

DEVELOPMENT OF A TIME-LIMITED GROUP FOR ADOLESCENTS WITH A
RELATIVE WHO HAS CANCER

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ABSTRACT

This study explores the emotional and psychological needs of a group of adolescents who have a relative diagnosed with cancer. When a family endures a diagnosis of cancer, the entire family can be profoundly affected, including the healthy children in the family. Relatives of children with cancer are at an increased risk for Post-Traumatic Stress Syndrome as well as other emotional disturbances (Woodgate, 2006). For the present study, five adolescents took part in a qualitative interview process, and were self-referred through the Relay for Life, Ocean County, NJ chapter of the American Cancer Society. The goal of the study was to operationalize and better define the experience of having a loved one diagnosed with cancer and then determine the components of an effective support group. It was hypothesized that if adolescents participate in the development of a social support group, it will be more successful in retaining participants in the future. A qualitative research design was used to: 1) gain a better understanding of the overall experience of having a relative diagnosed with cancer and 2) to identify the specific needs of the adolescents who participated in the qualitative interview. The results of this study illustrate the gravity of having a loved one diagnosed with cancer, especially during adolescence. The primary themes that arose in this study included: 1) a need for more information regarding cancer and its treatment; 2) a need for emotional support; and 3) a psychosocial component to address positive and negative coping mechanisms. With the increased demands of school and social pressures on adolescents, there is a corresponding need for groups to help adolescents understand what is occurring, and learn how to cope when a family member is diagnosed with cancer. The results of this study are intended to

guide future research, improve the experience of having a relative diagnosed with cancer, and provide a model for the development of future adolescent social support groups.

DEDICATION

This work is dedicated to my amazing and supportive family. They have seen me through an incredibly long journey. Having been a part of my father's diagnosis and subsequent treatments have shaped the person that I am today, and served as the foundation for this important work. I only hope that choosing this topic will serve to show how much my family means to me.

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I would not have been able to complete this paper if it was not for my family and loved ones. Thank you for always being there when I needed you and seeing me to the finish line. To my dissertation committee, Dr. Gantwerk and Dr. Haboush, you believed in an idea that I wanted to turn into something more, that will hopefully help other people in similar situations in the future, and I appreciate your support and guidance when it would have been easy to give up. To my mother and father, thank you for your years of support and dedication to my schooling. Thank you to my brother and sister, who have always been there when I needed them, no matter what the circumstances were. And thank you to Melanie, you have been an incredible support over the past few years and have kept me driven and focused. To the adolescents who took part in this study, I am eternally grateful for your participation and the information you provided. Having a relative diagnosed with cancer can feel like you have had the wind knocked out of you over and over again, and the courage that you showed answering every question that was asked is an inspiration to me and makes me want to continue this important work in the future.

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CHAPTER I

INTRODUCTION

Statement of Purpose

It is probably quite rare in today's day and age to not have been personally affected in some way by a diagnosis of cancer. According to the American Cancer Society, a lifetime risk of developing cancer refers to the probability that an individual, over the course of a lifetime, will develop or die of cancer (2009, ¶ 1). The most recent statistics provided by the American Cancer Society are sobering at best. In the United States, men have a slightly less than a 1 in 2 lifetime risk of developing cancer. With regards to women who live in the United States, the risk is slightly more than a 1 in 3 chance of developing cancer. In the tri-state area alone (NY, NJ and PA), it was predicted that 223,640 people would receive a new diagnosis of cancer in 2009 (2009, ¶ 3). The number of family members affected by a diagnosis of cancer is staggering and speaks to the need for qualified professionals to provide an effective way for individuals to deal with the emotions often associated with such a diagnosis. According to the American Cancer Society, cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells (2009, ¶ 2). If there is no medical intervention and the cells continue to grow and spread, death will occur. There are a number of factors that can cause cancer. External factors include: tobacco, infectious organisms, chemicals, and radiation. Internal factors include:

inherited mutations, hormones, immune conditions, and mutations that occur from metabolism.

Once a diagnosis is made, there are a number of available treatments that are given to combat the cancer. Surgery, radiation, chemotherapy, hormone therapy, biological therapy, and targeted therapy are all possible medical interventions. With advancements in the treatment of cancer, the likelihood of a person not only surviving, but thriving after treatment, has increased incrementally from where it was fifty years ago. The National Cancer Institute reported that 11.1 million Americans had a history of cancer in January of 2005: some of these individuals were cancer free, while others were still completing treatment (2009, ¶ 1). There are a number of possible reasons as to why people are surviving after completing treatment. The American Cancer Society (2009) reports that regular screenings and examinations by a doctor can result in the early detection and removal of pre-cancerous cells or growths. Medical advancements have resulted in doctors being able to make a diagnosis of cancer when the disease is at its earliest stages of development, thus allowing for a more successful treatment and post-treatment for the individual. Cancers that can be prevented by the removal of pre-cancerous tissues include cancers of the cervix, colon, and rectum. Cancers that can be diagnosed early through screening include cancers of the breast, colon, rectum, cervix, prostate, oral cavity, and skin. The American Cancer Society report states that cancers that can be prevented or detected earlier by screenings account for at least half of all new cancer cases in the United States (2009, ¶ 3).

The health care costs associated with the treatment of cancer are staggering. According to the National Institutes of Health (2008), the overall cost of cancer was \$228.1 billion. \$93.2 billion of that money was for direct medical costs, while \$18.8 billion was for indirect mobility costs (cost of lost productivity due to the illness). There was also \$116.1 billion spent for indirect mortality costs (cost of lost productivity due to premature death of the cancer patient) (2009, ¶ 8).

Despite the progress that has been made in prevention and early detection, cancer is still the second leading cause of death in the United States, accounting for 1 in 4 deaths (2009, ¶ 8). In the year 2009, the American Cancer Society estimated that 562,340 Americans died of cancer, which equates to about 1,500 people per day (2009, ¶ 8). Death is a natural part of the life cycle, but having a loved one die of natural causes in old age is very different than watching a loved one suffer and pass away prematurely after cancer has ravaged their body. The psychological and emotional toll that such an experience can have on a family is immense. Sometimes, the psychological needs of children are forgotten about, or not dealt with appropriately when they have a parent or sibling diagnosed with cancer (Eiser, 1997).

Personal Statement: Purpose of Study

For this study, I chose this topic for extremely personal reasons. My immediate family has been touched immensely by cancer, and if I could use this opportunity to help someone else who is currently going through what I have experienced, it would make this a rewarding topic and experience for me. My father was diagnosed with prostate cancer three years ago, and this affected my family in ways that I could not imagine. At first, we did not know what to think. You

immediately think the worst, and wonder how long your relative will be with you. I personally experienced a range of emotions, and despite having gone to undergraduate school and graduate school for psychology, I felt unprepared to deal with those emotions on my own. It made things even harder knowing the hereditary link that is present in my family. My paternal grandfather, my paternal uncle, and my father, all have been diagnosed with prostate cancer, so the lifetime risk for my brother and myself also being diagnosed with prostate cancer in our lifetimes, is significantly higher than the typical population. My father decided to travel to Mount Sinai Medical Center daily for two months where he underwent a seeded radiation procedure, and subsequent targeted radiation treatments. Thus far, treatment has been a success. To experience what my father went through was difficult, and it made me think about how it must affect younger children even more to have a parent or sibling diagnosed with cancer.

Background of the Study

Unfortunately, the area where I live has been determined to have a cancer cluster, and a number of children have been diagnosed with cancers caused by environmental pathogens. I contacted the local office of the American Cancer Society and was able to speak with the local coordinator for the organization. The American Cancer Society was created almost 65 years ago, and is the largest voluntary health organization in the United States. The American Cancer Society, Inc. comprises the National Home Office and 12 chartered, geographic Divison affiliates, throughout the United States, and has over 900 local offices nationwide. The organization relies on its more than three million volunteers to carry out its day-

to-day operations. The American Cancer Society and has spent billions of dollars on cancer research since 1946, millions of dollars in financial support to families dealing with a diagnosis of cancer, and also work with lawmakers to ensure that people have access to and coverage for lifesaving cancer screenings and treatments. Another important service of the organization is that it has developed and provided social support groups for children of various age groups.

After speaking with the coordinator for the Toms River, NJ office of the American Cancer Society, she stated that they have been successful meeting the emotional needs of their very young children, however, they have been less successful targeting the needs of adolescents. She states that for the healthy siblings who have a relative diagnosed with cancer, they initiate social support groups to help those children. The coordinator stated that the adolescent groups have been tried a number of times in the past, and they start out with a high number of participants, but after a few weeks, participation diminishes and the groups end prematurely. As a result of our discussion, it is my hypothesis that if the adolescents and their families were interviewed prior to the start of the social support group, and their needs were taken into account in its development, the group will be more successful. As a result of the semi-structured interviews, the coordinator will be left with a needs assessment of that specific population to use in the development of future social support groups.

This topic has affected my life immensely, so choosing to work with families afflicted with cancer was an easy choice for me. I want to use the opportunity that I have to make a difference in the lives of families in the area that I live. I know how difficult it can be to function when you have a loved one with cancer, so if my

personal experiences can alleviate some of the stress associated with a diagnosis of cancer, it will make this process even more rewarding for me.

CHAPTER II

BACKGROUND AND LITERATURE REVIEW

Introduction

This chapter provides an overview of the literature that highlights the experience of having a relative diagnosed with cancer. There are four sections: 1) *Cancer and the Family*; 2) *Social Support and Social Groups*; 3) *Social Learning Theory/Self-Efficacy*; 4) *Anticipatory Grief*.

Cancer and the Family

Effects of Cancer on the Healthy Sibling

When a child is diagnosed with cancer, the entire family can be profoundly affected, including the other children in that family. While it is understandable and necessary for parents to be overly focused on the care of the ill child, healthy siblings may feel their needs are neglected. Family activities such as movies or sports may be reduced or eliminated since so much time and energy is devoted to the sick child (Eiser, 1997). The healthy sibling may feel selfish if they complain or they may feel that they should just be happy because they are healthy (1997).

Relatives of children with cancer are at an increased risk for Post-Traumatic Stress Syndrome as well as other emotional disturbances (Woodgate, 2006). In her study, Woodgate found that 49% of siblings reported mild posttraumatic stress symptoms (PTS) and 32% indicated moderate to severe levels of PTS symptoms five

years after cancer treatment cessation. The lack of time and attention that parents have for the healthy sibling as well as the increased stress in the sibling's lives prevent them from successfully moving through the normal developmental stages for their age-group (Peterson and Revenson, 2005).

Childhood cancer is a life-changing diagnosis for the entire family, and the stress that parents experience is unimaginable to those who have not been in the same position. Not only do parents fear for the life of their child, they have to balance the increased expenses of life saving treatments along with decreased time both parents are able to work (Murray, 1999). The already hectic, normal, familial routines are magnified by repeated doctor visits, lab work visits, picking up medications, and research at home on the computer regarding their child's diagnosis and treatment options. In the midst of all the stress and chaos these changes cause, healthy siblings are often over-looked (Murray, 1999).

Although healthy siblings are often placed on the "back burner" to their sick brother or sister, this does not satisfy the needs of the healthy child. Healthy siblings also experience grief and worry, and they are often left to deal with these feelings on their own (Williams et al., 1997). Sometimes, there are additional burdens placed on healthy siblings which serve to magnify their grief and worry, especially when they are relied upon to provide an enduring support system for other children in their family (Williams et al, 1997). The burdens which are placed on the healthy sibling may inhibit normal social development and leave them unable to process what is occurring around them (Tempfer, 2006). Parents need to help them manage these feelings in a healthy manner. As the majority of attention in the family is placed on

the sick child, the healthy sibling is now left to work through the stress they are experiencing without as much support from parents.

There are three major categories of stressors that healthy siblings experience: emotional realignment, separation from the rest of the family, and the sick child's cancer regimen (Heffernan and Zanelli, 1997). Emotional realignment is rooted in the lack of time and attention that parents are able to spend with the healthy child. Lack of attention refers not only to the physical time that the parents spend with their children, but also the lack of emotional attention they are able to give them. Having a child battling a life-threatening illness is emotionally-taxing on parents, and this may result in parents being less able to meet the emotional needs of their healthy children. Parents may not have the emotional reserves to adequately tend to the needs of all of their children. The amount of time spent caring for the child with cancer also leaves parents with less time for the physical care of healthy children. According to Heffernan and Zanelli (1997), when their emotional needs are not met, healthy siblings may feel angry, frustrated, and guilty. In some cases, this can increase sibling rivalry because so much attention is paid to the child with cancer.

The healthy sibling may also feel that they are separated from their family. A cancer treatment regimen generally involves multiple hospital trips and hospital stays, and if the same parent always transports the sick child, the healthy sibling can go extended periods of time without seeing one of their parents. If one parent has to work, and the other parent has to transport the sick child, the healthy sibling may have to stay with relatives or family friends. This leaves the healthy sibling feeling dually separated, both emotionally and physically. According to Heffernan and

Zanelli (1997), healthy siblings may also feel “in the dark” regarding information about the condition of their brother or sister. Walker (1988) reports that healthy children commonly feel that they have inadequate information regarding the disease, treatment, and their sibling’s condition, which may lead them to believe that the situation is worse than it may actually be. The separation from the rest of the family leads the healthy child to feel sad, lonely, confused, anxious, and isolated (Heffernan and Zanelli, 1997).

The third stressor to create the emotional and physical separation of the healthy child from the rest of the family is the cancer regimen. The regimen takes a significant amount of time and frequently treatments are not close to home (Heffernan and Zanelli, 1997). The travel time required to maintain the intensive treatment regimen increases the amount of time the family is separated. The cancer regimen is a stress on the healthy sibling because of the separation, but also is a stressor because the healthy sibling has to watch their sibling as the cancer and its treatment causes adverse physical and psychological side effects. Heffernan and Zanelli (1997) state that watching their sibling suffer leads the healthy child to feel angry, guilty, afraid, anxious, embarrassed, and frustrated, and these children, generally, do not have an appropriate outlet to deal with the range of emotions.

Without an appropriate support to channel their emotions, the healthy sibling can be in a constant state of worry regarding the health and well-being of their brother or sister (Woodgate, 2006). It has been noted by Kazdin (1988), that healthy siblings often manifest their emotions through physical symptoms and behavior changes. According to Heffernan and Zanelli (1997), 69% of parents stated that their healthy

child displayed at least one form of a stress response related to having a sibling with cancer. Siblings of children with cancer have twice as many psychosomatic problems after diagnosis when compared to matched controls (Ballard, 2004). Sargent (1995) classified the manifestations of stress into three categories: emotional/behavioral, academic, and health. The emotional/behavioral responses that were noted by parents were most commonly swearing at peers or adults, arguing, irritability, and disrespecting adults. As the healthy sibling is placed in an unknown and stressful situation, over which they have no control, they are unable to process their feelings of sadness, fear, jealousy, resentment, and guilt (Fleitas, 2000). Often, the healthy siblings do not realize the basis for their emotional reactions, or if they do acknowledge they have a problem, they do not know how to verbalize what they are feeling, or work through the stress of the situation without formal intervention (Fleitas, 2000).

The educational setting is another area where the emotional vulnerabilities of the healthy sibling can be seen. As the stress mounts and the healthy sibling becomes overwhelmed, they may become less able to focus on their studies and their grades begin to fall (Murray, 1999). In his study, Murray interviewed 75 school-aged children with a sibling with cancer. The Personal Attribute Inventory for Children (PAIC) and the Piers-Harris Children's Self Concept Scale (PHSCS) were used to evaluate self-concept and affective functioning. Murray found that the healthy siblings were emotionally preoccupied with worrying about their loved one, which negatively impacted their ability to meet with success in school. Teachers or school staff can be the first line of defense when it comes to assessing whether or not a

child's behavior has changed in reaction to the cancer. Teachers might notice a change in the healthy sibling's personality, in the directions of becoming more reserved or more aggressive (Heffernan and Zanelli, 1997). A child who is socially involved with peers, may begin to isolate more, alienate themselves from peers, or become more aggressive with others (Heffernan and Zanelli, 1997).

Another negative outcome to the stress of the cancer diagnosis can be unexplained physiological complaints by the healthy sibling. It is a major upheaval in the family to have someone diagnosed with cancer, and if the healthy sibling is physically and emotionally drained, it can have a detrimental impact on their body's functioning (Hamama, Ronen, and Rahav, 2008). In their study, Hamama, Ronen, and Rahav conducted clinical interviews using the Frequent Symptoms Scale developed by Lapouse and Monk in 1958, with healthy adolescents, and found increased anxiety and a significantly higher level of psychosomatic symptoms when compared to adolescents who do not have a sibling with cancer. The researchers conducted a hierarchical regression, with psychosomatic symptoms as the dependent variable, and it explained 31 percent of the variance. According to Walker (1988), the most common physiological complaints of the healthy siblings are changes in their appetite, changes in their sleep pattern, changes in weight, and somatic complaints.

For all of the difficulty a cancer diagnosis can bring, some positive changes are possible as well. To be able to cope with the emotions and stress that comes with a diagnosis of cancer, its treatment, and the changes that occur in the family, leaves the healthy sibling with an experience that has the potential to enhance their

resilience. The experience often causes the healthy sibling to be given more responsibility at a younger age than their peers, which causes them to mature at a faster pace than their peers (Heffernan and Zanelli, 1997). The stress of the diagnosis can also cause a family to become closer, and a more cohesive unit (Fleitas, 2000). The experience may also make a family closer to their extended family, because frequently, the immediate family calls upon other family members to offer support (Fleitas, 2000). There is also the potential for the healthy siblings to be introduced to other healthy siblings who are dealing with the same stressors. This may enhance their coping skills and interactive skills with peers and adults (Fleitas, 2000).

Labay and Walco (2004) examined the psychological adjustment of children who have a sibling with cancer, with a particular emphasis on protective factors, such as “empathy, illness concepts, and aspects of the sibling relationship (warmth, status, conflict, rivalry)”. Labay and Walco noted that the capacity for empathy increases with age and is generally better developed in girls than in boys, and has been associated with better psychological adjustment in stressful situations in children. Empathy “involves both affective arousal and a cognitive ability to assume the psychological role of another individual” (2004). The researchers in the study found that siblings with greater levels of empathy experienced fewer difficulties with psychological adjustment. It was noted that empathy may help siblings cognitively process the significant alterations in family resources (parent’s time, financial resources, recreational activities). It is also probable that children who demonstrate lower levels of empathy may be less effective at understanding emotional states, and exhibit difficulties voicing their emotional needs and rely on impulsive or aggressive

behaviors to express how they feel. Labay and Walco (2004) found that empathy was significantly correlated with age, supporting their hypothesis that taking into account social, cognitive, and emotional development are crucial when developing social support groups for siblings. They also found that when the child with cancer is younger, older siblings tended to exhibit more behavioral, social, and academic difficulties. This suggests that the increased demands and responsibilities placed on older children, places them under more stress. Family size was also correlated with poorer adjustment. The researchers' hypothesized that as the number of individuals in the family increased, resources were stretched further and further, and individuals' needs were not met as effectively, which highlighted the need for social support groups.

Along with the changes mentioned above, healthy siblings may also experience long-lasting positive changes. Heffernan and Zanelli (1997) completed a study which showed that 51% of parents stated that the healthy sibling tended to be "more sensitive to the needs" of others. The healthy sibling may become more attuned to other people's emotions and needs, resulting in them becoming more caring and compassionate. According to Sargent et al (1995) the experience of cancer aids the healthy sibling grow in developing altruism as they transform into a person who recognizes the needs of others. According to Fleitas (2000), in addition to increased altruism, healthy siblings tend to become more patient and understanding of the needs of others around them, especially with those individuals who are medically or physically compromised. Despite the stress and grief that accompanies a cancer diagnosis, sometimes the healthy sibling can be changed for the better, and will learn

to better appreciate their family, appreciate their health, and appreciate life more than they did pre-cancer diagnosis.

According to Emswiler and Emswiler (2000), children have a number of coping mechanisms which become prevalent after a diagnosis of cancer is made. The coping mechanisms that children use are similar to the coping mechanisms that adults use, however children are often unable to understand how they are feeling, or why they are sad or depressed. The coping strategies which children use tend to be congruent with their level of cognitive and emotional development. According to Laor, Wolmer, and Cicchetti (2001) there are three specific categories of coping strategies which children typically use: self-oriented coping strategies, other-oriented coping strategies, and mature coping strategies.

When a child internalizes their emotions, Laor, Wolmer, and Cicchetti, label these self-oriented coping strategies (2001). Examples of self-oriented coping strategies are denial, fantasy, regression, and isolation. The most common example of a self-oriented coping strategy is denial. The healthy sibling may avoid the emotions of the cancer diagnosis by pretending their ill sibling is not sick. Denial serves to protect the healthy sibling from the feelings and stress associated with a diagnosis of cancer. A healthy sibling may also exhibit regression as a self-oriented coping strategy. Children may regress to a time prior to the diagnosis of cancer, when life was “easier” and the child may have felt safer and had less to worry about. Another example of a self-oriented coping strategy is fantasy. Children may attempt to escape the pain and difficulty they are experiencing in their lives, by using their

toys and their imaginations to set up an ideal life circumstance, where there is no diagnosis of cancer.

The second category of coping strategies identified by Laor, Wolmer, and Cicchetti (2001) were other-oriented coping strategies. These strategies are higher level strategies than the self-oriented type, and include: projection, acting out, and displacement. A common mechanism seen in adults and children is displacement. When a child uses displacement as a coping strategy, they take their feelings and emotions out on another person, rather than working through those emotions in a more positive way. Teachers, peers, and parents tend to be the targets for the healthy sibling. Another other-oriented coping strategy is acting out, and this is typically seen in the school environment (Araujo et al, 2006). The healthy sibling may have been a very well-behaved student in the past, and may have never gotten in trouble before the cancer diagnosis, however, they now disrupt class by talking or yelling out, or may start fights with peers. Often times, children do not even realize how they are acting, and have even less of an idea why they are acting the way they are. The acting out is a manifestation of the anger that is associated with the cancer diagnosis. The last other-oriented coping strategy described by Laor et al (2001) is projection. The healthy sibling is using projection when they perceive their own emotions are present in other people. An example of this is when a child feels that other people are angry, depressed, or sad, when there is no basis for these feelings.

Mature coping strategies are the highest-level and most advanced coping strategies described by Laor, Wolmer, and Cicchetti (2001). When a healthy sibling uses a mature coping strategy they are working through their emotions and feelings in

the healthiest manner. Humor, anticipation, sublimation, and altruism are examples of mature coping strategies. Altruism is when a healthy sibling will take the negative situation associated with a diagnosis of cancer, and turn it into something positive by reaching out to siblings of other cancer patients, volunteering to help cancer patients, or somehow being involved in doing something positive in the lives of others. The healthy siblings tend to find pro-social activities to express how they are feeling and do what they can to turn a negative experience into a positive one. When a healthy sibling uses the coping strategy of sublimation, the child tends to express their negative feelings and anger using a more positive outlet, such as running, working out, or creating art. The healthy sibling may paint how they are feeling on a canvas, hit a punching bag, or run on a treadmill to work out some of their emotions.

Ballard (2004) reports that healthy siblings tend to have a desire to learn all they can about their sibling's illness and the more knowledge that the healthy sibling has, the better they will function during and after treatment. Walker (1988) conducted a study with the purpose of identifying and describing cognitive and behavioral coping strategies used by siblings of pediatric oncology patients. She interviewed 15 families with 26 siblings between 7 and 11 years of age. She used open ended interviews and a questionnaire to obtain sibling data. The questionnaire included puppet play, kinetic family drawings, cartoon story telling, a sentence completion test, and a limited number of direct questions. Walker found that healthy siblings have a number of questions, such as: what caused their sibling's cancer in the first place? Why did their sibling get cancer? They also wanted to know whether it was something they would be diagnosed with in the future. In the same study,

healthy children stated that, for the most part, they felt that they were not given the information necessary to be able to understand and cope with their sibling being sick. They wanted to be informed about each step in the treatment process, so could know what to expect as something new happens. According to Fleitas (2000), parents can ensure that their healthy children are provided with information in an age-appropriate manner and at an intellectual level the child will be able to understand. Healthy siblings are much better served when they are given information regarding specific procedures, treatment goals, and expected outcomes, because it gives them some sense of control in an extremely chaotic situation. When the healthy sibling is given appropriate information it makes them feel as if they are still an integral part of the family unit. This conveys to the healthy sibling that they are important, and their parents still care greatly about them, despite the fact that they are so focused on the care of their ill sibling. This can also be seen when a healthy sibling develops a minor ailment and they are given the proper care and treatment by their parents. According to Zelter et al (1996), it is easy for a parent to minimize a minor illness, compared to cancer, but it is still necessary for the healthy sibling to receive the treatment they need. According to Fleitas (2000), healthy siblings want to “feel that their reactions and opinions are valued”. They noted that healthy children desire to be treated as children, and not as “adult caregivers”. Cancer treatments are extremely time-intensive and the healthy sibling is left to grow and mature at a quicker pace than typical peers. Often times their role in the family can change to include more adult responsibilities than they are able to handle; over-burdening the healthy sibling can have negative consequences including a higher level of anxiety, stress overload,

and psychosomatic symptoms (Hamama, Ronen, and Rahav, 2008). If they are given more responsibilities, parents need to be aware that they should not ask the child to do things that are beyond their developmental level, because the stress of having a loved one with cancer is difficult enough for the healthy sibling.

Social Support and Support Groups

Social support is defined as a “social network’s provision of psychological and material resources intended to benefit an individual’s ability to cope with stress” (Cohen, 2004). Social support is often divided into three categories, depending on the type of resources which are being utilized. The three types of support are: instrumental, informational, and emotional. Instrumental support refers to the provision of material aids, including financial assistance and help with daily tasks, if someone becomes disabled. Informational support refers to the “provision of relevant information intended to help the individual cope with current difficulties”, and typically takes the form of advice or guidance in dealing with one’s problems (Cohen, 2004). Emotional support refers to the demonstration of empathy, genuine caring about others, and opportunities for people to talk about worries or problems, and have someone who will listen to them. Social support differs from social integration, because social integration refers to inclusion in a wide range of social relationships, although it is felt that both social support and social integration serve to enhance health in stressful times (Cohen, 2004). According to Brissette et al (2000), social integration is a “multi-dimensional construct thought to include a behavioral component (active engagement in a wide range of social activities or relationships)

and a cognitive component (a sense of communality and identification with one's social roles)".

It is believed that both social support and social integration can benefit health through two mechanisms, stress buffering and main effects. Stress buffering posits that social closeness and social connection benefits health "by providing psychological and material resources needed to cope with stress" (Cohen, 1988). The stress buffering model is supported by an interaction of stress and social support (Cohen and Wills, 1985). It is felt that stress influences health by triggering maladaptive behavioral coping responses which are detrimental to health, and by "activating physiological systems such as the sympathetic nervous system and the hypothalamic-pituitary-adrenal cortical axis" (Cohen, Kessler, and Gordon, 1995). It is felt that repeated activation of these physiological networks can place a person at risk for a host of physical and psychiatric disorders. If someone perceives that they have others in their lives who provide support, this social support will then act as a buffer against stress. According to Uchino et al (1996), someone only has to perceive one other person as a source of support to have social support act as a stress buffer. If someone believes that that another person will provide any type of support, it will serve to bolster their perceived ability to cope with stress and demands, thus effectively changing how a situation is appraised and lowering the effect of the stressful situation. According to Wills and Cleary (1996), if someone believes that they have social support, the belief may alleviate the emotional and physiological reactions to the stress, or may serve to alter maladaptive coping strategies, and ensure adaptive coping strategies are used instead. In research conducted by Cohen and

Wills (1985), they found that social support is optimally effective in reducing stress levels when the type of support and assistance matches the demands of the stressful events, for example financial support is optimally effective when someone first loses their job and they are worried about how to pay their bills. According to Kawachi and Berkman (2001), there is "substantial evidence" that someone's perception of social support buffers the effects of stressful situations on psychological distress, depression, and anxiety. Cohen, Mermelstein, Kamarck, and Hoberman (1985) found that both student and adult samples reported more symptoms of depression and physical complaints when they were under stressful circumstances, but the levels of these complaints were lessened among those students and adults who perceived that social support was available from their social networks. The researchers found that emotional support worked across a variety of stressful situations, whereas instrumental and information support were more situation-specific.

Rosengren, Orth-Gomer, Wedel, and Wilhelmsen (1993), provided empirical support for the stress buffering hypothesis. In their study, they interviewed healthy men from Sweden who were 50 years or older. They found that those men who endorsed having stressful life events in the year before the exam were at much greater risk for mortality over a seven-year follow up period. The researchers found that the effects of the stressful situations were significantly reduced among those who perceived that they had high-levels of emotional support from their social networks. Support provided those individuals in the study with a solution to their problems, and initiated positive coping responses. In a study conducted by Cohen et al (1992), animals were rotated into cages with different animals on a monthly basis, in order to

simulate stressful conditions. The proportion of time the animals engaged in coping behaviors was assessed by 30-minute observations of each group made two times per week. The animal's T-cell immune response was assessed weekly for three weeks immediately following the 26-month rotation of cages. The coping behaviors demonstrated that certain animals were attempting to deal with a stressful situation. The animals who attempted to use coping responses also had the healthiest immunological responses, meaning they were better protected from the demands of the stressful situation.

The main effect is the second way that researchers feel social support benefits health outcomes. The main effect hypothesis argues that having an active social network is beneficial to someone, whether or not they are under stress. Social integration posits that individuals who are a part of a social network are "subject to social controls and peer pressures that influence positive, normative health behaviors" (Cohen 2004). Social networks can initiate pro-social and pro-health behaviors, such as exercising, eating proper diets, and cessation of drug and alcohol use. An active social network may also cause people to take responsibility for others, which may indirectly result in increased motivation to take care of themselves, so they can live up to their responsibilities in their group. In their study, Robinson and Tian (2009) found that adults diagnosed with cancer, as well as adults who have never been diagnosed from cancer, but were still provided informational support were both significantly more likely to talk about their health and reciprocate by providing information support to others. The researchers concluded that being integrated into an active social support network benefits not only the individual actively participating

in the network, but also provides secondary benefits to friends and family members as well. Cassel (1976) hypothesized that integration in a social network is thought to influence someone's sense of self and one's emotional tone. It is felt that role concepts that are shared among a social network guide interactions among the members by providing common goals and expectations about how members should act in different situations and in different roles. "In meeting normative role expectations, individuals gain a sense of identity, predictability, stability, of purpose, belonging, security, and self-worth (1976). Interacting with others is also thought to help with emotional regulation, increasing positive affect, and helping to limit the intensity of negative emotions in the face of stressful conditions. According to research conducted by Reis (1984), both main (direct) and buffering (indirect) effects influence health and well-being. Reis found that direct and buffering processes "may be linked with different conceptions (and hence types of measures) of social support. It was shown that main effects generally occur when the social support measure that is being used assesses the degree to which a person is integrated within a social network, while buffering effects occur when the social support measure assesses the availability of resources that helps someone respond to a stressful event.

Thoits (1995) provides a sociological perspective as to why social support affects health. Thoits assessed role involvement, which means that individuals will "derive behavioral guidance and a sense of purpose and a meaning in life from the roles they enact", and states that role relationships provide individuals with a set of identities, a "source of positive self-evaluation", and the "basis for a sense of control and mastery" over a difficult situation (1995). Good health is enhanced because role

involvement gives a purpose and meaning to someone's life, reduces the likelihood that stress will be too overwhelming to deal with, and lessens the chances of anxiety or despair in the face of stress.

According to Cohen and Syme (1985), social support has also been studied from two other perspectives. The main issue according to Cohen, was whether social support is conceptualized in terms of the structure of a social network, or in terms of the functions that a social network serves. Researchers who deal with the structure of a social network describe the presence of social ties, and the inter-connections that are present in the social network (marital status or number of close relationships), while researchers who use functional measures assess whether relationships serve particular functions for individuals. In these terms, structural measures are generally considered to be more objective measures, while functional measures ask people about their perceptions and tend to be more subjective in nature. The objective support measures provide information about the properties of someone's social network, such as number of social contacts and number of group affiliations, and tend to show how embedded someone is in their network. The more embedded someone is, the better stability and control they feel they have over their lives. Subjective measures tend to assess individuals' psychological representations of their support network. Subjective measures are used when researchers want to assess the role of perceived support and how that affects health.

According to Cohen and Syme (1985), there has been an increased focus and research on social support and its positive effects on individuals. One reason for the increased research is the hypothesis that social support may play a role in the etiology

of disease and illness. Another reason for the increased research in social support may be due to the fact that support has been shown to have a positive effect in treatment and rehabilitation programs instituted following the onset of an illness. Social support programs have been shown to be beneficial in altering behavioral and emotional responses to stressful situations. A third reason for the increased attention being paid to social support is due to the fact that a disruption in a social network places a person at higher risk for development of disease, especially among those who have experienced job loss, frequent moves, or the death of a loved one. The need for increased research on the benefits of social support and healthy sibling adjustment to cancer was highlighted in a study conducted by Barrera, Fleming, and Khan (2003). The researchers interviewed 72 siblings, and had them complete the Children's Depression Index (CDI), the Siblings Perception Questionnaire (SPQ), the State-Trait-Anxiety Inventory for Children (STAIC), and the Child Behavior Checklist (CBCL), and found that siblings with higher social support reported significantly fewer symptoms of depression, anxiety, and exhibited fewer behavior problems than siblings who had less social support (2003).

When creating social support groups there are a number of questions that should be kept in mind (Cohen and McKay, 1984). The first of these questions is who is providing the support? Support may be more beneficial when given from one person, but be less effective if it comes from someone else. "Roles of the giver and receiver, norms for these roles, and issues of the perceived equity, reciprocity, and appropriateness of the transaction are all relevant in determining if a supportive behavior for a giver will have a positive impact" (1984). For example, if someone is

having difficulties at their place of employment, support that is given by a fellow co-worker or a supervisor may be more beneficial than support provided by a spouse or close friend. The second question that can be asked is what kind of support is being provided? As stated earlier, the support that is provided should be appropriate for the situation to be optimally effective and better support well-being. The third question that should be asked is to whom is the support provided? Personal characteristics of the receiver will determine how beneficial the social support is. A receiver's personality, and their social and culture roles and norms play a big part in the success of the support that is provided. The next question that can be asked is for which problem is support provided? The kind of social support is dependent on a match between the type of support being given and the type of problem that the receiver is facing. For example, there are different support needs whether someone loses their job, has a loved one pass away, or is experiencing marital difficulties. The next question that needs to be asked is when is support provided? Social support may be more effective at one point in time than it would be at another time. For example, if someone loses their job but is given severance pay, social support will be more effective if it is provided after the severance pay is gone, rather than when they initially lose their job. This implies that the initiation of support should be optimally matched to a time when the individual would benefit most from support. Another question that can be asked when deciding if social support will be effective will be to ask how long the support is going to be provided? Social networks are usually good at providing short-term aid, however, if longer term care is necessary it may deplete the available resources of the social network. When developing a social support

group for individuals who have relatives diagnosed with a chronic illness, the planner's of the group must factor in that the group will be more long-term than short-term in nature to meet the needs of the participants. The last question that should be taken into account is, what are the costs of giving and receiving support? The cost of support may be a crucial factor in whether support is solicited by those who can use the support, or given by the providers of social support. The support will be maximally effective if the providers feel that they can meet the needs of the participants, and the participants will become more involved if they feel they are not over-burdening others with their request for support.

Research shows that there are immediate and long-term emotional and behavioral effects of having a sibling with a chronic childhood illness, which speak to the need for social support groups (Fanos et al, 2004). Serious and long-term effects were found in a sample of adults who had grown up with a sibling with a chronic illness. The healthy siblings endorsed feelings of survivor guilt, anxiety, fear of an early death for themselves, fear of intimacy or getting close to others, excessive concerns for others, somatic complaints, and depressive thoughts. The negative psychosocial complaints were exacerbated among children whose families had poor communication skills. The healthy siblings tended to feel anger and more isolated when they felt that parents were not communicating effectively with them. Woodgate (2006) interviewed healthy siblings, and found that communication between parents and healthy children is the most strained when their sibling's cancer is the most pronounced. As the physical symptoms of the cancer increase, the healthy sibling's adjustment to the cancer experience decreases. Unfortunately for the healthy siblings,

communication between family members tends to break-down at a time when it would be most beneficial. Fanos et al (2004) found that studies of siblings with cancer have shown that children coped better and felt less isolated when they were informed about their sibling's illness and the treatment program. This effect was even more pronounced after the unfortunate death for their sibling. Families who had good communication before the death of the sibling had better communication among family members after the sibling passed away, than those families who initially had poor communication skills. The communication among family members was indicative of how well the surviving siblings adjusted to the loss of their loved one. Support groups have been shown to be beneficial to siblings of children who have a chronic illness (McKeever, 1983). The siblings were classified as an "at-risk" population to experience emotional and psychological difficulties. A meta-analysis of studies revealed how important it is for siblings to receive emotional and social support when one of their loved one's is diagnosed with a chronic or debilitating illness. Howe (1993) found that four of eleven studies of siblings of children with chronic illness exhibited significant internalizing behaviors, compared to only one of eight studies where the siblings exhibited externalizing behaviors. This speaks to the need for social support for siblings, because on the surface it may appear that the siblings are coping well with the illness of their loved ones, because they are not exhibiting any overt signs of emotional disturbances. However, siblings may be internalizing their emotions and feelings, which is not easily recognizable by others. A meta-analysis conducted by Sharpe and Rossiter (2002) revealed a statistically significant and negative overall effect for having a sibling with a chronic illness and

subsequent internalizing behaviors. In their study, the researchers found that internalizing behaviors such as anxiety and depression were associated with larger negative effects than externalizing behaviors (2002). The researchers attempted to account for the presence of internalizing behaviors and stated that the healthy siblings tend to be placed in a care-giver role (quasi-parent), and given more responsibilities to care for their siblings, and the internalizing behaviors may be a response to the increased caretaking demands. Any emotional responses or feelings of frustration that arise from the increased demands or inattention paid by parents may not lead to externalizing or physical responses because of the fragile physical state that their siblings may be in. Lavigne and Faier-Routman (1992) found that siblings of children with a chronic illness such as cancer, that affects the day-to-day functioning of the family unit, will leave the sibling more negatively affected than siblings of children with a less intense and debilitating illness. It was felt that the increased caretaker demands accounted for a large part of the decreased emotional functioning in the healthy siblings. Newacheck and Halfon (1998) found that siblings of children with chronic illness tend to have more days of limited or no activity, number of school absences, and fewer physician contacts than children with healthy siblings. Coyne and DeLongis (1986) determined that children who were lower in social support tended to be more “alienated and cynical” than those with a strong support network. Individuals with low support perceived their social networks as less reliable and less supportive and generally had poorer coping responses in the face of stress.

Wong, Looney, Michaels, Palesh, and Koopman (2006) evaluated potential risk factors for posttraumatic stress disorder (PTSD) in adults who, during their

childhood, had a parent diagnosed with cancer. The researchers used a demographics questionnaire, the MacArthur Scale of Subjective Social Status, and the Post-Traumatic Stress Disorder Checklist-Specific Version (PCL-S), and found that adults reported greater PTSD and higher rates of dissociation than was reported among their control group. The researchers defined peritraumatic dissociation as “a state in which memory, identity, or perception may be experienced in an altered, disconnected manner, such as experiencing time in slow or rapid motion or perceiving that an ongoing event does not seem real” (2006). Peritraumatic dissociation at the time of the parent’s diagnosis was strongly, positively correlated with PTSD symptoms later in adulthood. The researchers also found that greater social support in the months after the parental cancer diagnosis was related to experiencing significantly fewer PTSD symptoms later in life. This speaks to the importance of providing social support to adolescents when they have a parent diagnosed with cancer.

When individuals have a weak support network, along with an avoidance of feelings, denial of concerns, feelings of helplessness, and feelings of isolation, they are placed at-risk for poorer health outcomes and poorer quality of life (Weis, 2003). Support groups have been shown to improve psychological well-being, reduce anxiety, and depression, and improve quality of life, coping, and mental adjustment, when a sibling has a loved one with cancer (2003). Age of the individual has been shown to be an important factor to consider when providing social support (Derevensky et al, 1998). Derevensky conducted a study and used the Social Support Scale for Children, and found that social support acts as a mediating “buffer” that dulls the effects of stress. The buffering effect was significantly higher for older

adolescents compared to younger children. It was hypothesized that as children grow older, peer support is described as increasingly important, while the need for family support also continues. Support groups can address cancer-related issues and enable group members to gain emotional support from others who are dealing with similar stressors.

The main goal of support groups is to improve an individual's coping strategies. According to Weis (2003), coping is a process of self-regulation, at the emotional, cognitive, and behavioral levels. Using denial and avoidance may be adaptive and beneficial in the short-term, but maladaptive in the long-term. Positive coping has been associated with the use of multiple and flexible coping strategies, which can be adjusted to the stressful situation (Meyer and Mark, 1995). Positive coping is not only an inter-individual process, but also an intra-individual process, because the group member also interacts with other family members and friends. As the group member increases positive coping strategies and distress is reduced, it will also serve to promote positive interactions in their social environment, and create a more positive and functional social network.

In their study, Williams, Williams, and Graff (2003) reported a decrease in behavioral problems and an overall improvement in self-esteem and mood for siblings who participated in a social support group when compared to control siblings who were placed on a waiting list for a group. Phillips (1999) reported a similar finding, where a self-reported decrease in anxiety and depression was seen in siblings enrolled in a support group, when compared to controls on a waiting list. In the above mentioned studies, siblings were found to be at increased risk for internalizing

behavior problems, and support groups that were focused on strengthening siblings' coping skills were shown to be an effective intervention approach. When social support groups are combined with a psycho-educational component, the siblings exhibited better adaptive coping responses. Houtzager, Grootenhuis, and Last (2001) conducted a study with 24 siblings of children with cancer, and reported decreased anxiety following participation in their group, which provided both psycho-education and problem-solving activities. Lobato and Kao (2002) evaluated a group intervention using a larger sample size of 54-sibling/parent pairs who had another child with a chronic illness. The researchers provided psycho-education, strategies for managing their emotions, and also worked on problem-solving activities. They found an increase in sibling knowledge of disability or illness, and an overall decrease in negative adjustment outcomes following the completion of the groups. The results of this study were maintained at a three month follow up.

Social Learning Theory/Self-Efficacy

One theory that attempts to explain the basis for the effectiveness of social support groups is social learning theory. Social learning theory emphasizes the role of "self-reactive influences in motivating and guiding someone's behavior" (Frayne and Latham, 1987). The underlying assumption in social learning theory is that by arranging environmental contingencies (rewards and punishments), establishing well-defined goals, and producing clearly defined consequences for their actions, individuals will learn to exercise self-control when it comes to their behavior. With respect to children, the theory states that children will form a cognitive representation from real-world experiences, such as observation of a peer or adult, and they will use

these cognitive representations to drive future behaviors in similar situations, based on the observed outcomes. Children will be motivated to repeat a certain behavior, and dissuaded to act in other ways, depending on the consequences that were observed in past situations. According to Bandura (1977), cognitive processes play a “prominent role in the acquisition and retention of new behavior patterns”. Because “acquisition of response information is a major aspect of learning, much of human behavior is developed through modeling” (1977). When children observe other peers or adults, they gain a cognitive representation of how behavior patterns are formed, and use this coded information to guide future actions. There are two main components of social learning theory that may explain how self-management of behavior occurs, perceived self-efficacy and outcome expectancies. Perceived self-efficacy refers to the strength of one’s belief that he or she can successfully complete a required task (Bandura, 1982). Self-efficacy is thought to influence what individuals choose to do, how much effort they will use in completing tasks, and how long they will persevere when completing an activity when they face real or perceived obstacles to success related to their efforts. Individuals with a weak sense of self-efficacy tend to perceive their difficulties as more severe than they may actually be, and subsequently not attempt to overcome their stressful situation. In contrast, individuals with a high sense of self-efficacy will be motivated to effectively cope with their stress and persevere with coping until they reach a defined goal. According to Ladd and Mize (1983), research shows that feelings of self-efficacy play a valuable role in pro-social skill acquisition and skill maintenance. The researchers found that an individual’s feelings of self-efficacy are in contrast to

feelings of anxiety, and self-efficacy may “mediate children’s persistence at performing interpersonal skills in situations where obstacles or low success rates are encountered”. An individual who has a perceived lack of self-efficacy may exhibit deterioration in skills, even in instances where they have demonstrated skill mastery in the past. Bandura (1977) states that an individual’s perceived sense of self-efficacy can be elevated by providing the individual with positive reinforcement paired with social learning experiences that maximize successful outcomes. Bandura also found that the leader of a social skills group can help an individual interpret negative thoughts as typical reactions anyone would have, rather than the individual misattributing those reactions to something negative about themselves.

Outcome expectancies are the second component of social learning theory. Outcome expectancies refer to an individual’s “beliefs concerning the extent to which one’s behavior will produce favorable or unfavorable outcomes” (Frayne and Latham, 1987). It is felt that people will be more willing to act when they believe that their actions will produce favorable outcomes. Individuals are less likely to alter their behavior when they believe they can perform successfully, but they feel the environment will be unresponsive to their behavior change.

Social learning theory explains human behavior “in terms of continuous reciprocal interaction among cognitive, behavioral, and environmental determinants” (Latham and Saari, 1979). Latham and Saari stated that it is unnecessary and “nonsensical” for researchers to argue whether behavior is due only to cognitive, or only to environmental variables. The authors hypothesized that behavior results from a combination of cognitive and environmental factors, arguing that it would be

impossible to demonstrate that one was solely responsible for behavioral change. They reported that in order to show that cognitions were solely responsible for behavior change, researchers would have to find a control group that was made up of subjects who “cannot think”, and in order to show behavior was due to environment, researchers would need to devise a control group where there was “no environment”, clearly making the point that behavior is determined by a combination of both variables (1979). Social learning theory posits that human thought and behavior are influenced by observing others, as well as engaging in activities that permit direct experiences. Social learning theory also states that individuals will use symbols to create representations of their environment, to communicate with others, to analyze their experiences, and to engage in predictive behavior. The representations that people internalize will help them decide whether or not to act in certain situations. In order for individuals to use cognitive representations, they must recognize that stimuli are correlated with a particular outcome. It is the predictive function of the stimuli that will drive future behaviors in individuals. Baum (1973) reports that behavior is not only controlled by its immediate consequences, but there is also an additive function for the cognitive representations that people make, meaning, repeated and similar consequences for a particular action will shape how individuals act in future instances. Individuals will process and retain feedback from similar events over time intervals, and the patterns that are retained will guide behavior when they see that a certain behavior obtains desired outcomes. According to Bandura (1977), individuals do not only react to external influences, but they will select, organize, and transform stimuli that impose on those influences. Social learning theory and operant learning

theory both attempt to explain how new behaviors are initiated, however they differ in the way they view reinforcers. In operant learning theory, researchers believe that a reinforcer strengthens preceding responses, while in social learning theory reinforcers “facilitate learning anticipatorily through its effects on attentional, organizational, and rehearsal processes”, which stresses the importance of both cognitive and environmental variables in shaping behavior (Latham and Saari, 1979). In his seminal study, Bandura (1979) found that learning is better achieved by informing participants of the consequences in advance of a specific task or behavior, rather than waiting for the behavior to be demonstrated and then giving a reinforcer. Bandura argued that this is particularly true when it comes to observational learning, because the anticipation of a reinforcer will influence what people observe and what they choose to ignore, and allow people to focus on the most salient details of a model’s behavior. Participant’s attentiveness to a task and subsequent learning from a model was increased when they knew the consequence of a model’s behavior was going to be rewarded or the model would have a punishing stimulus removed.

Social learning theory is valuable when it comes to social support groups, because according to Bandura (1977), an individual often learns the most from the people with whom they spend the most time; these are typically the people that are most frequently observed in everyday life. Significant others in people’s lives also tend to provide the strongest and most frequent reinforcers as well. The observations of others act as both motivators and informers for one’s own behaviors, thus if positive influences and behavioral models can be provided in a social support group,

it should result in more pro-social and positive behaviors in individuals who are enduring a highly stressful situation.

Anticipatory Grief

The concept of anticipatory grief was first introduced by Erich Lindemann in 1944. He states that the theory was an outgrowth of people working with individuals who lived through the atrocities of World War II. In his article, "Symptomatology and Management of Acute Grief" (1944), Lindemann described "the pathognomonic characteristics of grief", which were, "emancipation from the bondage of the deceased (decathexis), readjustment to the environment in which the deceased is missing, and the formation of new relationships". In his work with World War II survivors it was also noted that merely the threat of death or loss could cause a "bereavement reaction". When confronted with a real possibility of the loss of a loved one, an individual becomes so worried about adjusting after the death, that survivors can go through all of the phases of grief and dying while their loved one is still alive. Lindemann noted that these phases were: "depression, heightened preoccupation with the departed, a review of all of the forms of death which might befall him, and anticipation of the modes of readjustment which might be necessitated by it" (1944). While it was reported that this process of anticipatory grief was generally a positive experience for the survivors, it was also seen as a negative, because the survivor had a difficult time reconnecting with their loved one if the sick relative did not pass away. Despite the contradictory findings by researchers who argue whether anticipatory grief is beneficial to survivors, the fact remains that there is a significant grief reaction that needs to be attended to (Rando, 1986). Rando

argues that a justification for studying the concept of anticipatory grief is that it allows for the development of primary prevention activities for survivors-to-be. This is seen as beneficial because in typical grief therapies, services are provided after the loved one has died, thus the intervention focuses on helping the individual put their life back together after an emotionally draining, and life changing event has taken place. Rando (1983) developed a definition of anticipatory grief and stated it is "the phenomenon encompassing the processes of mourning, coping, interaction, planning, and psychological reorganization that are stimulated and begun in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future". Rando feels that anticipatory grief implies a delicate balance between the conflicting demands of "simultaneously holding onto, letting go of, and drawing closer to the dying patient". It is the constant pulling in multiple directions that must be dealt with when interventions that focus on anticipatory grief are implemented.

Anticipatory grief is an important avenue of intervention because the service provider can use primary prevention and intervention techniques that allow for "a more positive bereavement experience" (Rando, 1986). Rando (1986) states that the period of time where a diagnosis of a debilitating illness is received, to the point where the loved one finally passes away, can have a "profound influence on post-death bereavement". There were a number of factors that contributed to a poorer post-death outcome for the survivors according to Rando, including: unfinished business left after the death occurred, poor communication and interaction with the sick loved one during the illness period, and a lack of appropriate anticipation of the

ultimate outcome of the illness. Interventions that target anticipatory grief can help remedy some of the above problems for survivors. Anticipatory grief interventions have the ability to prevent problems associated with mourning from developing, or at least alleviate problems if they do occur, while post-death interventions can only alleviate difficulties that have already occurred. Interventions that provide pre-death services to individuals are more important now than they were 40 years ago, because as treatments have advanced, the duration of time that individuals survive with terminal illnesses has increased. Pattison (1977) noted that the increase of this “living-dying interval” creates a number of problems that are derived from illness: numerous remissions and relapses with the associated psychological reactions to each, a lengthier period of anticipatory grief, an increase in financial, social, physical, and emotional affects, a longer-term disruption of the family unit, a more progressive decline for the loved one with the illness, longer periods of uncertainty, more intensive treatments and their physically debilitating side effects, and the possibility of having to make more decisions regarding treatment regimens. While there has been an increase in the amount of time survivors have to spend with their loved ones as treatments have become more advanced, it is not always positive. There are times when the increased time is more difficult for survivors, because they observe their loved one’s disease progress over a longer period of time, and they are powerless to cure the disease. This speaks to the need for interventions that target anticipatory grief, because the survivors may experience better post-death experiences if they feel supported throughout this emotionally taxing period of their lives.

While much of the research completed on anticipatory grief demonstrates great value and significantly better post-death bereavement when individuals have some advanced warning regarding the ultimate outcome of a loved one's terminal illness, other researchers such as Burton (1974), Binger et al (1969), and Wiener (1970), state that a period of anticipatory grief is unrelated to post-death experience. Other researchers such as Gerber et al (1975), and Schwab et al (1975), did not find a significant correlation between anticipatory grief and subsequent post-death outcome; however they found that the individuals who had relatives with the longest-lasting and extended illnesses were more likely to have poorer adjustments after the eventual death of their loved ones. In her research, Rando (1983) found that illnesses that had both the shortest and longest periods of duration were associated with poorer outcomes, post-death, when compared to illnesses that were of medium length in duration. Rando theorizes as to why there is such a discrepancy in the findings in the research that have addressed anticipatory grief. She states that researchers tend to confuse the forewarning of a loss, with anticipatory grief. Individuals may be aware of an impending loss, however, they may not actually grieve in anticipation of the loss. Rando argues "neither anticipatory grief nor awareness of impending death can be assumed to exist merely based on the length of time the decedent was ill prior to the death or on the delivery of a fatal diagnosis by a physician" (1986). Siegel and Weinstein (1983) also speculated as to why there are such conflicting findings. They stated that there are factors associated with a serious illness such as "social isolation, physical exhaustion, emotional anguish, and depletion of emotional and financial resources" that may exacerbate post-death symptoms and be correlated with poor

bereavement outcomes. These factors can “overshadow” any benefits that may have been derived from a “period of anticipation”. Rando (1986) argues that it cannot be assumed that anticipatory grief has taken place simply because there was some warning of an impending death or a diagnosis of a terminal illness was given at time period sufficiently before a death occurs.

There are a number of misconceptions when it comes to anticipatory grief. Rando argues that one of the misconceptions is that anticipatory grief is just traditional grief which occurs earlier. She also states that it is a misconception to believe that there is a “set, fixed amount of grief” that a person must endure when there is a loss, and any grief that is endured prior to the death of a loved one will subsequently decrease the amount of grief that must be endured after the eventual loss. Rando postulates that if that theory was true, then grief following an unexpected death would be the same as an expected loss, but it would be assumed that it would last longer since none of the survivors’ grief was alleviated prior to the death. Two researchers, Parkes and Weiss (1983), demonstrated that grief following unanticipated death was different in form and duration from anticipated death. Parker and Weiss did not attribute the differences to a lessening of grief if a death is anticipated. They stated that when an individual endures an unexpected loss it “overwhelms the adaptive capacities of the person so intensely that normal functioning cannot be expected”. The experience is so overwhelming that they suffer feelings of “bewilderment, anxiety, self-reproach, and depression” and cannot function as they normally do. An unexpected death of a loved one leaves people unable to make sense of their world and leaves many people waiting for another

chaotic event to happen. The symptoms of grief last significantly longer than someone who endured the anticipated death of a loved one. In unanticipated loss the ability of a person to cope was also lessened. Parkes and Weiss (1983) feel that a period of anticipation is beneficial because it allows for “less of an assault on the mourner” because it gives an opportunity to emotionally prepare for the death. This allows the mourner to process the loss because they understand that the death is the eventual end of a process of a terminal illness. Once the death finally arrives, it is easier to make sense of the death of the loved one.

Rando believes that researchers who argue against the benefits of anticipatory grief are misunderstood in two ways. She suggests that researchers focus too heavily on the actual death of a loved one, rather than other losses that have occurred prior to the death of their loved one. She feels that “loss of previous functioning, health, abilities, body parts, loss of a future that had been planned, loss of hope and dreams, and expectations that had been invested in the relationship” should be focused on when talking about anticipatory grief. It was also felt, by Rando, that anticipatory grief does not necessarily mean a deatthexis from the sick family member, but it can stand for an emotional withdrawing from the hopes, dreams, and expectations that will not happen due to the loved one’s death. Rando states that there are three time periods and types of losses that treatments can target: losses that have already occurred due to the illness, losses that are actively occurring (when family members pull away from the sick family member), and losses that have yet to occur (actual death, and loss of a future with their family members). Rando feels that if her framework for understanding anticipatory grief is followed, and interventions can

target the differing types of losses that are suffered by the surviving family, it will lead to much better post-death outcomes. It will allow survivors to be more emotionally invested in making the remaining time with their sick, loved one, more meaningful, and not detach prematurely from the dying loved one.

According to Rando (1984) there are three classes of variables that influence anticipatory grief: psychological factors, social factors, and physiological factors. Rando states that psychological factors can be divided into three categories as well: there are those characteristics that pertain to the nature and meaning of the person and relationship to be lost, there are characteristics that represent the personal characteristics of the griever, and also those characteristics that pertain to the illness and type of death with which the survivors must contend with.

The social factors “encourage or discourage” anticipatory grief, “help define the psychosocial context in which it takes place”, and “serve to create some of the secondary losses that will be sustained” (1984). The social factors that influence the survivor’s anticipatory grief can also be divided into three categories: the first category deals with characteristics of the patient’s knowledge and subsequent response to the illness and death (subjective experience of the illness), the second category deals with the characteristics of the family and the members’ responses to the illness and subsequent death (the social make up of the family), and the last category that shapes a person’s anticipatory grief experience are general socioeconomic and environmental factors (quality and quantity of a support system and socioeconomic backgrounds).

Physiological factors are the third type of variable that influences an individual's anticipatory grief experience. These factors include: the griever's physical health, the amount of energy that is expended during the grieving process, the amount of sleep, rest, and ability to engage in other activities during the illness, the survivor's use of drugs, alcohol, and food during the illness, and finally the survivor's nutrition during the period of anticipatory grief.

As stated earlier, there appears to be an optimal length of time for a terminal illness, when it comes to more successful post-death functioning. Illnesses that were sudden or lasted a short amount of time, as well as illnesses that were long-lasting, were associated with poorer outcomes for the survivors. In a 1983 study by Rando, she found that parents whose child had died from an illness that was less than six months in duration, or more than 18 months in duration, left survivors least prepared for the death of their child. Rando found that when the illness was too long, the stress and intense emotional feelings associated with the illness, "appeared to exacerbate disturbed reactions following the death, increased the intensity of feelings of anger and hostility, and acted to militate against adequate preparation when death finally came following such a long course" (1983). She also found that when an illness lasted more than 18 months parents were sometimes left with false hope, because the illness waxed and waned so often (with multiple remissions and relapses) that the parent always felt that their child's final relapse was temporary. This long, emotionally taxing experience depleted the parent's ability to cope after their child finally passed away, and made adjusting to their new reality next to impossible. In her study, Rando found two associations to be of statistical significance. Anticipatory

grief was found to be positively correlated with preparedness at death, with participation of the parents increasing directly as the level of anticipatory grief was increased. She also found a correlation between anticipatory grief and subsequent "abnormal" post-death grief. It was determined that parents who had experienced more anticipatory grief, demonstrated significantly less abnormal grief after their child had passed away. As there was an optimal level when it came to length of illness and subsequent post-death outcomes, Rando (1983) also found that there was an optimal level of anticipatory grief. This optimal level was related to greater parental participation during their child's hospitalization and levels of anger and hostility. She found that parents who reported high and low amounts of anticipatory grief behaviors were found to have "engaged in fewer participation behaviors during the illness", with the largest number of "low participants" found among the group that was also low in anticipatory grief. The group that demonstrated the medium amount of anticipatory grief behaviors were found to be the most stable and engaged in the most appropriate levels of participation with their child. Parents who had the poorest post-death outcomes tended to be those that demonstrated the least amount of anticipatory grief behaviors prior to the death. Rando found that as the amount of anticipatory grief behaviors increased, so did the overall percentage of parents with better post-death outcomes.

Rosenblatt (1983) attempted to explain why there was the phenomenon that too much anticipatory grief was associated with poorer coping during the illness and after the death of a loved one. It was hypothesized that too much anticipatory grief can result in a premature detachment from the loved one who is dying. This can

"compromise the griever's participation during the patient's hospitalizations, preparation at the time of death, and subsequent adjustment following death".

Rosenblatt felt that anticipation of a death can cause greater post-death grief if it increases the survivors' involvement in the care of the dying person and this increased care makes the loss hurt more, or leaves the survivor with more memories and emotional involvement to "disengage from after the loss". Rosenblatt also found that when the sick loved one lived in the house of the survivor, this had an effect on anticipatory grief. He found that home care for the dying person made anticipatory grief more difficult, because it subsequently increased the survivors' involvement in the day-to-day care of the dying individual.

When a parent or child is diagnosed with cancer, the entire family is profoundly affected. Family routines are altered, and there is increased attention and focus on the individual diagnosed with cancer and their treatment. This experience can have a negative impact on the healthy sibling, and leave them at risk for a multitude of problems such as increased depression, anxiety, behavioral difficulties in school, decreased grades, and symptoms of post-traumatic stress disorder. Initiating social support has been shown to be an effective way of mediating some of the negative experiences of the cancer experience for the healthy sibling. Based on social learning theory, there are two main components that help to explain why social support is beneficial for healthy siblings. Self-efficacy is thought to influence what individuals choose to do, how much effort they will use in completing tasks, and how long they will persevere when completing an activity when they face real or perceived obstacles to success related to their efforts. The second component is

outcome expectancies. They refer to an individual's beliefs concerning the extent to which one's behavior will produce favorable or unfavorable outcomes. Using the concepts of social support and social learning theory as a foundation, it is believed that including siblings in the development of a social support program, and tailoring a program to their specific needs, will more effectively meet the needs of the healthy adolescents, and will result in a more successful program.

CHAPTER III

MATERIALS AND METHODS

Introduction

This chapter provides a brief outline of the materials and methods utilized for this study. I will be working with the American Cancer Society, which is a nationwide, community-based voluntary health organization, whose local office is located in Toms River, NJ, and specializes in providing support and resources to families affected by cancer. The American Cancer Society has been in existence for almost 65 years, and has provided billions of dollars for cancer research, millions of dollars for financial support to families dealing with a diagnosis of cancer, and also works with lawmakers to ensure that people have access to and coverage for lifesaving cancer screenings and treatments. Another important service of the organization is that it has developed and provided social support groups for children of various age groups. After speaking with the coordinator for the Toms River, NJ office of the organization, a need was identified for a support group that targets their adolescent population. The conversation with the coordinator spurred an idea that intensively interviewing adolescents and families who are currently dealing with a family member with a diagnosis of cancer, and determining their needs and worries would allow for the creation of a support group that is more successful than past groups. The hypothesis that will be the driving force behind this dissertation is that if

group participants have a voice in the group's development and the topics that are discussed, it will allow for a more successful group experience. Participants in the group will "buy in" to the group process and take ownership and ensure that the group is more successful, because their input was taken at the groups' inception. There are four sections: 1) Qualitative Interview Process; 2) Development of the Interview Questionnaire; 3) Participants in the Study; 4) Analysis of the Data.

Qualitative Interview Process

In order to ensure that there is a scholarly justification for the methods and procedures that will be used, I will conduct a qualitative interview with six families that have been referred to me by the coordinator of the organization. Grant McCracken (1988) described the "long interview" as an extremely important device to be used for qualitative research. A qualitative interview is considered beneficial because it shows how culture and experience can mediate human action. In other words, an in-depth qualitative interview will best assess the needs of an adolescent who is dealing with a relative diagnosed with cancer. It will allow for the development of a social support group that best meets the needs of a specific population. The qualitative interview is also beneficial because respondents typically lead lives that have time constraints and require them to divide up their time among differing social roles. This is even more apparent in the case where a respondent has a family member battling a deadly illness, because they now have a host of stressors and time constraints to deal with because of the illness and its treatment. According to McCracken (1988), respondents are generally willing to sit and complete a qualitative interview despite the fact that they have limited time and attention.

Qualitative interviews allow respondents to give a tremendous amount of information in a time-limited session. The interview gives access to individuals without violating their privacy or testing their patience and time constraints. The qualitative interview also allows the researcher to capture data needed for extensive, qualitative analysis without the laborious task of engaging in participant observation.

Qualitative research differs from quantitative research, in that quantitative researchers have a goal to isolate and define categories as precisely as possible prior to beginning a study, and then determine relationships between those limited sets of variables. With qualitative research, the goal is to isolate and define variables and categories during the process of conducting research. There is also a difference in the number of respondents that are required in qualitative and quantitative research.

Quantitative research requires researchers create a sample of necessary size and type to allow for greater power for the study, and generalization to the larger population.

In qualitative research, researchers do not want to know how many and what kinds of people share a certain characteristic. The purpose is to “gain access to the cultural categories and assumptions according to which one culture construes the world”

(McCracken, 1988). After the researcher is given access to an individual's cultural categories, the information can be used to develop a program that meets the needs of that population.

Development of the Interview Questionnaire

In order to develop the most effective social skills program for adolescents associated with the organization located in the New Jersey Shore area, I will follow McCracken's (1988) long interview format, which uses the four-step method of

inquiry. The first step of the process is a review of analytic categories. This step begins with an exhaustive review of the literature. It enables the researcher to define problems related to topic areas and assess data that is obtained through the qualitative interview. The second purpose of reviewing analytic categories is to help in the construction of the interview questionnaire. It establishes the domains the interview will explore, and what the researcher should ask about and listen for during the interview.

The second step in the long interview process is a review of cultural categories. This is a step where the researcher begins to use the “self as an instrument of inquiry” (1988). The cultural review has three purposes. It helps to prepare for the creation of the interview questionnaire. The second purpose is to prepare for the evaluation that will occur during data analysis. The researcher will examine cultural categories and their interrelationship. The third purpose is to establish the distance between the researcher and the topic. If the researcher knows cultural categories it puts him/her in a better position to know what is typical about an individual’s responses, as opposed to the responses that are brought in through the researcher being familiar with a particular topic.

The third step is the discovery of cultural categories, or the actual formulation of the interview questionnaire. The first component of the questionnaire is a set of biographical questions. It allows for the researcher to “ascertain the simple descriptive details of an individual’s life” (McCracken, 1988). The questionnaire will next have a list of “grand tour” questions that are non-directive, and move people to talk, “without over-specifying the substance or perspective of the talk”. To keep

individuals talking, “floating prompts” should also be used. Floating prompts can be as simple as repeating the respondent's remarks “with a more interrogative tone” that will coax the respondents into speaking more about a certain topic. If a topic area needs to be exhausted further, “planned prompts” can be used. Planned prompts can be used when a researcher asks questions that contrast two topics. This will cause the respondent to speak in a more in-depth nature regarding a topic. Category questions can also be used, so that all aspects of a topic are exhausted based on the literature review that was conducted. The questionnaire can also use “auto-driving” questions, where the researcher can show a video or picture, or some stimulus, and ask what the respondent’s reaction to the stimuli is. At the end of the third step, the questionnaire will be completed. It will consist of biographical questions, followed by a series of question areas based on the literature review. Each question area will have a set of grand-tour questions, with floating prompts if necessary, and there will also be contrast, category, and auto-driving questions, to fully exhaust each topic areas.

Participants in the Study

After the development of the questionnaire, I will interview six families who have a loved one diagnosed with cancer, and also have an adolescent child who is healthy. The coordinator of the Toms River, NJ office of the American Cancer Society will send a recruitment letter out to families in her organization that fit the study criteria, and the first six families that send a consent letter back will be included in the study. The interviews will take place in the homes of the adolescents, and will last approximately one hour. I will follow McCracken’s framework and use open, informational questions, and remain non-threatening to allow the respondents to

remain at ease during the interview. The semi-structured interview will attempt to answer a number of questions, as they relate to the experience of the family dealing with a life-threatening illness. Some of the questions that will be asked will gauge the respondent's initial reactions to hearing that they had a loved one who was sick. Specifically, I want to know: a) How the respondents heard their loved one was diagnosed with cancer, b) What their thoughts and feeling were when they initially heard their loved one had cancer, and c) Under what circumstances were they told. I will also attempt to ask questions that assess what occurred after they were told of the illness. I want to know if the respondent shared the information with anyone else, friends, teachers, other adults? When assessing the needs of the respondents, and for future development of a program that targets their needs, it will also be important to know how the diagnosis affected the individual families, and how relationships in the family were altered because of the cancer experience. It is also important to know whether the parents of the adolescents were open with the respondents, and if there was give-and-take when new information was learned, because future research can be conducted to determine if adjustment is better in the families that had better and more open communication among its members.

Analysis of the Data

The fourth step in the interview process will be analyzing the information and data obtained in the qualitative interview process. Using McCracken's (1988) qualitative interview process, there is a specific strategy and process to follow when analyzing qualitative data. Following the strategy outlined by McCracken, I will tape-record every interview session, and following each interview session, will have

the conversations transcribed in written text. The main objective of the analysis of the qualitative interview is to determine the categories, relationships, and assumptions that create the interviewee's view of their experiences. There are five stages when qualitative data is analyzed, each represents "a higher level of generality". The first stage in this process treats each utterance in the interview in its own terms, "ignoring its relationship to other aspects of the text". This treatment of each useful utterance forms an observation. The second stage in the process takes each newly formed observation and develops them initially by themselves, and second, according to the evidence in the transcript, and third, according to the previous literature and cultural review. The third step in the process investigates the interrelationship of the second level observations, using the literature and cultural reviews as the basis. The fourth step in the process takes observations generated at earlier levels and subjects them "to collective scrutiny". The main objective of this analysis is to determine the themes and patterns, as they appear in the family interviews that make up this dissertation. The fifth and final stage takes the patterns and themes that emerged during the interviews and relates them back to the original hypotheses that were developed prior to the interviews. During the fifth stage the interviewer moves away from the "particulars" of the individual families and interviewees and combines what is said into conclusions based on the needs of those families. Combining what is said in the individual interviews will allow for a needs assessment of the adolescents who are enduring a stressful time in their lives.

Based on the formal interviews that are completed with each family, and the subsequent qualitative data that is obtained, a needs assessment for this specific

population will be created. The needs assessment can be used by future researchers to develop a specific social support group for this population, that will provide emotional support during an extremely difficult time in the lives of these families. The local office of the American Cancer Society in Toms River, New Jersey will be given the needs assessment that was created through the qualitative interviews, and should allow for development of a social support group that is more successful than the groups that have been created in the past. The adolescents who have participated in this study will be given the opportunity to participate in the social support group based on the needs assessment that was created. After the interviews and the needs assessment are conducted, I will hold a follow-up session with the adolescents and the families and explain the findings of the needs assessment. I will allow them to ask any questions related to the study and allow them to provide feedback that can be further used when creating a social support group. The adolescent population is one whose needs have not been met in the past and it is my hope that by taking their specific needs into account when creating a program, it will be more successful and can fill a void in their lives.

CHAPTER IV

RESULTS SECTION

Introduction

This chapter delineates the foundation for a support group for adolescents who have a relative with cancer. The goal of the analysis of the data was to operationalize the experience of having a loved one diagnosed with cancer and then determine the components of an effective support group. The broad presentation of the interview results serves to generate discussion and improve the understanding of what an adolescent experiences after a diagnosis is made. This chapter is divided into four themes that were derived from the discussions with the respondents. The themes will be presented as follows: 1. Participant Demographics; a basic overview of the participants and the loved one who has been diagnosed with cancer; 2. A Summary of the Thematic Analysis of the Interviews; 3. Stories of the Adolescents: five narratives of the participants' experiences of living with a loved one diagnosed with cancer; and 4. Being the Researcher: a summary of the researcher's self-analysis.

Participant Demographics

Interviews were conducted with five adolescents who reported having a sibling or parent diagnosed with cancer. A sixth participant was scheduled to be interviewed on four different occasions, but declined to be interviewed for the study. This participant stated that it was "too hard" to discuss her cancer experience. All

participants who were interviewed signed assent, and their parents signed consent forms, prior to the interviews and all interviews were tape recorded and subsequently transcribed into written text.

Table 1

Demographics of Participants

Participant	Name	Age	Sex	Race	Number of Siblings	Grade	Type of Cancer	Family Member Diagnosed with Cancer
A	Alex	16	M	Caucasian	0	11	Breast	Mother
B	Steve	15	M	Caucasian	1	12	Brain	Brother
C	Paul	13	M	Caucasian	1	9	Brain	Mother
D	Angela	14	F	Caucasian	1	10	Brain	Mother
E	Alicia	17	F	Caucasian	0	12	Prostate	Father

The average age of the participants at the time of this study was 16.1 years of age. Their age range was age 14 to 17. There were three male participants and two female participants in this study. All five of the participants identified themselves as Caucasian and of Eastern European descent. All participants identified themselves as Christian, four participants were Catholic, and one was Protestant. All participants attend a public high school in the Jersey Shore area, and all have plans to go to college when they graduate high school. All participants described their family as a “middle class” family, and have at least one family member employed in steady, full-time work. In this study, two participants were “only children”, and three participants had one sibling. Four of the participants had biological parents who were still married, while one participant currently lives with her biological father and has had no contact with her mother since she was two years old. There were varying types of

cancer that were discussed in the present study. One participant had a parent with breast cancer, one participant's parent had prostate cancer, and three participants had a loved one with cancer of the brain. All of the participants loved ones who have been diagnosed with cancer are still alive and their cancers are in remission.

Content Analysis

The purpose of this section is present a range of reported experiences along a spectrum of themes that arose from the interviews. This section summarizes primary themes that arose from the content analysis of the semi-structured interview. Four themes were identified as important by the interviewees: 1) Communication Between Family Members; 2) A Need for Information About Cancer; 3) An Increase in Familial Responsibilities; and 4) A Need for Strong Peer Relationships.

Communication Between Family Members

All five participants described themselves as having reservations about discussing the cancer experience with their loved ones. The recurring reason for the adolescents not speaking with their parents or siblings about the cancer was that they did not want to upset them more, knowing that they were already under a great deal of stress. All participants worried about increasing the stress level of their loved one who had cancer if they brought up the fact that they were nervous about the uncertainty of the prognosis, and the course of treatment.

Participant A stated that he was “numb for days” after being told of his mother's cancer and he “didn't know what to say to her”. He said that he “didn't want to bother her” with repeated questions regarding her treatment and her physical well-being, so he “just said nothing”. This participant stated that his initial reaction

was not the most beneficial for himself or his mother, and it was not until his father sat down with him and discussed the importance of communication between the family members, that he spoke with his mother and began to open up about how he was feeling.

Participant B, who had a brother diagnosed with brain cancer, stated that he did not discuss how difficult it was to see his brother sick with his parents because “I didn’t want them to look at me like I was crazy since I was healthy”. He continued, “I figured they would tell me that my problems were nothing because I wasn’t the one who could die”. This participant also stated that he regrets not speaking more with his family because he “always felt on edge” and was “holding a lot in”. He stated he was never that way prior to his brother being sick and he believed it would be beneficial to participate in a group with adolescents who have a relative diagnosed with cancer, because they “would all know what I was dealing with”.

Participant C who had a grandmother and mother diagnosed with cancer stated that he initially did not talk to anyone, not even his biological sister; however, after they both broke down emotionally at the same time, their communication increased. The participant's sister stated that she initially spoke to a therapist, and was told that she should let her family know how she was feeling; however, she still worried that this would upset her immediate family so she “kept quiet”. The participant stated that this “may have been a mistake” and she now believes that if she had opened up with her family or friends, she “wouldn’t have been so emotional”.

Participant E, who currently lives with her father who was diagnosed with prostate cancer, had an extremely difficult time coping with her father’s illness. She

stated that she has no contact with her biological mother, and she and her father do everything together. This participant stated that she had no one at home to speak with, because she did not want to upset her father by speaking to him, so she “held it all in”. She reported that this lack of communication left her “alone and by herself constantly worrying”. She felt that if she had opened up to her father or someone else, she “could have slept much better, instead I was up nonstop wondering if my dad was going to die”.

All participants spoke of a positive outcome from the cancer experience. All participants reported that their families had become much closer post-treatment. One participant stated that his family is “more like a real family”, meaning that they are now more open and honest with each other, and better able to share their feelings. A recurring theme was that all family members had “beaten something” together, and if they can beat cancer they can withstand anything else.

All participants spoke about the need for a group where adolescents could share their experiences with other children who were also experiencing the illness of a loved one. Four of the participants stated that they would have had an easier time emotionally and psychologically if they had spoken with an adult or peer, soon after finding out their loved one had cancer. One participant stated that his schoolwork suffered as a result of his brother’s cancer. He stated that he “was lucky to get D’s” on his report card, because he was “a mess inside” and had “no one to talk to about it”.

A Need for Information About Cancer

All of the participants stated that they only had a vague understanding of what cancer was prior to their loved one being sick. One participant said “all I knew about cancer was it was bad and you were gonna die”. Another participant said, “I never knew how many kinds of cancer there actually are, and how many people have cancer”. All participants stated that they felt uncomfortable asking their loved ones what cancer was and the possible prognoses, the possible treatment options, and the possible side effects associated with the cancer treatment.

Understanding What Cancer Is and Possible Prognoses

Participants stated that they wanted more information about cancer and how it is treated, and they felt that they could not easily obtain this information. Participant A stated that he felt that asking his mother about her type of cancer and what was happening inside her “was really scary, because I didn’t want her to start crying”. He stated that the unknown regarding cancer made things worse. He stated that it was not until his father sat down to speak with him, that he understood what it “meant to have cancer, which was not as scary as I thought”.

Participant E whose father was diagnosed with prostate cancer, stated she “did not feel comfortable asking my dad anything because he was having a hard time already”. She felt the best way for her to help her father was to complete the necessary chores at home and continue doing well in school, because then “my dad can’t get mad at me for anything”. She stated “it was really hard sometimes in school because I would only be thinking of my dad” and she stated, “it sucked because I had no idea what prostate cancer actually meant, I just knew he could die”.

She also stated she wished she knew enough at that time to do research herself, and that if she had someone to talk to, she would have felt better. She stated she did not know until she went with her father to his radiation treatments that prostate cancer is common in males, and for the most part treatable. The participant stated that her father began to open up and explain things when they would drive to New York for his treatments, but she stated “it didn’t happen for almost a year, so I always thought the worst”.

Participants C and D stated that since their family members were not openly sharing information, it must have meant that the prognosis was dire. Participant C stated that “if things were going to be fine I figured my mother would have just told me that, but I heard nothing and I thought that meant my mom knew she was going to die but she just didn’t tell me”. Lack of info left them to conjecture and possibly imagine the worst.

Knowledge About Treatment Options

Only Participant B received information about the treatment options associated with his loved one's cancer. This participant stated that he was glad he went with his family to the hospital when his brother was undergoing tests to determine why he lost consciousness. He states that the doctors “explained things so we could understand what they were talking about”. Participant B spoke about how he was happy he was there “to hear things for myself”. The four other participants were not informed about their family member's treatment plans. Participant A stated that he did not inquire about his mother’s treatment plan because he was scared, and he feels that his parents were scared to talk to him as well, fearing his emotional

reaction. He stated that he “became numb” and wondered what his mother was going through, and when she would get better, and just hoped that the doctors “would cure her”. Participant E stated that her father informed her of his treatment options, however, she did not comprehend what he was saying, and did not ask further questions out of fear of upsetting him. She states that she did research on her own using the internet, however, “there was a lot of information” and she stated she “could not totally understand it”.

All participants spoke about the importance of being given information which would allow them to process the experience of having a family member diagnosed with cancer. Participant B, who was more involved in the pre-treatment process, was provided with more information, which allowed the process to be normalized for him. The other participants spoke about the difficulty of coping with their loved one being sick, and not being told exactly what was happening to them.

Side Effects of Treatment

One of the most difficult aspects of the cancer experience for the participants was reported to be seeing their loved ones enduring the side effects of the cancer treatment. One hundred percent of the participants stated that their loved ones lost their hair, lost weight, or had a physical appearance change due to the treatments. Participant C spoke of his mother losing her hair and how scary this was for him. He stated that, “I did not know she would lose hair, it freaked me out and I am sure my mom knew it did”. He stated that he “wish someone told me it would happen”. Providing information regarding cancer, its treatment, and its physical effects on the patient would have been beneficial. The participant felt that he would have known

what to expect when his mother had chemotherapy and it would not have been a surprise when he saw his mother lose all of her hair.

Participant B relayed how difficult it was to see his brother become physically sick. He reported, “He would throw up all the time, to the point where nothing would come out”. He stated, “it was so bad, I felt so bad for him, and I didn’t know why he kept doing that”. The participant’s reactions contained an affective component, when he voiced that he became emotionally upset watching his brother endure the side effects of treatment. He reports feeling helpless watching his brother become physically ill. Although this participant was informed of his brother’s treatment plan, he was not informed of the possible side effects associated with the treatment which did not allow for normalization of the vomiting, and left him feeling very helplessness.

Only one participant went to speak with a mental health specialist, and she described this experience as “no help because I wouldn’t talk to her”. This participant stated that a group that includes other peers would “probably be better than just one adult and one kid”. She felt that adolescents would feel more comfortable opening up to other adolescents rather than an adult, especially when the adolescents are “all dealing with the same things”. A social support group would serve to provide the healthy adolescents with age appropriate information regarding what cancer is and the possible prognoses, the different treatment options for cancer, and also the side effects that are associated with cancer treatment.

A Need For Strong Peer Relationships

All participants spoke about their reluctance to tell their peers about their loved one's diagnosis and their thoughts and fears regarding the treatment and prognosis associated with the cancer. Participants were worried about the reactions of their friends and family if they asked questions and worried how their reactions would be received by others. Participants also stated that after their family member was diagnosed, it altered their peer relationships, and having others who are dealing with the same emotions would be helpful.

Participant A stated that he was “afraid my friends would call me a baby if I started to get upset or cry”. He went on to say that he “kept everything to myself to the point where I would almost explode”. This participant stated that he instead chose to focus on playing baseball and doing the best he could on the field. He stated, “I didn’t even say anything to my team because I just wanted to play and forget it”. He said that he also “didn’t want anyone to make excuses if I struck out”. He felt that it was more advantageous to avoid conversations about his mother so he could “be normal”.

Participant B stated that he recognized his grades were slipping because he was focusing on his brother’s illness, however, he did not feel comfortable speaking with his friends or adults about it, because they “had no clue what I was going through”. This participant felt it was beneficial to participate in a group where everyone was sharing similar experiences, because people would be more open to talking when they know others understand them.

Participant E stated that her peer relationships changed as a result of her reluctance to speak to her peers. She stated that she “never went out with my friends

and wanted to be close to my dad”. She stated that if she did go out to the movies or the mall, she would worry about “something bad happening and I wouldn’t be there”. She clearly described how the reluctance to let her friends know how she was feeling, affected her friendships. She stated that her friends stopped asking her to do things with them, and would “just say hi and that is it”. At the time, the participant said, “I really didn’t care”, but reflecting back on the experience, she said it would have been beneficial for her friends to know, because she was positive they would have come to her house and she “wouldn’t have felt so alone”. She said that she has no contact with her mother, and she is an only child, so “it is just me and that got rough”.

All participants commented that it would have benefitted them to be involved in a group that allowed them to meet other peers who had a family member with cancer. It would have normalized the experience, and given them an outlet to talk about what they were feeling and what helps other teens who are faced with the same situation. Participant A commented, “it probably would have been weird at first, because I don’t normally talk to people like that, but everyone else would feel the same way”. Participants C and D, felt that a group that included other same-age peers would be preferable when compared to one-to-one therapy with a mental health professional. Participant D commented, “I hated going to talk to someone older about how I was doing, because she had no clue about me or kids these days”, while another participant stated, “it is easier to talk with other kids, because each one will know what the other is talking about”. None of the participants interviewed were aware of any peer support groups in their local neighborhoods that targeted adolescents who have a relative with cancer, nor did they know how to locate such a group.

Participant A stated that a group targeting adolescents should be held right after school, because “it could be promoted in the school and it is easy for kids to go if it starts when school ends”. Participant E stated, “a school group would be good because most kids feel comfortable in school, and it wouldn’t be as weird going to somewhere new”.

An Increase in Familial Responsibilities

Four of the five participants reported an increase in their familial responsibilities as a result of their loved one’s diagnosis. All participants reported that they did not mind the increase in familial responsibility, because they felt it was a way to show they were helping their loved one, but it was also stressful. The increase in responsibility revolved around an increase in the chores they were expected to complete, or the caring of a younger sibling who lives in the house.

Two participants reported that they engaged in more household chores as a way of avoiding talking to their parents about cancer. Participant A stated, “I knew I was helping my mom out when she was sick, so I could do that and make her feel better, since I knew she probably didn’t want to talk about cancer”, while Participant E stated “if I was busy I didn’t have to sit and think”. Sixty percent of the participants spoke about the guilt they felt when they would question internally why they “got stuck” doing extra chores around their house. Participant B spoke how “unfair” it seemed, but also said that he had “no one to complain to”. They feared upsetting their parent(s) if they complained about having so much to do.

Another participant who lives with her father, stated that she “had no life”. She said she did not want a life when her father was diagnosed with prostate cancer,

but she “was so stressed” ensuring that the house was clean and “tried to make sure my dad didn’t have to do anything when he got home”. Much like one of the other participants, she wondered if there were other peers who were going through the same experiences, and felt as much stress as she did.

Participants also spoke about the increased responsibilities when it came to helping to care for their siblings. Participants B and D stated that they did not mind helping their other sibling in the house, but states it was stressful. Participant D, whose mother was diagnosed with brain cancer, stated that her mom “was too tired to take care of my brother”, and states she took on “the role of a mom to my brother”. She states that she could not say anything to her mom about how stressful this was, because she did not want to upset her, but she knows that her schoolwork suffered and she “never did anything” that she wanted to. She states that she often wondered how other people dealt with the same responsibilities. Participant B stated that he “got stuck” taking care of his brother after he was diagnosed with cancer. He stated that he “really didn’t mind at first”, however, he “was never allowed to do anything fun” with his friends. The participant stated “I hated myself when I thought that”, because he kept hearing that he “should be happy” he was healthy, and would “resent” that his brother was sick and “getting all the attention”. He felt that if his brother was the healthy one, and he were sick instead, he “wouldn’t have to do anything”.

‘Stories’ of the Adolescents

Introduction

This section includes a narrative of the five interviews that were conducted for this study. All adolescents interviewed were included in this section. The purpose of these case stories is to highlight the individual experiences of adolescents who have had a relative or sibling with cancer, by presenting some of their thoughts, feelings, and behaviors. These stories have been compiled from the transcribed interviews. Identifying information has been removed to protect each participant's privacy. Pseudonyms have replaced the participant's real names. Each case summary is comprised of the following: 1) a basic demographic description of each adolescent; 2) a description of the relative who had/has cancer; 3) and a summary of the cancer experience for each adolescent.

“Alex”

Demographics

Alex is a 16-year old, Caucasian male who was 15-years old when his mother was diagnosed with cancer. Alex is an only child, and currently lives with his biological parents, who have been married for seventeen years. Alex states that his family is of Italian and Irish descent. Alex's father currently works as a nurse in a local hospital, and his mother worked as a teacher's aide prior to her diagnosis. Alex is currently a junior in a Jersey Shore high school and he states that he receives “good” grades by which he meant A's and B's. Alex described his family as Catholic, but states that his family only goes to church on holidays such as Christmas and Easter.

Description of Relative

Alex stated that his mother was diagnosed with cancer almost a year and a half ago. He states that she went for a routine mammogram and they saw a “spot that worried the doctor”. After a biopsy it was determined that she had cancer which was “found in the earliest stages”. Alex reported that his mother did not tell him about the cancer right away, but he was told “a few weeks later”. Alex stated that he and his mother were driving to the food store when she said “I have something to tell you”, and she proceeded to tell him that she had breast cancer. Alex stated that he felt like he was “hit by a train”, because he “did not know what to say”, and had “no clue anything was wrong”. He said that he was quiet initially and he started to cry when he saw his mother begin to cry. Alex said that they remained in the car “for what seemed like an hour even though it was probably only ten minutes”. He was told that they found the tumor early and the doctor’s felt she would “be fine”. Alex stated that after he was told about the cancer, they sat in the car for a while, and he did not know what to say next, so he got out of the car and told his mother he wanted to go food shopping. Alex said that his mother got out of the car and they went inside and “did not say too much, just shopped”. When they returned home, he told his mother that he knew she was going to be OK, and told her that the doctor will be right. Alex said that his mother did not ask if he had any questions regarding the cancer, the potential course of treatment, or how their lives were going to change as a result of the diagnosis.

Personal Experience

Coping responses. Alex described himself as “numb for days” after he was told. He said that he was quiet in school, which was not unusual for him, because he

described himself as generally shy unless people get to know him. He stated that he did not speak with anyone about his mother's diagnosis, including school personnel, friends, or other family members. He said his mother told him about her cancer during his baseball season, so he just focused on baseball and schoolwork.

Changes at home: Alex said he was given more responsibility at home due to his mother's diagnosis. He was asked to complete more household chores because his mother was often too tired to do the laundry, clean the bathrooms, or unload the dishwasher. Alex said he did not mind doing these tasks because he knew he was helping his mother, and his father could not do more because he needed to work so the family could pay their bills.

Family changes: Alex's family was initially more distant and had less communication among the family members, and Alex stated that he did not know what to say to his mother when he saw her. He was afraid of saying something that upset her and often "said nothing". Alex said that this changed midway through his mother's treatment, because his father spoke with him after one of his baseball games, and let him know that his mother would appreciate it if Alex would ask her how she was doing, and ask if she needed help with anything. Alex described himself as "scared" the first time he began to speak with his mother more openly, but he said things were "better because I did".

Treatment and Current Status

Alex said that once school ended for that year, he went with his mother to her last four treatments, and he described how much his mother appreciated that he spent that time with her. Alex said that his mother's cancer is now in remission and he

describes his family as “much closer”. He said that the family members talk a lot more to each other, and he said that he appreciates everything that they get to do together.

“Steve”

Demographics

Steve is 17-year old, Caucasian male who was 15 when his younger brother was diagnosed with cancer. Steve states that he lives with his mother, father, and 13 year old brother. He states his parents have been married for 20 years, and his family is of Greek and Polish descent. Steve stated that his father works as a construction manager, while his mother has always stayed home and cared for himself and his brother. Steve is a senior at a high school in Ocean County, NJ and he states that he receives “A’s, B’s, and a few C’s”. Steve states that his family is Greek Orthodox, however, they only attend church on major holidays.

Description of Relative

Steve stated that his brother was 11 years old when he was diagnosed with cancer. He states that he and his brother are “very” close and “do everything together”. He said that his younger brother looks up to him, and “used to follow me everywhere”. Steve said that he didn’t know much about cancer, until two years ago. He said that he and his brother would spend the majority of their days outside after getting home from school, playing soccer, baseball, and riding their bikes. His brother, “Jim”, knew how to ride a bike, but would constantly fall off his bike and he didn’t know why. In school, his brother would often complain of headaches and become easily fatigued. Steve’s parents took his brother to the pediatrician and, at first, they just

monitored his headaches. Steve said that “about three months later”, Jim lost consciousness while they were playing soccer on their driveway. Steve passed the ball to his brother and he saw him fall to the ground. Steve ran inside to get his mother, and Jim was taken to a local hospital. At the hospital, Jim underwent numerous tests, which included a CT scan, and the doctors saw a “spot” on the scan which was ultimately diagnosed as a tumor on his brain. Steve's family went to Children’s Hospital in Philadelphia for treatment, and doctors there diagnosed the tumor as a “Pineal tumor”, which was subsequently treated with surgery, chemotherapy, and radiation. Steve went to Philadelphia with his brother “a lot”, and he knows that his brother felt better when he was there. He said that his family was “completely turned around” when his brother “was sick”. Steve said that his mother transported Jim to his treatments, “a lot more” than his father, because his father needed to work. Steve's father currently works as a manager at a local construction company, and states that his mother is a “stay-at-home mom”.

Personal Experiences

Steve was a sophomore in high school when his brother was diagnosed with brain cancer. He states that “school wasn’t important” because he wanted to make sure his brother was going to get better. He “rarely” did homework and states that he would sit in school and think about how his brother and mother were doing and he “didn’t give a crap” about what his teachers were saying. Steve grades were “very good” prior to his brother being diagnosed but he “was lucky to get D’s” after the diagnosis. Steve said that he found out his brother had cancer the same time as his parents, because he went to the initial appointment at Children’s Hospital in

Philadelphia. He said that he was glad he was there, and that the doctor's at that facility were "awesome" and "explained things so we could understand what they were talking about". Steve was aware of the treatment recommendations and was glad that he was there "to hear things for myself".

Coping Responses: Steve said that he did not speak to anyone about his brother's cancer. He avoided speaking with his friends and avoided talking to teachers. He said that he "did not give a damn what they would say", because they "had no clue what I was going through". Steve regrets not opening up to people at school, or his friends, because he reports "holding a lot in" and "it wasn't good". Steve described himself as "always on edge" and he reports that he would "blow up" when something small happened. He was never that way prior to his brother being sick, but the cancer "really messed me up". Steve stated that he feels his reactions were typical of other peers his age, because he does not feel anyone would want to speak about something like that.

Treatment and Current Status

Steve states that his brother's cancer was treated with surgery, chemotherapy, and radiation. He states that his brother's cancer is now in remission and he "seems ok". He states that the experience brought his brother and he, "even closer". Steve reports that his family "is also much closer". He reports that his brother has returned to school and "gets good grades". Steve did report that he "sometimes wonders" if his brother's cancer is going to come back. He states that anytime his brother has a cold or virus, he "hopes" his cancer has not come back.

Recommendations for Adolescent Support Group

Steve said he believes it would have been beneficial to participate in a group with other adolescents who have a relative with cancer, because they “would know what I was dealing with”. He also stated that if he had an outlet to talk about things, he probably would have done better in school, because he “wouldn’t have shut everything and everyone out”.

“Paul”

Demographics

Paul is a 14-year old, Caucasian male who was 13-years old when his mother was diagnosed with a brain tumor in her parietal lobe. Paul has a 15-year old biological sister, Angela, who also lives with him. Paul is currently a freshman in a high school in Ocean County, NJ. Paul reports that he is a “great” student who receives “all A’s and B’s”. Paul states that his family is of German and Italian descent and describes them as a middle class. Paul states that his family is Catholic and reports that they “try” to go to church every week.

Description of Relative

Paul states that his mother was having chronic migraine headaches and her primary care physician eventually referred her for an MRI to determine their cause. Paul’s mother attributed her headaches to “stress” because another relative in their family had been diagnosed with cancer the previous year. Paul’s maternal grandmother is a long-time smoker and states that she has been diagnosed with terminal and inoperable lung cancer, because the tumor is located in close proximity to her heart. Paul’s mother had been dealing with his grandmother and her cancer, and that is when the frequent headaches started. Paul reported that the headaches

became so debilitating that she could not get out of bed on certain days without a tremendous amount of pain. Paul stated that his mother was becoming forgetful as well, and would ask the same questions again and again. Paul said that this did not concern him initially, because he could see “how much she was dealing with” and figured her mind was focused on helping his grandmother by taking her to doctor’s appointments. Paul’s mother eventually went to her primary care physician to find a medical reason for the headaches. The doctor prescribed medicine to alleviate the migraines, and for a few weeks it seemed to work, however after a few weeks, the headaches returned and his mother made another appointment to see her doctor, “because she felt like shit”. The doctor referred her for an MRI and a tumor was found on her parietal lobe. Paul stated that he did not know of his mother’s diagnosis for almost a month after his mother initially found out, because his mother did not want to worry him, especially because he was dealing with his grandmother being sick as well. About a month after his mother received her cancer diagnosis, his mother, father, and grandmother, “called a family meeting” where Paul, and his sister “Angela”, were told that their mother had cancer.

Personal Experiences

Paul’s initial reaction, and his sister’s initial reaction was to say “no way this can’t be”, “not two family members at the same time”. They did not understand how their grandmother and now their mother could be diagnosed with cancer. Paul said he asked his mother and father if both his mother and grandmother were now going to die. Paul recalled that he started to cry when he asked that question and his mother came over and gave him a hug and said she was going to fight the cancer and that she

was “not going anywhere”. Paul said that when he started crying his sister came over and gave him a hug and also started to cry. He kept thinking that he was too young to have his mother die, and how unfair it is that he has to deal with this. Paul and his sister, who is one year older than him, were never “really that close”, because they both “had our own friends and stuff we like to do”, however, it made him feel much better when his sister told him that everything was going to be OK.

Coping Responses

Paul said that his day-to-day life did not change all that much due to his mother’s diagnosis. He said that he feels his sister’s life changed more, because she “became more of a mom”. Paul was not given extra responsibilities at home and stated he was told to just keep doing well in school. He said that he is a “really good student” and he gets all A’s and B’s on his report card. Paul continued to do well through his mother’s treatment, because he promised her that he would “not slack off”.

Treatment and Current Status

Paul states that his mother’s cancer is now in remission, and their family is much closer. He said that his grandmother’s cancer is, unfortunately, still progressing, and the doctor has given her a year or two to live. He said that his family “always has family dinners” and states that they set time every week to “just be together”. Paul said he appreciates his sister much more as a result of this experience, and states that he is “lucky to have her”.

Recommendations for Adolescent Support Group

Paul stated that he did not participate in any social support groups when his mother was going through cancer treatment. He states at the time his mother was sick he would have thought it was “weird to just talk to people”, but he knows “it can help”. He states that he “had questions I did not want to ask” and he is sure peers would “wonder the same things”.

“Angela”

Demographics

Angela is a 15-year old, Caucasian female, who was 14-years old when her mother was diagnosed with cancer of her parietal lobe. Angela is the biological sister of Paul, who was also interviewed for this study. Angela’s appointment was initially set up for a Monday after her school day was completed. Angela drove to the office with her mother for the interview, however, she refused to get out of the car, and told her mother to tell the interviewer that she “did not feel like talking anymore”. The interviewer assured the mother that participation was completely voluntary, and if she did not feel like being interviewed it would be fine. Later that night, Angela had her mother email the interviewer and apologized for not speaking with him earlier in the day. She also indicated that she was going to “think about things for a few days” and then “decide if I want to talk”. A few days passed and the interviewer was contacted via email to set up another interview with Angela the following Monday. Angela was again transported to the interview after school and spoke at length regarding the experience of having a mother and grandmother diagnosed with cancer. Angela is currently a sophomore in high school in Ocean County, NJ. She states that she is “smart and gets good grades”.

Description of Relative

Angela talked about how difficult it was to hear that her grandmother was “so sick” and that there was “really nothing that can be done to help her”. She said that when she first noticed her mother experiencing migraines, she “got really scared” because she “knew something was not right”. Like her brother, she attributed the headaches to a stress reaction from dealing with her grandmother. Angela said that she “was sick to my stomach because I knew it was bad”, when she was asked to go to a family meeting. When she was told that her mother had brain cancer, she started to cry, but tried not showing how upset she was, because she did not want her mother to cry too. She “lost it” when she saw her “tough brother crying”. She said that the only thing she could think of doing was to walk over and give her brother a hug.

Personal Experience

Angela said that her life “became more stressful” when her mom was diagnosed. Her father “worked a ton” and she feels that this may have been due to the fact that he could not handle her mother being sick. Angela feels that it was difficult for him to see his wife going through her treatments, and if he continued to work he would feel he was contributing help, because the bills were being paid. Angela states that she took on the “role of a mom to my brother”. She said that there were many days that her mother was either too fatigued, or too physically sick to care for the house and cook meals, so Angela did. This experience has brought her “much closer” with her brother, because they “went through it together”. She states that she is a stronger person as a result of the experience, and she is “relieved” that her mother’s cancer is in remission.

Coping Responses

Angela apologized for not wanting to speak the previous week. She said that she felt it was going to be difficult to talk, because thinking about her mother sick makes her cry. She stated that she had gone to speak with a therapist when her mother was initially diagnosed, however, she only went two or three times, because she “played it off like I was fine, so no one thought anything was wrong”. She stated that she felt this “may have been a mistake” because she “held a lot in”. Angela then stated that she hopes her experiences can help someone else in the future, because she knows how difficult it is to go to school everyday thinking about her mom.

Treatment and Current Status

Angela stated that her family’s experience has made them “more like a real family”. She said that her family talks to each other now, and states they “don’t let the stupid things bother us”. Angela states that her mother’s cancer is now in remission, however, her grandmother’s cancer is still progressing and the doctor has given her a year or two to live. Like Paul, she states that her family does “everything we can together.”

Recommendations for adolescent support group

Angela stated that if she had other peers to speak with who had been through similar experiences, she “wouldn’t have been so emotional”. She states she had no one to talk to and spent a significant amount of time caring for her brother at the expense of her own needs, and it was reported that she was “exhausted” from this. Angela stated that she hopes her experiences can help someone else in the future

because she knows how difficult it is to go to school everyday thinking about a loved one with cancer.

“Alicia”

Demographics

Alicia is a 17-year old, whose father was recently diagnosed with prostate cancer, and is currently going through radiation treatments. Alicia, her father, her paternal aunt, and two younger cousins, were present at the American Cancer Society, Relay for Life kickoff celebration, and heard this research study described by the coordinator and was interested in helping other adolescents who have a family member with cancer. She said that she hasn't “really talked to anyone since my dad got sick”, and states she is “dealing with a lot of garbage”. Alicia described herself as “daddy's little girl” which she said means she is “super super close” with him and that she “prays everyday that he gets better”. Alicia's mother left their family when she was about two years old, and it has been mainly her father and herself “for as long as I can remember”. She has no contact with her mother, and does not know where she is currently living. Her father works as a researcher in the pharmaceutical industry near Princeton, N.J. She has lived in the Jersey Shore area her entire life. Alicia stated that she has had to “grow up fast”, mainly because there was no one else to take care of the house because her father works everyday. She stated that a lot of the household chores have been her responsibility since she was old enough to do them. Her aunt used to come over and care for her after school, but when she was old enough to stay home by herself, she did laundry and a lot of the cleaning herself. She

said she does not mind the responsibility because it is just the way things have always been, so it is normal for her.

Description of Relative

Alicia found her father had cancer by mistake. She came home after school in September of 2010 and the phone was ringing. She answered and it was the urologist's office confirming her father's appointment for the next day. Alicia said that when her father got home from work, she asked him what a urologist did, and her father wanted to know why she was asking him. Alicia said her father "started to act weird" when responding to her questions, and she asked him to tell her what was going on. Her father then said that "it is probably nothing" but explained that his primary care doctor had referred him to the urologist based on symptoms he was experiencing. Alicia said that her paternal grandfather had died when she was 10, and she only knew that he had cancer, but not what type. She asked her father what type of cancer his father passed away from, and he told her it was prostate cancer. Alicia then asked her dad what kind of cancer they were testing him for, and he stated it was prostate cancer as well. Alicia said she could not sleep that night and was "up nonstop wondering if my dad was going to get cancer and die". Her fears were confirmed the following day when her father's biopsy results came back positive for prostate cancer. When her father returned home from the doctor she was sitting on their couch waiting for him, and when she saw his face, she started to cry. She could tell by the way he looked that he did not hear good news, and she said that her dad walked over to her and just gave her a hug. Alicia said she asked her father what he

had to do next. Her father said that he was going to have his prostate removed and then had to go for radiation.

Personal Experience

Alicia reported that her father is currently going through the final stages of his radiation, and he is “doing really well”. He goes for radiation treatments five days per week, which take about 30 minutes or so, and he goes early in the morning, so he can still go to work later in the day. Her father has had to continue working because it is just the two of them at home, and “he can’t not work”. She feels terrible, because he is “usually really tired” and he sleeps a lot.

Coping Responses

Alicia has not talked with him about how hard it is to see him so tired, and what it felt like to experience what she has, because she did not want to upset him. She has focused on continuing to do well in school, and taking care of household duties. She stated that she has not spoken with any mental health professionals, and has kept everything to herself. She stated that she often feels "stressed" because she feels like "no one knows what I am thinking."

Treatment and Current Status

Alicia stated that the experience has had some positives, because she has decided she wants to go to college next year and become a nurse who deals with oncology patients. She continues to do well in school, and that is because her father frequently stresses how important it is to get good grades and go to college. Alicia said that she is nervous about going away to college next year, because she wants to

stay in close proximity to her father “in case he needs me”. She said that she is going to go to a college in NJ, and is considering commuting rather than living on campus.

Being the Researcher

When I first decided on this topic for my dissertation research, I did so based on extremely personal reasons. My family is very small when compared with the majority of my friends and acquaintances. Unfortunately for me, all four of my grandparents passed away from cancer either before I was born, or when I was very young and I have no recollection of them at all. Growing up, I often wondered how different my experiences would have been if I had grandparents in my life, and I often felt there was a void when I saw the experiences that my friends were having with their grandparents.

Due to the high cancer rate in my family, I have always tried to remain involved in events that fund cancer research, most notably the Relay for Life event that is held annually. Taking part in events and showing support for families that have dealt with cancer was always a rewarding and memorable experience. I could not have imagined a few years later my family would be drastically changed by a diagnosis of cancer. During my last year of graduate coursework, my father went to see a urologist due to signs and symptoms he was experiencing that were worrisome to him. He received a yearly physical examination, however, he never underwent a PSA, or prostate-specific antigen assessment, to test for a possible diagnosis of prostate cancer. His PSA counts were highly elevated and it was recommended that he undergo a biopsy to test for cancer. His biopsy revealed that he did, in fact, have prostate cancer and would need to start immediate treatments. This was a shock to

myself and my siblings, and my initial thought was how long my father was going to live. It was extremely difficult to focus on my graduate work, as well as the duties related to my job, and I was in a constant state of worry. I tried to hyper-focus on other things, such as my work, but in my mind I was constantly thinking about the course of cancer treatment, whether or not it would be successful, and unfortunately, what would happen if my father passed away from prostate cancer. Unfortunately my work and graduate studies suffered as a result, as I tried to process what the diagnosis meant for my family. Luckily for my family, the cancer was caught in an early stage, and with radiation treatments, my father went into remission. He has been cancer free now for almost 4 years, and his PSA tests are still low when he has them completed.

Family has always been very important to me, and I can honestly say that my parents and siblings have been very supportive of anything I have tried to do. When I was thinking about potential topics for my dissertation, I asked my father what he thought about my current topic and he stated that it sounded like a worthwhile endeavor. He has been in contact with many other cancer patients and cancer survivors and has spoken to other men who have adolescent children and he was told how difficult it has been for their children to accept that their family member has cancer and then be able to process all of the emotions that are associated with the diagnosis. I was in my late 20's when I found out my father had prostate cancer, and it left me thinking how an adolescent, who is not as emotionally mature would be able to handle such a difficult situation.

I have seen firsthand the wonderful things that the American Cancer Society does for cancer patients and their families and wanted to be able to give back and do

what I can to help them help others. The Relay For Life is a rewarding experience and serves to highlight the bond that is evident in families that have battled cancer. It brings different families together and honors individuals who have passed away from cancer. It was an easy decision for me to try and do work through the Relay for Life. To have the Ocean County Relay for Life coordinator meet with me and endorse my work meant so much, because I am immensely grateful for all they do for families. Each year that my family spends at the Relay for Life, we are brought closer together and can remember all of my family members that have passed away from cancer, but also celebrate the fact that my father is a cancer survivor.

Conducting the Research

From the beginning, I realized that this was not going to be an easy process. I knew how personally affected my life was by a diagnosis of cancer, and sitting with other families who have dealt with the same emotions was going to be difficult for me. I know how I reacted when my father was diagnosed, and I recognize that I withdrew from friends and was not the same person I was prior to him being diagnosed, and was unsure how I would handle speaking with adolescents whose family members were sick. I was extremely nervous prior to my first interview and read and re-read the interview script close to 50 times before I actually met with “Alex”. I worried about not being able to contain my emotional reactions to what the adolescents were going to say, and then worried about how my reactions were going to affect the interviewees. But, I also knew how important this study would be for the adolescents, and the future development of a support group. The adolescents who took part in this study were all amazing adolescents and showed a level of courage

and honesty with regard to their experiences that I admire and am in awe of. From my own personal experiences and how I handled my father's cancer diagnosis, I do not feel I would have been able to answer the questions that they were asked, and would not have been so open if my father was diagnosed with cancer when I was an adolescent as opposed to a graduate student.

The adolescents who were interviewed made my job as the researcher easy. I was able to ask every question that I had written down and received responses from every adolescent. At times, it was difficult to hear about their experiences, because they closely mirrored my reactions, and during the interview I caught myself thinking about my own experiences while I was asking the questions I had written down.

The Personal Impact of this Research

As it came to writing this dissertation, I found myself reflecting on what the adolescents told me and comparing it to my personal experience. It became crystal clear that support groups for adolescents are an underused, but extremely beneficial medium to provide services to a population that desperately needs it. I was in a graduate program in psychology and I was unable to recognize that a support group or individual counseling would have been beneficial to me, and attempted to cope with an extremely difficult situation on my own. It left me thinking, if a graduate student is unable to recognize that they can use help, it is even less likely that an adolescent will have the self-awareness to recognize that they need help as well. The present study highlights the psychological and emotional needs of an adolescent who has a loved one diagnosed with cancer, and their needs should be taken into account when a support group is created. The groups can be promoted through the adolescents'

schools and through the local hospitals where the patients' receive their cancer treatment. Working in a public school, I have seen a number of students whose families are affected by cancer, and it has negatively impacted their academic progress. A group that offers support to students and ensures they have a place where their needs are met and they have someone who will listen, will also help their academic functioning. School should be a safe and welcoming place for all students, and if school psychologists and other mental health professionals can recognize that they have an underserved population in their school and meet their needs, they can make a difficult situation much easier to handle.

This project has made me well-informed about the needs of adolescents and has inspired me to create a support group for adolescents in my present district. If I can share my experiences and what I have learned throughout the cancer experience, and be able to help other adolescents at a time when they greatly need help, then I am truly doing my job as a school psychologist.

CHAPTER V

DISCUSSION

Introduction

The purpose of this study was to gain a better understanding of the experience of adolescents who have a relative diagnosed with cancer. A secondary goal was to identify the specific needs of adolescents in order to develop a social support group to cope with the stressors that arise from having a family member diagnosed with cancer. It was hypothesized that designing a social support group based on the specific needs of these adolescents will lead to a more effective and longer-lasting group in the future. The agency with which I was working has previously attempted numerous adolescent support groups with limited success; however, a needs assessment of the support group's participants was never conducted. Thus, the group's participants were not given a voice.

This research arose from a deeply personal experience for me. During the last year of my graduate coursework, my father was diagnosed with prostate cancer. He was not the first of my family to be diagnosed with cancer; unfortunately, cancer is very prevalent on both sides of my family tree. However, to have one of my parents diagnosed with cancer was a huge blow. It affected me psychologically, emotionally, and in my social interactions with others. I withdrew from friends and co-workers. Unfortunately, my schoolwork also suffered as a result of this experience. Having

devoted my entire adult life to psychology and helping to heal others in their times of need, it left me wondering how this profound experience affects children during adolescence, when they are less prepared to handle such a difficult situation.

Adolescence is a time of increased responsibilities, increased maturity, and emotional growth. To disrupt this already difficult and confusing transition from childhood to young adulthood, by having a loved one diagnosed with cancer, can leave adolescents feeling frightened and vulnerable without answers or guidance.

Knowing how difficult the experience was for me, I wanted to design a study that would allow adolescents to share their stories and potentially help other teens in the future. The adolescents that participated in the interviews provided invaluable information regarding their needs and recommendations as to what would be beneficial to include in future support groups for adolescents. They have my eternal gratitude for being so courageous and answering such emotionally difficult questions and sharing their experiences. To have a father diagnosed with cancer while in graduate school was hard enough, but to consent to interviews as an adolescent demonstrates an emotional maturity that I do not feel I would have had when I was their age.

It is rare in today's society to find a family that has not been affected by a diagnosis of cancer. With the increased demands of school and social pressures on adolescents, there is a corresponding need for groups to help adolescents understand what is occurring and learn to cope when a family member is diagnosed with cancer. My hope is that future researchers will utilize the needs assessment that was created during this study to create a social support program to help adolescents. This will be

especially useful in schools, since children spend the majority of their time in school. School psychologists have extensive training when it comes to child development and addressing the social, emotional, and behavioral needs of adolescents, makes them an ideal facilitator of a social support program. A social support group run through a school setting would allow for a unique way of providing support in the school setting, and can meet the needs of varying populations. This in turn, would help to increase academic performance in the classroom, because the adolescents would not be as preoccupied with their unmet social, emotional, and psychological needs, and they can better focus on their academic work.

In review, this study was designed to gather information from the researcher's point-of-view, as well as the experience of the adolescents, in order to assess the needs of an adolescent who has a family member diagnosed with cancer. The interviews that were conducted with the adolescents were condensed into themes, and the range of experiences with regards to the themes were then presented. The adolescents' experiences were comprised in the form of "stories" to enable the reader to better understand what it was like to have a family member diagnosed with cancer. From the researcher's perspective, a personal narrative summarizing some of his own experiences having a father diagnosed with cancer was also provided. Each of these perspectives provided a beneficial avenue for gaining a better understanding of the experience of having a loved one diagnosed with cancer. For the purpose of this discussion, I will not review the results of this study as presented in the previous chapter, rather I will discuss specific implications of this study.

Information Regarding Cancer and Its Treatment

All participants in the study stated that they only had a vague understanding of what cancer was prior to their loved one being diagnosed. A time-limited group would be much more effective at addressing the needs of adolescents if it contained an informational component. Cancer disrupts every aspect of the adolescent's life. When they are not given age-appropriate information, the participant's reported feeling that their emotional and psychological needs were not being met. They felt as though they had been forgotten. Ballard (2004) reports that healthy siblings tend to have a desire to learn all they can about their sibling's illness and the more knowledge the healthy sibling has, the better they will function during and after treatment. Walker (1988) conducted a study with the purpose of identifying and describing cognitive and behavioral coping strategies used by healthy siblings, and found that healthy siblings have a number of questions, such as: (a) what caused their sibling's cancer? (b) Why did they not get cancer and their sibling did? (c) Is that form of cancer something they could be diagnosed with in the future? Healthy siblings in the study stated that they felt they were not given the information necessary to be able to understand and cope with their sibling being sick. Adolescents want to feel as if they are informed of each step in the treatment process, so they know what to expect when something new happens. Parents can ensure their healthy adolescents are presented with information in an age-appropriate manner and at an intellectual level they will be able to understand (Fleitas, 2000). The adolescents that were interviewed in the study stated that they did not feel comfortable asking their loved ones what cancer was, the possible treatment options, and the prognosis. Two participants in the study reported that the information that

was given to them was simplistic in nature, did not answer their questions, and did not let them to know what to expect as the treatment progressed, which caused them ultimately to expect the worst possible outcome, the death of their loved one. Thus, an adolescent group that includes information on the causes of cancer, the different treatment options, the prognoses of varying types of cancer, and a discussion of side effects as the patient progresses through their treatment plan, would reduce uncertainty. Since adolescents have a better understanding of biology and other sciences, medical information should be presented at a developmentally appropriate level. Adolescents may feel more comfortable asking follow-up questions to the group leader than they may feel asking their own relatives. This is consistent with the findings of Fleitas (2000), who found adolescents are better served when they are given information regarding specific procedures, treatment goals, and expected outcomes, because it provides a sense of control in an extremely chaotic situation. Including an informational component to an adolescent group will allow the adolescent to feel they are still an integral part of the family and not just being left alone to wonder what is actually happening to their loved one.

An Emotional Support Component

Emotional support should be the foundation of any effective social support group because fostering peer relationships and having an opportunity for adolescents to openly discuss difficult topics amongst themselves will allow for better coping through a painful time in their lives. Emotional support refers to demonstrations of empathy, genuine caring about others, and opportunities for people to talk about their problems and have someone listen to them (Cohen, 2004). Social support can benefit

health through two mechanisms, stress buffering and main effects. Stress buffering hypothesizes that social closeness and social connection benefits health “by providing psychological and material resources needed to cope with stress” (Cohen, 1988). It is believed that stress influences health by triggering maladaptive behavioral coping responses which are detrimental to health by “activating physiological systems such as the sympathetic nervous system and the hypothalamic-pituitary-adrenal cortical axis” (Cohen, Kessler, and Gordon, 1995). Repeated activation of these physiological networks can place a person at-risk for a host of physical and psychiatric disorders. If a person perceives that they have others in their lives that provide social support, this acts as a buffer against stress. All of the adolescents who were interviewed spoke about their reluctance to tell their friends or peers about their loved one's diagnosis and their fears regarding the treatment and prognosis, primarily because they were afraid of potential negative reactions from their peers. This reluctance to communicate about their stress and anxiety, can place them at risk for maladaptive physical and psychological functioning. All of the interviewees stated that it would have benefited them to be involved in a group that allowed them to meet other people who had a family member with cancer. This would have served to normalize the cancer experience for them and would have given them an outlet to talk about how they were feeling and learn which coping strategies have been effective for others. Adolescents would be able to see they are not alone with their anxiety, stress, and psychosomatic symptoms, and as a group, they could process the events that were occurring. Adolescence is a period in life when more responsibilities are placed on children; these responsibilities can be more numerous and overwhelming if a close

relative is battling cancer. The participants spoke about this point during the interview sessions. They were given more responsibilities in their home environments, either by their own choosing, or they had more responsibilities placed on them by their parents, and it was overwhelming for them to endure. Receiving emotional support in a group, processing the feelings associated with their increased responsibilities, and seeing that their experience is not unique to themselves, might serve to reduce their anxiety and stress.

A Psycho-Educational Component

Closely related to the emotional support component, an adolescent group would be more effective if it also includes a psycho-educational component. This component would be beneficial to the adolescents in a number of ways. Social learning theory postulates that children will form a cognitive representation from real-world experiences, such as observation of a peer or adult, and they will use these cognitive representations to drive future behaviors in similar situations, based on the observed outcomes. Children will be motivated to repeat certain behaviors, and dissuaded to act in other ways, depending on the observed consequences (Bandura, 1977). During the interviews for this study, all of the adolescents stated that they felt alone and that the problems they were facing needed to be internalized for fear of upsetting their sick relative. The adolescents saw that if they internalized what they were feeling and did not exhibit it outwardly to their relatives, their relatives would not become upset, thus, they continued to act in the same way, despite the fact that their emotional and psychological needs were not being met. The interviewees' perceived self-efficacy (the strength of one's belief that he or she can successfully

complete a required task) was low, in the sense that they perceived talking to their relatives as a more difficult task than it may have actually been; thus they did not attempt to speak with their family and express their own needs. A social support group offers the adolescents the opportunity to elevate their sense of self-efficacy by providing them with positive reinforcement paired with social learning experiences that maximize successful outcomes. The group's facilitator can help by assuring the group that their negative thoughts are typical reactions that the majority of peers would have, rather than the adolescent misattributing those reactions to something inherently negative about themselves. The facilitator should engage in discussions that serve to boost the participants' self-efficacy, and allow for normalization of the feelings that they have regarding their loved ones illness. It will be important for the facilitator of the group to have close and frequent contact with the family of the participants. Bandura (1977) stated that an individual learns the most from the people with whom they spend the most time, which are typically the people most frequently observed in their everyday life. The observations of others act as both motivators and informers of the adolescent's own behavior, thus if there are positive influences by the facilitator and peers in the group as well as a continuation in the home setting, it should result in more pro-social and positive behaviors in the adolescents.

The psycho-educational component should also focus on enhancing the adolescent's outcome expectancies. Outcome expectancies are an important component of social learning theory, and should be incorporated into a social support group. Outcome expectancies refer to an individual's "beliefs concerning the extent to which one's behavior will produce favorable or unfavorable outcomes" (Frayne

and Latham, 1987). It is felt that people will be more willing to act when they believe that their actions will produce favorable outcomes. Individuals are less likely to alter their behavior when they believe they can perform successfully, but they feel the social environment will be unresponsive to their behavior change. This is an important concept in the creation of a social support group for adolescents. The group can be used as a venue to include intensive discussions and role-playing activities that will ensure the adolescents experience favorable outcomes, and allow them to “practice” the conversations they will have with their family in a safe and accepting environment before actually having those discussions. The interviewees voiced concerns about being emotionally open with their family members, fearing the feedback they would receive. If their outcome expectancies are enhanced and they believe there will be favorable outcomes it might allow for more open discussion amongst the different families. Inclusion of outcome expectancies speaks to the need for open dialogue between the group facilitator and the families of the adolescents. These concerns can be relayed to the families, which should initiate productive conversations in the home environment and allow for maximal carryover from the group to the home.

It appears that adolescents would also benefit from a discussion of positive and mature coping strategies that can be used both inside the group and at home. According to Laor, Wolmer, and Cicchetti (2001) there are three categories of coping strategies which children typically use when they are presented with a stressful situation. The first two categories, self-oriented and other-oriented strategies are maladaptive in nature and it would be beneficial to the adolescents if this topic was

included in the support group. Adolescents are more mature than younger children and better able to understand and use mature coping strategies. When a healthy sibling is able to use mature coping strategies they are working through their emotions and feelings in the healthiest manner. Examples of mature coping strategies are humor, anticipation, sublimation, and altruism. A number of the interviewees spoke about feeling alone and constantly worrying. If the adolescents were provided with activities that enhanced positive coping strategies, it could help ensure that less effective coping means were not used by the adolescents. Altruism occurs when a healthy sibling will take the negative situation associated with a diagnosis of cancer, and turn it into something positive by reaching out to siblings of other cancer patients and doing something positive in the lives of others. Being included in an adolescent support group and speaking about their own experiences and listening to others' experiences will enhance their ability to cope with a difficult situation through this mature coping response. Sublimation should also be included in the social support group. The adolescent can express their negative feelings and anger towards their situation and use a more positive outlet in the group such as journal writing, art projects, drawing how they feel, or role playing situations they are currently dealing with.

Weaknesses and Challenges with the Study

While the current study speaks to the need for a time-limited support group for adolescents who have a relative with cancer, there are a number of limitations as well. The present study is more exploratory in nature, and was developed to obtain information regarding the emotional and psychological needs of adolescents, all of

whom lived in the New Jersey Shore area. Six adolescents were initially recruited to be interviewed, however, in the end five adolescents were interviewed as a part of this study and this small sample size is somewhat limiting. Although the adolescents that were interviewed reported having similar experiences and emotional needs, more information regarding the needs of adolescents could be obtained with a larger sample of interviewees. The interviewees were also all Caucasian residents from a specific geographical area and came from very similar socio-economic backgrounds. They all categorized their families as middle-class, stating they were neither rich nor poor. In the future, a similar study could be undertaken with a larger sample size of varying races and socio-economic backgrounds in order to assess any potential differences related to race and SES status. In the future it may also be beneficial to examine the needs of healthy adolescents when their relatives have different forms of cancer, and see if there are cancer-specific needs that should be addressed. To obtain information from the participants in this study, a qualitative interview format was utilized, thus providing a somewhat more subjective picture of the needs of the adolescents. Future researchers may want to use more objective measures when assessing the needs of adolescents who have a relative with cancer, in order to determine whether there are similar or different findings.

While the current study provides a framework for the design of a social support group that includes an informational component, an emotional support component, and a psycho-educational component, future research could also examine whether there is more satisfaction reported by group participants, or greater length of stay in groups designed with the presented recommendations.

Conclusion

This study was based on the contributions of five adolescents who described their experiences having a family member diagnosed with cancer. These adolescents represent only a small sample of a growing population of adolescents who are dealing with the same life-changing event. There is a growing awareness of the psychological needs of healthy adolescents and the impact of having a loved one diagnosed with cancer while still navigating the path from childhood to young adulthood. The American Cancer Society has devoted millions of dollars in research and support for families that have been touched by a diagnosis of cancer. My original intent in undertaking this study was to give back to an agency that has made a difference in the lives of so many cancer patients and their families. As I reflected on the results of the study I began to think about my job as a school psychologist and the many children that I have come into contact with in the different schools that I have worked. If the results of this study can be used to create groups in school, it could benefit many other children who can use an effective social support program.

The results are important in a school setting, because such a significant amount of a child's life is spent in school. If adults in a school have a better understanding of the needs of the children in their school, programs can be tailored that address the social and emotional needs of students when they encounter traumatic events. More specifically, the results of this study will serve to benefit school psychologists because with their intensive training in child and adolescent development, and their experience facilitating groups, developing a support group based on the specific needs of the adolescents who were interviewed will allow for a

more successful and enduring group. Toward this goal, this study adds to the growing body of literature that examines the psychological, social, and emotional needs of healthy adolescents who have a loved one diagnosed with cancer.

In conclusion, the adolescents in this study have bravely given us a chance to see the emotional and physical toll it takes on someone when they have a family member diagnosed with cancer. This study demonstrates the importance of taking into account the specific needs of a population when developing a social support program. It also shows that the experience of having a loved one diagnosed with cancer during adolescence is especially difficult and can deeply affect the transition into adulthood. The participants were open and discussed in detail their struggles dealing with a life-changing situation in the hope that what was learned from them can benefit other adolescents in the future. Having multiple members of my family diagnosed with cancer during my childhood and into my adulthood made this experience more difficult in some ways, because it forced me to reflect on times in my life that were emotionally taxing. In another sense, the experience with the participants was rewarding, because it demonstrated how resilient adolescents can be when faced with adversity and how willing they were to help other adolescents in the future.

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APPENDIX A

Consent Form

**Development of a Time-Limited Group for Adolescents Who Have a Relative
Who
Has Cancer**

Dear Parents,

You/Your child are invited to participate in a research study that is being conducted by Jason Ruch, who is a graduate student at the Graduate School for Applied and Professional Psychology at Rutgers University. The purpose of this research is to interview adolescents who have a sibling or parent with cancer and use the information obtained during the interview to develop a needs' assessment that will allow for the development of a social support group for that age group.

Approximately six children between the ages of 13 and 17 years old will participate in this study, and each child's participation will last approximately one hour and thirty minutes.

The study procedures include an interview with the adolescents regarding their experiences having a relative diagnosed with cancer. The questionnaire will contain demographic questions, as well as questions related to the cancer experience.

This research is confidential. The research records will include some information about you/your child and this information will be stored in such a manner that some linkage between you/your child's identity and the response in the research exists. Some of the information collected about you/your child includes: name, marital status, ethnic background, and occupation. Please note that we will keep this information confidential by limiting individuals' access to the research data and keeping it in a secure location. Names will be removed from the interviews and the list of names and code numbers will be stored separately from one another.

The research team and the Institutional Review Board (a committee that reviews research studies in order to protect research participants) at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. All study data will be kept for three years.

There will be minimal risks to your child for participating in this study. The questions that will be asked will be about the experience of having a relative with cancer, which can be an emotional topic to discuss.

You/your child have been told that the benefits of taking part in this study may be development of a future group that will better target this specific population.

Participation in this study is voluntary. You may choose for your child not to participate, and you may withdraw your child from participating at any time during the study activities without any penalty to your child. In addition, you/your child may choose not to answer questions with which you/your child are not comfortable.

If you/your child have any questions about the study or study procedures, you/your child may contact Jason T. Ruch at: 376 Begonia Court, Toms River, NJ 08753. jruch@trschoools.com, 732-608-3196.

If you/your child have any questions about your rights as a research subject, you may contact the Institutional Review Board (a committee that reviews research studies in order to protect those who participate). Please contact the IRB Administrator at Rutgers University at:

Rutgers University, The State University of New Jersey
 Institutional Review Board for the Protection of Human Subjects
 Office of Research and Sponsored Programs
 3 Rutgers Plaza
 New Brunswick, NJ 08901-8559
 Tel: 732-932-0150 ext. 2104
 Email: humansubjects@orsp.rutgers.edu

Your child will also be asked if they wish to participate in this study. You will be given a copy of this consent for your records.

Sign below if you agree to allow your child to participate in this research study:

Name of Child (Print)_____

Name of Parent/Legal Guardian (Print)_____

Parent/Legal Guardian's Signature_____ Date_____

Principal Investigator Signature_____ Date_____

APPENDIX B

Assent Form

Development of a Time-Limited Group for Adolescents Who Have a Relative Who Has Cancer.

This assent form may contain words that you do not understand. Please ask the researcher or your parent or teacher to explain any words or information that you do not clearly understand before signing this document.

1. Mr. Jason T. Ruch is inviting you to take part in his research study. Why is this study being done?

The researcher wants to interview adolescents who have a sibling or parent with cancer, to figure out what the cancer experience is like for those adolescents.

2. What will happen?

You will be interviewed for about an hour. You will be asked a number of questions about your family, and what it has been like to have a loved one diagnosed with cancer. You may skip any question that you do not want to answer and you may take a break if you need one. With your permission indicated below, I will make an audio recording of your session.

3. What does it cost and how much does it pay?

You will not have to pay, nor will you get paid for participation in this study.

4. There are very few risks in taking part in this research, but the following things could happen:

Probably: Nothing bad would happen.

Maybe: Your answers would be seen by somebody not involved in this study. We will do our absolute best to keep all your answers private. Your answers will be kept locked up. Your name will not appear on the interview sheets; we will use a code number instead. The researcher is very well-trained and understands the importance of confidentiality. But if the researcher learns that you, or someone else is in serious danger he would have to tell an appropriate family member, such as your mother, father, or caretaker, or the appropriate officials to protect you and other people.

Very unusual: You could be embarrassed or upset by a few of the questions. If this should occur, remember that you don't have to answer any questions you don't want to and either you or the researcher may choose to stop this project.

5. Are there any benefits that you or other will get out of being in this study?

The only direct benefit to you may be to talk about living through having a sibling or parent diagnosed with cancer. It may help you to share your story and how it affected your life. The knowledge gained through this study may allow the researcher to develop more effective programs to assist other adolescents who have a sibling or parent diagnosed with cancer.

It's completely up to you! Both you and your parents have to agree to allow you to take part in this study. If you choose not to take part in this study, we will honor that choice. No one will get angry or upset with you if you don't want to do this. If you agree to take part in it and then you change your mind later, that's OK too. It's always your choice!

6. CONFIDENTIALITY: We will do everything we can to protect the confidentiality of your records. If there are professional articles written about this research, it will never say your name or anything that could give away who you are. We will do a good job at keeping all of our records secret by following the rules made for researchers.

7. Do you have any questions? If you have any questions or worries regarding this study, or if any problems come up, you may call the principal investigator, Mr. Jason T. Ruch at: 376 Begonia Court, Toms River, NJ. jruch@trschoools.com. 732-608-3196.

You may also ask questions or talk about any worries to the Institutional Review Board (a committee that reviews research studies in order to protect those who participate). Please contact the IRB Administrator at Rutgers University at:

Rutgers University, the State University of New Jersey
 Institutional Review Board for the Protection of Human Subjects
 Office of Research and Sponsored Programs
 3 Rutgers Plaza
 New Brunswick, NJ 08901-8559
 Tel: 732-932-0150, ext. 2104
 Email: humansubjects@orsp.rutgers.edu

Your parent or guardian will also be asked if they wish for you to participate in this study. You will be given a copy of this form for your records.

Please sign below if you assent (that means you agree) to participate in this study.

Signature

Date

Name (Please print): _____

Investigator's Signature: _____ Date: _____

Audio/Videotape Addendum to Consent Form

You have already agreed to participate in a research study entitled: Development of a Time-Limited Group for Adolescents Who Have a Relative Who Has Cancer, conducted by Jason T. Ruch. We are asking for your permission to allow us to audiotape the interviews as part of that research study. You do not have to agree to be recorded in order to participate in the main part of the study.

The recordings will be used for data analysis purposes by the investigator to determine the needs of adolescents who have a relative or sibling diagnosed with cancer.

The recordings will include the number of the interview being conducted, not your actual name.

The recordings will be stored in a locked desk drawer and linked with a code to the subjects' identity, and will be retained for three years after the completion of the study, that time they will be erased.

By participating in this study, using the above procedures, you agree to be a study subject and you grant the investigator named above permission to record you as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than those stated in the consent form without your written permission.

Signature

Date

Name (Please Print): _____

Investigator's Signature: _____ Date: _____

APPENDIX C

Semi-Structured Questionnaire

Today's Date: _____**Place:** _____**Time:** _____**Interviewer's Name:** _____

Subject's Name: _____**Sex:** _____**Birth Date:** _____**Age:** _____**Birth Place:** _____

Familial Information:**Birth Order:** 1__ 2__ 3__ 4__ 5__ 6__ 7__ 8__**Brothers:****First name**_____ **Age**_____**First name**_____ **Age**_____**First name**_____ **Age**_____**First name**_____ **Age**_____

Sisters:

First name _____ Age _____

First name _____ Age _____

First name _____ Age _____

First name _____ Age _____

Parents:

Mother: First name, last name _____ age _____

Father: First name, last name _____ age _____

Parents are: married _____ divorced _____ separated _____ father/mother passed away _____ (If so, which parent and when)

(mother remarried when you were _____)(lived with mother from ages _____ to _____)

(father remarried when you were _____) (lived with father from ages _____ to _____)

Ethnic background of:

Mother: _____

Father: _____

Occupation of:

Mother: _____

Father: _____

Respondents Education:

Highest grade completed _____

Current Academic grades in school _____ (went down __, went up __, remained the same __)

Classified for Special Ed: yes __ or no __

Religious Background:

Identifying religion _____

How religious: strong _____ moderate _____ inactive _____ indifferent _____

Questions Related to Experience of Cancer:

Which family member has been diagnosed with cancer? What type of cancer have they been diagnosed with?

How did you hear about the diagnosis initially? Who told you? How did they tell you? What was that experience like? Could you have been told in a different way that would have made it easier on you? How old were you when you found out about the diagnosis?

Under what circumstances did you find out about the cancer? Were you alone at the time with your loved one? Were you given the opportunity to ask questions by the person/people who told you? Were your questions answered?

Did your parents discuss with you what the diagnosis meant? Did they discuss the potential outcomes of the cancer and the likelihood that it would eventually enter remission? What was your emotional reaction to hearing about your loved one?

Did they discuss what the treatment regimen was going to look like (chemo and radiation, surgeries)? Did they discuss what the physical side effects of the treatment would be, and how the treatment will affect the health of the loved one diagnosed with cancer? Were you given any responsibilities with regard to the treatment of your loved one?

How was your family affected by the cancer diagnosis, what changed in the family? Were any of the roles in the family changed as a result of the diagnosis of cancer? Did one of your parent's roles change as a result? Did either perform actions that were typical of the other parent prior to the diagnosis? How did your role change within your family? Were you given more responsibilities on a day-to-day basis? Were you more responsible for the care of your siblings? If so, what responsibilities were you given?

Did relationships among family members change as a result? Did you feel closer to the other members in your family? Did the diagnosis create a division in your family? How was the communication among family members after the diagnosis was made? Did you feel that you can talk about anything with your family members?

After you found out about the cancer diagnosis, did you talk to anyone immediately afterwards? Did you speak with close friends, your teachers, religious figures, other family members? If so, did you feel supported? What was said that made you feel supported by those you spoke with?

If you did speak with people right after finding out, how did you tell them about the cancer diagnosis? What was their reaction after you told them? Did you get a reaction that was beneficial? Did it make you feel better? Did you feel supported by those you told? If not, what was it about the reaction and subsequent actions by the other person that led you to not feel supported? What could have been said at that time that would have made the situation easier to handle?

How were your friends at school when they found out about your loved one? Did they call more frequently just to check up on you? Did certain friends avoid talking to you? Why do you feel they avoided talking with you? If you did not tell friends at school, why not? If you could change anything about the way you handled the initial way you dealt with the cancer diagnosis, what would you do differently? What would have made you feel more support from others?

How were your grades in school before you found out? How were they after you found out? What could have been done in the school setting to help you feel more supported? Could school staff have done anything for you? Was the amount of time you spent working on school work less after the diagnosis? If so, what was this due to? How could the school staff have helped when it came to work in school? Would it have helped you to have someone to speak with during the school day? Would you have felt more supported if a school staff member stepped up and initiated contact with you post diagnosis? What could that staff member talk about that would be beneficial to someone in the situation you were in?

Did you notice changes in your physical health after you were told of your loved one's cancer diagnosis? Were your eating/sleeping patterns altered after you found out about the diagnosis. Were you sick more often? If so, what type of illnesses did you have?

Did you feel the reactions you had to the diagnosis were typical of other people your age who are dealing with cancer? Have you had the opportunity to speak with peers who are dealing with the same situation that you are dealing with? Would it be helpful to have more contact with other peers who have a loved one with cancer? What could be talked about in those groups that would be helpful and make you feel supported?

Do you feel you were an emotionally strong person prior to the diagnosis? How has your ability to deal with stress gotten better/worse after enduring a diagnosis of cancer? What would you do differently if you were in the same situation again? As a person who works in a school setting, what can I do to help students in my school that are living through what you lived through? What can be included in a group that is beneficial? What topics should be discussed in those groups? Has living through a stressful situation had any positive effects on your life? On your ability to cope with stressful situations?

Do you feel that your actions post-diagnosis increased your ability to cope with your loved one being sick? If yes, what resulted from your actions that make you feel this way? If you feel your actions did not help you cope, what would you do differently having lived through what you did?