reassessing values and priorities effects many areas of the individual's life. For example, the individual reassesses health, lifestyle, social relationships, and career choices. On a deeper level, the individuals reported appreciating the relationships that supported them during treatment and hardship and they were now able to prioritize all of their relationships in this way. They also reported now making time to maintain the most meaningful relationships with friends and family and finding great enjoyment through these meaningful relationships. In terms of finding and making a career, they reported prioritizing happiness and career satisfaction over income. As quoted by one of the survivors, "I learned a lot, what is important in life. Like money is not important. I just want to be happy, have someone to love me" (Chesler & Parry, 2005, p.1063). In reference to their enhanced altruism, many reported choosing careers in the helping fields, finding much value in the service(s) they can provide to others (Chesler & Parry, 2005).

Many of these survivors reported feeling "stronger" as a person than they were before they had cancer. These feelings of strength come from a sense of faith in self and one's ability to handle what life hands them, they are self-reliant. This enhanced self-reliance comes from the fact that their feelings of accomplishment with their illness have led to increased strength in other areas of life. One survivor reported, "When you've accomplished something like that, even being so young, it gives you a determination, a drive, to achieve in school, to do well in your life, I'm a fighter" (Chesler & Parry, 2005, pg. 1064). They also reported strengths in their ability to handle problems with more ease than their peers. As quoted by one survivor, "I am able to accept newer things, adapt, and change" (Chesler & Parry, 2005, pg. 1064). Overall, these individuals reported enhanced coping skills. They have learned to apply these coping skills and ways of handling life circumstances to other areas of life (Chesler, 2005).

Increased awareness of the reality of human vulnerability and mortality and the inevitable life struggles was also a reported area of growth for these survivors. This increased awareness of the uncertainty of life led to an increased appreciation for life and enhanced life outlook. As a result, they reported being more conscious while making life choices, with a deeper understanding of human vulnerabilities and life uncertainty. This growing experience has been described as a psychological change through personal recognition of this vulnerability as well as a broader shift to a more philosophical life outlook. This realistic perspective of oneself in relation to the world is a perspective that typically develops in terms of age and life experiences (Chesler & Parry, 2005). However, it is a perspective that reaches a different level for individuals and families facing the possibility of death on a regular basis.

This concept of growth is not static. It is a continuous process that evolves with each life experience. Also, most of these positive aspects of growth are not immediately experienced. Individuals explained how these positive experiences and accomplishments to have occurred throughout time, and much of the benefits were long-term benefits (Chesler & Parry, 2005). It takes time to integrate the cancer experience and make meaning out of all that results from it.

It was also found that the primary support system of the individual is not only limited to familial and friendship bonds (Chesler & Parry, 2005). No matter where the individual finds that support, however, it is a crucial aspect for growth. Sustaining relationships proved to help people understand and appreciate a degree of continuity of their life despite the inevitable changes they are subject to in their social, psychological, and physical lives. If the individual has the ability to seek support from others like the nurses, social workers, psychiatrists, or any others involved in the individual's life, they can provide the means towards growth, resilience, and thriving (Chesler & Parry, 2005).

In addition, a study by Eiser (1998) on the long-term consequences of childhood cancer found a gender difference in the ability to transform this array of negative and distressing experiences into one where they could experience enhanced life satisfaction. As our society's gender roles set the stage for more acceptance of females being more nurturing and allowing themselves to be vulnerable, females are more likely to accept and embrace this vulnerability and turn their experienced hardships into an opportunity for growth (Eiser, 1998).

According to Eiser (1998), parent distress experienced during treatment was strongly correlated with reported internalized distress of the child in emerging adulthood. However, parent support was found to moderate this distress, as the subjects who felt supported by their parents during treatment experienced a level of alleviation of their internalized distress later on in life (Eiser, 1998). These findings and the fact that there are increasing numbers of adult childhood survivors in the population sets a need to focus on adjustment throughout the lifespan, especially in the time of emerging adulthood as these individuals are experiencing increased independence and are transitioning to adult health care providers during this time (Eiser, 1998).

Chesler and Zebrack (2001) focused on the worries, self-image, and life outlooks of childhood cancer survivors and acknowledged that survivors are resilient. However, these survivors also recognize the significance of addressing the inevitable problems in areas such as social adjustment and worries about their health and social futures. They define the cancer experience as a two way street, "one of celebration and hope, one of uncertainty and fear" (Chesler & Zebrack, 2001).

These worries include fear of relapse, the need of future treatments, the predicted late effects, fertility issues, academic and scholastic achievement, and one's general health. They have the power to help shape self-image and life outlook and affect one's ability to accomplish

developmental tasks such as dating, graduating school, entering a career path, leaving home, marriage, and so on. It is important for health care providers, social workers, and other helping professionals to be aware of these potential worries and acknowledge how it can effect the adjustment or quality of life of these survivors (Chesler & Zebrack, 2001).

More specifically, the worries of this particular sample consisted of the fear of their own child getting cancer, relapsing, losing their ability to have children, or decreased health in comparison to peers; these fears had a direct effect on their self-image. Side effects that interfered with their daily lives were strongly correlated to negative self-image and outlook, reporting feeling different from peers and having more worries. These worries have a direct affect on one's meaning making process of his/her cancer experience, and therefore have a direct effect on one's ability to experience resiliency or even thrive (Chesler & Zebrack, 2001). It is crucial for all professionals working with these individuals and their families to be well informed about the worries that haunt survivors from day to day.

Cancer survivors can experience positive life outlooks as well as overwhelming worries. Experiencing growth in self-image and life outlook does not require one to deny their worries. It simply suggests the individuals do not need to obsess over their worries and problems and can acknowledge the presence of the positive experiences as well as the negative. A process of reframing and reappraisal of these experiences is important to come to a realistic perspective on life; it is a system of counterbalancing. Through this process, they are living a realistic lifestyle and creating a more realistic self-concept and life outlook. They live meaningfully and consciously through adjusting their values and priorities but also acknowledge the reality of their worries and problems (Chesler & Zebrack, 2001).

### **Opposing points**

Despite the evidence that supports working from a strengths perspective through supportive means such as narrative therapy, the managed care system severely hinders the possibility of such approaches. Furthermore, the use of interdisciplinary and collaborative service is being challenged, as the hospitals and health/mental health providers must work in accordance to the managed care guidelines. Within various inpatient and outpatient medical and mental health care services, providers have been encouraged and expected to work independently. Often, the members of the different disciplines that are involved in a given case/client are expected to simply document their treatments, interventions, and professional opinions in a record as opposed to being provided with the time to work as a team with the family to provide the necessary service (Amodeo & Schofield, 1999). The face to face time that is so crucial for well-rounded, personalized, and strength-based service is not being encouraged in the realities of the current managed care health care system.

Helping professionals, especially social workers, are constantly challenged by the demands of the managed care system, sometimes forcing them to adjust their traditional professional practice to fit in with the mandated guidelines. As the primary objective of managed care is cost containment, the psychosocial needs of patients are not always met (Chesler & Zebrack, 2000). As childhood cancer diagnosis brings a set of psychosocial needs and desires, there is a need for expansion of these services. Unfortunately, the cost-containment approaches of the managed care system do not always allow this.

The social worker's ability to commit to client-centered service is challenged. Despite the increase in survivors of childhood cancer due to improvements in the medical field meeting their physical needs, improvements in the long-term psychological and social treatment are not keeping up (Chesler & Zebrack, 2000). In sum, the needs of survivors and their families require

long-term expansion of services, dedication of health care professionals, mobilization of community resources, and management of emotional and financial impact on the individual and family. As the managed care system sets some financial limitations on these services, it is an even bigger challenge for professionals to provide their clients/patients with what they need (Chesler & Zebrack, 2000).

As the services these families need are often loosely defined and change as the life circumstances of the family change, it is even more difficult to provide psychosocial services because they do not always fit in with the managed care objectives. For example, time-limited psychotherapy would be a timely and cost-efficient approach. However, if the family is in need of broader support and advocacy that is not necessarily in accordance with the guidelines of managed care they will be adequately served (Chesler & Zebrack, 2000).

Unfortunately, many social workers must rely on objective accounts of their clients to determine the effectiveness of their service. There are many instances where oncology social workers are forced to try to balance their commitments to the needs of their client and the organizational demands of the employing institution (Berger, 2000). Steps such as collaborating with the oncologists, nurses, and other professionals involved in the child's care is a challenge with these limitations. However, it is an aspect of the individual's treatment and survivorship that is necessary in order to provide service(s) best suited to fit their needs (Chesler & Zebrack, 2000). The reality of the health care system is a constant challenge for providers and social workers that are trying to provide a strength-based and empowering service that is in tune to the specific needs and circumstances of the client's life story.

### **Synthesis of research**

A large gap in the research is apparent surrounding resiliency of cancer survivors. The literature discovered the key aspects of resiliency and what leads to stories of resilience in childhood cancer survivors. It also recognizes the series of hardships and disadvantages of a cancer diagnosis that must be addressed if the goal is to provide well-rounded and empowering services. Finally, society depends on the medical model. We are focused on treating the symptoms of a disease. Especially when working with people and families with a chronic disease like childhood cancer, it is a challenge to work from the strengths perspective and look for the strengths and positive aspects of these experiences. However, resilience and thriving is possible while coping and living with a cancer diagnosis and more attention should be spent on finding what policies, practices, resources, and influences help to contribute to these inspirational thriving narratives. This study will explore the narrative accounts of childhood cancer survivors to find what factors and influences contribute to stories of resilience and thriving.

### **Methodology**

This was an exploratory qualitative study, using interviews to identify the needs of childhood cancer survivors from diagnosis through remission and the factors that helped them cope with the realities and hardships of their illness. It explored the stories of these survivors and their experiences with cancer, identifying the supports and influences that helped them persevere despite hardship. This was also a descriptive study that provided a summary of observations made by the participants, providing a picture of their experiences of illness, survivorship, and resilience.

### **Sample**

The sample of participants was selected by convenience. Childhood cancer survivors were identified from a pool of participants who received treatment from a hospital in Connecticut

and attended a camp for children with cancer or in remission. The participants were individuals whom the researcher could personally ask for participation and consent. This was done in one of two ways. The researcher contacted twenty survivors through e-mail, providing background information on the study and what their role as a participant would be if they chose to accept. The names of those individuals who responded were put into two different boxes, one for males and one for females, and the researcher selected three from each. This process provided the researcher with six participants.

All of the six participants were at least eighteen years of age and have been in remission for at least six months. They were from the state of Connecticut, among different towns, but all received treatment from a large hospital in New England. They also all attended the same camp in Connecticut for children diagnosed with cancer. They are all survivors of a childhood cancer, time of diagnosis ranging from age six through age eighteen. The participants were reassured the study was anonymous and were asked to read and sign the informed consent (See Appendix A). This form included information about the study and how their interviews and responses would be used. The informed consent also informed them that they could choose to discontinue participation at any time.

### **Data gathering**

All of the participants were asked seventeen interview questions in the same order. The interviews were face-to-face and recorded by the use of a tape recorder to ensure accuracy. The researcher asked permission to record the interview before beginning. The interviewer began with a straightforward set of questions asking the survivor's current age, age of diagnosis, cancer type, and presence of parental support throughout treatment. The following questions were open-ended, allowing the participant to provide flexible answers that most genuinely reflected his/her



unique experience. The questions were designed to elicit information in various domains of the survivor's life, physically, psychologically, and socially. For example, one question was, "describe the physical effects of your cancer/treatment. Describe any changes your body went through as a result of your illness and treatment." A question addressing the social aspect of one's life was, "how would you describe your relationships with peers in general? Describe any changes that happened within these relationships throughout your illness." A question geared towards the psychological domain was, "how would you describe your coping style? What sort of things did you do to help you handle the hardships?" (See Appendix B).

Much of the interview content was completed by the use of additional questions that the researcher created in response to the interviewee's response and/or lack of response to the primary questions. Even though there was a set of guiding questions that the researcher did ask every participant, the flow and dynamic of each interview varied and the researcher intuitively asked more thought-provoking and probing questions throughout the conversation that were unique for the participant.

### **Data analysis**

The researcher analyzed the interviews by attending to reoccurring themes, influences, and factors that were within the individual's narrative accounts indicating growth and resilience. The researcher used the same approach to find reoccurring themes, factors, and influences that indicated distress and hardship. The researcher also analyzed the psychological process of making meaning out of his/her experience. This approach was utilized to find specific experiences and influences that lead to resiliency, taking into consideration both positive and negative (or challenging) aspects.

## Findings

Through the means of analyzing the narrative accounts of six randomly selected childhood cancer survivors, this study sought to elicit common factors and themes of support that helped these individuals cope and persevere to the point of resilience. The estimated average time of the interviews was thirty minutes. The analysis focused on their experiences with cancer, diagnosis through remission. In turn, the factors and themes the researcher found were intended to indicate the immediate and life-long needs of cancer survivors to be acknowledged at a professional level in order to foster stories of resilience.

The sample consisted of three males and three females. The six survivors are currently in remission, two of which are in the midst of a two-year duration protocol chemotherapy treatment to prevent relapse. Remission, a relatively subjective term, is defined for the purpose of this study as: having previously undergone treatment for a cancer diagnosis and currently having no physical trace of illness. Age of diagnosis ranged from age six to eighteen. The cancer types consisted of acute myelogenous leukemia (AML), acute lymphoblastic leukemia (ALL), non-Hodgkin's lymphoma, Hodgkin's lymphoma, and Ewing's sarcoma. Two survivors shared the same diagnosis, AML. One survivor had two diagnoses of two different cancers, Hodgkin's lymphoma in 2004 and AML in 2008.

There was a set of prevalent themes within these narratives, all of which the survivors experienced differently, contributing to their unique stories of resilience. These themes consisted of: a family diagnosis and familial support, a supportive hospital atmosphere, the fear of transition from the hospital atmosphere into the home atmosphere, a support system of other childhood cancer survivors, changes in peer and community support, a new mindset with new

values and priorities, a good outcome at the expense of ‘unfair’ means, and a gradual process of acceptance.

### **A Family Diagnosis**

A primary means of support for all six of these survivors was, without a doubt, familial support. Every participant talked at length about the effect their diagnosis had on each member of the family and the adjustments they all had to make to cope with and support each other through the experience. As each survivor spoke to the experiences of each member and the effect their family’s support or lack of support had on their own experience, they all indirectly validated the theme of a cancer diagnosis being a family diagnosis.

Two out of the six reflected on learning the depth of their family’s love for them through their illness. They found much of their motivation to fight rooted in their concern and love for their family. One survivor quoted:

My biggest fears were and still are my family. If I were to ‘go,’ I don’t know how my family would respond. At this point, and for a long time now, I haven’t fought for myself. I fight for my family because I just care for them so much.

Another participant discussed how her parents experienced “sympathy pains” and she saw in action the strength of her parent’s love and loyalty. “I really and truly learned how much they love me and how they would do anything for me,” she explained. She proceeded to describe how her mother and father showed their love and support in different ways, but how each played a crucial role:

My dad really went through it too. Every time I was sick, he felt the pain too. He and my mom would actually get sympathy pains. They would get the same pains as me sometimes, for no reason. It’s like you are really part of your parents. My dad would always say how he wanted to trade places with me so badly, and it was killing him that he couldn’t. I really and truly learned how much they love me and how they would do anything for me. I look at my mom in such a different light; she held our family together. I have such a greater appreciation for her.

Despite the different roles, modes of coping, and ways of providing support that each member demonstrated in the course of illness, all participants acknowledged the significance of family support throughout the course of their disease.

A common trend within all of these families was the re-arrangement of roles depending on the emotional/psychological state of each member. Three out of the six described one parent slipping into a depressive state as a result of the stress and the other stepping up and acting as the primary caretaker.

One survivor described her father's relapse into alcoholism, which led to her parents' divorce and her mother having to fill that void. She stated that she knew it was not her fault but was also aware that the stress of her illness was a major trigger for this sequence of events:

My dad was ten years sober. Then, his mom died right before I got sick so he was already starting to drink again. When I got sick, he fell off the edge. We had an intervention for him and everything. He moved out for a week because my mom said that he could not be in the house if he was drinking.

The second survivor described his mother's struggle with depression throughout his illness and how his father took on the role as primary care taker. "He was my right hand," he described. The third survivor also indicated her mother's struggle. "My mom was too scared, she couldn't handle it. She was just, gone." Therefore, it was her father who held her hand through her treatment.

Despite the changes in family dynamic and roles resulting from the stresses of a cancer diagnosis, all six survivors emphasized the significance of support from family. Each family system reacted and arranged their roles and responsibilities differently in relation to the sick member. However, the presence of that support was crucial and significant in the lives of all six of these survivors. They all discussed the sacrifices their families made, big and small, in order to help alleviate some of the stress. Five out of the six stated that the support of extended family

(aunts, uncles, grandparents, etc.) made a huge difference in supporting the family system as a whole.

The survivor whose parents were in the midst of a divorce described how her extended family was an incredible support. They helped in areas that may have been lacking as a result of the drastic changes to the system as a whole:

I'm really lucky, my whole extended family helped out. My mom and dad did the best they could. But my entire family, everyone, is what really got me through. They would call me every day, visit me every day, and bring me whatever I needed.

Another survivor described how her support from extended family, in particular her uncle and grandparents, was what her parents needed in order to realistically be there for her around the clock. As her uncle took on some concrete responsibilities in the family business, her mother was able to be there for her every day and night during the long hospital stays:

It was tough for my mom and dad. We own a bus company so my mom has to drive every day. My uncle stepped up and drove for my mom for the year so that she could stay with me every day in the hospital. She stayed every night on that hard blue couch.

Sibling sacrifice was another common theme, as two survivors went into detail concerning the life choices their siblings made in order to be available throughout the course of their illness. One survivor described how his sisters, even though they were away at school, visited every weekend and were always around during the summer time. Another survivor described:

My brother was a senior in high school. It was tough for him because I got sick in the summer and he was supposed to be going away to school in September. So, he chose to stay at home and go to the University of New Haven instead. You know, it was just so he could be home and be there for me.

Despite how these survivors found support from their families, one word used universally for all six was "strong." Whether that strength came from one individual, a select few, or the entire system as a whole; the presence of a strong sense of family support was

significant in their illness. As a whole, there was only one survivor who indicated the stress and responsibilities solely relying on one “strong” member, her father, as the rest of the members were unable to provide support for different reasons. The remaining five indicated the presence of a strong family system as a whole. They worked together to find appropriate and necessary ways to support the sick family member, through the means of various adjustments in roles and lifestyles.

### **A Supportive Hospital Atmosphere**

The time spent in the hospital during treatment and illness inevitably leads to the formation of new relationships within a new environment. Along with a cancer diagnosis and treatment, one is going to be spending an extended period of time in the hospital, some more than others. The most common theme from the interviews of these six survivors was the support they formed with other patients and families while in the hospital. Whether these relationships happened in the hospital or at a clinic, the bonds they formed with families facing similar hardships at the same time was an irreplaceable realm of support. Four out of the six gave specific accounts of bonds they had formed with other patients and families while receiving treatment:

I would say that people affected me the most, being around A and B, especially. They were just so inspirational. I remember sitting in the chemo room with A. It was just... I don't know... I can't describe it. I become very close friends with A, B, and C. Even little kids, like D, but he passed away. Seeing my friends and little kids go through what I was going through, and seeing them tolerate it; that was inspirational.

Another survivor discussed how the bonds she made with other patients helped to prepare her for what was to come. As she saw what others were dealing with and listened to their advice and accounts of their experiences, she was able to prepare for what she might be experiencing in the near future:

I met \_\_\_\_\_ at the doctor's office. She had no hair at the time because she was two years ahead of me and I was getting my first chemo treatment. She was explaining everything to me. She explained how I was going to lose my hair.

Another survivor talked about his experience with a family while at a Ronald McDonald House in New York, a place located near a hospital for families with children fighting cancer:

There was a boy whose first diagnosis was the same time as mine, but he was several years younger than me. His relapse was the same year my relapse was too. We had the same doctors. His mom and I built a relationship because, you know, we lived together and ate in the same room.

He went on to describe the connection he shared with this family, and how they had shared an experience that he described as a "miraculous turn of events that he will always hold onto."

Another survivor described a similar circumstance with her roommate and her roommate's mother. The child was an infant fighting leukemia. As the interviewed survivor was in the hospital for long periods of time receiving in-patient treatment, her father was not available to be there around the clock. She found support in other ways. The support and care she received from this particular mother was one. It is a bond she describes to be still strong today:

We would sit in the office getting chemo; we were 'chemo buddies.' She was eleven months; I think she is seven years old now. She doesn't remember, but she hugged me at camp when I first told her who I was. Her mother would always take care of me. I love her.

Another dominant area of support in the hospitals and clinics were from the medical personnel, especially the nurses. As these nurses spent hours and days tending to their needs and making sure they were comfortable, personal relationships were bound to develop. The value of these relationships was clear as all six mentioned how the nurses' support helped their entire family through the experience. Three of the survivors gave intricate descriptions of their

relationships with their nurses, two describing how they still are in contact with some of them today.

The significance of these bonds with nurses was that they “made the stay bearable.” One survivor described, “I tried to build a personal relationship with anyone and everyone who was involved. I try to keep in touch with these people because, at one point, they were taking care of me. We have each other’s numbers.” Another survivor stated:

They would come into my room and we would watch movies. I would want to go to the hospital just to see them. Even now, we keep in touch all of the time. Some of my oldest friends are my nurses. We go out to lunch maybe once a month just to keep in touch. My mom would stay up late talking to them. In the beginning, we saw old patients coming back for checkups and the nurses told us that they had been in remission for years and that would be me someday. They would give us reassurance.

The latter statement shows the effect a supportive hospital atmosphere has on the entire family system and how these relationships were primary areas of support. One survivor stated that it was the nurses who were always there and “coached” them through it.

Five of these survivors made constant references to their life in the hospital, making a clear distinction between life inside and life outside the facility. Four out of the six had endured in-patient treatment and long hospital stays that lasted weeks at a time. They were forced to create a life for themselves within these walls. “I did a lot of pranks on the nurses. I brought a lot of life to the hospital. My doors were always open. I became well known on 7-2,” one survivor described.

Another common theme for all six survivors was the support they received from their nurses and/or doctors that went beyond the scope of their medical needs. They felt supported and at ease when they were able to form trusting and light-hearted relationships with those who took care of them. “He would talk to me about life, not just medically speaking,” one survivor described her pediatric oncologist. A similar characteristic of all these relationships stemmed



from the medical personnel's willingness and ability to connect with and support the patient in ways that were not always based on the cancer, but rather on the patient's and family's personality and emotional needs.

### **Fear of Transition from the Hospital Atmosphere into the Home Atmosphere**

Two out of the six survivors described experiencing anxiety and fear when transitioning from the hospital into the home atmosphere for the first time. This anxiety came from a sense of loss of security, as they felt they were provided with quality and around-the-clock care while in the hospital. There were many things to consider and be aware of when transitioning back into the home life; it would be different in comparison to their previous home life. That is, life before cancer:

I was having anxiety about leaving the hospital, which sounds weird because you would think that I would want to leave. But I was kind of afraid because I was catered to and taken care of at the hospital. I was just afraid of the outside. I didn't really mention it to other people, but it freaked me out.

Another survivor verified that anxious feeling as well. Her fear was the degree of responsibility that was going to be put on her parents since she could not take care of her self or even walk up the stairs without support. She felt guilty putting this extra stress on them and also fearful of what would happen if they could not handle it:

My mom and dad were responsible for taking care of me; there was no nurse around the clock. I couldn't do anything. They even had to bathe me and help me go to the bathroom. I had a baby monitor in my room.

### **A Support System of Other Cancer Survivors**

All six of these survivors had spent at least one week at a camp sponsored by the American Cancer Society for children fighting cancer or in remission. Four out of the six went into depth about how the relationships they formed at the camp have supported and continue to support them through their cancer experience(s). These four are still involved with the camp

today, working as counselors for upcoming generations of campers facing similar hardships. The most frequent word used in discussion about this support system was “incredible.” The researcher found that the “incredibility” of this place came from the array of unique relationships one “has to experience in order to understand.”

It really does something to you. I was able to rely on it. Other people looked like me. I think it's just that they understand. You don't have to explain anything, answer questions, or have people treat you like you are dying. It makes me feel like I'm not the only one. I can't explain it.

While in this atmosphere, these survivors feel at ease and comfortable enough to be themselves. One survivor described it as her “second family.” When the researcher asked one survivor about his most memorable experience(s) with cancer he responded:

I would have to say those days at camp were my most memorable moments while being sick, just being around kids who were also going through cancer. I think it's just the atmosphere that helped. Just being around them was helpful; the air was intoxicating.

There was a clear distinction between the support they received from family or friends at home and the support they received from friends at the camp. The key link was the degree of genuine understanding; it was support from others who have “been in their shoes.”

I got to spend time with other kids who had gone through what I had gone through. It is easy to talk to and relate to other people who have gone through the same things you have. It's the atmosphere. You know, you will always have someone you can talk to who knows what you've gone through and has been in your shoes. Outside of camp, you can have a great family but they still don't really understand what you've gone through. Having camp has obviously had a great effect on my life.

### **Change in Peer and Community Support**

A cancer diagnosis brings a change in lifestyle, which changes one's social life. Five out of the six survivors reported changes in their peer and/or community relationships and the sixth reported the struggle of having to make new friends as she switched school systems entering her freshman year of high school. Four out of the six survivors stated that they felt their peer and

community support system grew, one stated that it definitely decreased, and one reported that it generally stayed the same.

One survivor was six when he was sick and another was eight. Their experiences with friendships were different. As they, along with their peers, did not fully comprehend what it all meant. Their experiences were adjusting to being the “different” one in class. “In second grade, everything seemed fine. People were just cautious around me. It was like they were worried about getting sick or something. I had four main friends; they were my ‘crew.’”

For the four individuals who were old enough to be fully aware of the changes in friendships, they all described learning who their real friends were through the process. “It affected my relationships with my friends. People, who were once significant in my life, were no longer. It made me realize who my real friends are. Unfortunately, it has to happen that way. It’s funny, people I least thought I would stay so close with, I’ve learned will always be there,” one described.

Three out of the six survivors mentioned their deep gratitude towards their friends for their patience, commitment, and for respecting the fact that they were not the same person and could not necessarily do the same things as before their diagnosis. One survivor, who is currently in remission but in the two- year protocol of chemotherapy for leukemia, stated:

I give them a lot of credit. It’s different when your close friend has cancer; you need a lot of patience and understanding. They need to give me breathing room and healing time. At the same time, they are with me even if they can’t always be there. Sometimes, I need to do things on my own and I may not see them as often but they know it’s not that I don’t want to hang out with them. It’s just that I need to take care of myself first and then make time for them after. That’s why I give so much credit to my friends. It takes a lot of understanding and strength to be friends with someone who is going through this. All they want is for me to get better so that I can do all of the crazy things that I did before. They want me to be living at the fullest, the fullest capability and not say no because of health or any other reason. They will do anything to get me back.

Another survivor reported a similar experience:

They were understanding and patient. We could just stay in on a Saturday night and watch a movie. We didn't have to go to the mall or anything. I didn't have to wear my wig with them. I could be myself. I was in eighth grade, it was a tough time: getting ready to go to high school, meeting guys, going to parties. I would say that I found my true friends. Even though I wasn't at all the parties that they were at, I knew who was always going to be there for me.

Another significant finding was that their diagnosis made people more “cancer aware.”

As the diagnosis hit home, their families and communities were thrown into a whole new reality.

“I feel like I made people a lot more cancer aware. I think I opened their eyes a little bit; that things like this do exist and giving blood and being part of the marrow registry is a big deal.”

Two survivors recalled how their peers and communities made public and concrete contributions to spreading cancer awareness in their name. They publicly demonstrated their commitment and support through means such as donating blood and running blood drives. “My softball team is very close. They organized blood drives for me, a relay for life team, and gave to the Tommy Fund.”

### **New Mindset, Values, and Priorities**

A cancer diagnosis is a complete lifestyle change, physically, psychologically, and socially. This is an aspect the researcher found through the descriptions of various changes these survivors experienced in different realms of their lives. As their lives completely changed, their life perceptions were bound to change as well. Five out of the six survivors explicitly talked about their shift in priorities and values, which ultimately led to a deeper appreciation for life and a new mindset:

Cancer has given me strength, determination, patience, and it has kind of made me limitless. I feel like there is no limit to anything. I'm not afraid to go out in the world and tackle it anymore. It's given me such a strong backbone. It changed my outlook on my investments; my biggest investment is my time. I value it a lot and I make sure none of it will go to waste. I have so many plans and goals that I know I will achieve and the motivation of never giving up. I feel like I understand physical endurance. I have a better

understanding of what the body is capable of doing, mentally and physically. I see how far a person can go because I had to push myself to the limit; and I still don't even know my limits.

Another survivor described her new mindset in both a positive and negative light. She realized that the experience brought her a much more mature and appreciative attitude towards life in general. However, she also realized that this enhanced maturity led to disconnect among her peers as she was not necessarily at the same place as they were anymore and it was not possible for her to regress. She was a different person now.

My outlook on life is so different now. I am so much less selfish than I used to be. Before, I was just a typical teenager who wanted life to be perfect and I thought everything would always go my way. But now, I have a much deeper appreciation for life. I mean, I don't think I know anyone who has gone through an experience like this and not have that happen. I have a different mindset on life in general. So, it is harder for me to relate to peers because of the way I live my life. I'm not as carefree as I used to be, I'm more serious minded. My friends are all about partying and I'm not always so into it. I kind of miss being carefree, but there is no way to go back and erase everything that has happened.

Another common trend that resulted from this deeper life appreciation led to the impulse to "pay it forward." All six survivors indicated areas in their life where they have chosen to do so. Four are currently volunteers at a camp for children with cancer, two are in nursing school, and one volunteers at the hospital in which she had received treatment. "I had a big priority shift and I appreciate life much more. I learned that things can change at any given moment. I try to 'pay it forward' in different ways like through volunteering at the hospital, becoming a nurse, and volunteering at camp." One survivor stated, "My experience is going to help me a lot in life. I'm going to try to become an oncology registered nurse. I just want to help out other people, mostly kids," one described.

Another survivor talked about how she feels as though she can relate to others more now, and how that has motivated her to be more compassionate towards others and it has increased her desire to give.

I definitely feel for people so much more now. Not just with cancer, but with anyone who is sick. I just feel it; I can truly sympathize and empathize. I can feel their pain. I had never experienced that before. It's like my gut hurts. I finally know true pain. I also know what it's like to overcome the pain. I know strength; I guess that's the word.

Another survivor was very specific in how his enhanced appreciation for life has led to specific ways that he feels inclined and obligated to give to others. His inspirations were clear in his distinction between childhood cancer and adulthood cancer and how childhood cancer is unique in the fact that it “molds” its victims as they are still developing and growing throughout the experience.

You know, you only live once. It made me understand what kids these days are going through. If I see a kid diagnosed with cancer today, I feel like I know what they are going through and I often try to extend my help and experience. I tell them that they will get through this and that they should look towards the future and to us as other kids who have survived. I do feel like I am a better person because of it, I don't know how to explain it. It's just something you have to go through to understand. It's almost like my perception on life has changed. And a lot of people don't see things the way that us survivors do. When you're a kid, you are growing up and you're still learning. It molds us.

### **Good Outcome at the Expense of “Unfair” Means**

All six survivors stated that cancer had positively influenced their life. However, four out of the six survivors indicated that the means towards achieving this positive outcome was not necessarily worth it. Two of the survivors were very clear in this distinction as they verified that they acknowledged the positive outcomes that came out of these life experiences and realized they had been changed for the better. However, it was a very “unfair” process and it is not an experience anyone should have to endure. Two survivors described their positive, yet, “unfair” experience in very descriptive terms:

It positively influenced my life but it was unfortunate. It has made me who I am today which I am very happy about but I feel like that wasn't the right way about it. I hope it's not the way about it for everyone else. I think cancer is unfair. If you look at it from the other perspective, it has given me everything I need to be happy and the strength I need to go on. But I will say it is a little bit unfair, but my fearlessness is what came out of it.

People say, ‘oh, you are such a better person now from this experience, it was so worth it.’ But it wasn’t worth it. I would never choose to go through that again. Everyone says things like, ‘you’re so much better and stronger, it was the best thing!’ But it wasn’t the best thing. It shouldn’t have had to happen. It happened, and I dealt with it the best I could. But I wish I didn’t have to. Even though I was able to make the best out of the situation, it shouldn’t have happened.

When another survivor was asked if he felt he was positively influenced by the experience, he stated that he did feel as though he was a better person because of it but also made it clear that he had no choice in the matter, referring to the “unfairness” of the circumstance. “Well, without having a choice in the matter, yes, I do think it has positively affected me.”

Despite the “unfair” experiences they were subject to, all six survivors provided concrete reasons why they appreciate their cancer experience and how they believe it has molded them into “better people.” A dominant theme among all six survivors was that the people they met along the way were what led them to their appreciation for their experience with cancer. The relationships they formed with particular individuals have inspired them and participated in molding them into better people. A significant part of their descriptions was that they acknowledged they would not have met and formed relationships with these people in ordinary circumstances, in circumstances where they did not have cancer. One survivor was very extreme in this claim:

I’m glad I got cancer because I got to meet a lot of great people. I experienced something that not a lot of people wish to experience but it’s going to help me in life. I never would have met Doctor \_\_\_\_\_ or gone to camp and met everybody. I’m happy that I’m a survivor; it made me strong. I had good and bad experiences and I met great people that I wouldn’t have met if I didn’t. I experienced a lot. It has definitely positively influenced my life. It made me happy to be alive.

### **Gradual Process of Acceptance**

All six survivors mentioned the process they experienced of coming to terms with their diagnosis, treatment, and remission. They inferred that it was a gradual process of subjective

stages that eventually led him/her to the reality of the situation. Another major factor contributing to this process was the survivor's age at the time, as the younger survivors did not fully comprehend what cancer was until they reached a developmentally appropriate age.

However, when they were old enough to understand, they still had to learn ways to cope.

It was definitely a process to get to this point. You know, I've spoken to a lot of cancer survivors and many have posttraumatic stress disorder or anxiety attacks. Everyone has his or her own kind of thing and I am just getting over mine. It is definitely a process. For me, I finally understood what I had when I was twelve. It hit me again in high school and I coped with all of that. I learned how to say 'I'm a survivor.'

As stated previously, two of the six survivors were significantly younger when diagnosed, age six and age eight. They both expressed a day-by-day perspective when they were sick which consisted of concrete fears such as nausea and needles. They both mentioned analyzing the situation when they were old enough to understand and having to proceed with methods of coping when they fully absorbed the reality of their experience. However, they also mentioned their appreciation for their young age as their innocence allowed them to live life day by day, and simply focus on feeling better on that given day. The survivor who was diagnosed at age eight stated, "I didn't even comprehend what I actually had. I think my biggest fears were the needles, and the sick feeling, and how I was going to feel that day. It was more of a day-by-day basis rather than long term. I think that was actually better."

The other survivor diagnosed at age six described a similar experience: "I don't believe I was overly shocked. I don't think at that age I could comprehend what was going on. I just knew I was sick and just felt very tired most of the time. I don't think death crossed my mind at that age." He went on to talk about how he still struggles with accepting and understanding what happened to him. There are certain triggers that cause him to mentally regress to his cancer experience(s).



I think when I got older I thought about what could have happened. Sometimes, I just think about being 'laid up' in the hospital. It hits home that things were 'not okay.' Still, walking into a hospital, I remember when I was sick. It's like a trigger. You know, I go for check-ups at the hospital and I just think about when I was younger. I think that I definitely think about it more now than I did when I was younger. I analyze the situation; why things happened, what could have been, and where we are today. But I think, obviously, who I am today has been largely effected by treatment and what I have gone through when I was younger.

The remaining four survivors were diagnosed at ages that they understood the realities of a cancer diagnosis, at least to a certain extent. These ages consisted of age eighteen, twelve, and thirteen. Two of the survivors were thirteen when diagnosed and the twelve year old had two diagnoses, relapsing at age sixteen. This survivor stated his experience of acceptance through comparison of his two diagnoses, the first time consisting of mainly anger and fear and the second time of being "prepared" and ready to fight.

When I found out, in general, I want to say I was angry. The second time, I was prepared. I don't know why, I was just like 'I know what I need to do; I need to just do it.' I kind of bite my tongue through it. I somewhat knew what to expect.

Later in the interview, he went into more detail concerning how he learned how to accept both of his experiences, as his second treatment was significantly longer and severe than his first. As stated above, he felt prepared. However, the process of acceptance and finding the strength to fight was a gradual one as each realization came "in its separate way."

I don't think it was an epiphany or all at once. It came separately, at its own time, in its separate way. I don't think that it was all of a sudden. I think the fact that my treatment took so long built me up. I think that the longer it takes, the more it will build someone up. The longer it takes, the more strength you need. It takes full body and full mind, all at once.

Among these four survivors who were fully aware, three associated this awareness of the seriousness of their illness with their experience of physical and concrete changes. Most significantly, the loss of hair forced them to accept reality. These three survivors mentioned hair loss as the most significant event and reminder of their disease.

When I found out I had cancer, it was complete shock. It didn't hit me until I would say the first month because I was so numbed up from all of the drugs. I would say it didn't hit me until I got home from the hospital about a month later, my hair started falling out. That was when I realized, when the physical and concrete changes were taking place. When I couldn't go back to school, and everyone else was, I realized what was happening.

Another survivor also mentioned realizing what was happening when her friends were going to school and living their lives and she had to stay at home or go to the hospital.

I would say I was devastated at first. I was young, only thirteen. I thought of the movie, *A Walk to Remember*, because she had leukemia and I thought I was going to die. I was so surprised. I was also drugged up. So, I don't really remember the beginning. I would say it hit me probably a month later. It was probably when I saw my friends again and I had to go back to the hospital. I was home for my birthday and my friends came over but I couldn't even touch them because of the germs.

Another survivor who was thirteen at diagnosis described an experience of being left in the dark by her parents and the doctors. Through her own fear, denial, or ignorance, and her parents desire to protect her; it took a significant amount of time for her to learn what was wrong.

The doctors didn't tell me anything; my parents just told me I was sick. For some reason, I don't think that I asked any questions because I was so tired and kind of didn't even care. I just sort of took it. But I did find out in the middle of a treatment and I asked my dad 'what the heck do I have?' It was actually funny. When he told me I was shocked and wondered 'how did I not ask this sooner?'

These narrative accounts of six survivors' experience with cancer and survivorship are indicators of what needs to be done at both the personal and professional level in order to promote growth and resilience and ensure they are given opportunities to thrive. As these stories point to both the pain and joy they have experienced and continue to experience, families and professionals can learn how to improve practice to more adequately meet these short term and long-term needs from diagnosis through remission.

### Summary of Findings

This study sought to find some of the most prevalent themes, factors, and experiences that helped these cancer survivors cope in the midst of their hardships and persevere to the point of resilience. This was done through analyzing six narrative accounts of childhood cancer survivors. The researcher found eight common themes that were experienced by these survivors in different ways as each child's diagnosis, personality, and life circumstance was unique. These eight themes consisted of: a family diagnosis, a supportive hospital atmosphere, the fear of transition from the hospital to a home atmosphere, a support system of childhood cancer survivors, changes in peer and community support, a new mindset with new values and priorities, the experience of a good outcome at the expense of "unfair" means, and the gradual process of acceptance.

The most common theme in this study, a cancer diagnosis being a family diagnosis, parallels the literature. Jones says, "when a child is diagnosed with cancer, the whole family is diagnosed with cancer"(2010). The researcher found this perspective present in all six survivors' stories as they described how their illness directly changed their family and they witnessed changes within each member. Participants reported that every member was affected, had to make personal sacrifices, experienced changes in roles and responsibilities, and had to create their own coping style.

Another interesting finding for this researcher was how a majority of these survivors not only vividly remember the support they received from medical personnel and other families in the hospital but they continue to work to maintain those relationships. These memories consisted of times of preparing them for what was to come, role modeling that it was possible to get through these hardships, coaching them through the experience, and simply "making the stay bearable." Support from others who have "been in their shoes" provides them with an outlet

where they feel comfortable to be themselves without fear(s) of being labeled as the “cancer kid.”

The concept of transition and acceptance was another significant finding. These cancer patients and survivors are constantly subject to a number of changes, adjustments, and the eventual acceptance of their survivor identity. In essence, their life from the moment of diagnosis consists of a series of psychological, social, and physical transitions. In this study, it was a process that was experienced differently for each individual. It is important to note that the final acceptance of this survivor identity did not mean that struggles and hardships relating to their cancer experience disappeared.

In addition, the process of accepting what happened and what could have happened is an internal process that each survivor goes through in their own way and time. In this study, those who were diagnosed earlier in life described accepting the experience and its meaning after years of being in remission when they were developmentally able to comprehend it. This study found that every cancer survivor eventually goes through this process; it is just a matter of when they are ready to do so.

All six survivors discussed a deeper appreciation for life as a result of their cancer experiences. They also described their journey of realizing how it has modeled them into “better people” and how they seem to enjoy different things in comparison to their “life before cancer.” They are, in some ways, different people. This finding was also present in the literature by Chesler and Parry (2005). A new life outlook inevitably leads to a sense of enhanced maturity and a loss of innocence that is generally irreversible since they cannot “erase what happened.”

Finally, the life insights and meanings these survivors developed were found to lead to acts and expressions of resiliency. They felt driven and “obligated” to take advantage of life’s

opportunities and “pay it forward” to others. Once again, this finding was in accordance to the literature in that every one of these survivors not only expressed a natural desire to give back to others facing pain, struggle, and hardship but also have taken actions to do so (Chesler & Parry, 2005). The survivors in this study were able to find true meaning through their cancer experience, have carried it over to their survivor role, and are continuously thriving and building stories of resilience.

### **Limitations**

The sample possesses potential limitations. All participants received treatment in the same hospital in New England and all had attended the same camp sponsored by the American Cancer Society. Also, the sample size was small, only consisting of six subjects. The researcher had a relationship with these survivors, which may have increased bias and hindered objectivity. In addition, half of one of the subject’s recording was lost as the researcher ran out of space on the tape and she had to rely on notes taken during the process to compensate for that loss that was an equivalent of approximately fifteen minutes of the actual interview.

### **Implications for Practice, Policy, and Research**

Approaching a cancer diagnosis as a family diagnosis indicates that a family typically reacts by “rallying” to support the critically ill child (Jones, 2010). In order to ensure this “rally” of support is done in a way that is truly helping the family members to support the ill child in ways that is not at the expense of their own wellbeing, professional effort needs to be made to continuously facilitate open and honest communication from diagnosis to remission. As the changes that each individual in the family undergoes during and after treatment can have long term effects, it is important to work to maintain that atmosphere of open and honest

communication. Dr. Barbara Jones, a pediatric oncology social worker and past president to the Association of Pediatric Oncology Social Workers describes her role with children and families:

So, that's another big role for the social worker; facilitating communication within the family and then between the family and the medical team. There's a lot of communication facilitation that goes on (Jones, 2010).

Communication facilitation within the family system is especially important to ensure that the family is not avoiding discussing certain topics out of fear of how their loved ones will react. Dr. Barbara Jones stated, "It's not uncommon at all for children to protect their parents from their own suffering" (2010). This study validated this claim. The researcher found that many survivors had significant memories of watching their family experience pain as a result of simply bearing witness and feeling helpless in being able to ease their suffering. Work needs to be done professionally to transform this mode of protection and/or fear into one of honesty within the family.

Furthermore, a majority of the most memorable support and experiences in the hospitals came from the doctors' and nurses' ability and willingness to connect with their patients in ways that were not solely based on cancer. These are the memories they most strongly hold onto through survivorship. This finding implies that a primary area of support for these survivors came from their doctors' and nurses' ability to connect with them on a personal and emotional level, not just medically. Professionals' psychosocial skills are just as important as their concrete medical skills and knowledge in supporting these survivors through their journey. Medical professionals should practice and utilize these skills in order to provide the patient with the most well-rounded and beneficial treatment.

The concept of transition into the survivor identity is also significant. It indicates the need of those involved in the helping process to be aware of these continuous changes, as they begin

at diagnosis and continue through survivorship. It is important to note that the final acceptance of this identity does not mean that the struggles and hardships disappeared, as a cancer diagnosis was found to be, in many ways, a life-long diagnosis and struggle. Professionals need to approach each patient and survivor with flexibility, acknowledging that his/her health and general well being is constantly evolving.

In addition, the unpredictability of a cancer diagnosis brings a sense of unpredictability to each day, physically and emotionally. Sometimes, simply supporting these patients and families through the hardships of each day, hour, or even minute is the ideal approach. Barbara Jones summarizes her experiences with children and families in the field:

Each child is unique. Each family is unique. Each moment is unique. So, when I ask a child or a family how they are doing I'll ask, 'how are you doing today,' or 'how are you doing since lunchtime,' or 'how are you doing since the doctor came in?' My intervention is going to be changed based on how they're doing. How they're doing changes all day long.

Barbara Jones supports these findings of continuous transition by implying that the role of social workers and professionals working with these individuals should not only be one of support but also one of health promotion. Practicing social workers need to look at the cancer patient as a life-long patient; the main goal being to support these survivors towards becoming self advocates for their health and well -being. Her words imply the power of knowledge for survivors.

Ideally, we have a way to help transition that child from being on treatment to their identity as a survivor. Making sure that the child, now survivor, has written information about what happened and what their treatment was that they can take with them through their lives. This is so that when they meet new doctors or professionals they can say 'I had cancer and this is what happened.' That helps with long-term healthcare. It's a way of health promotion.

Changes in social relationships are another significant finding for practice with survivors. Childhood and adolescence is a time in which individuals are still developing and becoming

comfortable with their social status and identity. Changes in one's social life during this time can have long-term effects. In this study, all survivors spoke to learning who their real friends were in times of crisis. Helping professionals should take advantage of this in approaching their work with cancer patients and survivors by acknowledging the impact that the presence or lack of presence of social support has on the survivor. Ideally, the professional should attempt to engage them in the process.

Furthermore, the findings of a new life outlook and appreciation implies that as professionals interact with and support survivors, they should keep in mind that they are engaging with individuals whom have experienced things that they themselves may never experience. These survivors have proven to be able to provide insight to their own life meanings that are often beyond what is developmentally expected. The role of the helping professional should be to meet the survivor where he/she is in their psychological development and facilitate the process of making meaning out of his/her experience(s) with cancer and what it truly means for him/her to identify oneself as a child hood cancer survivor.

A final implication was one that parallels with the literature of Chesler and Parry (2005). As the researcher of this study listened to these survivor's stories, she witnessed them come to new insights as they analyzed their cancer experiences and said the words out loud. As they were given the opportunity to recall and share these thoughts and experiences and the researcher rephrased and paraphrased what she was hearing, she witnessed the power of narrative therapy. Giving individuals an outlet to reflect and tell their story is truly therapeutic. This particular finding indicated that narrative therapy is beneficial in practice with survivors despite the years spent in remission or amount of times he/she has already told his/her story. Each time the



survivor tells the story, he/she is given an opportunity to further develop insight about their cancer experiences and truly own their stories of resilience.

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## Appendix A

Dear Potential Participant:

I am a social work major at Providence College, inviting you to participate in a study on the needs of cancer survivors and the factors that lead to stories of resiliency and growth. The purpose is to identify the short term and long- term needs associated with survivorship and what can be done to meet these needs and lead to stories of resilience. Data gathered in this study will be reported in a thesis paper in a social work capstone course at Providence College. It will also be added to the Providence College digital commons database.

At this time, cancer survivors are being recruited for this research. Participation will involve answering questions about cancer related experiences from a bio-psycho-social approach. The interview time should not exceed 30-40 minutes. The interviews will be recorded using an audio recorder and the tapes will be destroyed once the data is transcribed.

There are no anticipated significant risks associated with involvement in this research. There is always the possibility that uncomfortable or stressful memories or emotions may arise while thinking about these past experiences. Participants are free to stop participation in the study at any time until identifying information is removed from the responses. The researcher, if necessary, will also provide referral resources for psychological support.

Benefits of participating in this study include helping researchers to formulate a better understanding of the life-long needs of cancer survivors in order to potentially improve future practice.

Confidentiality will be protected by storing signed consent forms separately from data obtained in the study. Once the data are obtained, all identifying information linking the participant to his or her response will be destroyed so that responses can no longer be identified with individuals. Data will be reported by making generalizations of all of the data that has been gathered. Brief excerpts of individual responses may be quoted without any personal identifying information.

Participation in this study is voluntary. A decision to decline to participate will not have any negative effects for you. You may withdraw from the study at any time up until Thursday, March 24<sup>th</sup> when the researchers will finalize the data.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTOOD THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.**

Thank you for participating in this study.

Gabrielle LeMarier, Social Work Student, 203-506-1729, [glemarie@friars.providence.edu](mailto:glemarie@friars.providence.edu)

\_\_\_\_\_

(Name)

\_\_\_\_\_

(Date)

PLEASE KEEP A COPY OF THIS FORM FOR YOUR RECORDS

Appendix B  
Interview Questions

1. What is your age?
2. What was your diagnosis?
  - a. How would you describe the severity of your diagnosis and treatment?
3. What was your age at diagnosis?
4. How would you describe your reaction when you found out you had cancer?
5. What is your family make-up?
6. Describe the physical effects of your cancer/treatment?
  - a. Describe the changes your body went through as a result of your illness and treatment (if old enough to remember).
7. Describe your support system at home when you were sick.
  - a. Describe your primary support system at home. (mother, father, siblings, etc.)
8. How would you describe your support system to have changed throughout the course of your illness?
  - a. Describe if and how anyone has left, joined, or simply changed their supportive role in your life.
9. How would you describe your relationships with peers in general? Did relationships change with peers throughout your illness?
10. Beyond immediate family and peers, did your support system go beyond these individuals? (Doctors, friends, extended family, etc)
11. How would you describe your coping style? What sort of things did you do to help you get through the hardships?
12. What were your biggest fears or thoughts when you were sick?
13. How would you describe your reaction when you found out you were in remission?
14. Describe your fears and thoughts when you were in remission.
15. What is your most significant and memorable experience with cancer?
  - a. What is it about this experience that makes it so memorable?
16. Today, what are your thoughts and feelings towards your experience with cancer? How do you consider them to have changed throughout time?
17. Do you think that cancer has positively influenced your life?
  - a. Why? Why not?