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Adolescents’ Lived Experiences During Treatment of Cancer and Impact on Social Participation

Gary Grimaldi
Nova Southeastern University, ggrimaldi@iona.edu

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ADOLESCENTS' LIVED EXPERIENCES DURING TREATMENT OF CANCER AND IMPACT ON SOCIAL PARTICIPATION

by

Gary Grimaldi

Submitted in partial fulfillment of the requirements for the degree of
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NOVA SOUTHEASTERN UNIVERSITY
HEALTH PROFESSIONS DIVISION
COLLEGE OF ALLIED HEALTH AND NURSING
OCCUPATIONAL THERAPY DEPARTMENT
FORT LAUDERDALE, FL 33328

This dissertation, written by Gary Grimaldi under direction of his Dissertation Committee, and approved by all of its members, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF PHILOSOPHY

DISSERTATION COMMITTEE

____ ________________
Sandee Dunbar, D.P.A, OTR/L, FAOTA Date
Chairperson of Dissertation Committee

____ ________________
Ferol Ludwig, Ph.D., OTR/L, FAOTA, GCG Date
Dissertation Committee Member

____ ________________
Sandra Countee, Ph.D., OTR/L Date
Dissertation Committee Member

NOVA SOUTHEASTERN UNIVERSITY
HEALTH PROFESSIONS DIVISION
COLLEGE OF ALLIED HEALTH AND NURSING
OCCUPATIONAL THERAPY DEPARTMENT
FORT LAUDERDALE, FL 33328

Certification

We hereby certify that this dissertation, submitted by Gary Grimaldi, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the dissertation requirement for the Doctor of Philosophy degree.

Approved:

Max A. Ito, Ph.D., OTR/L — Date
Ph.D. In OT Program Director

Sandee Dunbar, D.P.A., OTR/L, FAOTA — Date
Chair, Occupational Therapy Department

Richard E. Davis, Ed.D., PA-C — Date
Dean, College of Allied Health and Nursing

Abstract

This phenomenological study was designed to understand the lived experience of adolescents being treating for cancer and the impact of their lived experience on engagement in occupations and social participation. Participants in this study included four young adolescents 17-19 years of ages attending school on a part-time basis. They were on active treatment protocols for cancer and enjoyed participating in sports or other activities with friends. In-depth structured interviews with questions to illuminate the impact of cancer treatment on social participation were completed and audio recorded. Data analysis was completed utilizing a phenomenological reduction method to determine emerging themes and significant statements. A description of the experience and its meaning were then developed from themes emerging from the perspective of the participants.

The four major themes and sub themes resulting from this study were: 1. Change of Lifestyle a) *Physical & Emotional Pain of Living* b) *School Re-entry—A Saving Grace*; 2. Exploring New Occupations a) *Adapting Occupations* b) *Awakening or Confirming Beliefs*; 3. Reconnecting with Family a) *Importance of Support* b) *A Kid Again*. 4. Living with Cancer Isn't Easy a) *Isolation* b) *Hidden Disability*.

The findings revealed lifestyle changes, which these adolescents needed to deal with in order to maintain a sense of routine and engagement in occupation. Changes in appearance, physical strength, and overall endurance impacted the participants' ability to engage in occupation(s) which often led to isolation among their peers. In spite of this, participants discovered new occupations that were less physically demanding but still fostered social participation with peers. The study of social participation for adolescents

with cancer has implications for and can assist in developing client-centered interventions and simultaneously increase occupational therapy’s understanding of these individuals during a transitional period of their lives.

Acknowledgements

This is not the dissertation I ever expected to write. When I was diagnosed with Leukemia during my senior year of high school, I found that I had no passion to return to school. However, I met a nurse, Hope Castoria, who asked me in January 1985, what are you going to do with your life? She went on to say, “Kids who don’t return to school become boring.” With those words I began my education at a community college receiving my Associates Degree and now 20 years later my Doctoral Degree. I am ever grateful for those words of wisdom.

To the young adults who gave me an intimate look into their lives as impacted by cancer, saying “thank you” is simply not adequate. You entrusted me with your stories, and you shared your struggles, fears, doubts, and most of all your hopes. You shared your voices with me and I feel humbled and privileged to have joined you in telling your stories.

To my dissertation chair and advisor, Dr. Sandee Dunbar, thank you for being a mentor for allowing me to have the space I needed to negotiate my journey, while supporting me all the way. You have been a true role model for me of a professional counselor and educator. To Dr. Ferol Ludwig, thank you for your guidance throughout this journey. I really caught the vision and excitement of qualitative methods through your love of research. And to the other member of my committee, Dr. Sandra Countee of Dominican College, thank you for giving freely of your time and scholarly expertise.

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Chapter 1

Introduction to the Chapter

Statistics reveal that cancer affects about 14 of every 100,000 children in the United States each year. Pediatric oncology is a broad field, encompassing a variety of cancers with various medical consequences, treatment plans, and prognoses. Among all age groups, the most common childhood cancers are leukemia, which make up about one third of all cases; brain tumors contribute about a quarter of the numbers; and lymphomas (Hodgkin lymphoma and non-Hodgkin lymphomas) another tenth. As children enter their teen years, there has been an increased incidence of osteosarcoma (bone cancer) reported (Barr, 2007).

More than three decades ago, before the introduction of modern cancer treatment, most children diagnosed with cancer died a rapid death. Today, due to the advancements in modern technology, new drug therapies, and facilities focused in the treatment of childhood cancers, increased survival rates remain strong among this population (American Cancer Society, 2010; Ariffin, 2002; Bleyer, O'Leary, Barr, & Ries, 2006; National Cancer Institute [NCI], 2009). The survival rates for childhood cancer have risen steadily over the past 20 years. In the United States, more than 75% of children with cancer are now alive 5 years after diagnosis compared with about 60% in the mid-1970s. Long-term survival rates stand at 80%, 10 years post diagnosis, followed by a 77% survival rate 15 years post diagnosis (NCI, 2009). Although the statistics are encouraging, they fail to represent the psychosocial impact cancer has on the individual person.

As mentioned, scientific advances in pediatric cancer have yielded improvements in long-term survival of children and adolescents with cancer. However, with this long-term survival rate, studies (Abrams, Hazen, Penson, 2007; Albritton & Bleyer, 2003) have reflected that adolescents with cancer experience many “illness related stressors” (Neville, 2000, p. 14). These stressors manifest into difficulty building new relationships with peers, poor socialization secondary to body changes, and a change in overall lifestyle. These factors may impact these young adults’ lives in terms of social participation and overall engagement in occupation.

Occupation-based and occupation-centered models of practice, which are client-centered, are grounded in the belief that successful engagement in occupation is an intrinsically motivated human need that ultimately promotes health and well-being (Baum & Baptiste, 2002; Baum & Law, 1997). Successful engagement in occupation relies on a satisfactory relationship between the person, the environment, and the occupation (Dunn, Brown, & McGuigan, 1994; Law et al., 1996; Ludwig, 2004). The foundation within an occupation-centered model is that health and well-being develop through active participation and “doing,” which in turn fosters new activity patterns that enhance an individual’s quality of life. This engagement in meaningful occupations can be influential in an individual’s need in balancing health and well-being (Fidler, 1996). Through this resurgence in occupation, which incorporates many aspects of daily life, it enables occupational therapists in exploring new perspectives of treatment for these young patients, beyond the medical model.

This client-centered philosophy, a cornerstone within the profession, is congruent with the current Occupational Therapy Practice 2008 Framework: Domain and Process (2nd ed.). The idea of “supporting health and participation in life through engagement in occupation” (American Occupational Therapy Association [AOTA] 2008, p. 626), preserves the rights of the client to make choices in activities or tasks that are meaningful to him/her. Secondly, it fosters a therapeutic relationship between a client and therapist to collaborate in identifying intervention strategies and outcome goals. Both factors are essential in the healing process and overall satisfaction with occupational therapy services (Law & Baptiste, 2002). As the early literature reveals, the profession’s founders conceptualized that purposeful activities and self- actualization through meaningful tasks were necessary to maintain health (Wilcock, 1998). Furthermore, the profession’s focus has been and will continue to center on the use of therapeutic occupation to promote health and prevent dysfunction.

Occupation-centered and occupation-based methods of assessment and treatment redefine the medical model approach and require that occupational therapists “move beyond setting goals to achieve functional independence and into a client-centered approach that makes the individual’s need for occupation central to the treatment process and has participation as the outcome”(Baum & Baptiste, 2002, p. 3). In order to practice in an occupational context, it will call for therapists to have a client-centered focal point within their area of expertise. The idea of “function” must be redefined to be understood as “occupational performance” (Nelson, 1988).

Occupation-based programs are client-centered which are paramount to overall success. These approaches bring meaningful occupations into daily routines. In an occupation-centered practice, interactions with the person, the environment, and the activities required to engage in everyday occupation become central to assessment, planning, and implementation of care. When using an occupation centered framework, the ultimate goal of OT is to improve the individual’s occupational performance (Baum & Baptiste, 2002). Through meaningful tasks or activities, individuals are more likely to accomplish goals if they have a vested interest in the final outcome (Fisher, 1998; Nelson, 1988; Schemm, 1987).

Social participation, the underlying theme of this study, reflects the philosophical cornerstone of occupational therapy since its inception. OT focuses on enabling individuals or groups to participate in everyday occupations that are meaningful, provide a sense of accomplishment, and foster participation (Law, 2002a, p. 640). Early pioneers in OT believed that work or other forms of occupation involving physical or cognitive skills resulted in tangible products, acquisition of new or improved skills, and produced desirable changes in individuals’ behaviors and attitudes (Johnson, 1977). Enhancing participation through sustained occupation has been a positive influence on the health and well-being of individuals as early as World War I. During this turbulent time returning veterans and mentally impaired patients were given the opportunity to participate in arts, crafts, and manual labor. Improved behaviors and faster recovery times were noted reflecting an overall positive response to active participation in occupation (Ambrosi & Schwartz, 1995).

Social participation is considered to be a vital part of a young adult’s development, which is related to his/her quality of life and future life goals (King et al., 2003). The World Health Organization (WHO, 2001) defines participation as the nature and extent of a person’s involvement in life situations and categorizes participation in terms of personal maintenance; mobility; information exchange; social relationships; home life; education, and overall involvement in community (Bedell, Haley, Coster, & Smith, 2002). Social participation typically entails being or doing with others in a social context (Law, 2002a; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001) with activities chosen to have meaning to the individual. Participation is only achieved through individual choice or control over an activity, rather than passive involvement (Law, 2002a). Often social participation among these young adults with cancer is restricted in their homes, school, and community life (Bedell et al., 2002; King et al., 2003; Law et al., 1999) secondary to disability, age, family issues, or co-morbidities (Bedell & Dumas, 2004).

Studies have revealed cancer treatment has impacted these young adults’ engagement in social participation in their ability to “get around,” acquire peer relationships, and develop a balance of dependence and independence, which evolves through social maturation (Enskar, Carlsson, Golsater, & Hamrin, 1997). It is anticipated that understanding the issues of social participation from the participants’ perception would assist the profession in developing its current body of knowledge in a topic that has remains unexplored.

Problem Statement

This qualitative research study describes the lived experiences of adolescent patients in the treatment process of cancer, and its impact on their ability to participate with peers, maintain social activities, and involvement in daily occupation(s). The need for this study was based on the limited available research in the occupational therapy

(OT) and social science literature that described the reported experiences of adolescents undergoing cancer treatment, and the secondary impact on social participation.

Each year in the United States, approximately 12,400 children and adolescents younger than 20 years of age are diagnosed with cancer (NCI, 2009). Cancer among children is a substantial public concern, as society appears to empathize with a child who has not experienced life versus an older adult who is at the end of his/her life. This appears evident from media sources promoting such places as St. Jude's Children's Hospital, Ronald McDonald's Home for Children, and Paul Newman's "Hole in the Wall Camp" for children.

Adolescence is a developmental milestone in the human life cycle where young adults explore relationships with peers, develop their own identities, aspire to future goals, and begin to break away from the family nest. Young adults are also concerned with the latest trends in music and fashion, their physical appearance, and acceptance into peer groups (Katz, Varm, Rubenstein, Blew, & Hubert, 1992; Larouche & Chin-Peuckert, 2006; Whyte & Smith, 1997; Woodgate, 2006a). It is a period when an individual begins the transition from being a young adult with little or no responsibilities, to someone who is expected to care and support him or herself. Cancer in adolescence raises a number of unique challenges for both the patients and their families. Adolescence is a period of significant physical and emotional changes and a diagnosis of cancer during this time has a major impact on their psychological and physical development (Hokkanen, Eriksson, Ahonen, & Salantera, 2004). However, it is unclear how individuals experience life during this turbulent period. There is still little research on how these young adults feel about their lives in this situation and what they think about the future shape of their lives.

Although literature exists that describes OT intervention for individuals with cancer, there has been limited research conducted in OT that has described the reported experiences of adolescents in the treatment process of cancer and the secondary impact on their occupations. In reviewing the literature over a 10-year period, three distinct topics repeatedly appeared. Although these topics were related to adolescents with cancer, none addressed the proposed research questions. Studies located in the nursing literature focused on the lived experiences of adolescent patients with cancer utilizing a phenomenological research design; however, the studies fail to capture the true essence of the experience, as they were completed post chemotherapy, where thoughts and feelings may have changed over time (Earle, Davies, Greenfield, Ross, & Eiser, 2005; Prouty, Ward-Smith, & Hutto, 2006; Wallace, Harcourt, Rumsey, & Foot, 2007). The focus of these studies was to describe the impact of coping mechanisms, positive attitudes, and social support systems required to deal with being ill. Additionally, the theoretical base was grounded in developmental theory, rather than theories supporting the use of occupation and wellness.

The literature reviewed focused on school re-entry after cancer treatment; coping and psychosocial aspects of adolescent cancer survivors; and self-image issues of adolescent patients with cancer. Although qualitative studies were located (Hokkanen et al., 2004; Kameny & Bearison, 2002; Yeh, 2002) the means of inquiry were through general descriptive, narrative, or grounded theory research. There were, however, many studies documented through quantitative means on quality of life after completion of therapy (Armstrong & Reaman, 2005; Bessell, 2001; Shankar et al., 2005), self-esteem (von Essen, Enskär, Kreuger, Larsson, & Sjödén, 2000; Zebrack & Chesler, 2001), and coping strategies (Kyngäs et al., 2001; Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2002; Trask et al., 2003). However, none of the literature addressed the proposed question of this study.

Purpose of the Study

The focus of the present phenomenological qualitative research was to obtain plausible and coherent understandings of the phenomenon of adolescents in the treatment process of cancer and the impact on occupation, particularly social participation. This study was initiated to provide a voice for these adolescents to express their life-world, everyday experiences and stories, in order to foster an increased awareness on the importance of social participation in everyday life. Documentation of these life-worlds can bring into focus new insights into aspects of care relevant to this patient population. Additionally, this study can provide the missing link in occupational therapy's present body of knowledge to support further research in the area of social participation.

A qualitative approach was chosen because this was considered the most appropriate approach to capture the true experiences of these young adults to reflect the raw emotion of the moment. The researcher's area of interest is describing the experiences of these young adults living with cancer and the ultimate impact on occupation, particularly social participation.

Research Question

What is the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically social participation?

Definitions of Terms

The idea of *adolescence* emerged when psychologists began investigating the abilities and behaviors of individuals as they passed between the onset of puberty and marriage. The definition of adolescence was first established by G. Stanley Hall, a pioneer in adolescent research, in 1904 (Neville, 2000). Prior to Hall, adolescence was not considered a separate stage of human development. Since the early philosophers Plato, Aristotle, Comenius, and Rousseau focused on understanding the theoretical foundation of human development; it was not until the 15th century the word "adolescence" was first documented in the literature (Hall, 1904).

Stanley Hall, considered the father of adolescence, was the first psychologist to formulate a theory of adolescence (Hall, 1904; Neville, 2000). His theory was based on Darwin's concept of biologic evolution which he formulated into a psychological theory. The theory reflected that individuals proceeded through stages of development similar to Darwin's theory of how mankind proceeded through stages of development in history (Hall, S., 2009; Flanigan, 2001; Neville, 2000). Hall suggested that physiological changes cause psychological changes. These physiologic changes create "sturm and drang," (storm and stress), which add to a turbulent stage of life for these young adults. Throughout this period, it is common to observe adolescent behaviors fluctuating between the extremes of emotion. Unlike other stage theorists, who claimed adolescence ends earlier in life, Hall defined the end of adolescence, culminating at the beginning of adulthood (approximately 22-25 years of age) (Hall, 1904; Neville, 2000).

Adolescence has been defined many ways in the literature with most definitions not focusing on the chronological years but rather describing this period of time as a transition between the immaturity of childhood to the maturity of adulthood (Dell Children's Medical Center of Central Texas, 2009; Hollis & Morgan, 2001). This transition is not defined by a single event but rather a period of changes in an individual's development (Csikszentmihalyi & Larson, 1984). Adolescence is a complex time in life as physiologic, cognitive, emotional, and social changes are occurring. Relationships with peers and those of the opposite sex unfold which lead to self identity and autonym from parents or caregivers (Schultz et al., 2007). It is characterized as a period of transition where concrete thinking results in abstract reasoning.

Although no consensus was found what constitutes the age range of adolescence (Table 1), the literature revealed researchers, organizations, and academics label chronological years based on their individual justifications. For example, the WHO (2009) defines 10-19 years of age as being an adolescent. This wide range allows for cultural diversity as in some areas of the world, responsibilities and roles vary based on culture. Others view the start of adolescence with the appearance of puberty, 12 years of age, a time of hormonal changes and the appearance of secondary sex characteristics (Neville, 2000). Meanwhile, such large organizations as the NCI and the Children's Oncology Group of the United States recognize 15-19 years of age as the period of adolescence. This consensus is neither based in a developmental, social, cultural, or theoretical model, but rather a policy within these organizations to study cancer in 5 year periods (Barr, 2007; Hollis & Morgan, 2001).

Adolescence is also a period of biological changes which are controlled by genetics and hormones. Puberty, a stage within the developmental process, is responsible for the development of sexual maturation where secondary sex characteristics develop.

Females begin this process approximately 1-2 years earlier than boys (with average ages of 9 to 14 for girls and 10 to 17 for boys), and reach completion in a shorter time. Visually, adolescent girls begin to develop breasts, hips, and pubic hair followed with hormonal changes resulting in menarche, the first sign of possible fertility. During this period, boys develop deeper voices, facial hair, and increased testicular size (Christie & Viner, 2005; Neville, 2000; Shaffer, 1989).

Puberty is also a period where physical growth takes place. Adolescents usually have a growth spurt which can last 2-3 years encompassing increased skeletal and muscle mass. Boys usually reach their full height between 18-21 years of age, whereas girls plateau between 16-17 years of age. Besides this outward physical growth, internal organs mature in size to meet the changing needs of an adolescent's body (Dworetzky, 1984; Neville, 2000).

Operationally, the terms *adolescent* and *young adult* for the purpose of this study relate to individuals between 13-19 years of age according to *Dorland's Illustrated Medical Dictionary* (2003).

Table 1

Definitions of Adolescence

"The period of life between childhood and adulthood" (Kaplan, 2004, p. 1, Adolescence)
"A child means every human being below the age of 18 years unless . . . majority is attained earlier" *(Article 1*: contained in the United Nations Convention on the Rights of the Child, 1989)
"Adolescence—the years between childhood and adulthood; often identified with the teens or with the period from puberty to full skeletal and reproductive maturity" (Peterson, C., *Looking Forward Through the Lifespan* [2nd ed.], p. 613)
"Adolescence – in the process of developing from a child into an adult" *(Oxford Dictionary of Current English* (3rd ed., p. 11*)*

Childhood cancer, pediatric cancer, adolescent cancer, and *pediatric oncology* mentioned in this study all refer to cancers most often associated with individuals less than 19 years of age (NCI, 2009). Patterns of cancer in this age group differ greatly from young adults (see Table 2) with no true explanation (Hollis & Morgan, 2001). Cancer, an abnormal uncontrolled increase of cells, can occur in any part of the body (Bearison & Mulhern, 1994). The most common types of cancer in the adolescent population are lymphomas and leukemia, which today result in high cure rates secondary to aggressive treatment interventions (NCI, 2009).

Table 2

Relative Frequencies (%) of Cancer by Primary Site and Age

Site	**15-19 yrs.**	**20-24 yrs.**
Lymphoma	26%	22%
Leukemia	12%	7%
Central Nervous System	10%	7%
Endocrine Syatem	9%	12%
Skin	8%	14%
Male & Female Genital System	8%	Male 13% Female 8%
Bone & Joint	8%	3%
Soft Tissue	5%	3%
Digestive System	2%	3%
Oral cavity/Pharynx	2%	3%
Respiratory System	2%	2%
Urinary System	2%	2%
Breast	-	2%
Other	2%	2%

From “Common Cancers in Adolescents” by R. Barr, 2007, *Cancer Treatment Reviews, 33*, p. 597.

The construct of *social participation* relates to "the nature and extent of a person's involvement in life situations or the lived experiences" (WHO, 2001, p. 15). The ability for individuals to participate in life's daily occupations is a vital component of human development (Law, 2002a). Social participation allows individuals to become involved in activities which foster relationships with others, stimulates a sense of personal growth and satisfaction, and instills meaning in peoples' lives. Studies reflect individuals involved in occupations or shared activities gain secondary benefits of improved health and overall well-being (Law 2002a; Nelson, 1988; Reilly, 1962). Social participation does not occur in a narrow window of life but rather incorporates environmental, personal, and family factors, as individuals are complex occupational beings (King et al., 2003). This holistic view of social participation in everyday occupations remains a foundation of the profession (Law, 2002a). Additionally, social participation is one of the profession's core beliefs as outlined in the AOTA 2008 Framework (2nd ed.) (AOTA, 2008).

Occupation, a term defined as “activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture” (Christiansen & Townsend, 2004, p. 279), is congruent with occupational therapy's core philosophy of engaging individuals in tasks or activities (occupations) that are both meaningful and purposeful to maintain health (Wilcock, 1998). Occupations are personally constructed subjective events perceived in temporal, spatial, and socio-cultural conditions that are unique to that one time experience (Pierce, 2001). They are perceived by the individual as goal-directed and having meaning (Pierce, 2001).

Research establishing the use of sustained occupation is well documented in occupational therapy’s body of knowledge. In his 1996 Slagle lecture, Nelson supports the concept of therapeutic occupation, which he states “Human beings can attain enhanced health and quality of life by actively doing things that are personally meaningful and purposeful, in other words, through occupation” (1997, p. 11). Likewise, Fisher (1998) strongly advocates that OT concentrate on the use of occupations which she describes as “activities, not any purposeful activity, but those that are meaningful and purposeful to the person who engages in them” (p. 511). Through meaningful occupations, individuals are more likely to accomplish goals if they have a vested interest, in the final outcome (Schemm, 1987). However, when occupations are meaningless to an individual, a functional decline or a withdrawal is imminent. Throughout an individual’s life, engagement in occupations that contribute to his/her own well-being or those of society represents a measure of a healthy individual (Breines, 1989). In essence, these interactions between the individual and the environment will contribute to long-lasting life and health. Throughout this study, the term occupation is operationalized as activities which individuals identify as meaningful and enjoy participating in during the course of their day.

Rationale and Need for the Study

Significance for Occupational Therapy

Adolescence is an important period of growth and development that involves significant psychological, social, and maturational adjustments as adolescents move toward adulthood. This transition can be a time filled with anxiety and uncertainty as these young adults strive to achieve independence, establish an identity, and plan for the future. A diagnosis of cancer at this critical time is devastating and brings with it many difficulties for the patient, family, friends, and health-care professionals (Hollis & Morgan, 2001).

Understanding the complexity of social participation including factors that influence participation in this population remains unclear. It is important to know what environmental, family, and personal factors influence participation (Law, 2002a). Knowledge gained from research about participation and this population will assist occupational therapists in developing client-centered treatment interventions. Past research has demonstrated that client-centered approaches have led to greater satisfaction among individuals and improved outcome measures (Baum & Baptiste, 2002; Law, 2002a).

The aim of this study was to illuminate the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically social participation from an OT perspective, in order to increase the profession’s present body of knowledge and better understand these individuals at a transitional period in their live. The need for this study was based on the limited research in OT that described the reported experiences of adolescents undergoing cancer treatment and the secondary impact on social participation. Additionally, it is congruent with the occupational therapy’s founding philosophy to consider contextual factors (environmental and temporal) in which one performs his or her occupation(s). Since this context is unique to each individual, generalization is not possible; however, results of this study will enlighten the profession to factors which may inhibit or enhance adolescents in the treatment process of cancer from engaging in age related occupation(s) that are necessary for their growth and development.

Significance for Society

The idea of surviving pediatric cancer was unheard of 40 years ago and no studies reflected the idea of survivorship, but rather coping or anticipatory grieving (Koocher, O'Malley, Gogan, & Foster, 1980). Most psychologists who worked with these pediatric cancer patients and their families in a sense were guided by the medical model (Koocher & O'Malley, 1981; Koocher et al., 1980) which led them to believe that cancer was a traditional death sentence and psychological intervention should incorporate acceptance and preparing for the worst.

Since the cure rates in the past years for pediatric cancer(s) continue to surge, the challenges are now to illuminate the lived experiences of these young patients in order to understand their daily lives of living with cancer in relationship to their occupational engagement, specifically social participation. However, limited literature within the OT profession fails to acknowledge the need to explore this topic beyond the medical model, as evident in a 1981 article published in a basic OT textbook addressing the physical dysfunction of children with leukemia (Bieringer, 1981).

Outside the profession, literature was also non-existent as in the early years; very few mental health professionals were actively working with families and children secondary to the emotional burden of the situation. Throughout the 1950s little interest in terms of psychological assistance was given to children with cancer as psychologists and psychiatrists faced meeting with parents and offering very little prospect of a cure

(Pinkel, 1994). Studies in this area were often overlooked due to the few survivors to study (Armstrong & Reaman, 2005; Koocher et al., 1980).

The idea of being truthful to young patients with cancer was first documented in a 1965 article “Who’s Afraid of Death on a Leukemia Ward?” Vernick and Karon explored the difficulty physicians faced when dealing with a child with a fatal illness. At the time the medical model guided treatment interventions, so it was highly unlikely that a child would be told about the extent of his/her illness. The role of the physician was to cure disease, so the idea of dealing with the psychological part of dying was outside the norm. However, it was often regarded as protecting the patient from the truth, but in reality, health professionals did not want to deal with their own anxieties of death and dying, as they were not immune to their own feelings. Eisenberg (1981) and Evans and Edin (1968) argued that shielding such young patients from the concept of death provided hope versus despair, although oncologists preferred a more direct truthful approach.

Not until the introduction of chemotherapy and surgical interventions in the 1960s were psychological aspects of pediatric cancer examined. Although this was a step in the right direction, throughout the 1970s psychology concentrated heavily on death and dying, rather than the occupation of living (Pinkel, 1994). A noticeable growth in research grew out of the need to discover how individuals cope with cancer, as the pediatric survival rate was approximately 10% during this period. Emphasis was placed on the family and siblings of the patients with cancer rather than the patients themselves as it was felt they required more emotional support in dealing with an inevitable situation.

In a review of the literature between 1955 and 1976, Slavin (1981) highlighted 13 initial studies that reflected the experiences of these families to explain their coping strategies throughout the experience and after death of the child. These early psychological studies combined demographic data of childhood cancer patients into one category without consideration of age, sex, or diagnosis. Data collection methods lacked the rigor of today's standards, and were often completed through impersonal questionnaires, clinical observations, and judgments made by staff without standardized assessment tools (Kupst, 1994; Redd, 1994; Slavin, 1981; Zeltzer, 1993).

As effective medical treatments became established, with multiple drug "cocktails", resulting in significant survival rates, the area of psychological research in the care of these patients became evident (Eisenberg, 1981). Since the 1960s there have been more than 200 studies published related to coping and adjustment in the area of pediatric oncology (Kupst, 1994). This increase in research is correlated to the increased survival rates among this population. Additionally, as the survival rates increased in children and adolescents, the focus of research shifted from the family to survivors as the primary subjects (Kupst, 1994).

Throughout the 1980s studies in psychology began to focus on long-term survivors, with the first psychological study to be published in 1981 by Koocher and O'Malley. In this initial study which began in 1975 and concluded in 1980, both the psychosocial impact among childhood cancer survivors and their families were examined, including the late effects of survivorship. This descriptive retrospective study broke new ground in exploring aspects of psychosocial functioning not explored prior. Subsequent studies over the next two decades involved standardized assessment tools, personalized interviews, and highlighted survivorship among this population (Kazak, 1994; Redd, 1994).

Although current research has expanded to develop interventions and procedures, especially in the area of pain management, there are areas of research which still need to be explored. Research emphasizing the long-term effects on survivorship over the past 20 years has been influential in implementing new policies at the national level and informing physicians of new cancer protocols. However, further research in the psychosocial aspects of childhood cancer offers many opportunities to advance our knowledge and understanding of how this population handles stress and adaptation to trauma (Armstrong & Reaman, 2005; Redd, 1994).

Unfortunately, most studies in naturalistic research are generated through universities or individual researchers where financial support is often not available. Prioritization of studies and resources remain within the medical model (Redd, 1994) where clinical-trials continue to be funded through health insurance, pharmaceutical companies, or philanthropic donors (Armstrong & Reaman, 2005). Barriers to naturalist inquiry examining the impact of the psychosocial aspects of cancer remain a relatively low priority within the major Cooperative Cancer Group(s), secondary to time and limited resources.

Overall, the literature has grown over the last 40 years to reflect the changes in survivorship secondary to advances within the world of medicine. This shift from the lack of research to the study of the family in terms of coping, adjustment, and death and dying, to finally survivorship, reflects internal growth within the fields of medicine and psychology. However, to truly comprehend the experience of these young adults, studies within the lived experience have the potential to illuminate our understanding of adaptive methods utilized by these individuals in their daily lives.

Occupational Therapy's Changing Role in Cancer Care

Occupational therapy practitioners who work with individuals with cancer have traditionally addressed psychosocial, physical, and cognitive performance component problems such as depression, fatigue, pain, poor motor control, and memory loss (Bieringer, 1981). However, individuals often experience an inability to pursue meaningful tasks, secondary to busy treatment schedules, hospitalizations, fatigue, side effects of medications, and self-image issues (Christiansen & Townsend, 2004). Thus, the individual may experience occupational deprivation. Occupational therapy is a holistic profession that not only focuses on people with disabilities, but how their disability affects engagement in occupations (Christiansen & Townsend, 2004). The need to explore this phenomenon and develop new frames of reference is limited secondary to a lack of research within this population.

Today there is resurgence within the profession with a focus on "enhancing health and quality of life by actively doing things that are personally meaningful and purposeful" (Nelson, 1997, p. 11; Yerxa, 1991). Literature supporting the use of occupation is well documented in OT as a connection has been made that an individual involved in purposeful tasks developed routines, which in the end, led to individuals who were healthier and better organized in life (Kielhofner, 1996). With this emphasis on the use of occupation, this phenomenological study hopes to illuminate and discover the impact of sustained occupation(s) on adolescents in the treatment process of cancer. Furthermore, it is important for occupational therapists to understand the essence and human experiences of these adolescent cancer patients, in order to plan individualized interventions that are meaningful and effective (Yerxa, 1991).

Any disruption in an adolescent’s life resulting from a chronic illness such as cancer brings about changes in an individual’s lifestyle. The side effects of chemotherapy and the rigors of treatment can lead to physical impairments and emotional imbalances (Armstrong & Reaman, 2005; Kyngäs et al., 2001). Changes in eating and sleeping patterns, mood changes, and self-image issues interrupt routines and habits (Bauld, Anderson, & Arnold, 1998; Dolgin, Katz, Zeltzer, & Landsverk, 1989). In a global sense these factors may lead to maladaptive behaviors, poor or inappropriate social skills, and the inability to fulfill occupational roles (parent, sibling, student, worker, etc.). This overall breakdown can be a barrier in preparing the adolescent population for a productive role in adult society (Csikszentmihalyi & Larson, 1984).

Through qualitative research designs the experiences of these adolescents have the potential to make positive changes within their local communities and impact national and international policy. Opportunities exist to influence political and social thinking to promote, apply, and evaluate changes that will positively influence outcomes for these young adults. Through raised awareness public health policy makers can identify barriers young people face in accessing youth-friendly health services; increase the number of facilities prepared to address the needs of this population; and on a global scale facilitate innovations in practice to continuously improve quality of care (Eden, Barr, Bleyer, & Whiteson, 2005).

Occupational therapy practitioners working with individuals with cancer address psychosocial, physical, and cognitive performance component skills such as depression, fatigue, pain, poor motor control, and memory loss (Bieringer, 1981). Addressing deficits in particular performance areas such as basic and instrumental activities of daily living, leisure pursuits, work transition, and modifications of the physical environment, have been within our traditional scope of practice.

The need for individuals to engage in occupation, as suggested by Wilcock (1993), is to “fulfill the basic human need for survival; provide a mechanism for individuals to develop innate abilities of a biological, social, and cultural nature; and to adapt to environmental changes in order to flourish as individuals” (p. 17). The focus on social participation leads to the identification of barriers related to these young adults that interfere with everyday performance in the areas self care, daily routines, education, play, social interaction, and community integration. In order for occupational therapists to gauge further insights into this area, studies examining chronic illness and the influence on occupations are needed to illuminate the problems of young adult patients with cancer. Additionally, from an occupational therapy perspective it would be interesting to study how these patients are influenced by their environment, culture, traditions, and spirituality in developing adaptive strategies to participate in meaningful, satisfying, and healthy occupations. It is important for occupational therapists to understand the essence and human experiences of these young adults, in order to support interventions that are meaningful and effective.

Currently, OT literature lacks research in this area of study. Contributions can enhance our body of knowledge by providing insights into the resulting effects of adolescents when faced with a life-threatening disease. Second, new studies can lay the foundation in developing strategies for this population undergoing cancer treatment and the factors, which may be barriers from engaging in occupation.

Assumptions and Limitations of the Study

Qualitative research is a method of inquiry that differs philosophically from the methods of quantitative research. It is naturalistic, individualized, and assumes a socially constructed reality through life-stories of participants. The foundation of inquiry searches for understanding of an experience instead of causality, and is conducted by a researcher immersed in the setting as an instrument of the study (Moustakas, 1994). The underlying objective of qualitative research is to understand the participants' life experience(s) or the phenomenon of interest from the perspective of the participant (Creswell, 1998; Moustakas, 1994).

Certain assumptions must be recognized when engaging in qualitative research. First, one or two interviews within a period of time may not apply to another point in the participant's life as individuals and life experiences change over time. Second, qualitative research is bound in both time and context making generalization not possible to other young adults with cancer (Creswell, 1998; Moustakas, 1994). A third assumption relates to interpretation of participants' life-stories through phenomenological reduction. Moustakas suggests the importance of the researcher in bringing personal experiences into the study to arrive at the essence of the experience. Although bracketing is a standard method of data reduction, it cannot be assumed that my personal experience with cancer will not impact interpretation of data. Finally, within phenomenology, all aspects of a participant's life-stories are assumed to be true. While this cannot be guaranteed, methods were utilized in the research method to increase the rigor of this study.

Limitations existed in developing this study. Such limitations consisted of long periods of time waiting for the gatekeeper to find participants who met the criteria for the study. Because a majority of the patients at Hackensack University Medical Center are younger than the study criteria, it was often difficult to first identify potential participants. Often follow-up contacts with potential participant(s) by the researcher resulted in commitments to participate in the study; however, most did not materialize due to various reasons. However, when interviews did take place, they were frequently scheduled around the participants’ treatment appointments, as side effects of the medications often dictated meeting times.

In addition to the limitations of the study, delimitating parameters were imposed. First, interviews with only four adolescent patients between 17-19 years of age undergoing cancer treatment were completed. The few participants reflects a phenomenological approach intended to illuminate the essence of individual experiences in depth, rather than broaden the experiences to understand groups of people, or generalized results (Moustakas, 1994; Patton, 1990). Second, parameters regarding the sample pool were imposed to meet the study criteria. Through the use of these parameters participants were identified who met the criteria and may have similar life-stories related to the phenomena under study.

Chapter 2: Review of the Literature

Introduction to the Chapter

The purpose of this chapter is to establish a foundation of previous qualitative and quantitative research conducted with adolescents dealing with cancer and the ultimate impact on occupation, particularly social participation. Reviewing and critiquing existing literature about the adolescent patient with cancer, with respect to his or her everyday experiences, allows for identification of gaps in the literature.

Initial findings emphasized studies within the medical model regarding new medical treatments for the pediatric population. Further review utilizing Medline, OVID, Ebsco Host, and Cinhal databases with different search terms such as pediatric oncology, adolescent oncology, and social participation, located additional studies. These studies focused on school re-entry after cancer treatment, coping skills, and psychosocial aspects of adolescent cancer survivors. No research study was identified which addressed the question related to social participation and adolescents within the lived experience. However, phenomenological studies were located in the nursing literature which explored other themes. These themes highlighted the past lived experience of adolescent patients who had cancer, for example, living with uncertainty and the ongoing consequences of having cancer.

The search was limited to research completed from 1999-2010 to reflect current trends in the literature. However, if a significant article was located outside of this period, it was utilized to fill missing gaps in the current literature. Additionally, any literature outside this time period which identified any landmark papers first acknowledging the lived experiences of adolescents and social participation, were included. A synthesis, which follows, expands on the most common themes identified in the literature.

Developmental Theories

Various theories of development have addressed the physical, emotional, intellectual, and/or social growth of the adolescent (Gesell, 1954; Shirley, 1931). Theoretical literature in the area of psychosocial intervention has derived from the works of Freud, Erikson, and Piaget to name a few. Illuminating these theories within this study will provide a basis for understanding the impact cancer may have on the developmental stages of these young adults.

Freud’s psychoanalytic theory stated that mental health and mental illness are determined by the relationships individuals have with objects either physical (nonhuman) or people (human) (Early, 1987). Within an individual’s personality coexist the id, ego, and superego which develop in childhood to assist in the satisfaction of innate instincts. If conflict arises between the three structures, resulting anxiety will lead to the use of unconscious strategies (defense mechanisms) as a way of dealing with the consequences of that anxiety (Simon & Daub, 1993).

Besides this psychoanalytic theory, Freud also developed a psychosexual theory similar to his previous stage model. Once again, an individual must pass through all stages successfully in order to reach adulthood. The stages described in the model were in relationship to body zones (oral, anal, phallic, and genital) where pleasure is achieved (Neville, 2000). The genital stage, as Freud described as the adolescent stage, is characterized as a reawakening of an adolescent’s sexual drive, where gratification of sexual urges becomes unleashed. Adolescents are often in a state of turmoil within this stage, secondary to the conflicts of the id, ego, and superego, as feelings of sexual gratification are developing (Freud, 1946; Muuss, 1996). Adolescent behaviors within this period may not reflect social or moral norms as internal conflicts lead to a psychological imbalance. Although internal conflicts exist throughout the adolescent's lifetime, most people achieve a state of stability by the end of the genital stage (Miller, 1983).

In terms of the developmental theories, Erikson and Piaget also believed that psychosocial development occurs in stages (Erickson, 1968; Muuss, 1996; Piaget, 1950). At each stage of development specific developmental tasks need to be mastered. Erickson outlined eight stages of human development related to psychosocial theory, based on a continuum through an individual's lifespan. These stages are accompanied by periods of crisis in which resolution is necessary to precede to the next stage of development. Successful resolution of conflicts encountered in earlier developmental stages builds a more mature perspective. Erickson notes that factors such as disease, poverty, and emotional or social deprivation can inhibit mastery of any stage of development. If this occurs an individual's behavior will not reflect the maturity of his/her peers (Early, 1987; Erickson, 1968; Neville, 2000). However, when mastery is achieved self-certainty as opposed to self consciousness and self doubt are instilled in the individual (Early, 1987).

Erickson's (1968) fifth stage of development, Identity vs. Role Confusion (14-20 years of age), addresses the developmental aspect of adolescence. At this stage, development now depends on the independent actions or decisions of the adolescent in contrast to those of the parents or caregivers. In this period of development, the adolescent is searching for self-identity asking the questions “Who am I?” “What do I want to become?” “Where did I come from?”

Historically, the older generation (parents, grandparents) acted as role models in assisting adolescents in constructing their self-identity. However, due to rapidly changing social roles, this is no longer possible (Muuss, 1996). In seeking these answers, peer relationships become a major influence on an adolescent’s identity as approval is sought from others. Through peer relationships, the establishment of one’s identity is formulated through social feedback. An adolescent must struggle to discover and find his or her own identity, while developing a sense of morality and right from wrong.

In seeking one’s identity, adolescents often become preoccupied with their appearance as body image is inherently related to identity. It is a period where maturity develops as the adolescent acquires a sense of self-certainty as opposed to self-consciousness and self-doubt. Socially accepted behaviors are developed rather than behaviors that reflect poor social norms (Erickson, 1968; Muuss, 1996). A new sense of achievement is anticipated as goals are established for future occupational or educational endeavors. Rebellious behaviors within the family unit lead to conflict which is normal and healthy as it assists the adolescent in developing his/her own set of values and identity. Through the development and integration of these new values and self-identity, adolescents develop their own philosophy of the world and the ability to participate in new social roles within society (Neville, 2000).

Piaget, on the other hand, focused on cognitive development, which resulted from experiences of everyday living. In a similar nature to Erikson, he theorized that cognitive development occurred in four major stages with each stage building on the next. The stages include infancy, preschool, childhood, and adolescence. Each stage is characterized by both an individual’s cognitive abilities and his/her understanding of reality during that period, which impacts the thinking process (Muuss, 1996; Piaget, 1950). This cumulative sequence enables a child to progress through these steps ultimately resulting in cognitive development (Simon & Daub, 1993). Cognitive development involves changes in cognitive process and abilities. In Piaget’s view, early cognitive development involves processes based upon actions and later progresses into changes in mental operations. The formal operational period is the fourth and final stage in Piaget's theory of cognitive development. This stage begins at approximately age 12 and lasts into adulthood. During this time, adolescents develop the ability to think about abstract concepts and draw conclusions from existing information. The ability to assimilate this information into hypothetical or real situations reflects a move beyond concrete thinking. Skills such as logical thought, deductive reasoning, and systematic planning also emerge during this stage (Miller, 1983; Muuss, 1996). In reflecting on the stages of cognitive development, thought processes become increasingly organized and focused, building on previous stages of development. This progression assists in the transitional process from childhood to adulthood.

Traditionally, approaches to human development have highlighted milestones of human growth in a stage-specific sequence. In contrast, contemporary theories explore the influences of changing relationships and their impact throughout childhood into adolescence (Lewis, 1997). One theory as proposed by Lerner (2001), describes how physical, cognitive, and social growth in children are interdependent on factors such as family, culture, community, and physical ecology. When change occurs in these areas, an internal equilibrium is created to meet the demands of the external environment. In essence, human development is the outcome of change between individuals and their changing context.

Beyond the scope of childhood development, Arnett (2000) proposed his "Emerging Adulthood" theory of development targeting the 18-25 year old population. The theory is a framework that recognizes that the transition to adulthood is complex in nature and based on cultural and societal influences. These influences have changed since the mid 20th century, when most people in industrialized societies married and obtained stable full-time work by age 20. Today, the trends of the 21st century have shifted to the pursuit of postsecondary education over job security, with marriage occurring later in life. Unlike Erickson, Arnett recognizes that this stage of life is not only a transitional period, but a separate period of an individual's life course, with features unto itself. These features (*age of identity/explorations,* the *age of instability,* the *self-focused age,* the *age of feeling in-between,* and *the age of possibilities*), as he theorizes are not proposed as universal, but are most common during emerging adulthood rather than any other developmental period.

Adolescent Culture

Traditionally, adolescence was considered only as a biological stage of development concerning physical changes. Today, the social and emotional changes that happen during adolescence are recognized as a stage in life that brings excitement, discovery, and achievement (Gunstone, Maddock, Matthews, & Roy, 2003). The term adolescence has existed since the early 1900s in Western society, transforming expectations based on cultural and social customs rather than biological markers

(Gunstone et al., 2003; Kaplan, 2004). Prior to this, adolescence as a stage in the developmental process did not exist. The cultural growth of adolescence erupted in American society after World War II when the economy was strong and a post baby boom took place. As educational systems improved and expanded their curricula, an influx of students promoted the creation of extracurricular organizations and peer groups. This fostered socialization of these young people at the time. Through this further expansion into social outlets, young people created a youth culture identified with styles and music (Kaplan, 2004).

This new “counter culture” was not always in line with family values, often leading to conflicts with adults (Anderson & Carter, 1990). However, since the economy was strong, these young adults had the purchasing power to become a marketable demographic. Through the ensuing decades the adolescent population had strong influences on the consumer economy and social issues of the time. Their disruptive activism throughout the 1960s was seen as widening the generation gap.

In traditional societies, physical changes determined the transitional period from childhood to adulthood, without recognizing the milestone of adolescence. This transition included all aspects of life from daily attire to the roles and responsibilities of the time. Gunstone et al. (2003) note that during medieval times, girls often got married as young as 13 years of age, or younger. This was usually followed by the birth of the first child very soon after. These young women had the responsibilities of maintaining a household, performing a parenting role, and assisting in providing for the needs of the family. Even as recently as the beginning of the 20th century, girls were married by the age of 18 reflecting the moral and social climate of the time.

Cultural and Social Context of Adolescence

In understanding the occupations of an adolescent it is necessary to acknowledge that engagement in occupation occurs in the contexts of a physical or social environment (AOTA, 2008). In accordance with the *Occupational Therapy Practice Framework: Domain and Process* (2nd ed., 2008), these contexts or environments (cultural, personal, temporal, and virtual) play an influential role in how occupations are chosen, prioritized, and organized. Culture, for instance, highly influences the specific occupations chosen by an individual (Toulmin, 1995), subsequently setting the foundation for one's beliefs and behavioral standards (Moore, 1996). In order to recognize the impact of culture on the development of young adults, one must first understand the many facets which impact occupational choices.

Cultural traditions or rituals within the social norms of a specific society dictate the transition from adolescence to adulthood. Cultural differences are the differences between the ideas, beliefs, and customs of different groups of people. Transition from adolescence to adulthood occurs in a nonlinear pattern and is often representative of the culture at large (Degner, 2006). Differences in values and customs shape the adolescent experience to meet the cultural norms of that society. In some cultures, value is placed on achievement, with high expectations of educational success. However, in other cultures, education may take a secondary role to family responsibilities. In the nontraditional nuclear family, adolescent members may be called upon to play parenting roles secondary to divorce or poor socioeconomic conditions (Neville, 2000).

In some cultures ceremonies celebrating the transition into adulthood typically occur during adolescence, for example, seijin shiki an adult ceremony in Japanese culture and upanayanam for males in the Hindu world represent the step into adulthood (Tweed & Prothero, 1999). In Judaism, 13 year old boys become bar mitzvah, a celebration to mark the coming of adulthood (Dworetzky, 1984). Among some denominations of Christianity, the rite or sacrament of confirmation is received and is considered the time at which adolescents become members of the church in their own right (Csikszentmihalyi & Larson, 1984; Dues, 1998). In the United States a “Sweet 16” birthday party for a young girl represents moving into another stage of life. A similar tradition occurs in Latin cultures, however, celebrated at age 15. These traditions may often mark the end of adolescence with social maturity, economic independence, and family autonomy (Neville, 2000).

The transition into adolescence and onto adulthood is not always based on rituals, but rather widely recognized tangible markers within that society. An individual’s first part-time or full-time job, a driver’s license, the right to vote or be married, the ability to join the military, finishing high school and preparing for college are all significant symbols of transition (DeLany & Pendzick, 2009; Dworetzky, 1984). These markers of transition are frequently achieved throughout the period of adolescence and most often based in a chronically sequence ranging from 13-19 years of age.

Similar to the influences of culture on occupational decision making, adolescents are influenced by their social environment (relationships with friends, spouse, caregivers, organizations, etc.). These social environments or relationships they create are unique in nature; therefore, patterns of daily occupations are individualized (Christiansen & Townsend, 2004). In understanding this social relationship, the link between occupation and health and well-being can be established. This philosophy remains a core value within the profession and is congruent with the Occupational Therapy Framework (AOTA, 2008). In this study, the social influences of peers and other relationships will assist in highlighting meaningful occupation(s) of these young adults, and its overall impact on social participation.

Adolescence is a period of social transition between childhood and adulthood in which an individual often seeks more independence. As a result of social development, the relationship between an adolescent and his or her parents and peers change (Rice, 1997). A shift in strong family relationships to peer relationships often does not lessen the significance of the family in the adolescent's life, but rather builds the foundation for personal identity and autonomy. It is a way of preparing for adulthood (Dworetzky, 1984; Pruitt, 2000).

Traditionally, the family is the center of social life for children. During adolescence, the peer group begins to replace the family as the child's primary social focus. This period eventually materializes during adolescence with an increasing involvement with peer group(s). These groups are friends or acquaintances of the same sex who “hang out” together. Peer groups become very influential, especially, if members want to remain as part of the group. Members who want to remain in the group often go to extremes to fit in with changing their appearance or behavior, alternating the way they dress, or sometimes adopting a new language. Piercings, tattoos, brandings, and sometimes smoking are often seen as the adolescent builds stronger ties within the group. This behavior is most often a response to the fear of rejection from group members, which can lead to social isolation and loneliness (Crouter, 1995).

Throughout the later years as the adolescent matures, more intimate relationships are developed with the opposite sex. The consequences of decision making now shift from the parents’ responsibility to that of the adolescent. Interest in developing future goals in terms of college or vocational pursuits begin which fosters independence and social autonomy from family and peers. The adolescent is now building a personal identity and establishing his/her own beliefs and values which may not be consistent with the social norms of society (Crouter, 1995).

In summary, adolescence is defined in many ways; however, the core foundation remains as a transitional period into adulthood. Societal and cultural norms define adolescence based on rituals, socioeconomic class, or cultural traditions. In psychology adolescence is grounded in a theoretical framework built on aspects of developmental stages within the life cycle. These stages place labels on defining periods throughout the life span including adolescence. In the medical model, physical and biological changes represent markers that reflect developmental milestones into young adulthood. These milestones are based on growth spurts and hormonal changes. Although adolescence is not universally, but culturally defined, it remains a pivotal period in human development as it represents future leaders in our society.

History of Adolescent Oncology

Cancer, a hyperplasia of normal cells, has been documented in the writings of the Egyptians dating back as early as 1500 BC. Later, Hippocrates (450-370 BC) recognized cancer calling it the “black bile which comes from the spleen” (Tebbi, 2007, p. 27). He originated the term “carcinoma” from the Greek language meaning “a cancer arising from the tissues within the skin” (Dorland, 2003). Throughout this period of history the etiology of cancer remained in the scientific realm as many speculated divine beginnings (Ramoutsaki, Dimitriou, Galanakis, Stiakaki, & Kalmanti, 2001). Hippocrates' view and understanding of cancer lasted for the next 1,000 years.

Throughout the years, theories changed within the medical community which led to innovative ideas and more holistic interventions. Medical treatments improved, however, anesthesia and sterile working conditions did not improve. By the 17th century, solid tumor removal and amputations in the lower extremities were not uncommon with the introduction of the tourniquet to control bleeding. Advances in surgical procedures allowed for the first mastectomies. Progress was also seen in the development of medical equipment, such as the microscope, which helped scientists examine the structures of cells, body tissues, and bacteria. Additionally, the microscope opened the doorway for experiments in cancer research. As a result of these advances, expanded public awareness through newspapers and magazines increased the numbers of people seeking annual medical examinations. The century ended with the establishment of modern pathology and the birth of oncology as a medical discipline (Bowden, 2003).

The recognition that children had different medical needs compared to the adult population began to emerge in the 18th century in Europe. The first hospitals to focus on the needs of children were in Berlin and London. This philosophy that children and adults are unique to each other in terms of medical needs took another century to be accepted. This change of attitudes within the medical establishment recognized the concept that "teenagers did really exist" (Craft, 2003, p. 2694). During this period in the United States, the Children's Hospital in Philadelphia was first to establish an adolescent care unit. The unit was a combination of adolescent oncology and a general medical unit for this age group. Although cancer has been documented in the literature to have existed for centuries, pediatric oncology remained an undeveloped area of research until the late 20th century. Prior to WWII the only treatment offered to individuals with cancer was a combination of surgery and radiation (Hammond, 1992; Neville, 2000). The idea to remove solid tumors from the body or reduce them prior to surgery was the main modality of treatment. These procedures did not work for all types of cancer as most were not in a solid form.

The breakthrough in cancer treatment came out of a disastrous event during WWII. During a military operation a group of people were accidentally exposed to mustard gas and developed very low white blood cell counts. Scientists theorized the same effect could be accomplished with man-made chemicals produced in a lab. This would offer oncologists another treatment option in fighting rapidly-growing cancerous white blood cells (Tebbi, 2007). Therefore, in the 1940s, several patients with advanced lymphomas (cancers of certain white blood cells) were given chemical compounds intravenously. Their improvement, although temporary, was significant leading researchers to evaluate other substances that might have similar effects against cancer (Barnes, 2005). These chemical substances came to be known as chemotherapy, a term coined by its founder Paul Ehrlich, a German scientist (Bowden, 2003; National Institutes of Health [NIH], 1998; Neville, 2000). As a result, many other drugs have been developed throughout the years to treat cancer based on the principles of early researchers.

Pediatric oncology emerged as a subspecialty in the United States following the observations in 1948 of Sidney Farber and his associates in Boston. They reported the benefits of chemotherapy for acute leukemia in children with their first remission (Hammond, 1992; Tebbi, 2007). The establishment of the Children's Cancer Group (CCG) in 1955 became pivotal in the early stages of clinical research in childhood cancers. Although subdivisions within the organization were established in the areas of adult and pediatric oncology, an adolescent specialty failed to materialize. Over the next two decades additional organizations partnered with the CCG, however, with this expansion, adolescent clinical trials remained in the pediatric domain (Bleyer, 1997). In 2000 four national pediatric organizations merged to form the Children's Oncology Group (COG), where the first Adolescent and Young Adult Committee was established (Tebbi, 2007; Tilstone, 2004).

Advances in pediatric oncology have been increasing in the last 50 years. The median survival rate of children with Acute Lymphocytic Leukemia (ALL) in 1956 was approximately 6 months (Hammond, 1992). In 1972 the survival rate in the pediatric population grew to 25% (Cohen, 2003). By the mid-1990s, nearly 75% of children with cancer survived at least 5 years after diagnosis. In the most current Centers for Disease Control report (2007), overall cancer death rates declined significantly among the adolescent population. Through the use of combinations of chemotherapy, more than 80% of children with cancer can now be cured. Besides chemotherapy, increased cure rates can be attributed to improved bone marrow transplantation methods (Centers for Disease Control, 2007) utilized today.

Current Literature Findings

In searching the research literature on adolescence, cancer, and the lived experience, it became apparent that several topics addressed survivorship, school re-entry, coping with cancer, and quality of life of adult survivors of childhood cancer. It is my intention to introduce these topics briefly in this literature review to establish a framework for this research study by identifying and analyzing the existing literature. Although no research was found directly related to adolescents and social participation, the following review lays the foundation for the research of this study. It also includes an in-depth history of phenomenology, the methodology which underscores this research.

Survivorship

Medical Model

Survivorship, a term first introduced by the National Coalition for Cancer Survivorship (NCCS) in 1985, has been defined in the literature from a medical model perspective to a more conceptual interpretation (Haylock, 2006). In medicine, a 5-year time span from initial remission to the end of treatment is the usual benchmark for estimating the prognosis of the disease (Brenner & Arndt, 2004; Lewis, 2006*)*. This benchmark is also significant in that a patient who remains cancer free with no relapse of disease is considered “cured” (Leigh, 1992; Neville, 2000). On a conceptual level, outside of the medical model, survivorship represents a period of time where individuals move from diagnosis and lasting for the rest of their lives (Lewis, 2006; Miedema, Hamilton, & Easley, 2007; NCCS, 2003; Zebrack, 2000). In essence, survivorship is considered to be a continuum through phases of life rather than any one point in time (Leigh, 1992).

Progress has been made in the last 50 years treating young adults with cancer. Increased survival among the adolescent population is a direct consequence of improved aggressive treatment interventions and early detection (Boydell, Stasiulis, Greenberg,

Greenberg, & Spiegler, 2008; Jones, 2008; Whyte & Smith, 1997). In the early decades of the 1900s with the appearance of radiation therapy to recent times with advancements in chemotherapy, survivorship continues to rise among this population. It is estimated that by the year 2010, 1 in every 250 young adults will be a survivor of childhood cancer (Haylock, 2006; Keene, Hobbie, & Ruccione, 2000; Viner, 2003). Because long-term survival is a new reality for many patients, who are now adults, the chance to live a normal life is now possible. Survivors, once unable to engage in meaningful occupation, now have the opportunity to fulfill prior roles and participate in school, work, recreational activities, and resume being a family caregiver (Curtiss & Haylock, 2006; Zebrack, 2000). This increase survival rate although positive has led to significant late effects which impact the quality of life among these survivors (Boydell et al., 2008).

Late effects among this maturing population include physical disabilities, infertility, growth problems, and cardiac dysfunction. Cognitive, emotional, and psychological issues have also been reported (Hill et al., 1998; Hobbie et al., 2000). In a qualitative study utilizing focus groups and in-depth interviews with 14 childhood cancer survivors, Boydell et al. (2008) examined the late effects of childhood cancer. Participants ranged from 17-29 years of age with significant neurocognitive deficits, secondary to full brain radiation therapy for malignant brain tumors. Most participants were living with their families except two (one in college and one lived independently). All participants graduated from high school with the exception of three, who were still attending school. Findings revealed that although these young adults demonstrated the drive to succeed in school, they resisted additional support for a desire to be treated the same as other students. As a result, high school was very frustrating and became a disappointing experience based on their struggle for normalcy in their lives. The ability to maintain academic competency in the face of acknowledged cognitive deficits was found to be a factor in their wish to be accepted and treated the same prior to their cancer experience. Other long-term effects of persistent fatigue, depression, anxiety, family discourse, and economic challenges, have been stumbling blocks to many survivors' new lives (Curtiss & Haylock, 2006).

In contrast, Eiser, Hill, and Vance (2000), investigated the psychological consequences of surviving childhood cancer. Through a systematic review they identified 25 studies based on an inclusion criterion of a 10 year period and the use of standardized measures with statistical analysis. The review focused specifically on studies involving general mental health issues. Subjects ranged in age from 3 to 37 years of age with samples sizes varying from 20-309. Findings suggest survivors did not show deficits in measures of anxiety, depression, or self-esteem when compared with the normal population or matched controls. Similarly, Langeveld, Stam, Grootenhuis, and Last (2002) reviewed 30 studies published in 2001 on survivors of childhood cancer. Data reflected that most survivors were in good health and functioning well psychologically, however, worried about reproduction and their children's future health.

Although survivorship remains high among this population, the effects of treatment-related morbidity from the use of toxins and its relationship to the normal aging process remains unexplored. Researchers' hypothesized patients who have been treated successfully during their youth may develop impairments in their vital organs, thus increasing their risk for a premature death (Skinner, Wallace, & Levitt, 2006). Cardous-Ubbink et al. support this hypothesis. In their 2004 study they reviewed 1,378 patient records that were treated for childhood cancer in the Netherlands between 1966 and 1996 and survived at least 5 years. Cause specific mortality was compared to the general population in order to establish a baseline. After a median follow-up (16 year point), 120 patients had died from their primary cancer. Further results indicated patients followed 20 years post cancer, demonstrated increased mortality, correlated to treatment-related factors rather than original diagnosis of cancer.

In a similar study, Green, Hyland, Chung, Zevon, and Hall (1999), reviewed medical records of all patients younger than 20 years of age at diagnosis who were referred to the Department of Pediatrics at Roswell Park Cancer Institute between January 1, 1960, and December 31, 1989. A total of 1,441 subjects were identified who met the researchers' inclusion criteria. Three primary statistical analyses were conducted: (1) standardized mortality ratios (SMRs) were calculated to determine whether identified subjects were at a greater risk of dying than the general population; (2) log-rank tests were performed to determine the statistical significance of factors that may have modified the risk of death; and (3) a Cox's regression which is designed for analysis of time until an event or time between events. In this case, the Cox analysis assisted in determining whether particular predictor variables were associated with increased survival time. Results found that the original cancer was the most common cause of death followed by a secondary malignancy in patients who survived 15 years post treatment. In spite of the many challenges cancer survivors must endure, the idea of long-term survivorship which was once very rare, continues to be a common occurrence.

Quality of Life

Health related quality of life (QOL) refers specifically to health and illness and the impact within an individual. It can only be described by an individual considering the many facets of life. In defining QOL it is multifaceted considering domains of physical, social, emotional, spiritual, and cognitive functioning rather than the general concept of well-being (see Table 3) (Calman, 1984; Eiser, 2007; Ferrell & Dow, 1997). Any disruptions in any area can impact another area leading to an imbalance in an individual's overall well-being.

Table 3

Quality of Life Indicators

1. Physical well-being: control or relief of symptoms and maintenance of function and independence.
2. Psychological well-being: an attempt to maintain a sense of control in the face of a life threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown, as well as positive life changes.
3. Social well-being: the effort to deal with the impact of cancer on individuals, their roles, and relationships.
4. Spiritual well-being: the ability to maintain hope and derive meaning from the cancer experience, which is characterized by uncertainty.

From "Quality of Life Among Long-Term Cancer Survivors" by B. Ferrell and K. Dow, 1997, *Oncology*, *11*, p. 569.

Quality of life studies are well documented among adolescents with cancer, however, emphasis was found to focus on survivorship rather than the actual treatment period (Bradlyn, 2004; Bryant, 2003; Hicks, Bartholomew, Ward-Smith, & Hutto, 2003; Ward-Smith, Hamlin, Bartholomew, & Stegenga, 2007). Although outside the realm of occupational therapy, they offer unique perspectives from an adolescent's viewpoint.

In studies pertaining to QOL, participants report concerns over the uncertainty about their future health, possible relapse, or accepting the long-term effects of cancer (Eiser, 2007). Studies indicate that QOL and self-esteem in young adult survivors of childhood cancer is not significantly different from their healthy peers (Langeveld, Grootenhuis, Voute, Hann, & Van Den Bos, 2004; Stam, Grootenhuis, Caron, & Last, 2006; Ward-Smith et al., 2007). However, cancer survivors described several problematic late effects that influence their ability to function and negatively influenced their QOL. The most common late effects were lower physical functioning scores as compared to non cancer survivors. Pain and fatigue were also identified as impacting QOL. Pain often occurs in advanced diseases related to bone metastasis and compression of adjacent nerves and tissues. Similar to the impact of pain, fatigue has been reported to disrupt the lives of cancer survivors and decrease overall participation in daily activities (Mattsson, Ringnér, Ljungman, & von Essen, 2007).

However, in terms of general health concerns, no significant differences were noted. Although general health concerns appear to be the same, cancer survivors often mention future health concerns (e.g., relapse, infertility, children will develop cancer, etc.) (Albritton & Bleyer, 2003; Gavahan & Roach, 1987, Stam et al., 2006) as part of surviving cancer. Other QOL findings (Zebrack & Chesler, 2002) suggest that young adult survivors of childhood cancer are at a level or above their peers in terms of psychological well-being. The most negative aspect of QOL was the fear of a second cancer. Qualitative studies that explore individuals’ perceptions of their cancer diagnosis and treatment exist within the literature (Adamson et al., 2004; Coyle, 2004; Persson & Hallberg, 2004; Schulmeister, Quiett, & Mayer, 2005). These studies are oriented to issues of survivorship such as quality of life and coping with secondary physical and psychological effects of cancer.

Health related quality of life (HRQOL) has also been examined. Stam et al. (2006) compared the HRQOL of 353 young adult cancer survivors (18-30 years of age), to that of 507 of their healthy peers. The RAND-36, a standardized health related questionnaire was utilized to gauge both quality of life issues and to explore the role of coping. Data analysis was completed through the Statistical Package for Social Sciences (SPSS). Results indicate survivors reported a lower HRQOL than their peers, which confirmed researchers' hypothesis. Secondary long-term effects such as pain, disfigurement, and infection, all resulted in poor quality of life outcomes. However, data regarding coping behaviors between the two groups was significantly small. Researchers attribute this to both positive thinking of the subjects and the expectations of the health care team.

In summary, with the advancement in biochemistry research and new forms of drug therapy, young adults with cancer are living into adulthood. Cognitive, emotional, and physical late effects of treatment have been noted in the literature which impacts aspects of these individuals' quality of life. Although these issues exist, research reflects these individuals demonstrate the drive to excel in all aspects of life.

Impacting Factors on Occupation

Psychological Issues

Research data among young adult survivors reflects a 15-30% increase in psychological problems. There appears to be many studies (Sanjari, Heidari, Shirazi, & Salemi, 2008; Wallace et al., 2007) describing the nature of psychological distress among cancer survivors. Through the use of questionnaires and psychiatric interviews assessing posttraumatic stress and anxiety, Hobbie et al. (2000) examined 78 childhood cancer survivors, 18-40 years of age. Results reflected 20.5% of the subjects met the criteria for Post Traumatic Stress Disorder (PTSD) according to the American Psychiatric Association Diagnostic and Statistical Manual. A correlation between these subjects and elevated levels of anxiety were also noted when compared to subjects who did not have PTSD.

Similarly, Zebrack and Chesler (2002) found a different aspect of psychological distress among childhood cancer survivors. Through self-report questionnaires of 176 childhood survivors, subjects rated themselves highest on their ability to cope with having cancer; however, the stress and uncertainty of a future relapse remained a concern. Researchers hypothesized that although quality of life and coping strategies show an increase, the psychological impact of long-term survivorship still exists.

Chronic late effects noted in other studies demonstrate increased risk for depression which was attributed to PTSD. Symptoms consistent with PTSD have been suggested in the literature to be the cause of both physical and emotional discourse within the adolescent cancer survivor population. Alter et al. (1996) interviewed 27 childhood cancer survivors 3 years post treatment to measure the rate of PTSD within this population. Interview data was compared to a control group comprised of their peers matched in age and socioeconomic status. Results reflect 96% of the survivors met the criteria for PTSD, while no members of the control group demonstrated signs of PTSD. Similarly, Rourke, Hobbie, Schwartz, and Kazak, (2007), concluded comparable results through psychiatric interviews and self-report questionnaires. Although the sample size was larger, (182 cancer survivors 18-37 years of age), 16% had PTSD. These subjects reported more psychological problems and negative beliefs about their illness and health.

Survivors of childhood cancer remain susceptible to depression and anxiety secondary to chronic conditions post treatment (de Boer, Verbeek, & van Dijk, 2006; Langeveld et al., 2002). In a survey of 450 cancer survivors, Teta, Del, and Kasi (1986), found the frequency of lifetime major depression (men 15% and women 22%) impacted overall quality of life. Poor physical health was also found to be significantly associated with suicidal ideation and past suicide attempts in adult survivors of childhood cancer. Recklitis, Lockwood, and Rothwell (2006) sampled 226 adult survivors of childhood cancer (mean age 28) with 12.83% reporting suicidal ideations and major depression, based on results of the Short Form-36 and Beck Depression Inventory (BDI). Analysis revealed that suicidal tendency was not related to age or sex but rather an earlier age of diagnosis as younger children may suffer the long-term toxic effects of treatment. Researchers identified cranial radiation as a risk factor secondary to its correlation in causing psychological problems and physical disfigurement. Since both cranial radiation and an earlier cancer diagnosis are related to leukemia, researchers surmised that leukemia may be a diagnostic risk factor for suicidal tendency.

In contrast, Mackie, Hill, Kondryn, and McNally (2000) and Servitzoglou, Papadatou, Tsiantis, and Vasilatou-Kosmidis (2007) found no evidence of an increase in psychiatric disorders among cancer survivors when compared with their healthy peers. In fact, Servitzoglou et al. found that survivors experience growth and maturity through traumatic life experiences leading to a positive view cancer has had in their lives.

Although in both studies results were small, they underscore the need to further examine this area of long-term survivorship.

The experience of cancer in young adults impacts the normal identity development of oneself. Through the treatment process, bodily changes occur, thus altering these individuals' physical self-perception from being attractive to peers to being sickly and unattractive (Tindle, Denver, & Lilley, 2009). Glasson (1995) utilized a grounded theory method to explore the problems of adolescent students returning to school and the barriers they faced. Five participants, 12-16 years of age, receiving outpatient oncology treatments, who attended mainstream school, participated in the study. Most participants identified cancer as a disruption and acknowledged the importance of fitting back into normal school life. An obstacle in returning to school was not the cancer itself, but the school environment. Reaction of other students affected the participants' already poor self-esteem and body image. Participants reported teachers were over protective and often had a "why educate them, they have no future" attitude (p. 754)**.**

In a related study, Langeveld et al. (2004) examined self-esteem and worries between 400 long-term cancer survivors, 16-49 years of age, and 560 persons, age 16-53, with no history of cancer. The Rosenberg Self-Esteem Scale (RSE) was utilized to measure self-esteem in terms of an individual's sense of being capable, worthwhile, and competent. A Worry scale captured individual issues ranging from cancer specific concerns, general health, and present and future concerns. Both self-reporting scales were completed by all study participants. Data analysis was completed with the Statistical Package for Social Sciences (SPSS). Results indicated that the level of self-esteem in adult survivors of childhood cancer is not significantly different from their healthy peers. However, cancer survivors worried significantly more about their fertility, gaining employment, and obtaining health insurance. Researchers hypothesized that all of these concerns can contribute to low self-esteem and impact an individual's quality of life.

Lower self-esteem and higher levels of depression in subjects off treatment were reported in a Swedish study (von Essen et al., 2000). The "I Think I Am" self-reporting scale with children and adolescents on and off cancer therapy was utilized. Results were assessed and compared to determine differences in the areas of self-esteem, depression, and anxiety. Results indicated lower self-esteem and higher levels of depression in subjects off treatment. Contributing factors reported include physical appearance and body image issues. It was hypothesized that subjects on treatment have extensive support from family and medical personal verses subjects off treatment. In terms of the entire experience of cancer treatment, both groups felt that altered appearance, feelings of alienation, and the physical pain were the worst aspects of the disease and treatment. All factors mentioned above contribute to an individual's withdrawal from social, family, and peer interactions possibility leading to deficits in psychosocial adjustment later in life (Deimling, Kahana, Bowman, & Schaefer, 2002).

The increase in survival rates has led researchers to examine the influence of the disease on self-image. Jamison, Lewis, and Burish (1986) and Maggiolini et al. (2000) reported similar findings when they examined the attitudes of present and former adolescent cancer patients, in comparison to groups of school students equal in terms of age and geographic area. Comparing results indicated that adolescent cancer survivors demonstrated a more positive and mature self-image in comparison to the control group.

However, statistical analysis (analysis of variance [ANOVA], mean scores, paired t-tests) revealed no significant difference between the 2 groups in terms of self-image in either study. Differences were noted in locus of control, as the cancer survivors scored lower internal locus of control scores and higher on the external locus of control scales. These findings reflect that adolescent patients with cancer feel they have more control of their environments rather than their internal self.

The results also indicate that the groups of adolescents who had leukemia appear to have reached a greater level of maturity than their peers. Researchers hypothesized that the majority of adolescent patients grew into mature young adults who are able to adapt to the pressures of the outside world. Similarly, Mattsson et al. (2007), in a longitudinal study 2 years post cancer, found subjects reporting “I have become more adult in my thoughts” … “You are more mature, maybe you mature more quickly”… “Well I take things a little more seriously than to do things half–heartedly” (p. 1007). These findings suggest that when individuals are faced with a chronic or terminal illness the need to adapt to their situation can facilitate moving towards a normal life (Prouty et al., 2006; Weeks & Kagan, 1994).

In summary, researchers examined long-term cancer survivors from a psychological viewpoint. Results reflect that individuals who have survived cancer demonstrate symptoms of PTSD. In most cases individuals have a higher level of anxiety secondary to concerns about their futures and a relapse of cancer. Studies also reflect that changes in body appearance may impact self-esteem thus leading to depression and/or a decrease in social participation among friends and family.

Educational Barriers

In recent decades, improved cancer treatments have increased the life expectancy in young adults with cancer. As a result, the physical, emotional, and psychological problems which accompany the disease have become more observable. These factors have an impact on these young adults as they may restrict activity and overall social participation within their environments (Egilson & Traustadottir, 2009). Returning or maintaining the ability to attend school is an important routine in the lives of these young adults. However, reintegration into the daily routine of school life is a major challenge after the diagnosis and treatment of cancer (Katz et al., 1992).

Physical changes in appearance are most often difficult for children returning to school. This difficulty is not just hard for the child returning, but also for classmates and teachers. Often young adults may be returning to school without hair, which often raises attention of peers (Larcombe et al., 1990; Spinetta & Deasy-Spinetta, 1986). In addition to the hair loss, bloating, stretch marks, puffiness in the face, drastic weight loss or weight gains are secondary effects of large doses of steroids. All of these factors contribute to poor social participation within this population.

Similarly, more aggressive cancers may result in greater disfigurement, which has shown to impact success in completing a degree. Nagarajan et al. (2003), in a cohort study of 14,054 survivors observed differences in education achievement among survivors of lower extremity bone tumors. Ninety-three percent graduated from high school with 50% of them completing college. This result when compared to their healthy peers reflects a small percentage that completed college. Due to significant chemotherapy and extensive surgery consisting of amputation or limb sparing procedures, the physical consequences of the disease are often noticeable, thus impacting self-image.

The ability to participate in school can also be hampered by fatigue, “a subjective feeling of tiredness, weakness, or lack of energy” (Stone & Minton, 2008, p. 1097). Students are often tired and demonstrate poor endurance secondary to radiation, chemotherapy, or even post surgeries. Besides the actual treatment of cancer, boredom, fears, being in a hospital environment, waiting for appointments, and other secondary issues related to treatment have all been mentioned as underlying causes of fatigue in this population (Edwards, Gibson, Richardson, Sepion, & Ream, 2003; Hockenberry-Eaton & Hinds, 2000). However, Sandeberg, Johnansson, Bjork, and Wettergren (2008) reported the most common reasons for absence from school and not meeting friends were hospital visits and fatigue. Results from their cohort study of 101 newly diagnosed school children, 7-16 years of age, indicate that although subjects reported pain, nausea, and the fear of infection, over 50% acknowledge multiple appointments and fatigue as barriers from attending school. Additionally, self-reported HRQOL questionnaires resulted in a lower quality of life for subjects who often missed school compared to their peers who attended daily.

Students in the treatment process of cancer may not have normal sleep patterns or interrupted patterns of sleep secondary to the side effects of medication. They often cannot sleep through the night and will often demonstrate signs of fatigue during the day. Such inability to get up for school in the morning or the need to rest throughout the day, will impact the student’s ability to actively participate in the learning process, student activities, and leads to social isolation (Hockenberry-Eaton & Hinds, 2000; Ward-Smith et al., 2007).

In addition to the physical or emotional late effects of cancer treatment, survivors may experience a wide range of learning problems. These problems often impede the individual’s ability to process information and multi-task. Consequently, survivors are less likely to attend college, which impedes future potential job opportunities (Langeveld et al., 2004). Positive success in school is less likely with survivors of brain or central nervous system tumors secondary to the effects of cranial radiation and a lack of physical energy (Brown et al., 1996; Granowetter, 1994; Hays et al., 1992; Mitby et al., 2003; Sandeberg et al., 2008). This has made completion of a high school or graduate degree less likely (Mattsson et al., 2007). This reflects a significant difference when compared to their healthy peers (Langeveld et al., 2004).

The impact of radiation, chemotherapy, and high absenteeism has all been identified as correlating factors in the incidences of special education within this population. Childhood cancer survivors compared to similarly aged peers are more likely to require special education services. Ness et al. (2005) found higher numbers of childhood cancer survivors requiring special education after hematopoietic stem cell transplantation (HCT). Two hundred thirty-five patients who underwent HCT under the age of 21 were studied. A comparative group of individuals was recruited based on age, sex, and ethnicity of the study group. Data were collected through medical records and a 24-page survey subjects completed. When groups were compared, data resulted in a 3x greater likelihood of the HCT survivors requiring special education.

Comparable finding were suggested in a retrospective cohort study of 800 cancer survivors 17 years of age or younger. Barrera, Shaw, Speechley, Maunsell, and Pogany (2005) mailed surveys to parents or guardians of childhood cancer survivors which addressed their child's enrollment in disability or special education programs, repeating a grade, and academic or other school problems. A comparative control group of 923 healthy peers matched by gender and age was utilized for data analysis. Based on parental feedback, results indicated that more survivors than the control group repeated a grade (21% vs. 9%), survivors had an increased enrollment in special education (20% vs. 8%), and a higher percentages of survivors were involved in educational or other school problems (46% vs. 23%). Besides results related to education, socially, survivors were less likely to use friends as confidants (58% vs. 67%). Based on these findings, researchers suggest that survivors of childhood cancer be monitored for early signs of difficulties in school to maximize their academic success.

Finally, Lahteenmaki, Huostila, Hinkka, and Salmi (2002), in a cross-sectional questionnaire study compared the school-related problems of childhood cancer patients with their healthy peers. The age range of subjects was 8-18 years of age who were paired with their healthy classmates. In those with cancer 30.8% required extra tutoring versus 15.7% of their healthy peers. Similar findings (Koch, Kejs, Engholm, Johansen, & Schmiegelow, 2004) support Lahteenmaki et al. when survivors of childhood cancer were compared to age-related governmental records. Authors contribute these findings to the cancer treatment itself rather than the high absenteeism rate which when compared to healthy peers, was not significant.

Educational Barriers—Socialization

Because school and peer relationships are a major part of a young adult's development, school re-entry is viewed as a key indicator of functioning within this population. Besides the academics of school, it often provides these young adults the opportunity to socialize with peers. "School the place where I live my life, where my friends are, and where I spend most of my time when I'm not at home" (Bessell, 2001, p. 355), appears to be a theme throughout studies reviewed. Although this sounds positive, socialization including school related activities have been reported to be negatively affected by being diagnosed with and treated for cancer (Hedström, Ljungman, & von Essen, 2005; Moody, Meyer, Mancuso, Charlson, & Robbins, 2006). Adolescents involved in a retrospective cohort study (Barrera et al., 2005) who survived cancer, reported having no close friends when compared to their healthy peers. Decreased socialization is often perpetuated when these young adults cannot return to mainstream school, which leads to alterative education models. Alternative school instruction such as homebound instruction was found to be inadequate and socially isolating as it prohibits interaction with peers (Bessell, 2001).

In summary, studies examining students returning to school post cancer have reflected higher absenteeism rates secondary to poor endurance, fatigue, and conflicting medical appointments. The side effects of both chemotherapy and cranial radiation have resulted in students requiring special education services when compared to their peers. In light of this, students often demonstrate cognitive deficits such as poor attention or other learning disabilities which has shown to impact higher education endeavors. Research also indicates students attending school outside the mainstream education system have resulted in decreased socialization among peers.

Dealing with Cancer

Coping

The diagnosis of cancer and aggressive treatment presents new challenges and uncertainties in an adolescent's life. The experience of cancer becomes an overwhelming process for many adolescents secondary to inadequate social supports and coping mechanisms (Sanjari et al., 2008). Adolescents are at a transitional point in their lives as they begin to develop new social and emotional roles and learn to deal with altered body changes secondary to cancer treatment. These young adults are more vulnerable to psychological and social problems. Positive outlooks, the hope for recovery, and an enthusiasm to remain active in family life, hobbies, and school assist in developing good coping skills (Kyngäs et al., 2001; Meijer et al., 2002; Weekes & Kagan, 1994). Coping is not always utilized to deal with the disease process itself, but rather to tolerate the situation (Trask et al., 2003).

An important aspect of coping during this turbulent time is the need to keep balance in one's life. The onset of cancer changes the dynamics of relationships with family, friends, and peers. The ability to maintain balance or a sense of normalcy is an important step in the coping process. Returning to a life prior to cancer provides stability for both these young adults and their families (Miedema et al., 2007; Trask et al., 2003; Woodgate, 2006b). Social support networks have also been found to be a crucial part in the re-adjustment process. Networks of family, friends, teachers, and healthcare professionals allow adolescents and their families to share ideas, experiences, and feelings. Social support from parents, teachers, friends, and classmates, is beneficial in helping children deal with the strain of a chronic illness (Sanjari et al., 2008; Trask et al., 2003).

The need to reconnect with peers during this turbulent period is reflected in the literature (Miedema et al., 2007). Parents often represent primary care givers, while peers offer an outlet for emotional support, which plays an important aspect in the developmental process. Adolescents report that their parents and close friends were the greatest source of social support (Sanjari et al., 2008; Trask et al., 2003) in dealing with their illness. The ability to return to prior social realms for these young adults remains an important source of social support and is largely focused toward helping the adolescent feel accepted. Coping styles among adolescents who sought social support appear to develop better positive psychosocial functioning. The relevance of social support in relationship to coping has been demonstrated in several studies (Kyngäs et al., 2001; Meijer et al., 2002; Trask et al., 2003) indicating that social support may be effective in reducing maladaptive behaviors. In a 2008 study, Sanjari et al. supported the findings of Trask and his colleagues (2003) concluding that adolescents with cancer and their parents rely more on adaptive coping strategies (e.g., actively being a part of the solution) than maladaptive strategies (e.g., being passive to the situation). These findings may be reflective of improved prognosis and the increasing survival rates among this population.

In similar research, Edwards et al. (2003) and Miedema et al. (2007) noted in their qualitative studies of coping strategies of young adults with cancer, that the ability to rely on existing social networks was important part of their recovery. However, due to the exhausting nature of treatment, many participants suffered from fatigue resulting in the inability to socialize outside their immediate network of friends. Findings suggest that young adults draw on prior life experiences, although limited, to cope with life events and treatment, especially, during the treatment phase, where stress is high.

Coping within the literature has generally been defined as managing or confronting a problem, finding ways to solve the problem, or managing the stressors which accompanies the problem (Blum, 2008; Nichols, 1995). In order to explore the issue of coping within this population, studies have not only focused on the adolescent patient but rather the entire family. This philosophy underscores the importance of the impact illness has on the dynamics of family life (Mitchell, 2007; Shapiro, 1983; Trask et al., 2003; Wong & Chan, 2006). The family was found to be the most important source of emotional support (Sanjari et al., 2008; Trask et al., 2003). The need to cope with everyday life requires resources, social supports from both family and medical staff, and a belief in recovery.

Studies reflect that adolescents who were afflicted with cancer report good physical and emotional states in adulthood (Miedema et al., 2007; Trask et al., 2003). Although areas of dysfunction in educational pursuits and relationships have been reported, the censuses reveal effective coping strategies lead to life adjustments. Movement towards a normal life or “getting on with life” was widely reported among this population (Prouty et al., 2006; Rechner, 1990; Woodgate, 2006b). The need to remain occupied either by being with friends, resuming prior activities, or returning to school often resulted in effective coping strategies. Cognitively, positive thinking enabled adolescents to get through therapy by focusing on the “light at the end of the tunnel.” Positive thinking also resulted in the ability to function on a daily basis, while living with uncertainty of therapy (Sanjari et al., 2008; Weekes & Kagan, 1994). In a related qualitative study, Kameny and Bearison (2002) found thinking positive, praying, displaying anger, and sharing feelings with family and medical staff as a key theme in the adolescent cancer population.

Within the nursing literature, much of the research on adolescent cancer has concentrated on the concept of coping. Studies have focused on strategies to enhance adolescents' coping skills around the time of diagnosis (Allen, 1997; Neville, 1996). Others have investigated coping needs throughout the course of the illness (Hinds & Martin, 1988; Moore, Holton, & Marten, 1969; Woodgate, 2005). Similar to a stage theory approach, Hinds and Martin suggested developmental stages (cognitive discomfort, distraction, cognitive comfort, and personal competence) assist adolescents to remain hopeful in order to cope with their cancer. These studies signify that adolescents may adopt a range of coping processes including adaptive denial. This emphasizes 'normality' and a belief that everything will work out in the end (Neville, 1996).

Comparative studies within the literature focused on coping from a different viewpoint. Bauld et al. (1998) compared the psychosocial statuses of adolescent cancer survivors with their healthy peers. Results revealed that adolescent cancer survivors are coping despite long-term physical and psychological effects of treatment. However, cancer survivors reported a higher level of nonproductive avoidance strategies (e.g., ignoring the problem, self-blame, and not coping) as coping mechanisms and increased anxiety levels. Researchers also found a correlation between future psychological functioning and age at diagnosis and participant's gender. It may be suggested that this correlation between age at diagnosis and gender indicates early intervention may be most beneficial to this population.

In contrast, Boman and Bodegard (2000) and Sanjari et al. (2008) report opposite results in terms of coping skills related to age and gender. After analysis of data no correlation between coping skills were noted when compared to gender and age at diagnosis. Boman and Bodegard (2000) found longer remission periods (no signs or symptoms of cancer) were associated with better coping strategies, versus longer treatment regimens, which resulted in poorer coping skills, over the long term. Both studies provided insight into the coping or maladaptive behaviors utilized by adolescent patients with cancer. It appears from the literature based on coping and the adolescent patient with cancer, a mixture of cognitive restructuring (positive thinking), social supports, and networking is a major source of effective coping, as it lowers levels of distress.

In summary, young adults with cancer utilize coping skills in order to deal with the many changes in their lives. Results of studies indicate that social support networks among friends, family, and classmates provide a backbone in dealing with cancer on a daily basis. The ability to return to a life with normal routines assist in the coping process as it lends normalcy in the lives of these young adults.

Phenomenology—Research Method

An in-depth literature review was undertaken to further understand the history and intricacies of phenomenology, which this study is based. In the late 19th century Edward Husserl, a German philosopher was intrigued with how individuals experience the world and the meanings they attach to these experiences. He rebelled against the idea that modern scientific methods could capture the human experience, which is subjective in nature. In order to capture the practicality of life experiences, he developed the human science of phenomenology, which focused on the conscious world, in order to understand an individual's life-world experience (van Manen, 2002).

In its most basic form, phenomenology is the study of the consciousness from a first-person perspective, as opposed to a third-person perspective. It attempts to reflect on pre-reflexive experiences in an individual's everyday life-world to understand how the ordinary is experienced and expressed in the consciousness of an individual (Luborsky & Lysack, 2006). Phenomenology is a school of thought within philosophy whose primary purpose is to study the phenomena, or appearances, of human experience while attempting to suspend all consideration of their objective reality or subjective association. The everyday phenomena studied are those experienced in various acts of consciousness, mainly cognitive or perceptual in nature (Giorgi, 1985). This principle, intentionality, can be simply stated as "the world is what we perceive and experience it to be" (Finlay, 1999, p. 302). Thus, individuals' life-worlds are made up of unique meanings and interpretations based on perceived objects in their environment, which construct their reality.

Through this conscious awareness, the aim to understand, describe, and interpret human behavior from the perspective of the person being studied can be achieved. A true understanding of the experience can only be made through data analysis where meanings are given a textural description (what was experienced) and a structural description (how it was experienced). This analysis or reduction ends with a description of the essence which characterizes the experience of the participant(s) (Creswell, 1998; Moustakas, 1994).

In addition to being a research method, phenomenology was also a philosophical movement that gave rise to other philosophical traditions within phenomenology such as transcendental and hermeneutics (Kelly, 1996). Although under the same umbrella, differences exist in the philosophical bases of transcendental phenomenology compared to hermeneutics (van Manen, 2002).

Transcendental phenomenology grew out of Husserl's original philosophical assumption, which indicates that entering an individual's life-world; one can formulate and understand the lived experience, keeping in mind the meaning(s) of the experience rather than the explanation of the experience. Transcendental phenomenology builds on this general premise, however, relies on rigorous phenomenological reduction methods to ensure the essential structures of the experience are left in pure consciousness of the researcher (Conroy, 2003; Moustakas, 1994; van Manen, 2002).

Major differences exist between Husserl's transcendental phenomenology model and other genres of qualitative research including those within phenomenology. Transcendental phenomenology offers researchers no flexibility in terms of data analysis or "phenomenological reduction methods." Disciplined and systematic efforts to set aside prejudgments regarding the phenomena being investigated (bracketing) are essential. This meticulous method also separates beliefs and knowledge of the phenomena from prior personal and/or professional experiences thus leaving the researcher clear of preconceptions of the universe (Moustakas, 1994; van Manen, 2002). Consequently, the process is called transcendental because the researcher sees the phenomenon “freshly, as for the first time” and is open to its totality (Moustakas, p. 34).

Although controversial in nature, Husserl believed one must separate out preconceived experiences to better understand the experience of the phenomena in its purest form (Grbich, 1999). This technique was sharply differentiated from that of traditional psychology, as it cleared an individual’s presuppositions and prejudices, whether philosophical, scientific, or naïve, concerning the world and his/her knowledge of it. This reduction of a “bracketed” phenomenon is a technique to gain conjectural insight into the meaning of elements of consciousness (Moustakas, 1994). In concrete terms, this approach lifts a phenomena under investigation from its meaning context in the common-sense world, with all judgments suspended in order to be reduced to an individual’s lived experience, the personal world an individual experiences (Giorgi, 1985).

Hermeneutical phenomenology predominantly stems from the works of Martin Heidegger, a German philosopher and Husserl's colleague and most stark critic. A key difference between Husserl’s transcendental phenomenology and hermeneutics is the emphasis on the method of interpretation. Heidegger believed phenomenology should not only be descriptive in nature and based on pure reflection, but rather, be interpretive, making visible what is hidden in ordinary, everyday experience (outside an individual’s life-world) (van Manen, 2002). According to Heidegger, the ability to gain understanding within the world of the participant, allows the merger of his/her life-world and the concrete universe (Heidegger, 1954).

Unlike phenomenology, hermeneutics allows the researcher to enter the participant’s life-world with a perspective of preconceived ideas on social or historical knowledge, professional experiences, and/or knowledge based on text and literature. This fusion of the conscious description of an experience and the structure that accounts for the experience links both the context and essence of the experience (Moustakas, 1994), to formulate a holistic picture (van Manen, 2002).

In balancing hermeneutics versus transcendental phenomenology choosing the latter meant the researcher had the opportunity to bracket his knowledge and any preconceived ideas based on the researcher’s own life-world experiences. Since strong assumptions existed from many years in the healthcare field as a patient and then a therapist, transcendental phenomenology grounded this study.

The use of phenomenology as a method of naturalist inquiry for over a century has been a valuable tool as it allowed researchers to illuminate complex issues in the realm of social sciences. A review of frameworks related to the lived experience was undertaken, which led to the method described by Clark Moustakas (1994). Although a professor in the field of psychology, he relates his method to other fields such as healthcare and social sciences.

The design guiding this study is both complex and highly abstract in nature but offers the ability to capture rich structural and textural descriptions of the experiences of these adolescents in their life-worlds. Phenomenology offers direct observation in a natural setting compared to experimental or other empirical research methods. The researcher has the ability to enter into the participant’s natural setting, allowing the participant’s life-world to unfold. In experimental research methods subjects are placed in controlled or artificial situations where variables are manipulated. This manipulation of variables seeks to discover and describe statistically-defined norms and central tendencies in the distribution of data, rather than capturing the meanings participants attach to their everyday experiences (Lysack, Luborsky, & Dillaway, 2006; Moore, 1998). A phenomenological approach is intended to illuminate the essence of individual experiences, rather than produce generalized results (Moustakas, 1994; Patton, 1990). These strengths within the design cannot be achieved through the collection of empirical data, which is often objective in nature.

Critique of Current Literature

Critique of Qualitative Research Studies

Since the intention of this current study was to document the lived experience, the four papers located were either labeled as the “lived experience” or “phenomenological” in nature. Although the literature review was from 1999-2010, a study from 1990 was included as it offered further insight into this unique population. Only four articles from the literature reviewed dealt with the lived experience and adolescents with cancer that met the true philosophy of phenomenology. Crombie’s (2004) guide to critical appraisal was consulted in preparing this critique of the literature, as it offered a concise, organized method for critical review.

The quantity of articles uncovered utilizing a phenomenology approach was considered lower than expected for an area of research suggested. In a phenomenological study designed from a nursing perspective, Rechner’s (1990) focus was to understand and describe the experiences of adolescents living with cancer. There were 5 participants in the study, 4 presently on treatment. Participants were interviewed twice with 10 interviews completed. Although the study’s aim was to describe the lived experience, the methodology section negated to describe the interview questions or format utilized. Justification for data collection and analysis were not clearly provided so steps taken to establish trustworthiness were not incorporated.

In the other three phenomenological studies located (Earle et al., 2005; Prouty et al., 2006; Wallace et al., 2007), the focus dealt with survivors of childhood cancer, although labeled as the lived experience they described participants’ past lived experiences. Participants in the studies were all interviewed post treatment, which may have lessened the raw emotion of having cancer and the impact chemotherapy had on their lives. In order to understand individuals as occupational beings and the human experience, studies must occur in their natural environment and in the moment of the experience, in order to capture their true reality (Kelly, 1996). Participants in these studies ranged from 2-49 years post treatment. In one study (Prouty et al., 2006), a participant was diagnosed with a Wilms’ tumor at age 2, and is presently 51 years of age. Other participants in the same study also have decades between their diagnosis and the time they were interviewed. The fact that most of the participants had been diagnosed with cancer many years prior, raises the issue of whether the experiences for them were the same as for someone newly diagnosed. The methodology for this study does not reflect the true meaning of phenomenology as described by Husserl, Heidegger, or Moustakas which was to understand the essence of the lived experience. One can argue that the qualitative design chosen does not fit the objectives of the study. Interestingly the authors admit that “phenomenologists build knowledge when they demonstrate phenomena as they occur from the perspective of the person undergoing the experience”

(p. 144). The key is “when they occur” which is not the case in any of the latter three studies as they are so many years post the experience. In analyzing the rigor of these four qualitative studies, two studies demonstrated no member checks or triangulation of sources to increase trustworthiness. One study notes that data were validated through subsequent interviews, but does not elaborate further on these methods. Bracketing, one of the most important aspects of phenomenological reduction, is never mentioned in any of the studies. The last study notes a modified version of phenomenological analysis as only 4 participants engaged in member checking. Overall, these four phenomenological studies demonstrated flaws in data collection, procedural methods in establishing trustworthiness, and not providing question guides. These are all important aspects in building rigor within a phenomenology study. Although additional qualitative studies were located (Hokkanen et al., 2004; Kameny & Bearison, 2002; Yeh, 2002) the means of inquiry were through general descriptive, narrative, or grounded theory research.

Besides studies which utilized phenomenology as a research methodology, the bulk of the other literature related to the adolescent cancer patient were surveys (Calman, 1984; Eiser, 2007; Ferrell & Dow, 1997; Hedström et al., 2005; Katz et al., 1992; Lahteenmaki et al., 2002; Recklitis et al., 2006; Stam et al., 2006; Zebrack, & Chesler, 2001), retrospective (Koch et al., 2004; Mackie et al., 2000; Zebrack, & Chesler, 2002) and longitudinal research designs (Bauld et al., 1998; Mitby et al., 2003; Sandeberg et al., 2008; Weekes, & Kagan, 1994; Woodgate, 2006a) , and literature reviews (Shapiro, 1983; Whyte & Smith, 1997). The differences in study designs make it difficult to make comparisons and generalizations from any one study. More than one half of the studies included a variety of cancer diagnoses ending in mixed results. Although most studies found that there were no differences between cancer survivors and population norms, one study found that survivors had fewer symptoms, and another found that they had more symptoms.

Critique of Quantitative Research Studies

Within the quantitative studies various measurement scales were utilized to gauge quality of life issues to coping strategies. The most common among the studies were the Short Form-36 (SF36) and Health-Related Quality of Life (HRQOL) measurement tools. Hedström et al. (2005) and Recklitis et al. (2006) utilized the Short Form-36 (SF36) to assess health-related quality of life. Evidence (Gómez-Besteiro, Santiago-Pérez, Alonso-Hernández, Valdés-Cañedo, & Rebollo-Álvarez, 2004; Jenkinson, Coulter, & Wright, 1993) has demonstrated strong reliability and validity exist when utilizing this tool across gender, age, and disability. Similarly, the HRQOL measurement tool was utilized by Stam et al. (2006) in exploring long-term adjustment of young adult survivors of childhood cancer. The focus of the study was to assess health related quality of life issues and to explore the role of cognitive coping. Results of their study reflected a lower health related quality of life in the cancer survivor population. Through the use of the HRQOL tool, the necessary data were captured in order to perform further analysis. External evidence (Andresen, Catlin, Wyrwich, & Jackson-Thompson, 2003; Peyrot & Rubin, 2000) other than those referenced by the authors of this study exists supporting the reliability and validity of this assessment tool.

In contrast, Sandeberg et al. (2008) utilized the DISKABKIDS Chronic Generic Module (DCGM-37) that was developed to assess health related quality of life issues in children and adolescents with chronic conditions and their parents. This study was the first to utilize this instrument with the pediatric oncology population. Although the authors provide sufficient data to support this tool, there have been no reliability and validity studies to support its use with the oncology population. Utilizing standardized instruments that are not applicable across different illnesses and ages decreases the level of evidence and the success of implementing new treatment interventions.

Besides the failure to establish reliability and validity within quantitative studies, Crombie (2004) points out that consistency between research titles and subject samples as being part of the critical appraisal process. In a study designed to enhance the body of knowledge within the nursing profession, Ward-Smith et al. (2007) designed a quality of life study. The aim was to enable adolescents with cancer to self-evaluate their quality of life. At the time of the data collection 54.7% of the participants were currently receiving treatment, while 45.3% were in pretreatment or post treatment modes. This sample appears to conflict with the title “Quality of Life Among Adolescents with Cancer” as it infers that all participants are in the midst of cancer treatment, which is not the case. Only 54.7% were actually on chemotherapy, with the rest in pretesting stages or post treatment. This confusion can lead readers into believing that results were based on a sample size of adolescents who are in the active phase of cancer treatment.

Many literature reviews addressing the psychosocial, physical, or quality of life of adolescent patients with cancer or survivors were located. Although they provided no original research findings, they present findings comparable to a systematic review (Crombie, 2004). Criticism often associated with this form of research stems from the idea that no authentic research is completed, but rather a cookie-cutter approach is taken (Egger, Smith, & Phillips, 1997; Naylor, 1997). However, a literature review can answer practical questions on a smaller scale where budgets or time is limited (Egger et al., 1997; Portney & Watkins, 2000).

The literature offered further insight to the adolescent cancer population. All reviews were very specific in terms of the aim of the review, keeping with the title of the review. The reviews were discipline specific, rather than interdisciplinary, which may impact implementation of findings to patient care. An inclusion and exclusion criterion was clearly evident throughout all the reviews with specifics related to patients' diagnosis, gender, and age. Only one literature review article provided details of the search procedures utilized in gathering articles for the review.

Individual cohort and retrospective studies were located that aimed to understand physical activity in adolescent cancer survivors; educational and social outcomes for survivors of childhood cancer; and comparison of self-reported rates of special education and educational attainment among childhood cancer survivors and their siblings. Major elements of cohort studies are the aspect of time (Crombie, 2004), which is well defined in each study. Researchers identified cancer survivors at one point in time and compared them to control groups based on demographic data. In keeping with this research design, large sample sizes were reduced based on specific criteria, thus decreasing bias within the study. Although rigorous criteria were utilized to decrease bias, it also decreases generalizability of the findings (Crombie, 2004).

In a study (Mitby et al., 2003) that investigated special education and long-term survivorship, data were utilized. The accuracy of the data appears problematic as subjects were dependent on memories years after finishing treatment. In this approach, data collection relied on subjects' recall of their feeling and emotions which may have faded over time. This flaw was not acknowledged by researchers as a limitation of the study. Similarly, data collected surveys were utilized in longitudinal studies located which examined cancer survivorship. Recruitment for these studies was completed through purposive samplings methods. Subjects were screened and enrolled from local hospitals. This method of sampling lacks randomization, which may increase bias as all subjects may not be well represented. Likewise, qualitative data gauged from surveys is limited to what subjects are willing to say under various conditions. In addition, perceptions may not have represented accurate assessments of experiences. However, the depth and richness of qualitative data collected compared to the limited information generated through quantitative data of standardized instruments; further indicate the need for additional descriptive and qualitative studies.

Unlike random control trials (RCTs), where data analysis is based on certain variables, methods within cohort studies appear highly complex in nature (Gurwitz et al., 2005). Multivariable analysis was a common term throughout the cohort studies reviewed. This analysis incorporates demographic data, questionnaire results, and other criterion-based raw data. Since analysis appears to be more complex, clinical implementation may be more difficult based on the reader’s comprehension level of study results (Crombie, 2004).

As stated earlier the bulk of the articles related to adolescent cancer patients were surveys, retrospective and longitudinal studies, literature reviews, and mixed qualitative studies. In terms of level of evidence, the criterion utilized for this review was based on a hierarchy which grades the evidence from strongest (Level 1) to the weakest (Level 5) (see Table 4). In this review, the majority of articles fell into the lower categories (Level

III-V) of evidence. Because most of the quantitative studies utilized convenience samples, they failed to meet the criteria of a random control trial (RCT). Although this lowered the level of evidence throughout the studies reviewed, it does not discount the importance of research done on the topic areas. In fact lower level studies have the potential to be the foundation for future research.

Table 4

Hierarchy of Levels of Evidence for Evidence-Based Practice

Level	*Description*
I.	Strong evidence from at least one systematic review of multiple well-designed randomized controlled trials
II.	Strong evidence from at least one properly designed randomized controlled trial of appropriate size
III.	Evidence from well-designed trials without randomization, single group pre–post, cohort, time series, or matched case-controlled studies
IV.	Evidence from well-designed non experimental studies from more than one center or research group
V.	Opinions of respected authorities, based on clinical evidence, descriptive studies, or reports of expert committees

From “The 2000 Eleanor Clarke Slagle Lecture: Our mandate for the new millennium: Evidence-based practice,” by M. Holm, 2000, *American Journal of Occupational Therapy*, *54*(6), p. 576.

Reflexivity and Prior Experience

In qualitative research, it is important for the credibility of the study that the researcher provides pertinent personal and professional information that might influence the research process including data collection, analysis, or interpretation (Rudestam & Newton, 2007). The researcher, an instrument of data collection, gathers words, analyzes them, and focuses on the meaning of the phenomena. This interactive process between the researcher and the participant assists in shaping the essence of the participant’s lived experience (Creswell, 1998; Moustakas, 1994; Patton, 1990).

In utilizing a phenomenological stance it is not uncommon for the researcher to have a personal and intense interest in the phenomena under investigation. This intense interest can mirror personal experiences in the researcher's life thus making his/her memories and history an essential part of the discovery process (Moustakas, 1994). This interconnected mesh of both the participant's and researcher's experiences has potential to distort the data collection and the analysis process. It is through self-reflection (reflexivity) this researcher seeks insights to influential biases, thus limiting external worldly experiences (Grbich, 1999; Kielhofner, 2006).

From the start of this study, I had reservations investigating the lived experiences of young adults in the process treatment of cancer, as I myself had a similar experience in my youth. However, through doctoral studies and additional research courses I have attended, they have helped me to recognize the importance of bracketing. During the data collection phase of this study, I utilized journaling to assist me in identifying any biases I may have had from my past experiences which were related to these participants' lived experiences.

Summary

In summary, the literature review revealed a lack of research examining the issue describing the experiences of young adults living with cancer and the ultimate impact on occupation, particularly social participation. This review yielded only one research article that addressed the present affects of cancer and the perception of young adults living with cancer (Rechner, 1990). Although it was from a nursing perspective, it provided useful suggestions in the discussion section, for healthcare providers to change their approach, when working with this population. However, the article failed to address the issue of occupations and the impact of occupational disruption.

Literature pertaining to the adolescent cancer patient demonstrates the increasing incidence of survival among this population. Although there has been a gradual increase in the quantity of literature within the research journals, it is fragmented across cancer diagnoses. Many studies have included the young adult population, but only a minority. There appears to be no consensus in characterizing an adolescent throughout the literature secondary to biological and cultural interpretations. No lived experiences have been published on the adolescent population that examined young adults in the treatment process of cancer that reflects social participation. Literature examining all aspects of survivorship is plentiful; however, the lived experience within the adolescent oncology group is sparse or does not reflect the true meaning of phenomenology. As individuals become more remote from the actual treatment process of cancer, memories fade, leaving the true essence of the experience behind.

Chapter 3: Methodology

Research Design, Methodology, and Rationale

The aim of this study was to answer the question: What is the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically social participation? This study was conducted utilizing a transcendental phenomenological framework which seeks to shed light on the complexity of the human experience. Interview data were collected and analyzed using a phenomenological reduction method. The study consisted of young adults in the treatment process of cancer.

A phenomenological research design was essential to understand the experiences of adolescents with cancer by entering into their field of perception in order to understand life as they see it. This approach can reveal the essence of an individual's experience (Bruyn, 1966; Moustakas, 1994) and is congruent with occupational therapy's philosophy as it views individuals holistically considering the environment in which they function (Kelly, 1996; Moustakas, 1994).

Moustakas's approach to transcendental phenomenology was chosen for a number of reasons. First, Moustakas encourages researchers to develop a research question that "grows out of an intense interest in a particular problem or topic . . . where personal history brings the core of the problem into focus" (1994, p. 104). Second, he follows transcendental phenomenology as developed by Husserl, which encompasses the ability to "bracket" thoughts and preconceived ideas, so my own reflections remain clear and unbiased. This process is essential as I had a similar experience with cancer as a young adult; subsequently the need to bracket past experiences is a valuable tool in investigating the phenomena of present day adolescents in the treatment of cancer.

Specific Procedures

Strengths and Weaknesses of Design

Confusion surrounds phenomenology and its application, as mislabeling and insufficient detailed analysis often support a more generalized qualitative method, secondary to the researcher's poor understanding of Husserl's ideas (Finlay, 1999). This lack of understanding from the participant's perspective and misinterpretation of data, may lead to poor theme development.

In order to lessen these factors within this study, participant(s) reviewed the findings, interpretations, and conclusions drawn to ensure accuracy of the data collected (Creswell, 1998). Second, due to the complexity of transcendental phenomenology and its application, the works of Moustakas (1994), and van Manen (2002) were utilized to provide guidance in developing this study. Ideas and basic assumptions between phenomenology and transcendental phenomenology were incorporated and synthesized into this study based on the works of Creswell, Finlay (1999), and Heidegger (1954). In order to ensure quality theme development and analysis of data, steps outlined by Moustakas, a scholar widely published and an expert in the field of transcendental phenomenology, were applied. His method of phenomenological reduction is synonymous with the work of Husserl and widely accepted in qualitative research designs (Creswell, 1998; Rudestam & Newton, 2007).

In another criticism, Moerer-Urdahl and Creswell (2004), argue the lack of data saturation and the inability to generalize study results to a wider population is a problem inherent in a phenomenology designs. In an attempt to diminish the criticism that more is better and to strengthen the design within this study, interviews were longer; more detailed, and better representative of the breadth and depth of the phenomena conveying a well defined life-world of each participant (Rudestam & Newton, 2007). The goal of phenomenology is to illuminate the individual's lived experiences to capture the intensity in which they occur. In reality, saturation will never occur because each new participant has something unique to contribute to the study as phenomena are experienced and reflect a particular time and place in the individual's life-world with significance and meaning, thus generalization is not possible.

Inclusion Criteria and How Determined

Participants were required to be between 17-19 years of age. The rationale for targeting this group was that individuals at this age level could express themselves and communicate their feelings and would be at a transitional point in their lives, where the burden of treatment would be significant. Young adults in this age group are faced with finishing school, preparing for college, or seeking some type of employment. Part-time employment while in school is possible with a General Employment Certificate, which most States offer to minors over 16 years of age (New York State Department of Labor, 2010). Whether the individual enters college or the job market, the balancing of school and/or work plays a crucial role in entering young adulthood (Pruitt, 2000, p. 63).

All participants had to be on an active treatment protocols which consisted of chemotherapy or radiation therapy or a combination of both. Participants had to be receiving treatment at Tomorrows Children's Institute at HUMC as it has a large adolescent cancer outpatient unit and where I received IRB approval. This made the probability of patients meeting the study criteria greater then exploring a small local hospital. All participants needed to attend regular school at least 2 days a week, in order to provide experiences relating to social interactions with peers. Participants had to agree to a total of 3 interviews (2 interviews 1 month apart and a final interview for approximately 4 hours (total) over a course of time). Additionally, the participants had to be fluent in English.

Participants

Number and How Determined

The number of participants recruited for this study was based on the literature reviewed, which was often conflicting in nature. Although many researchers suggested a sample size of 10 or fewer (Rudestam & Newton, 2007), others suggested 4-5 (Dukes, 1984), until thematic saturation is achieved. As previously noted, saturation, although possible in other qualitative methods, may never occur in phenomenology as new participants add their uniqueness to the study (Josselson & Lieblich, 2003). The focus remains on representing the breadth and depth of the phenomena being explored rather than the overwhelming themes that may be unrelated to the research question. In keeping with Moustakas's phenomenological research method, 4 participants were interviewed in-depth for this study.

In these brief profiles below participants' demographic information is highlighted including past and present occupations. Additionally, these profiles provide insight into the family structure of each participant. Four adolescent participants were interviewed for this study and consisted of 3 males and 1 female. The participants in the study came from diverse backgrounds and have been diagnosed with various types of cancer.

Participant 1

Emma, a 19 year old Caucasian female who lives in a suburban neighborhood in New Jersey, was 2 months away from finishing her cancer treatments when interviewed. After her initial diagnosis of Anaplastic Large Cell Lymphoma (ALCL), in June 2006, she returned home from her first year of studies at Dickenson College in Pennsylvania, to live with her parents and older sister, transferring to a local college to meet her intense cancer regimen. Her diagnosis of ALCL can be described as an aggressive (fast-growing) type of non-Hodgkin lymphoma that may appear in the lymph nodes, skin, bones, soft tissues, lungs, or liver. It is a rare type of cancer, accounting for about 1in 50 of all cases of children and young adults. Statistically, twice as many men are diagnosed with ALCL than women (Barr, 2007; NIH, 2000; Neville, 2000).

Prior to cancer she was very physically active enjoying sports, keeping company with friends, enjoying her pet rabbit, and having a boyfriend for many months. Her sister recently graduated from college and her mother is receiving treatment for breast cancer. She takes classes 3 days a week and goes for treatment once a week. Since she has extra time within her day she went back to performing in the musical theater at school. This was an occupation she enjoyed throughout high school and thought it might be good to be involved in something that brought her great satisfaction. This experience provided her with an outlet to meet new people and become part of a group (cast) that relied on her to keep the show moving. Overall, she reports feeling very proud of herself as she did not need to drop out secondary to her illness.

Participant 2

Oliver, a 19 year old Hispanic male, lives with his two younger brothers and parents in Paterson, New Jersey, an urban city. He was diagnosed with Acute Lymphocytic Leukemia (ALL) in January 2006, which is the most common childhood cancer in which too many immature white blood cells are found in the blood and bone marrow (Barr, 2007; NIH, 2000; Neville, 2000). His cancer protocol consists of 3 years of chemotherapy. Prior to his diagnosis he was a freshman at New Jersey Institute of Technology studying electrical engineering. Since the diagnosis of cancer he continues to attend college on a part-time basis and receives monthly cancer treatments. In his free time, being with friends and playing sports are important to him. He recently met a girl and is in a long distance relationship where he travels down to Virginia for the weekends when not on treatment. One of his goals is to find a part-time job to ease his financial situation. School remains his top priority as he knows it will lead to a brighter future for him and his family.

Participant 3

Adam, a 19 year old Jewish male, was born and raised in Fort Lee, New Jersey, and lives with his parents and two brothers, with him being the middle child. He was diagnosed with Acute Lymphocytic Leukemia in March 2005 during his sophomore year at Yeshiva University, where he is an Accounting major. He is scheduled to finish treatment in July 2008, and be followed-up with monthly check-ups thereafter. Once an avid contact sports player, he relies now on sports that are less physical to occupy his time, such as swimming. Socially, he finds being with the “Tenacious Ten,” old friends that have formed a close bond throughout the years, very rewarding. Besides school he recently found a part-time job in an accounting firm, which he hopes may lead to other jobs in his major.

Participant 4

Eric, a 17 year old Egyptian male, was first diagnosed in Cairo, Egypt, with Acute Lymphocytic Leukemia in June 2006, where he was born and lived until April 2007, when he came to the United States for treatment. He is the second-born and only male of four children and presently lives and attends high school in Lyndhurst, New Jersey with his family. However, prior to coming to the United States for treatment, he was finishing his senior year of high school, and had just been accepted to medical school. Once in the United States, he was given senior year status due to educational differences between countries. Also, his treatment in the United States is very different than in Egypt, where it was longer and much more intense (daily). Thus, in Egypt attending school daily was hard secondary to intense treatment protocols. Today, he attends high school 5 days a week and approximately twice a month receives cancer treatments.

When not in school or at the hospital, he spends most of his time studying, surfing the Internet, or playing soccer with his cousins. Culturally, soccer was a staple in his daily routine in Egypt, as it is widely played and accepted as a national pastime. Socially, life has changed for him, as he has many new friends who are not uncomfortable by him having leukemia, whereas, in Egypt he had a very isolated life because people do not understand cancer, and often shunned him.

Exclusion Criteria and How Determined

Exclusion criteria from the study included the diagnosis of brain cancer, as there was the likelihood that patients may not be at a cognitive level to express their experiences due to the intensity of treatments. Patients or guardians who refused to give informed consent or were reluctant to participate in a lengthy recorded interview and perhaps a follow-up interview were excluded. Final exclusion criteria included patients who lacked commitment to the study, due to severe medical side effects of the medications.

Recruitment Procedures

Participants were recruited from Tomorrows Children's Institute at HUMC, a large teaching hospital in Hackensack, New Jersey. After IRB approval from both Nova Southeastern University and Hackensack University Medical Center, the oncology nurse identified patients through the established inclusion/exclusion criteria, secondary to Health Insurance Portability and Accountability Act (HIPPA) regulations. All potential participants were patients being treated at the Tomorrows Children's Institute. She informed patients about the proposed study and the benefits in understanding the experiences of adolescent patients with cancer, in order to plan individual interventions that are meaningful and effective. It was also explained to them that the risk in participating was minimal. Patients interested in participating in the study were contacted via telephone by the researcher clarifying the details of the study and to address any questions. The first 4 participants who met the criteria, agreed to participate in the study, and gave consent were chosen. During this initial contact, eligibility criteria were again reviewed and interview time and location arranged.

A number of difficulties were encountered in the recruitment process. Although the inclusion criteria were large enough to capture a variety of cancer diagnosis, the age requirement hindered the recruitment process. Many patients were entering or preparing for college, thus leaving them with limited time availability to participate in a research study. Since their time commitment could not be guaranteed, they were excluded from the study. Additionally, many potential participants, who initially agreed to participate in the study, however, failed to follow-up after repeated requests, were also excluded from the study. It is theorized from speaking with many prospective participants that time, scheduling conflicts with appointments, and secondary effects from chemotherapy were factors in an extended recruiting process.

Ethical Considerations

After being identified through the established inclusion criteria and initial contact confirming the patients' interest in the study, informed consent was obtained in writing at the first face to face meeting. Additionally, participants were given an opportunity to ask questions prior to completing the IRB approved consent forms. If the patient was a minor, parental consent was also obtained. Included in the consent was a statement indicating that the participant was free at any time to withdraw from the study without any repercussions. A signed copy of the NSU and HUMC consent forms were completed. Each participant and researcher received a copy of the completed signed consents.

This study was submitted to the NSU IRB to examine and ensure that adequate safeguards minimized risk to the participants and that other ethical considerations were implemented. NSU IRB approval (#HPD-ALL09200605, initial date 10/26/06) was granted for a period of 1 year with the option to renew with further approval. A second IRB approval was required from HUMC; however, a peer review committee within the nursing department required an oral defense of the proposed study to determine its benefit to the healthcare community. Pending this approval, the study was submitted to

HUMC IRB with approval granted (#06.02.112, initial date 12/14/06). This approval was also for a 1 year period. Both approvals have been renewed four times since initial approval.

The IRB requires documentation to be stored in a secured area and then discarded to prevent a breech in confidentiality. All digital files and transcripts were stored on my personal computer that has appropriate security safeguards such as password protection for authorized users, firewall protection, Internet security, and automatic backup to prevent loss or theft of data. Additionally, data were backed up on a flash drive with password protection. Journal and demographic notes, and all related written transcripts are secured in a locked filing cabinet in my home office only containing pseudonyms, rather than the participants' real names. At no time did I reveal any information from the interviews to the sponsors or any other healthcare professional including participants' pseudonyms. A paid transcriber, the graduate advisor, and I will have sole access to the verbatim transcription of the interview data. Additionally, the transcriber took an oath of confidentiality.

All interviews were conducted in a private conference room at HUMC or at the participant's home. When done at HUMC arrangements were completed through the oncology nurse. At no time did employees within HUMC know participants were part of a research study. On one or two occasions interviews were interrupted for building maintenance workers to enter, so the tape recorder was turned off to avoid recording the participant's name. The participants, if needed, were to receive a pamphlet with contact information to discuss issues, which arose through the interview, with trained health care professionals. However, this was not necessary.

Study Setting

The study was conducted in the Tomorrow's Children's Fund (TCF) conference room away from the main clinic areas. TCF is the fundraising organization that supports the Tomorrows Children's Institute at Hackensack University Medical Center. Since this area is offset from the main patient treatment areas, privacy and confidentiality were maintained. Hackensack University Medical Center is a large teaching hospital in Hackensack, New Jersey. The facility maintains a large pediatric cancer population and is comprised of both ambulatory and inpatient care units. It serves the tri-state areas of New York, New Jersey, and Connecticut.

The four participants were given a choice for the interview setting, either at the facility or in their home. Three of the participants chose to be interviewed at the facility prior to treatment or while awaiting blood results. The fourth participant was interviewed at her home in New Jersey. All interviews were conducted face to face and tape recorded, over the span of several months.

Instruments and Measures

The interview guide (Appendix A) was developed to generate rich descriptive data, which sought to understand the human experience of an adolescent in the treatment process of cancer rather than attempting to explain its occurrence. The questions aimed to illuminate the experience of living with cancer and the ultimate impact on occupation, particularly social participation. Initially, 17 structured open-ended questions were formulated based on the aid of an interview guide that was developed through guidelines discovered in the literature (Creswell, 1998; Moustakas, 1994; Patton, 1990). Probing was only done if a participant discussed a topic unrelated to the original question asked.

In the case where participants elaborated on their experiences or answered questions together, questions were altered or not utilized (Moustakas, 1994).

Data Collection Procedures

The interviews were completed between March 2007 and July 2008 and began with recording demographic data including age, ethnicity, education level, work history, social support, living arrangements, type of cancer, and the length of treatment. Such demographic questions are aimed to creating a more relaxed and trusting environment (Moustakas, 1994). Other informational data that were recorded consisted of time, date and location of each interview. Throughout the interview, the participants' real names were never spoken or recorded, to maintain confidentiality.

Data collection consisted of participants responding to structured questions developed prior to the interviews which focused on the experience of having cancer and its impact on their daily lives, in terms of occupation. Interviews were conducted face to face and digitally recorded for accuracy. Journal notes were written during the interviews by the interviewer to solidify ideas and assist in bracketing. Since I had a similar experience as a young adult and experiences as an occupational therapist, some personal and professional feelings were included in the journaling notes. All participants were interviewed twice at a 30 day interval lasting approximately 75 minutes in duration. During the second interview, the first transcribed transcript was reviewed with the participants to allow for clarification or to elaborate on the initial interview. The second interview utilized the same questions with one additional question allowing the participants to reflect on the experiences of the previous month. This was a valuable step as participants identified traumatic events or unique experiences which were not reflected in the first interview.

Data Analysis

Data analysis began by utilizing the method outlined by Moustakas (1994), which is consistent with the aim of phenomenology and the works of Husserl (Creswell, 1998). His method of phenomenological reduction incorporates the foundation of transcendental phenomenology, rather than a more general approach to qualitative research. This reduction process occur at times simultaneously incorporating data collection, analysis, and interpretation, which are interrelated in a circular fashion. This process of analysis allowed me to organize the data in a way to reflect the lived experience of the participants.

To begin the data analysis process 4 adolescents with cancer were interviewed. The interviews were transcribed verbatim by a professional transcriber within 1 week following the interview. This allowed the researcher to reflect on the data as a whole in order to prepare for the second interview. After completion of the second interviews, data analysis began through reading the interview transcripts to gain a sense of the whole experience. This process assisted in isolating common statements between participants which were given equal value (horizonalization), and were highlighted on a chart for easy review. Clusters of common categories or themes developed through this process built textural (what was experienced by the participant) and structural descriptions (how was the phenomena experienced by the participant) (Creswell, 1998; Moustakas, 1994).

To confirm the accuracy of my interpretations, drafts of significant statements were provided to the participants (member check) to increase the trustworthiness of the data. Participants then had the opportunity to comment and provide feedback on interpretations I developed. This form of verification not only confirmed my assumptions and interpretations, but also assisted me in ensuring that my conclusions made sense from the participants' perspective. Written clarification and feedback on inaccuracies of interpretive meanings were documented. Through this integration of textural and structural descriptions and participants' feedback, the meanings of the phenomenon were constructed (Creswell, 1998; Moustakas, 1994).

Bracketing

One core element of transcendental phenomenology is the concept of bracketing, which has been highly criticized as difficult to achieve. This method assists in reducing data to descriptive meanings in order to create the essence of an individual's life-world. Heidegger (1954) and van Manen, Gadamer, and Ricoeur (van Manen, 2002) fail to acknowledge the ability for a researcher to set aside all biases and assumptions (and personal experiences) to focus entirely on the participants' experiences, through phenomenological reduction. Moustakas, on the other hand, looks at bracketing as a tool to facilitate an open and fresh approach to new knowledge, while being mindful of one's biases. He recognizes the existence of one's own preconceived ideas and their influence. However, in his view "the value of bracketing is that it inspires one to examine biases and enhances one's openness even if a perfect and pure state is not achieved" (p. 61). He recognizes the ability to refrain from all biases and preconceived ideas is not possible, but nevertheless, considers bracketing a valuable tool in making the researcher aware of them.

Bracketing in this context was achieved through journaling, which made me conscious of biases and prejudices towards the participants in terms of how chemotherapy regimens have changed in the last 20 years. For example, I bracketed the notion that these participants would have a similar experience to me, as I may have had a similar experience 20 years prior. Furthermore, bracketing was achieved in this study by identifying beliefs, preconceptions, and assumptions written down after the interviews were completed for self-reflection. This was to express my thoughts and set them aside which would help to maintain an open approach during the data analysis process (Bruce & Grove, 2003). Utilization of bracketing was implemented from data collection to theme development and assisted in understanding the experiences of the participant and reduced bias (Creswell, 1998; Moustakas, 1994). Through bracketing I acknowledge that the participants' life-worlds were very different, as current treatments have advanced into a weekly doctor's visit, rather than painstaking weeks in the hospital.

Study results will be presented in a narrative format with established themes highlighted to illuminate the experiences of these young adults with cancer. Through the development of textural and structural descriptions of the experience, readers will be able to step inside the life-world of the participants and understand the reality of living with cancer and its impact on occupation. Besides the resulting data, only demographic information and participants' profiles will be included to maintain confidentiality.

Assumptions and Limitations of Methods

Trustworthiness

Because phenomenology is a reflective and interpretative method based in understanding the lived experiences and meanings attached to these experiences, the likelihood of misinterpretation by the researcher is always there (Luborsky & Lysack, 2006). Trustworthiness was established through formulating structured questions in advance to minimize bias and increase consistency between questions asked. This uniformity prevented the use of “lead in” questions, which also tends to bias responses from research participants (Moustakas, 1994). Unlike methods in traditional empirical research, where tools are objective in nature, interview questions in naturalistic inquiry are subjective and open for interpretation (Pollio, Henley, & Thompson, 1997).

The establishment of trustworthiness is a critical component to ensure the methodological quality of this study, in addition to the framework described by Moustakas (1994). A number of steps were implemented to enhance trustworthiness and increase the rigor within the study design. The use of repeated interviews and discussions with the participants (member check) to clarify data, assisted in establishing themes and confirmed accuracy and credibility of the findings. Data collection was completed through a consistent interview technique involving open-ended non-leading questions. All interviews were digitally voice recorded with typed verbatim transcriptions for both the researcher and participant to verify for accuracy. An audit trail tracing the steps of the research process from raw data through phenomenological reduction and synthesis was established.

Additionally, triangulation, an approach to data analysis that synthesizes data from multiple sources was completed. Participants were interviewed twice at a 30 day interval and then participated in a third meeting to clarify transcribed transcripts. This cycle of analyzing data to verify information was utilized to reduce the impact of potential biases, add credibility to the study, and strengthen interpretations for theme development (Creswell, 1998; Kielhofner, 2006; Patton, 1990).

Because this study is so closely related to my own experience of childhood leukemia, the need to document my thought process on interpreting data and subsequent conclusions assisted me in reducing any bias and increased the neutrality of the study results (Creswell, 1998; Hallett, 1995; Rudestam & Newton, 2007). A journal was kept with my personal thoughts, feelings, and reaction to people throughout the data collection and analysis process (reflexivity) (Kielhofner, 2006; Moustakas, 1994). Journaling descriptive personal notes documenting my thoughts and biases enabled me to acknowledge my biases and how these might influence my interpretations of the data (Crabtree & Miller, 1999). This process also assisted in bracketing to understand the essence of the experiences as stated by the participants. Although a complete lack of bias is not humanly possible, the use of these techniques assisted me in understanding the experience of the participants.

Summary

A number of factors were considered in selecting a methodology for this study. Principles based in transcendental phenomenology were reviewed and recognized as a method in discovering the essence of the phenomena under investigation and allowed illumination of the participants' life-worlds. Strategies to reduce threats in the research design build overall trustworthiness. Perspective participants met all criteria outlined above, prior to beginning in this research project. Data collection and analysis were grounded in the phenomenology reduction model outlined by Moustakas (1994), in which common themes are developed and interpreted by the researcher. This reductive method was a powerful tool in the bracketing process as my preconceived ideas and bias became apparent in my conscious state. This structured method of data analysis reduced my professional and personal experiences to enhance and enrich the findings through creation of text drawn from the narrative data with further research recommendations suggested.

Chapter 4: Results

Introduction to the Chapter

The focus of this chapter is to present the findings from the analysis of interview data, memos, and field notes to answer the following research question: What is the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically social participation? The focus of the present phenomenological qualitative research was to obtain plausible and coherent understandings of the phenomenon of adolescents in the treatment process of cancer and the impact on occupation.

The goal was to identify themes that illuminated the impact of cancer treatment adolescents undergoing cancer treatment, and the impact it may have on occupation, specifically, social participation. During the actual interview process, the participant-researcher interaction influenced what was shared. In sharing their stories, participants co-created their self-identities as survivors and how they desired to be known. In reading the transcripts and listening to the recording of their words, the researcher used a selective process of what to include in the final report. In this process the researcher extrapolated only data related to the research question of the study, further co-creating the participants' lived experiences for the purpose of the research.

Additionally, all participants were interviewed twice within a 1 month period, with an opportunity to give feedback on the researcher's interpretations of identified themes. This procedure provided a form of member checking for the researcher or a form of investigator triangulation (Creswell, 1998). Transcripts were also read and compared to the actual recorded interviews for accuracy. The actual analysis began with the first interview and continued throughout the entire process. These personal reflections served as the primary source of information for the individual descriptions which were developed. The phenomenological approach offered the opportunity for in-depth reflection during the analysis process.

Results of the thematic analysis illuminated the many challenges adolescents in the treatment process of cancer endure in relationship to being a typical teenager. I will present the research question followed with several themes related to how the participants internalized the experience of having cancer and the impact on occupation. Themes will be organized as shown in Table 5, followed with sub-themes with individual textual descriptions.

Table 5

Thematic Themes

Major Themes	Sub-Themes
Change of Lifestyle	Physical & Emotional Pain of Living School Re-entry—A Saving Grace
Exploring New Occupations	Adapting Occupations Awakening or Confirming Religious Beliefs
Reconnecting with Family	Importance of Support A Kid Again
Living with Cancer Isn’t Easy	Isolation Hidden Disability

Data Analysis Results

Research Question:

What is the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically, social participation?

Theme 1: Change in Lifestyle

In this theme, participants described specific changes in their lifestyles while living with cancer. Although participants voiced how living with cancer changed their lives, they were all realistic in understanding that cancer is a disease that requires constant attention over a lifetime. These participants portray young adults who have changed their way of life to meet their immediate medical needs. Each participant described their lives as built around days that are filled with appointments, medical procedures, and the residual side effects of treatment. They have all accepted that their lives have been changed forever, and in some cases, must live with the physical signs of cancer.

Emma reflected on her life prior to cancer, which included attending a college out of state. This was her first time away from her family and living on her own, an idea she always dreamed about, although her family was just a phone call or a few hours drive away. She recalled the day she was told she had cancer after a few weeks of being ill. She described it as a relief, as she had aches and pains for some time, however, doctors were not sure of the underlying cause. It took awhile for her to really understand what was happing as she described it as a “big blur” due to her multiple hospital visits and pain killers, which often impacted her mental status. She described herself as a very outgoing person, loved being with friends, participating in school activities, and being physically active. She recognized that cancer was now going to become a major part of life. She mentioned how her life would never be the same again:

> *Emma:* I've accepted the fact that my life has changed and you know, this is going to have to be something that I'm going to deal with the rest of my life.

Oliver, after being told he had cancer told the doctors "let's fix the problem and move on." He viewed cancer differently than Emma, as he would not accept the idea that cancer was going to impact his lifestyle. He wanted to very much remain in control of his health to be able to "get back to a normal lifestyle" as soon as possible.

> *Oliver:* I'm getting into a new phase in life. Cancer is not going to bring me down because you know I had just finished my first year of college. It was my first semester. I didn't really want to stop my life just because this happened.

Most of the participants were in the transitional period of graduating from high school to starting their freshmen year in college. They all enjoyed the feeling of independence at this period in life where they become less reliant on their parents and more responsible for their own decisions. However, due to their illness, each participant shared the experience of a loss of autonomy and the sense that they lost control of their lives.

> *Oliver:* I don't know how to explain it, I have less liberties. I know that because before I used to drink when I was in college, now I can't because I am taking medication.

> *Adam*: The doctor told me that treatment was 3 years and made up of medications, so I didn't think it was so bad, take my meds and get on with my life, what's the big deal. Being on chemo feels like you are losing control of your life, meaning you have to devote so much of your time going to the hospital, sometimes being admitted for treatment, spending weekends in the emergency room for treatment as only a doctor could give the treatment, dealing with the side effects of nausea or pain which restricts you from doing anything.

Participants expressed frustrations related to losing the flexibility of participating in occupations on their own time, versus the predetermined schedules of doctors, treatment appointments, lab, and other appointments. A number of the participants identified themselves as being very organized, disciplined, and structured as they were all in the midst of attending school. As they were already somewhat frustrated by having their days planned for them, coupled with a loss of control, all felt it was a very difficult period.

Chemotherapy imposed a schedule on their lives rather than them imposing a schedule on chemotherapy treatments. The whole experience was reported to be very time consuming. It was not just the treatments and other appointments; it was the severe after effects which lasted from hours to days.

> *Emma:* It's like my days are kind of scheduled as long as I feel well, but then if I'm having a bad day, I'll just spend the whole day in bed. You know by 9:00 o'clock, I'm just spent, so then I try to fall asleep.

> *Oliver:* I didn't want to do anything. You are tired because usually your hemoglobin was down or my white blood cells were down. Even though when I had free time, I probably didn't have the strength to do anything. After I come home from the hospital, I'll be just laying down. I was at home recovering and then I'll go back to the hospital. So it really didn't give me a chance like to do stuff.

> *Adam:* Chemo definitely plays some part in life. A typical day "pretty much get chemo, come home, hope the day ended soon to go back to sleep. Sleeping was big.

With experience of dealing with repeated medications, participants developed an ability to schedule weekly occupations to allow for maximum opportunity to engage in activities they enjoyed. While discussing their balance of occupations, it became evident that the participants' time was primarily divided into four key areas, as follows: hospital visits for treatment, sleep, being with friends, and school. The scheduling of time in the first two areas was often geared toward dealing with their treatment for cancer. For example, they arranged their class schedules to avoid classes on certain days not to conflict with their medical treatments. Of course, this was not always possible, as their blood counts dictated if they were to receive treatment for that week. Participation in occupation(s) often took advance planning rather than being spontaneous.

Scheduling ahead also allowed them to participate in planning occupations with friends as they knew how fatigue impacted their bodies after treatment. This was considered “recovery” time when participants knew they would need to rest from the side effects of the medication. Participants found scheduling naps throughout the day to be helpful as it allowed them to be with friends at night, even if only to “hang out” and watch TV. In some instances, participants acknowledged this was the only time that they could catch up with friends who often worked or had different school schedules. These results show a link in how participants engaged in social participation through closely scheduling their lives around intense treatments for cancer. Although changes in their routines occurred often, their ability to develop somewhat of a normal schedule, gave them all a sense of control.

The diagnosis of cancer came as a relief to the participants, in some strange way. Although all were confused and fearful of having cancer, not knowing was more anxiety provoking. In Emma’s case she was suffering extreme pain secondary to a tumor, which was misdiagnosed. When she was finally diagnosed she felt “They figured out what was wrong and now they can start treating it, and hopefully I’ll feel better soon.” This positive attitude radiated throughout the interviews. Oliver recalled after learning he had cancer, “what can we do about it? I was just like ok, you know, fix it.”

Participants defined cancer in the realm of “time” rather than a serious illness which can have lasting effects. Cancer was perceived as a condition with a definite end and as something to be dealt with for a period of time. Participants all had a goal to “do their time” and take the next step of moving on with life.

> *Emma:* Hey they given me a date, June 26th is going to be your last treatment, it’s like, OK! It’s coming. I have a definitive thing that I’m working towards. Whereas, at the beginning is like, is this ever going to end?
>
> *Adam:* I’m doing my two years at a time. I just imagine being tied down to a chair and like you want to go out and do stuff and you just can’t. You are stuck in a chair.
>
> *Oliver:* I had to stay in the hospital for weeks at a time. It felt like prison. I look outside and I couldn’t go out. I’m going to get through this, it’s just a process.

Sub-Theme: Physical and Emotional Pain of Living

In this sub-theme, participants described specific physical and emotional issues that impacted their ability to participate in occupation. The participants identified the treatment and side effects of chemotherapy and/or radiation as a very painful process. Differing treatment protocols resulted in various treatment schedules. Surgery, recovering from surgery, or having weekly chemotherapy sessions have impacted both their physical and emotional well-being. Beside the days of chemotherapy, participants find the days between treatments to be “rough” because of the long-lasting side effects, which are often as painful as the treatment itself. Nausea and fatigue have been more or less constant, which often leaves the participants housebound, thus leaving them unable to socialize with peers. Besides the medications, the participants described procedures such as spinal taps and bone marrow biopsies as being somewhat “torturous.”

> *Emma:* Being in pain, feeling the pain was never going to end, or that the sickness part of it was never going to end and not being able to see, the light at the end of the tunnel at the beginning, is difficult. I lost my hair already, which is a very traumatic experience for me. It was painful and being sick all the time at the beginning it was so intense and I remember the first day of chemotherapy I told my mom, I looked at her right in the eye and said if the cancer doesn't kill me, the treatment for it will.

> *Adam:* Losing your hair, it's no fun. You look and feel very different. No one wants to look like that (without hair); no one wants to look different and feel different if they don't have control of it at least, I think. When I started losing my hair it took a while. Something with the hair, I looked and just felt terrible.

> *Oliver:* Ah, pain, pains, I can't explain this but it was horrible. I got use to the needle and stabbing, but nothing could prepare you for the pain.

> *Eric:* Chemotherapy was hard. I felt tired and would be in my bed for three days. Some medicines would make me throw up, vomit, and caused constipation. You feel like a different person, not the same person.

For the participants, a large fraction of mental energy was spent managing the emotional and physical pain of chemotherapy and often the medications that dealt with the side effects of treatment. Emma and Adam discussed their hair loss as very traumatic and devastating as it changed their outward appearance. Although to some a small price to pay for surviving cancer, participants viewed this as an outward sign of illness. The use of wigs, caps, or scarfs was their only defense against an outside world where appearance is often dictated through the media.

> *Emma:* I think it has been an emotional journey as well as physical. You know being in the hospital setting. Losing my hair and then like the Prednisone, moon face, and everything you know. I would like avoid walking pass the mirrors and even at home I would always have a scarf or something on.

> *Eric***:** I encountered the problem and the trouble of getting out from my house because of my hair. I have to wear cap on my head because I don't want any of my friends to know that I have leukemia.

> *Adam*: It was socially a little awkward (being without hair) at first people always staring at you, going out to eat with your ID bracelet.

Participants discussed both the physical and psychological problems faced when on chemotherapy. Many described the physical pain of chemotherapy as a cause that prevented or limited their ability to participate in occupations with others. The physical problems of tiredness, joint pain, and changes in appearance, all contributed to a decrease in social participation.

Sub-Theme: School Re-entry—A Saving Grace

The return to school, a key to normalcy in the participants' lives, as Oliver recalls "school saved me getting back to the rhythm of life because school is my life right now," was a sentiment experienced by all the participants. Adam was very happy to return to school "it was, for the first time in my life (returning to school), awesome, because I just needed to get away from being sick and sitting at home being so bored everyday and just doing nothing."

However, their return to school was also scarred with the physical and emotional pain that came with cancer treatment. Although school provided them an occupation outside of their daily hospitals routines, it also became a challenge to overcome effects of chemotherapy which impacted their lives. The ability to focus on material, maintain attention, to poor handwriting skills were noted to be problem areas upon returning to school. Emma, for instance, recalled how she enjoyed school and it came very easy for her, however, now she needed to work much harder to gain the same results.

Although described by the participants as a step to normalcy in their lives, school was an occupation which took a lot of effort and energy due to the participants' treatment protocols and the side effects of chemotherapy. The desire to return to school became a central occupation which helped them organize their time and provided an outlet away from the hospital. It also provided a window to meet new friends and set future goals they wished to achieve. However, participants came to the realization that school was now more of a challenge, whereas, before cancer, it was much easier to achieve high grades.

> *Emma*: Chemo, it affects like your brain, your whole body so like I have trouble reading now, the letters get mixed up in the page, or get to the end of a page and have no idea what I just read, like trouble concentrating, trouble focusing for any amount of time when I'm trying to read. It's just frustrating because it's something new and I have to put so much more effort into it and, like if I'm trying to read a book and I get to the end of the chapter and like none of that sunk in, then it's like OK, I have to go back and do it again.

In Adams' situation, steroids, a component of his treatment protocol, not only impacted his mental status, but his ability to function on a daily basis. Due to the side effects of the steroids it was sometimes impossible to sleep at night. Since he never achieved a full night sleep, his ability to participate in school activities with his peers was impacted as he often suffered from fatigue. Besides fatigue, medications to lessen the side effects of treatment often led to depression, which he mentioned. In the end he shared how he felt isolated from friends as his mind was "not all there."

> *Adam*: Sometimes I can't take tests because I'm on steroids so some nights I can't sleep well. It kind of drives you nuts, it's like a feeling that I get very depressed from them.

Besides the cognitive changes which impacted participation in school, residual side effects of chemotherapy caused physical limitations affecting daily participation in school. Emma and Eric expressed their frustration with the physical effects of the medications; however, there was also a social component to participating in school. Both appeared to be concerned with how their peers viewed them, in terms of being in school and not being able to write.

> *Emma:* My handwriting is so horrible now because I can't really stay on the line that well. In class people I'm staying next to they'll notice that my handwriting is horrible. I'll be like ok. You are a sophomore in college and you still can't read and write? Then with my fingers, it's hard for me to hold a pen or write. I went to OT for I would say four months and that was so frustrating. Eventually, my hands got stronger and they graduated me from OT.

> *Eric:* It affected my hands, because I can't write very fast like other students. I write slowly. When I write very fast, it hurts my hand.

Returning to school was not easy; however, it provided the participants with a daily occupation which they found meaningful. Participants identified the physical and cognitive impact of chemotherapy as a disruption in their educational pursuits. All were good students prior to cancer; however, now with the inability to maintain focus, retain attention, and dealing with physical pain, participants had to relearn what came easy to them. Most importantly, participants realized that they are not the same person returning to school. Now they need to face new challenges balancing treatment, school, home, and building new friendships as many of their friends have moved on, since they were last in school.

The return to school brought anxiety, although all the participants considered school as a step in the right direction, signifying "moving on with life." Participants were beginning new schools in unfamiliar environments. Although all were excited, they were concerned about attending schools where all of their peers have moved on. Meeting new people was often a challenge, as their appearance was sometimes difficult to accept. Attending a new school, wearing a wig in public, or having a disfigurement impacted their ability to socialize with others.

Along with attending a new school was the insecurity of being able to succeed in academic studies. The many side effects of treatment at times left participants tired and fatigued. Since participants were not in school for a period of time, they often questioned would they be able to handle full class days and homework. Although all the participants shared their reservations about beginning school, in the end school became a refuge as it afforded participants the opportunity to establish routines and mingle among their peers.

> *Emma*: I think going back to school was scary because I don’t really know what to expect. I haven’t been to this school before, so just trying to find my way around and meeting new professors and all these new people was scary and intimidating in itself. I was so conscious about who knows if I am wearing a wig.

> *Adam:* I was like scared, I won't even be able to like write a paper. I thought I may have become so stupid for not doing anything for so long, but thank God I got back into the swing of it and it felt great. I really enjoyed my first semester because I hadn’t been in school for so long.

> *Oliver*: School saved me getting back to the rhythm of life. School is my life because right now, it’s the only thing I could focus on for now. I’m trying to focus on school. I’m trying to get it over with.

In summary, this theme reflects lifestyle changes which these young adults needed to deal with in order to maintain a sense of routine and engagement in occupation. Changes in appearance led to barriers in social participation, especially in school, a place where they all wanted to “fit back in.” However, due to the anxiety of developing new friendships, dealing with the side effects of treatment, and being in a new environment, this was not always the case. Although these issues existed, participants felt returning to school was a positive step in moving forward with their lives.

Theme 2: **Exploring new Occupations**

This theme related to how participants explored alternative occupations that allowed them to participate in routine activities secondary to the intense side effects of cancer treatment, which often left them weak and fatigued. All the participants described a particular passion for sports which played a vital role in their everyday occupations. However, due the side effects of treatment, which they described as debilitating, engagement in sports was not possible. Being on chemotherapy impacted the participants' ability to engage in occupations once enjoyed, which has been described as a very painful process. However, new occupations have emerged throughout this period which has given them great personal satisfaction. Since the participants stayed home for days on end, less strenuous occupations such as video games, watching TV, or having friends over occupied their time.

> *Emma:* I used to be really active before. I would go to the gym two times a day. I just don't have the stamina, the endurance, or the muscle mass to do that anymore. I like working out and like being physically fit and everything. I miss doing that.

> *Adam:* The only way I really feel like I'm still sick is like I can't play sports and stuff like that. Sports were sometimes one of my daily routines. I tried to get back into sports, just before I knew I had osteonecrosis. I was playing soccer with my friends, and I kept hurting my ankles, so eventually I ended up fracturing it.

> *Oliver:* If I am not feeling well, I am not going to be playing basketball. I'll definitely be home. During the rough period it was just like trying to get as much sleep as possible, help the time go by faster honestly because it was horrible times it was either I was awake I would be just lying there, but I had some chemotherapy I probably be nauseous so really I tried to sleep as much as possible help the time go fast.

> *Eric:* First, when I was diagnosed I couldn’t walk. I couldn’t play my favorite sport, soccer. My dad, when I walked on the street, had to carry me because I couldn’t walk on the sidewalk.

Adapting Occupations

Although many hours were devoted to their medical needs, most participants learned to adapt to new sports or activities to keep themselves occupied, thus preventing that sense of loneliness or isolation from their peers. Chemotherapy changed the way they chose occupations to participate in secondary to unplanned daily schedules and occupations requiring little effort or physical involvement. The ability to participate in new occupations not only brought a sense of normalcy to the participants, but also an opportunity to once again be part of a social environment of people, who were interested in the same occupation(s). Additionally, it filled their time with occupations they enjoyed and routines which were often difficult to establish at this stage in their lives.

In Emma’s case, she returned to acting at the local theater where she once performed during grade school. Being creative in theater was an outlet to express herself in what seemed to be a dark period in her life which brought her peace and empowered her to move forward in her life.

> *Emma:* I can’t play sports to the degree, or close to the degree that I used to, which is very frustrating. I auditioned for a few shows at the community theaters. I had something to do three times a week and it was over by about 9:30 so it was good timing for me.

Adam, on the other hand, explored swimming as an alternative as it was less stress on his joints than contact sports.

> Adam: I can’t play sports to the degree, or close to the degree that I used to, which is very frustrating. I feel accomplished after I swim a bunch of laps because like who’s laughing now cancer?

Eric became more involved in his studies to compensate for his inability to participate in sports. Although he played soccer and other sports before being diagnosed with cancer, he remained concerned about the impact of physical activities on his body. Unlike the other three participants, Oliver settled for spending time with friends playing video games at the hospital or at his home secondary to feeling tired from his daily chemotherapy routines.

Sub-Theme: Awaking or Confirming Religious Beliefs

This sub-theme of *Awaking or Confirming Religious Beliefs* tends to focus on the degree in which God or religion has emerged in becoming a significance part of the participants’ lives. Participants often expressed the need to regain a relationship with God and to be thankful for their lives. The illness of cancer was described by the participants as a life-changing event which made them think beyond their physical needs and more about a higher being assisting them through this period. They all recognized that they were at different stages in their lives, where religion not only became a spiritual occupation, but provided an environment for social participation.

Religion became a source of social support for theses participants. They participated in mass, synagogue, or mosque services on a regular basis with family or friends which provided an opportunity to meet others with the same spirituality beliefs. This social interaction also offered them the ability to participate in a community where people shared the same values, which participants found comforting.

It was also an environment where participants felt “acceptance” from the standpoint of not being judged or pitied about their illness or appearance. In essence, attending religious services may have becoming a coping mechanism which enabled occupation as it got the participants involved in community activities which offered them meaning in their lives.

> *Eric*: I have become closer to my God.
>
> *Adam*: I got closer to God. When you are in your bed and like you don’t feel good or I don’t know, you are hallucinating because of the chemo, you find comfort in just murmuring to God and just asking Him for help and just knowing that there is someone out there that can help. I’m closer to God. I felt a lot more personal connection. God and religion influences my decisions, I make on a daily basis. I’ve developed a closer relationship with God. I feel I speak to Him on a very personal level.
>
> *Oliver*: Church is an activity that’s important to me. Sunday we go to church and then we have a prayer group, but I remember before since I couldn’t go to church the prayer group would come and have a little eulogy (at my home).

In summary, this theme reflects how participants explored new occupations, due to the residual effects of chemotherapy, such as poor physical endurance, decrease mobility, and an overall decrease in stamina. Since all the participants were active in sports and school activities, the inability to participate in such occupations, had a major impact on their lives. This inability to participate in occupation also led to isolation among their peers as they were not able to engage in strenuous activities. In light of this, participants discovered new occupations which were less demanding on their bodies and fostered social participation among their peers.

Theme 3: Reconnecting with Family

In this theme participants shared how their families played an important supportive role in their recovery. It was apparent from the stories these participants shared that they were all in a transitional point in their lives, either away at college, working, or finishing high school, preparing for college entrance exams. In a traditional sense, returning home soon after college or living with your family is a simple way to save money. However, in these participants' lives, the unexpected onset of cancer, once again made them rely on their families for support, both emotional and financial.

This theme of *Reconnecting with Family* grew out of participants returning home or living at home facing new family dynamics, where parents are once again in the caregiver role. In some cases, participants shared how family bonds were re-established after many years apart or how relationships between families grew stronger.

Importance of Support

Participants often identify their family as the most important source of support throughout this period. They shared how their families bonded and in some cases, came together after many years of separation. Their illnesses affected their relationship with their parents which made it harder for them to gain independence, especially in terms of decision making. Parents tended to be overly cautious and protective with their children. Both parents and siblings alike were impacted on an emotional level, which in some instances led to siblings acting out.

All the participants reported the importance of supportive families who helped them in the road to recovery, both in a physical and emotional sense. Out of this situation, participants recalled how their families grew closer and how new caregiver roles developed. Three of the participants were in their freshman year of college, living away on campus. After their diagnosis, they all returned to their parents' homes, thus losing their autonomy, which they enjoyed while at school. Participants felt they became less involved in their daily decision making and more of a "dependent" of their parents, which precipitated a sense of over protectiveness.

> *Emma*: I think this experience made me so much closer with my family. I decided that I want to be close to my family, hospital, and my doctors. I have realized that I would not feel comfortable going far away again. I think for right now the next 2 years of college I need to have that secured place.
>
> *Oliver*: I think I got kind of close with my dad during that whole time. Usually my dad was here always with me. I know it affected my dad very badly, he lost a lot of weight at the time.

In Eric's case, he mentioned his sisters as being very supportive and describes his dad as the one who spoils him with "special treatment," which he likes to believe, is not given to his siblings.

Beyond their immediate families, the participants described becoming much closer with their extended families.

> *Adam*: I've become closer with my mom's sister and her husband. Whenever I needed blood or platelets they would organize a blood drive. I've definitely grown a lot closer to them, probably more than anyone. I don't know the words for it, but it's significantly more of a bond.
>
> *Oliver*: I remember my uncle would come to see me whenever he got a chance. Whenever he got out of work, he would come, stop by. We (our family) split up and now we have to start getting back together.

In Eric's situation, since a majority of his extended family resides in Egypt, most contact is done by phone or a yearly visit to New Jersey. However, when the family was told of his illness they were concerned “they sent me a lot of money and my young uncle sent me a Play Station in Egypt. They wanted to make me happy.”

Family was identified as a source of support for the participants. Family members who did not live with the participants visited often and became a positive distraction during this period. There are many accounts of the strong emotional support provided by the family, as many often attended treatment sessions with the participants. Although not having cancer themselves, family members lived the disease and treatment alongside the participants. Participants felt grateful to their families in so many ways, as without them cancer treatment would be more of a burden. Besides the emotional support families displayed, the physical support assisted participants in rediscovering occupations. Often participants were driven to do shopping, meet up with friends, or to friends’ homes to watch television or play video games.

> Emma: I wasn’t allowed to drive at all. I have to take Tylenol with Codeine or Percoset or something for pain management. I lost my independence, I guess, because I have to rely on other people to get me somewhere if I need to be there.

It appears that all the participants described how this experience brought family members closer in terms of an emotional bond. Although some participants described parents as overprotective, they all were grateful to their parents for the support they offered. Additionally, in spite of losing a degree of independence, participants found being with their families a comforting and secure experience.

Sub-Theme: A Kid Again

In this sub-theme participants describe the transition from living independently to returning home to reside with their parents. All the participants expressed the desire to become less dependent on others and to have more opportunities to make choices for themselves. Each participant described how he/she became more dependent on his/her families to carry out daily occupations. In essence, this dependency resulted in parents once again becoming caregivers to their young adult children. This role reversal often resulted in frustrating situations and overprotective parents. As with all young adults this age autonomy is extremely important, however, a cancer diagnosis puts them back into the dependent category.

> *Oliver:* It feels weird because I feel like I am younger again, having my mom there. I do not know if she sees me as a little kid again. She feels that she has to take care of me. She has to keep me under her arms and stuff. My mom takes more care of me now.
>
> *Emma*: My parents would go take off from work to bring me to the hospital for getting scans or blood work that day or something, they'll both be there. I would say that, they probably always have been overprotective. She makes decisions for me. They try not to (be overprotective) but I think sometimes they are.

Although Emma loved her mother, it came to a point where she felt her mother was too controlling. However, she admitted it was comforting to have someone looking over her shoulder, despite losing some independence.

> *Emma*: You know sometimes it's annoying, my mom will be like "You know don't go to class today if you are not feeling well." I will be like "Mom I have to go to class", "No, no, no, don't go." "No, mom, I have to go." It does become annoying. She double checks my pills, it's kind of a sigh of relief, because it's so important. I realize I had to give up some independence you know.

In Eric's case, overprotective parents resulted in an apparent lack of discipline. He described how differently he was disciplined versus his siblings when they acted inappropriately.

> *Eric:* When I was young before I had leukemia, when I did something wrong, my father punished me; now no punishment. My parents are afraid for me and get scared when I hurt myself or something like that.

Adam, in previous years prior to cancer, had worked at summer camps during school breaks, which he really enjoyed. However, due to a rigorous treatment protocol for cancer, his mother and doctor decided it would not be safe for him to return to the camp. This had an emotional toll on Adam, as he felt his life was out of control as others were making decisions for him. He recalled how he desired to return to the camp performing any job available despite his change in appearance.

> *Adam*: My mom and my doctor told me I shouldn’t go back (summer camp) because I couldn’t be in the sun, I was also very upset about that, you know limitations, really. I was feeling different and again it goes back to when you can’t control, it’s just so much worse.

In summary, family played a major supporting role in these participants’ lives. Although participants felt their parents often became overprotective, which precipitated a sense of dependence; all felt without their families’ support they would not have survived such a traumatic experience. Besides support, participants shared how they became closer with their families during this period. They reflected on the importance of participating in family dinners, attending religious services as a family, and attending family gatherings, which provided a sense of comfort in their lives.

Theme 4: Living with Cancer Isn’t Easy

This theme reflects how participants experienced isolation while living with cancer from a social viewpoint. It also entails how participants did not want others to know about their cancer in fear of being treated like an outcast. Participants expressed how their lives seemed out of control through this turbulent period. Frequent doctors’ appointments, multiple medications, and lab appointments impact your daily routine. Socially, participants reported that many hours spent in the hospital or at home resting can be a very isolating experience.

In terms of developing new relationships, participants mentioned there is a fear secondary to the uncertainty of how you will be accepted by others. Similarly, current friendships and relationships do not always survive, as friends may not know what to say or have a preconceived idea that survival is not always possible.

When describing their relationship with friends, participants acknowledged that best friends will often become closer and friends who are less close will disappear. Because the participants were unable to engage in daily occupations secondary to the residuals of treatment, friends played a major supportive role. Although some friends were not there in the physical sense, they called or e-mailed on a regular basis. Participants found this comforting, as some friends without reason, stopped calling altogether. This factor, combined with the lack of occupation, led to a feeling of isolation or loneliness among the participants.

> *Emma*: You learn who your real friends are as some found out that I was sick, I really haven’t heard from them since. Whereas, other friends did their best to make sure that I’m feeling well.
>
> *Adam*: I think at the beginning we (my friends) grew a lot closer. I'm still friends with every single friend I have. I have a group of ten guys I'm friends with, we’re the Tenacious Ten.
>
> *Oliver*: I lost touch with a lot of people. I don’t know what happened. They (friends) found out I got sick and then after a while we just lost contact. I don’t think they were afraid; I really don’t know and don’t have time to go up to them and ask them why.

Participants felt friends helped them through the hard times. Unlike family who supported the participants from a health standpoint, friends appeared to be confidantes and motivated them to socialize. Participants mentioned how long-term friends remained intact while it was much harder to make new friends due to their busy and unpredictable schedules. Participants shared many experiences of “hanging out with friends,” going places etc. as long as they were feeling well enough. Socializing with others did not always come easy. Participants, in some cases talk about how planning ahead became part of their daily routines if they were planning a day or night out secondary to the side effects of their medications. Although participants shared how they wanted to be more social, they spoke about not always being able to participate in activities fully or having to cut their time short, based on the lasting effects of chemotherapy.

> *Adam*: I happened to think that friendship and companionship during this process is so important. I mean obviously the chemo is probably what cured me, but I would venture to say that between the friends and the family the closeness and companionship that did the other half and just really put it over the top and brings me to where I am today.

In contrast, Oliver shared a very different perspective of friends who supported him from his neighborhood.

> *Oliver*: Well, I told my close friends I have leukemia but I know they weren’t going to pity me or anything. They (my friends) used to take care of me more when I was really sick. Like if anything I needed help or I needed something, they would always be there. If I wanted something, they’d go get it for me.

It was clearly difficult for the adolescents with cancer to foster friendships when they were receiving treatment, as they felt they were isolated from their peers. The development of new friendships was not always easy, as participants only attended school on a part-time basis and often struggled with the changes in their physical appearance. This led to an overall decrease in socialization among their peers. This was only made worse with the participants’ or their families’ desire to keep their illnesses hidden from others due to various reasons. In the end, this created stress, a barrier to socialization, and the uneasiness of not being truthful with their peers, classmates, or friends.

> *Emma*: I tried a lot to make new friends at college. I think a lot of people are scared of cancer. They may not necessarily know that much about it. It's hard to make friends when you are the transfer student to begin with, but then you are also the girl with cancer on campus, so that's been hard.
>
> *Oliver*: I was starting to become more social again, I made a lot of friends during that semester. That took a while, but it's not the same when you are living on campus and when you are living off campus. Like my two friends from school and from here (neighborhood) know that I have cancer, they see me as a normal person because they didn't find out until they asked me. I don't go around telling people I have cancer.

Emma recounted how she met an old friend over the summer and how people can be insensitive of others who look different.

> *Emma*: I remember one time over the summer, I saw a friend that I haven't seen in a while, and I went with him to another friend's house and there was a bunch people there that I didn't know I wasn't wearing the wig only a scarf and this girl who was standing behind me, she was like, oh, I guess you are trying out for Julia Styles? I turned around and I was like "no actually I was trying out how the girl with cancer looks, thanks"!

The feeling of isolation was expressed in all the participants' lived experience. The uniqueness among their lived experience was the underlying cause creating such feelings of loneliness or isolation. This sense of loneliness or isolation was defined by the inability to participate in occupations once enjoyed prior to cancer. Others expressed their changing appearance or the emotional and/or physical impact of cancer treatment on their bodies, as being an influential on their ability to participate in occupation.

The participants also found being on treatment for cancer an issue that set them apart from their peers who had difficulty understanding what they were going through. This may have been related to maturity, as young adults do not deal with cancer at such a young age. Participants often felt judged about their appearance or physical limitations they had secondary to chemotherapy and radiation treatments. Two of the participants were attending the teen cancer support group to speak with others in the same situation. This was also a safe haven as they felt accepted and were comfortable in sharing their experiences with other young adults. Beyond the opportunity to enjoy time with close friends, participants felt having cancer isolated themselves from developing new relationships with peers or others due to their treatment schedule and other complications of treatment. In reality, two of the four participants had romantic relationships at the time of the interviews. The other two participants were single, with Emma having recently broken up with her boyfriend who could not handle having a girlfriend with cancer.

> *Emma:* My boyfriend actually broke off with me when I got sick. He couldn’t handle having a girlfriend who has cancer, in his words. I honestly don’t blame him. It’s a hard thing for somebody to have to deal with it at our age. So if you don’t have to, why would you want to?

This lack of having significant others or friends who were mature enough to handle the situation might explain why participants held strong bonds with patients who were in the same situation. Conversely, it might be that they did not develop new relationships because they felt more comfortable with being with friends who understood their situation where the possibility of rejection is nonexistent. In any case, they felt supported by other patients with cancer, family, and close friends who assisted them if the need arose.

Sub-Theme: Hidden Disability

In this sub-theme participants described how their fears and concerns about sharing their illness with others may impact their lives. A major fear among the participants was being “found out” by others. The need to keep their illnesses a secret was not always by choice. In the case of Adam, it was his parents who did not want him to tell anyone. He describes it as his parents looking out for his future. In tightly knit Jewish circles, as he describes, rumors of illness can impact the possibility of dating and marriage within the Jewish community. “In our dating circles people do backup checks and if they hear oh, he had like bone problems, somehow it affects people. I have Leukemia that was enough that’s all anyone had to know.”

This secrecy as he described created additional stress in his life, as he was always on guard not to tell others about his illness. This secret he held impacted his ability to play sports, which was always a passion in his life.

> *Adam*: If I had it my way I would tell my friends, it probably would make things easier on me also because my friends were asking me to play sports and I have to tell him, I can’t, I am busy. I just have to think of different excuses every time and sometimes I don’t even have an excuse.

Similar to Adam, Eric kept his illness hidden from others for much different reasons. When he was first diagnosed with leukemia, he was in his homeland of Egypt, before his family sought more intense treatment for him in America. The understanding of cancer, as he explains, is very different in Egypt, as people with cancer are isolated from others for fear of catching the disease. In the end, he felt content not telling his friends in Egypt, as this would impact his relationships with others.

> *Eric*: In Egypt, nobody in my school knew I had leukemia except two teachers. My friends didn’t know that I had leukemia, because in Egypt, it is different from America. When you have leukemia, you are kind of isolated; your friends begin to go far from you.

After arriving in America for additional treatment, he realized that people with cancer were treated very differently. Rather than be shunned, those living with cancer are embraced and supported as having a very difficult illness to endure.

> *Eric*: Here (America) I don't think my friends have changed. When they knew I had leukemia, they didn’t change. Everyone (friends and classmates in America) loved me. My teachers also liked me. They treat me like any other friend. No difference.

In contrast, Emma and Oliver kept their illness from others, so they would be seen as “normal.” In Emma’s case, the experience of living with cancer has taken on a very personal meaning. Living with cancer has been the single most important issue in her life. The need to tell others about her illness does not come easily. Her concerns stem from what others think of her and the genuineness of their kindness. She feels most comfortable telling others only when necessary.

> *Emma:* I have tried not to tell my classmates what’s going on. I find that when people don’t know that I am sick, then it's easier for me to be involved in class and have conversations with my classmates. However, as soon as people do find out then it's in the back of my head I am thinking are they just being nice to me because they know I am sick?

Oliver, on the other hand, was concerned with how people would perceive him. He did not want to be perceived as a person to pity, but rather a normal person who loved to have fun with friends. He knew his friends viewed him as one of the guys, so he was very open about his illness. Otherwise, he kept his illness hidden from others, who may stereotype him as being sick all the time with cancer.

> *Oliver*: If I’m going to miss school assignment because I had to receive chemotherapy or something, I try not to let them know because I wouldn’t want them to feel sympathy for me.

Similarly, he did not want to share his illness with his family in Peru, as he was not a person who wanted or looked for the sympathy of others. In the end all his relativities found out.

> *Oliver*: Well, at first I didn’t really want to tell anybody because I didn’t want anybody to feel sorry for me, but then my mom was like oh, we have to let them know, if something happens you have to let them know. It was not like I went around and told everybody “Oh I have cancer,” you know. I didn’t want to tell anybody.

In summary, this theme focused on how social participation was impacted as participants shared how their busy schedules outside of school became a barrier to developing new relationships among peers. Additionally, participants felt it was easier to keep their medical conditions hidden from others, for fear of not being accepted. This fear also became of the root of isolation for many of the participants.

Summary of Results

These participants portray young adults who have changed their way of life to meet their immediate medical needs. They have accepted that their lives have been changed forever, and in some case, must live with the physical signs of cancer. Participants describe their lives as built around days that are filled with appointments, medical procedures, and the residual side effects of treatment.

Living with cancer is not easy due to the many side effects that impact the physical and emotional well-being of an individual. Although engagement in occupation is impacted by the intensity of cancer treatment, the human drive to engage in occupation remains. When engagement in prior occupation(s) is not possible, secondary to the physical or mental challenges faced by these individuals, new occupations can be constructed or adapted to meet their needs.

Being on chemotherapy has impacted their ability to engage in occupations once enjoyed, which has been described as a very painful process. However, new occupations have emerged throughout this period which has given them great personal satisfaction. Participants described returning to school, a first step back to a normal life, as scary, due to the unknown reality of meeting new teachers, peers, and others who may view them differently.

Results reflect that daily engagement in occupation such as attending school, religious services, and being with family or friends, give meaning in the lives of these young adults. When occupation was nonexistent, participants experienced isolation and/or loneliness which perpetuated a feeling of poor self-esteem and self-confidence. Overall, the descriptions are meant to be a compilation of the participants' experiences and the individual details may not apply to every participant.

Summary

The purpose of Chapter IV was to present the findings which resulted from the analysis of interview data, memos, and bracketing. Results of the thematic analysis illuminated the many challenges adolescents in the treatment process of cancer endure. Several themes were discovered related to the participants and how they internalized the experience of living with cancer and the daily grind of chemotherapy and radiation treatment. This phenomenological study increased the understanding of their lives and the meaning it had for them, and how those meanings were developed. As the participants described their experiences, I listened for not only the words which were spoken, but also for the significance behind the words, in an effort to better understand how treatment for cancer had integrated itself in their lives.

It was not the intent of the study to discover universal truths or to predict what others would experience living with cancer, but to illuminate the process for a selected group of participants. The following Chapter V will discuss the themes that emerged from the data analysis, possible areas for future research, and implications for occupational therapists surrounding the needs of adolescents in the treatment process of cancer.

Chapter 5: Discussion

Introduction to the Chapter

A phenomenological approach was utilized to explore the thematic meanings adolescents attach to the experience of undergoing cancer treatment and the secondary impact on occupation, specifically, social participation. The need to illuminate this issue arose out of a lack of literature in occupational therapy, which details this phenomenon from the lived experience viewpoint of four adolescents.

Four participants participated in this study, ranging from 17-19 years of age. All were in the process of being treated for various types of leukemia on an outpatient basis at Hackensack University Medical Center in Hackensack, New Jersey. At the time of the interviews, two of the participants had recently moved back home from their freshman year in college. Both were in the process of transferring to a local college in their areas. One other participant was a senior in high school and the other recently graduated high school preparing for college, both living with their families.

Prior to recruitment, approval was sought from both Hackensack University Medical Center and Nova Southeastern University’s Institutional Review Boards. Participant recruitment was done through an oncology nurse who worked on the outpatient unit at the hospital, who knew the inclusion and exclusion criteria for the study. After this initial contact, each participant was called by the researcher and interviews were scheduled that did not conflict with their medical treatments.

Data analysis was based on Husserl’s transcendental phenomenology reduction methods as outlined by Moustakas (1994) and Creswell (1998). These methods allowed me to set aside (bracket), as much as humanly possible, all preconceived experiences to better understand the experiences of the participants in the study. This was an important aspect of the data analysis process, as I had a similar experience to the participants in my young adulthood.

Study findings resulted in four major themes (see Table 5) with supporting sub-themes which further describe the lived experience of dealing with cancer treatment on a regular basis and subsequent impact on occupation: 1. *Change of Lifestyle* (a) physical and emotional pain of living (b) school re-entry—a saving grace; 2. *Exploring New Occupations* (a) adapting occupations (b) awakening or confirming religious beliefs; 3. *Reconnecting with Family* (a) importance of support (b) a kid again; and 4. *Living with Cancer Isn’t Easy* (a) isolation (b) hidden disability. These findings have led to further understanding of the lived experience of these young adults with cancer and the impact on social participation.

In this chapter, the results of the study which examined the research question, “What is the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically social participation?” are discussed. Additionally, conclusions are drawn based on the findings to illuminate the impact of cancer treatment on social participation among these young adults. The importance of these findings are discussed which may impact occupational therapy from a global perspective. Furthermore, the potential role occupational therapists may assume from a clinical standpoint in order to provide services to the adolescent cancer population is discussed.

Additionally, limitations of the study and findings in relation to previous research are discussed. Finally, suggestions for future research related to social participation and adolescents in the treatment process of cancer are discussed.

Discussion

Change of Lifestyle

Participants discussed how their lifestyles changed during this period of uncertainty. A feeling of losing control was related by the perception of being taken over by outside environmental factors such as chemotherapy treatments, medical and lab appointments, and the inability to make decisions. Participants felt displaced and disengaged from their everyday world. Having to attend daily chemotherapy treatments and dealing with the after effects were found to be disruptive and unexpected, as participants were not prepared for such experiences.

Without exception, the changes in one’s physical appearance (e.g., loss of hair and weight changes) were found to be an influential issue which facilitated isolation and became a barrier in developing new friendships. Research studies (Larcombe et al., 1990; Spinetta & Deasy-Spinetta, 1986) have concluded these factors contribute to poor social participation within this population. In addition, participants shared in detail the physical pain of the experience as being “horrible” or “pain which cannot be described.” These factors also impacted engagement in occupation or social participation, as the residual effects of treatments left participants exhausted, unable to maintain focus, or feeling sick.

Because most of their time was spent at home, participants felt isolated from their peers as participation in sports, going out to the movies, or other activities were all dependent upon the way they felt. Boredom was expressed as a change in their lifestyle in which they had little or no control over. Farnworth (1995) describes boredom as a symptom resulting from a lack of engagement in productive occupation and unmet human needs. Since most participants were not full-time students or unable to tolerate activities for more than a few hours, they often stayed home watching TV or sleeping. For these participants who were very active in sports, this was considered a significant change in their lives. “I really hate being bored and I’m not the kind of person that will sit down and watch movies or TV, which is something that I’ve had to do a lot since being sick” (Emma).

Participants shared how such activities as driving a car were often impossible secondary to chemotherapy or radiation treatments. This was a hardship for the participants as mass transit was not always reliable and as young adults, they were unable to “get up and go” as they pleased. Over time this became frustrating as participants had to rely on others for simple tasks. It was also difficult to schedule activities with friends, as some chemotherapy regimens were given over days or on the weekends with long lasting side effects.

The need to engage in meaningful occupation is substantiated in the literature. Hannam points out that “Everyday occupation plays a dynamic part in keeping an individual in a meaningful social world” (1997, p. 72). Engagement in occupation gives us a sense of balance in our lives and helps us flourish within our environments (Wilcock, 1993). The inability to participate in occupation or socialize with others may impede in building new life skills, deciding future roles, and engaging in social interactions and societal norms (Wilcock, 1993). In dealing with the adolescent population, their whole “culture” is based on social participation, so any disruption in their development may lead to poor social maturity in the future (Gunstone et al., 2003; Kaplan, 2004).

Changes in lifestyle are not uncommon as participants in this study described a sense of isolation and frustration that came from being on cancer treatment. Larcombe et al. (1990) and Spinetta and Deasy-Spinetta (1986) noted in their studies that treatment for cancer is often a lonely journey and an isolating experience. Hours are spent at hospitals waiting for chemotherapy or radiation treatments to be administered based on earlier lab reports. In some cases, participants arrived for their scheduled appointments only to be told their blood counts were too low to be treated. In instances such as this participants often missed school or other planned activities. This instability in the participants’ lives caused great anxiety as daily routines could not be developed.

In light of this uncertainty in their lives, participants are limited to their ability to participate in meaningful occupations which in the end may lead to an imbalance in their health and well-being. Research supporting the need for occupation is widely acknowledged in the literature (AOTA, 2008; Hemmingsson & Jonsson, 2005; Wilcock, 1993; WHO, 2001). The need for individuals to engage in occupation, as suggested by Wilcock (1993), is to “fulfill the basic human need for survival; provide a mechanism for individuals to develop innate abilities of a biological, social, and cultural nature; and to adapt to environmental changes in order to flourish as individuals” (p. 17). This implies that staying engaged in life, and being able to participate in occupation has credible impact on health and well-being. In the absence of regular opportunities to participate in meaningful occupations the possibility of isolation and poor social development exist.

Return to School

This study also highlighted the many aspects related to returning to school while actively on an intensive chemotherapy treatment protocol. Participants reported feeling “scared” or were “fearful” in returning to school, where they had to develop new friendships with peers and their professors. These feelings may stem from being self-conscious in their appearance or possibly the fear of the unknown, in beginning a new school. In a study by von Essen et al. (2000), results indicate that adolescents frequently mentioned an altered appearance as a basis for feeling isolated from peers and friends.

This concern over physical appearance was also echoed in a phenomenological study by Wallace et al. (2007), where participants expressed changes in their appearance to be worse than the most painful treatments they had to endure. Several of the participants in the study utilized practical ideas such as wigs, caps, scarfs, or shaving their heads when they needed to go out in public: “When you wear a hat, nobody can tell that your hair fell out or if you had shaved your hair” (Eric). These findings are congruent with participants in this study who felt more comfortable wearing some type of head gear rather than telling the world “I’m the kid with cancer on campus” (Emily).

Wallace et al. (2007) explored the impact of cancer treatment and the residual physical appearance changes which may occur from treatment. Results indicated that most participants would rather not be seen in public alone even with their head covered. Besides the hair loss participants shared how bloating, scarring, weight change, and stretch marks all restricted social interaction with others, especially, with peers. The loss of hair or physical changes as shared by the participants became a barrier which limited their access in exploring opportunities to participate in activities within their home or school environments. In essence, a change in appearance was of enormous concern during cancer treatment and impacted self-esteem and other behaviors such as social participation.

Participation in everyday activities plays an important role in developing a young adult's social relationships and skills, which will influence overall mental and physical well-being (Law et al., 2004). Participants in this study have reported the greatest stress of having cancer is the disruption in body image where physical changes in appearance may have been a contributing factor to overall poor self-esteem and a decrease in social participation. Humans use occupation as a way to sustain their lives and to better cope with situations they may encounter. When social participation is limited in any way, the potential in developing a sense of health and well-being may be compromised (Wilcock, 1993).

Participants, who returned to school after the diagnosis and treatment for cancer, were happy to resume school activities because they were once again part of a "normal" environment (Prouty et al., 2006). They often saw school as more than just a place for learning, but also a place to participant in activities and socialize with peers. However, participants in the current study expressed how it was not easy to make new friends as they were not full-time student, were often absent secondary to medical appointments, or were often too tired to join clubs on a regular basis which met after school. Glasson (1995) found an obstacle in returning to school was not the cancer itself, but the school environment. Reaction of other students affected the participants' already poor self-esteem and body image.

Returning to School—Physical and Emotional Impact of Treatment

Although school was a refuge of normalcy for all the participants in their chaotic world, it did not come easy. Participants endured joint pains, muscle weakness, nausea, mouth ulcers, and other side effects of chemotherapy. Participants revealed what it meant to exist, live through, and survive the many physical and psychological effects arising from their illness while enduring the daily occupation of being a student. The participants in this study described their school life as satisfying, although, hindered by the many side effects of treatment.

Participants mentioned the inability to remain focused in class, unable to retain information, poor handwriting skills secondary to neuropathies in their fingertips, and an overall decrease in alertness. Mitchell (2007) also identified the impact of side effects on treatment on school performance. Her study regarding the social and emotional toll of chemotherapy revealed that individuals on active chemotherapy endure both physical and cognitive changes which impact their ability to focus on school activities. All of these issues are supported in the literature to be disruptions in the lives of these young adults who face the many challenges of returning to school. Adam, Emma, and Eric all shared how their inability to maintain focus or retain information, made them work that much harder to achieve the same results. “Chemo, it effects your brain, it effects your whole body so I have trouble reading now, like the letters get mixed up in the page” (Emma).

The inability to fully participate in school was an experience felt by the participants “Sometimes I can’t take tests because I’m on steroids so some nights I can’t sleep well” (Adam). This was often the reality for most participants. Research reflects that students often dealing with the side effects of treatment require extra tutoring or enrolling in special education. Lahteenmaki et al. (2002), Koch et al. (2004), and Mitchell (2007) found that individuals, who had received cranial radiation or chemotherapy when compared to healthy control groups, resulted in poor intellectual and educational skills. Similarly, studies (Larouche & Chin-Peuckert, 2006; Mattsson et al., 2007), also indicate that students returning to school found it difficult to catch up and keep up with their peers secondary to clinic appointments.

Returning to School—Social Impact of Treatment

Due to the physical demands of school, juggling clinical appointments and disturbances in participants' thought process, social participation among friends and peers was not always easy. Social participation in the adolescent population places demands on individuals that require quick thinking, organization, and multitasking skills. In order to remain active with peers, the ability to process information quickly is needed as young adults are often involved in texting, instant messaging, participating in social networking websites, iPods, and other electronics. Decreased alertness, numerous clinic appointments, and fatigue may impede the fast paced life of these adolescents as they seem to operate at a pace above the rest of the population. These are all potential barriers or factors which may limit social participation among these young adults in the treatment process of cancer.

Religion

Results of this study indicate the need for occupational therapy to further explore the impact of religion and spiritually within this population. Participating in religious services became a meaningful occupation in the lives of these young adults. As mentioned earlier, religion or spirituality was not found in the literature review related to this population. Based on the results of this study, which highlighted the importance of religion or spirituality in the lives of these participants, new literature is reviewed to help understand the role religion plays in people who are dealing with chronic illnesses.

This study highlighted the importance of religion in these participants' lives. Although religion or spirituality issues were not located or discussed in the literature review, as pertaining to this population, three of the participants had a religious awakening. Participants felt they became closer to God or were reconnecting with their religious upbringing. From these participants' life stories, it could only be speculated that religion played a major part in their well-being in terms of coping, support, hope, and meaning on a psychological level. Additionally, prayer appears to have given the participants the belief that they had control over their situations which would lead to improved health.

Prior to their illnesses the participants shared they were all involved in various sports, partying with friends, or hanging out with their peers. Religion or participating in any religious activities or rituals was not in their daily routines. Adam participated in religious activities on a regular basis prior to his diagnosis of cancer. He felt that he became closer to God and in such, believed that people, who suffer during their lifetime on earth, would be at a higher level to God, than those who did not have this experience.

Due to the many side effects of cancer treatment, participants were not always able to attend a house of worship. As this became a meaningful occupation, participants described ways they created religious experiences or prayer groups in their homes. Oliver, who could not sit for long periods of time, had regular religious services at his home. This enabled him the ability to accommodate for his poor endurance often associated with cancer treatment. Adam described how his family and friends created a temple in his home in order to celebrate the Sabbath on weekly basis. Both of these examples reflect the participants' desire to engage in faith-based occupations, which have become more meaningful in their current life situations.

In the current OT Practice Framework (2008) spirituality is supported as being influential to motive clients to engage in occupations. Spiritually gives meaning to one's life, "which may lead to or arise from the development of religious rituals and the formation of community" (AOTA, 2008, p. 633). Participants found community in their lives as they became involved in religious services not only outside their homes, but established ceremonial rituals within their homes, fostering social participation among themselves and church and/or synagogue members. This example reflects the importance of social participation, a core belief within the profession's 2008 OT Practice Framework (AOTA, 2008). In participating with family and others in faith-based occupations, participants became involved in life events and situations which not only provided meaning in their lives, but also fostered a sense of community in their environment (WHO, 2001). Acknowledging that OT is a profession based on the premise that individuals are occupational beings only underscores the importance to explore this spiritual dimension of an individual' s life (Christiansen, 1997; McColl, 2000). The goal of occupational therapy is to support health and participation in life through engagement in occupation (AOTA, 2008), including spirituality.

In understanding religion and spirituality it first must be defined. Spirituality is "the personal quest for understanding answers to ultimate questions about life, about meaning, and the sacred" (AOTA, 2008, p. 634). Religion, on the other hand, is recognized as an outward expression associated with traditions, rituals, beliefs, and a moral code shared by a faith-based group (Johnstone, Glass, & Oliver, 2007, p. 1154).

In this study three participants became more involved in their religious practices which they found comforting during this traumatic experience. It is not uncommon for individuals to seek God or other higher beings when faced with a chronic illness. Cotton et al. (2009), in a pilot study dealing with adolescents and chronic illness, found higher rates of attendance at religious services, a stronger belief in God, involvement in praying more often, and participants who found comfort in their faith, which in turn led to better coping skills. Results also indicated prayer reduced negative emotions such as anger, depression, and fear.

Faith in a higher power may be sufficient for individuals to deal with their disability (Weaver & Flannelly, 2004); however, Koenig (2002) suggests many people feel helpless at this point in their lives. Involvement in religion provides them with a sense of control in which a higher power will handle the situation for them. The power of prayer was the most common coping mechanism among this population as individuals felt they had direct control over the outcome of their illness (Cotton et al., 2009; Soderstrom & Martinson, 1987).

Research (Johnstone et al., 2007; Weaver & Flannelly, 2004) that explored the relationship between spirituality, religion, and health for the disabled population resulted in religious involvement being a significant contribution to an individual’s psychosocial adjustment to cancer and its treatment. Koenig, McCullough, and Larson (2001) found similar results in their meta analysis of 7,724 studies related to religion and health which indicated 66% significant relationship between religion and better mental health and overall social support.

Participants in this study, as mentioned prior, felt comfort in attending religious services. Besides the need to attend services, participants had the opportunities to pray and worship with others which in turn fostered both a sense of community and social participation among church members. Although social participation was shown to increase, involvement in religious communities also offers access to supportive social networks (Weaver & Flannelly, 2004; Williams & Sternthal, 2007). Support systems were either in the form of group prayer sessions or visits by church members to pray with individuals. Attending religious services and developing new support systems were identified as significant coping mechanisms when dealing with a disability (Weaver & Flannelly, 2004). Similarly, Howsepian and Merluzzi (2009) point out that religious belief may not directly affect adjustment or coping with cancer, but rather cancer patients who have religious beliefs may experience a sense of social support from a community with whom they share those beliefs.

The need to explore the relationship between religion, health, and well-being would be congruent with occupational therapy’s core beliefs (AOTA, 2008). In order for occupational therapists to implement interventions that incorporate spirituality, established guidelines must be developed to disseminate in both educational and clinical settings. In neglecting to explore spirituality within this population, occupational therapy loses important opportunities for understanding the potential of utilizing occupation to enhance the well-being of these participants (Christiansen, 1997).

Family Support

Sanjari et al. (2008) and Trask et al. (2003) identified parents and close friends to be the greatest source of social support in dealing with their children's illness. Similarly, results from this study also found that supportive family and friends played an essential and significant role in enabling participants to engage in occupations. Family members who did not live with the participants visited often and became a positive distraction during this period. There are many accounts of the strong emotional support provided by the family, as many often attended treatment sessions with the participants. Although not having cancer themselves, family members lived the disease and treatment alongside the participants. Participants felt grateful to their families in so many ways, as without them cancer treatment would be more of a burden. Besides the emotional support families displayed, the physical support assisted participants in rediscovering occupations. Often participants were driven to do shopping, meet up with friends, or to friends' homes to watch television or play video games.

In terms of education, participants expressed that their parents wanted them to return to school, even if only on a part-time bases, as it would allow them to be focused on something besides the routine hospital visits. Koch et al. (2004) and Meijer, Sinnema, Bijstra, Mellenbergh, and Wolters (2000), found that parents were a motivational factor in supporting their adolescent children in returning to school. Results indicate that support from well educated parents tended to increase the probability of achieving the highest education possible. In the case of the participants, Emma, Adam, and Oliver were all freshmen enrolled in four year State colleges seeking bachelor's degrees from business to the sciences. Eric, on the other hand, was finishing high school preparing for the college entrance exams. Overall, the desire to return to school was the choice of each participant, as it gave them a sense of autonomy and the ability to engage in meaningful occupation, which was lacking in their lives.

Although families were supportive, Emma, Adam, and Oliver experienced feeling like a “kid again” as their parents once again took on the role of caregiver. All had recently returned from their first semester at college living on campus, for the first time living independently. They became accustom to staying out all night, going to parties, and scheduling their own time. Their parents, for the most part, provided the financial support rather than structure in their daily lives. In the wake of being diagnosed with cancer, all felt it was important to return home as it provided them a sense of comfort and security. “I decided to transfer back to my old school because it’s three and a half hours away. I decided I wanted to be close to my family, my hospital and my doctors. Comfort wise, I’ve been rearranging my life. I realized that I would not feel comfortable going far away again” (Emma).

Although returning home gave them peace of mind, it also fostered a sense of dependency as they were now transitioning back from living on a college campus to living with their parents. This led to a loss of autonomy and overprotective parents and caregivers. In spite of these factors, all the participants spoke highly about their families and expressed how they depended on them to survive cancer.

As noted earlier in the literature review, adolescence is a period of independence where young adults are transitioning in making their own decisions rather than their parents. As Erickson (1968) describes, adolescents are searching for their own identity, which can only be formulated through building social and peer relationships. Given the greater independence, young adults formulate their ideas of the world where they establish future goals and occupations. Although participants in this study all felt very comfortable returning home, I can only speculate how it may impact their ability in achieving this developmental milestone.

In a 1987 study, Gavahan and Roach explored the psychosocial adjustment of teen-age cancer patients from a developmental perspective. They found that adolescents with cancer had difficulty making future plans and were uncertain about the future. Many of these adolescents were restricted from normal socialization experiences with peers due to hospitalizations and cancer treatments. In light of these findings, this study lends support to the theoretical notions that serious illness may impede an individual's progress through normal psychosocial developmental stages.

Social participation incorporates the ability to meet new people, experience new environments, and participate with others in activities. At this point in the participants' lives, developing new relationships, taking on new roles, and exploring new opportunities is a normal developmental process. However, many of the participants returned home secondary to the intensity of dealing with cancer to be with family. The transition from living at college to returning home may not offer them the same opportunities as living on campus where they had the ability to meet new people and participate in community activities.

Occupational therapy through its tools of practice can assist participants during this transitional period in meeting this developmental milestone. Our tools of practice including activity analysis and understanding the use of occupation can assist in facilitating social participation. Besides these traditional tools, occupational therapy modifies environments to foster individual adaptation to overcome challenges thus leading to mastery of occupational performance (Schkade & Schultz, 2003). Additionally, training in the medical model affords occupational therapy the ability to further understand disability from a different perspective than other non medical disciplines.

Although this study is congruent with the literature from other disciplines such as psychology and nursing, what this study offers is a way of looking at these participants through a different lens. As occupational therapists we view social participation through occupation, taking into account the person's abilities and the environment in which activities occur (Ludwig, 2004). A psychologist may view an individual from a strictly mental state of mind or from a cognitive standpoint to investigate a problem. As occupational therapists we incorporate these aspects of the mind and also consider an individual's medical status, as we have training in the medical model. This assists us in evaluating individuals from a holistic viewpoint which supports the profession's core belief, that engagement in occupation leads to health and well-being (Wilcock, 1998).

Friend Support

Outside the school environment, long-term friendships did not always survive, as friends moved on in their lives. Most friends went on to college or universities outside of New Jersey or entered the work force. However, close friends maintained contact through e-mail to say hello or just say "how are you doing". Participants appreciated these occasional e-mails as they provided them with a sense of belonging and that they are still part of a larger group. It also provided them an outlet to share current gossip or more serious issues that young adults would often discuss with their peers rather than their parents.

In contrast, friends were not always supportive or slowly faded out of the participants' lives. "You know there are some people who I really thought I was friends with, and once they found out that I was sick, I haven't heard from them since. Whereas, other friends, did their best to make sure that I'm feeling well" (Emma). As friends moved on with their lives, they became enveloped in new peer relationships, often leaving participants behind without cause. From the data, I speculate that when dealing with the adolescent population, they may not know how to show support or handle a situation when a friend is ill, where survival is not always possible.

Normalcy was highly valued by the participants in this study. These participants were unsure how they would be treated if others knew they had cancer. In an attempt to "fit in," participants were often reluctant to share their cancer experience with peers or teachers. For instance, Adam was pressured by his parents not to reveal that he had cancer; Eric was afraid of being rejected by friends; Oliver did not want special treatment from others; and Emma felt it was a very private matter in her life.

Although not addressed in the lived experience literature, these findings are congruent with a 1995 study by Christ, Lane, and Marcove, who explored this topic in survivors of adolescent cancer. Participants in this study went to great lengths to keep their cancer secret, while others shared their stories with trusted friends. Keeping their illness hidden from others helped these participants feel more normal, yet increased their sense of isolation.

All the participants struggled with this dilemma of disclosure. It may be surmised that by maintaining their “hidden disability,” participants retained a certain public image of themselves. As within this study, participants downplayed their illnesses secondary to cultural, social, and privacy reasons. By revealing their cancer, they risk identifying themselves as a sick and/or disabled person outside of societal norms. Studies involving social relationships generally conclude that children with cancer are more sensitive and isolated than peers, according to both peer and teacher reports (Vance & Eiser, 2002).

Exploring New Occupation

The need to engage in occupation was quite evident throughout the study. Participants shared they were often bored at home, unable to go out secondary to feeling physically ill or fatigued from chemotherapy. All were very active sports enthusiasts involved in contact physical activities, which now were prohibited by the medical establishment or even their parents. They were unable to engage in any type of contact sports, as injuries may complicate their health status. Emma shared how on a beautiful day her friends were at the beach while she rested in bed waiting for time to pass “All my friends are going to the beach and doing their summer jobs and I was either in the hospital or in my bed; and, it was lonely, very lonely.”

The idea of time passing was reiterated by all the participants, as boredom or the lack of meaningful occupation was a major factor that contributed to loneliness, as social participation among friends and peers was impacted. However, due to their need to engage in some type of occupation, participants discovered or adapted occupations which were less strenuous to participate in on a daily basis.

All participants as mentioned earlier participated in physical sports, which became more difficult over time secondary to changes in their physical conditions. This lack of participation encouraged participants to engage in new occupations that would meet both their psychological, social, and physical needs. For example, Eric found academic competitions in science as a new occupation to compensate for his inability to participate in soccer, a sport he grew up playing in Egypt. He described it as meeting his needs to remain active and busy. It also afforded him the ability to meet new people who were interested in the same love of science.

Other participants adapted to their situation remaining in some type of sporting programs. For example, due to a lack of significant hemoglobin, Adam went from contact sports such as basketball and soccer to swimming daily at the local school pool. He found this to be very satisfying and gave him a sense of health and well-being. It also gave him the ability to once again be part of the “Tenacious Ten,” a group of his long-time friends who did everything together. Being engaged in a new activity was a significant step for him, as he shared “life was pretty much get chemo, come home, hope the day ended soon, to go back to sleep”, to a life once again filled with meaningful occupation. Similarly, Oliver chose to develop interest in sports video games. Both of the participants found this to be an alternative to satisfy their need to engage in sports and also to increase their social participation with peers.

In this study participants demonstrated an alternative occupation to feel fulfilled in their occupational roles. It also led to greater satisfaction and increased social participation among friends and peers, which these participants lacked secondary to illness. It was through occupational adaptation that participants demonstrated the desire to adapt to new occupations or adapt current occupations to meet their needs. For example, Emma used to be very active going to the gym to take spinning classes and cardio kick boxing two times a week, however, found it impossible secondary to poor stamina and endurance. In light of this, she auditioned for a few shows at a local community theater. It provided her an occupation she enjoyed in her youth and met her physical needs as it was less strenuous than the gym. By being involved in such a community project, it gave her the opportunity to meet new people with a common interest, "Your cast is like your family I think it was a great experience" (Emma).

Theoretical Model

The model of Occupational Adaptation (Schkade & Schultz, 1993) is consistent with the historically central theme in OT, occupation and adaptation. In the OA model, adaptation (change) that occurs through occupation reflects the fundamental process of occupational development leading to mastery in occupational performance. The catalyst for OA is a lifetime of occupational challenges, which unfold as part of an individual's interaction within his/her occupational role. This model is an example of an occupation-based format, in that the individual is empowered to be his/her own agent of change. Adaptation (change) that occurs through engagement in occupation reflects the fundamental process of occupational development leading to competence in occupational functioning.

Occupational Adaptation—Clinical Example

Within this study, results indicated that participates were all active in their communities, sports, religious services, school, and enjoyed being with friends and family. Due to changes in body appearance, physical endurance, and inability to be with others secondary to side effect of treatment and their busy schedules, participants found themselves lacking meaningful occupation in their lives. All participants realized their own limitations and recognized how it impacted their ability to participate in occupations which they found meaningful.

Adam, for instance, found playing football a pastime he enjoyed with friends. However, football being a contact sport, the probability of injury is much higher than being involved in activities that were less strenuous and dangerous. Adam understood from a medical standpoint he could no longer be involved with contact sports, so he explored competitive team swimming. Upon realizing the amount of time and effort required to be in peak performance, he found it not possible secondary to fatigue from the chemotherapy. In his desire to remain active and be involved with friends, he found swimming laps as a meaningful occupation as he was able to swim at his own pace and endurance level. Although not on a team, friends from his football team swam with him as part of their football training.

From an occupational therapy perspective, Adam became his own agent of change in realizing he could not engage in contact sports, so he explored competitive swimming. After realizing the strength and endurance needed to stay competitive, he once again adapted to his physical limitations. He found that individual lap swimming met both his physical and social needs. In each step Adam encountered new challenges which facilitated an internal modified adaptive response.

In Adam’s case, a modified adaptive response occurred as the first response to being on a competitive swimming team was unsuccessful. He realized that non competitive swimming would best fit his physical limitations. This internal change within

Adam was a result of his adaptive process including mastery of new skills and challenges which would continuously unfold in his environment. In the Occupational Adaptation model adaptation is a normative process that leads to competence in occupational functioning (Schkade & Schultz, 1993). In Adam’s case, the internal adaptive response enabled him to explore alternative occupations which led to an overall sense of health and well-being. This internal change or adaptive response was highlighted in a study (Prouty et al., 2006) of adolescent cancer survivors which found that participants demonstrated the ability to adjust to their limitations and move on despite their limitations.

Occupational Adaptation Model—Description

Occupational Adaptation seeks to understand occupation and adaptation and the relationship to health (Schkade & Schultz, 1993). This model assists in identifying how young adults with cancer generate adaptive responses in relationship to social participation. Schkade and Schultz proposed the concepts of occupation and adaptation as being the foundation for their model, which is congruent with this study. This study analyzed the role of occupation(s) in these participants’ lives and the process leading to mastery and satisfaction to engage in social participation. It is suggested in this study, understanding these participants’ adaptive responses can only be expressed by those who have experienced occupational adaptation (Bontje, Kinebanian, Josephsson, & Tamura, 2004).

Schkade and Schultz (1992, 2003) present a model incorporating the constructs of occupation and adaptation into a single interactive construct, which mirrors the multidimensional facets of individuals assisted in OT which has been the foundation of the profession. This model sets out to understand occupation and adaptation and their relationship to health (Baum, 1998; Schkade & Schultz, 1993, 2003). The OA model offers an explanation for an adaptation process that proposes occupation both as the means through which adaptation occurs and the end for which functional adaptation is wanted.

General assumptions underlying the model of OA consider individuals as systems consisting of the sensorimotor, psychosocial, and cognitive subsystems in which they interact with and adapt to their environment through occupation (McRae, Kessler, Julin, Padilla, & Schultz, 1998; Schkade & Schultz, 1992). This interaction within their environment and "desire to participate in occupation is the intrinsic motivational force leading to adaptation" (Schkade & Schultz, 1992, p. 829). Due to the uniqueness of individuals' cultures, social networks, and capacities, OA is processed-based, non-hierarchical, and non-stage specific and emphasizes experiences within the context of individuals occupational environment (work, play/leisure, self-maintenance). As individuals engage in occupation, it is a way of mastering the environment and adapting to changes (survival). Occupation becomes the mechanism individuals utilize to demonstrate their capacities of being. One's biological need contributes to motivating factors of engagement in occupation. The desire to succeed and survive in a changing world influences individuals' behavior patterns and performance.

Occupational Adaptation is considered a theoretical model contemporary in nature with underpinnings derived from the theory of Spatiotemporal Adaptation (Gilfoyle, Grady, & Moore, 1981, 1990), the Model of Adaptation Through Occupation (Reed, 1984), the Model of Human Occupation (Kielhofner, 1985), and the Model of Occupation (Nelson, 1988), which seek to explain the relationship between occupation and adaptation. However, in the model of OA, although similarities exist with the base theoretical concepts, Schkade and Schultz (1992) and Schultz and Schkade (1992) present a model which focuses on the client being the agent of change rather than the therapist being the agent of change, which have been in more traditional practice areas (Schkade & Schultz, 2003).

In terms of a clinical viewpoint, approaches based on OA differ from treatment that focuses on acquisition of functional skills as this model directs OT intervention towards the individual’s internal processes and how these processes are facilitated to improve occupational function (Schkade & Schultz, 2003). Change occurs through the individual’s adaptive capacity with the therapist setting the stage (environment) to facilitate change by assisting in a healthy occupational adaptation process. The individual is involved not only in goal setting, but also in assessing the outcome of intervention as he or she experiences it.

Occupational Adaptation does not exclude specific treatment techniques, but rather places emphasis on therapeutic intervention based on the individual’s occupational role, involvement in controlling and evaluating the results of the therapy process, and affecting the adaptation outcome. An individual engaged in personally meaningful occupational activities will most likely experience restoration of a functional adaptation process (Dolecheck & Schkade, 1999). An adaptive response will result in the individual achieving greater relative mastery in his or her occupational activities. Meaningless or non-existent occupations in an individual’s life will lead to a functional decline or withdrawal from occupational participation (Breines, 1989).

In essence this model de-emphasizes the idea of adapting occupations for the individual to achieve mastery in occupational performance. The belief is that occupation requires adaptation through the individual’s need for change or modification (internal process) of an occupational response, to master the challenges of his/her occupational environment. This is in direct contrast to the belief that enhancing occupation performance will lead to adaptiveness. Occupation is intrinsically motivating, and it is the vehicle for overall adaptation or mastery (Schkade & Schultz, 2003).

A focal point of the OA approach to intervention is that the individual evaluates his or her own progress in therapy by self-assessing the three properties of relative mastery: efficiency (use of time, energy, resources), effectiveness (extent to which the desired goal was achieved), and satisfaction to self and society (extent to which the patient feels personally satisfied with progress and the satisfaction of others with progress) (Schkade & Schultz, 2003).

Today, the profession has developed its own body of knowledge and tools that we offer our clients in developing occupational-based programs. The model presented by Schkade and Schultz supports the revised *Occupational Therapy Practice Framework: Domain and Process* (2nd ed.) (AOTA, 2008) as it captures what the profession has labeled “the breath and meaning of everyday activity” (occupation) (p. 628).

Implications for Practice

Crabtree and Miller (1999) stated that the purpose of research was to inform clinical practice in order to improve an individual’s life. While listening to the lived experiences of these young adults with cancer, I was struck by how insightful their stories were, and by how occupational therapists could have made a difference in their lives.

This study sheds light on the impact that cancer treatment can have on a young adult in terms of engagement in occupation and social participation. It illuminates the areas of occupation which are meaningful so they may be addressed in clinical practice. As these participants were at a loss of engaging in most meaningful occupation, an occupational therapist could assist them in identifying and developing new areas of occupation based on their interest and psychological and physical state. Through occupational therapy, new strategies can be developed that would assist clients in building new lived experiences. Based on the client's interest, new occupations may need to be adapted to the situation rather than accepted in their original format.

Social participation, a core belief within the profession of occupational therapy and area of occupation, is the foundation for this study. Social participation as defined in the AOTA 2008 Framework is "Organized patterns of behaviors that are characteristic and expected of an individual or a given position within a social system" (p. 633). Similarly, the WHO defines participation as "involvement in life situations", (2001, p. 10). Occupational therapy's focus on engaging in occupation and social participation complements the WHO's perspective of health as both recognize the positive influence on individuals' health and well-being.

On further reflection, participation in everyday occupations of life is a vital part of human development as it leads to life satisfaction and an essential factor in the growth of psychological, emotional, and skill development of an individual (Law, 2002a, p. 641). Participation in occupation does not occur in isolation, but rather is interdependent on contextual factors such as time, place, and with others (Townsend & Wilcock, 2004). The fundamental idea is that humans are occupational beings who create meaning in their lives through the occupations in which they engage, assist in coping with situations they may encounter. Occupation also fills a biological need for humans to take care of themselves, develop skills to manipulate their environment, and expand their personal capacity. Engagement in occupation is necessary as it facilitates building life skills, deciding future roles, and engaging in social interactions and societal norms (Wilcock. 1993).

This study raises the awareness for therapists, especially, novice therapists to recognize the occupational needs of these clients beyond the biomechanical frame of reference. If a diagnostic reasoning approach is utilized, it may not represent a holistic picture of the client’s needs, as the assessment is solely based on the client’s deficits with a “cookie cutter” approach to treatment (Rogers & Holm, 1991). This idea of creating new lived experiences is based on the therapist understanding the client’s occupational needs. A more experienced therapist, however, may be more adept in assisting these clients in the development of new meaningful occupations, which could be the beginning of a positive roadmap for their future as adults.

OT Evaluation and Treatment—An Occupational Adaptation Perspective

Occupational Adaptation differs in addressing the needs of this population as it is client-centered versus an AOTA (1958) protocol for treating children with leukemia. This document was the only protocol discovered in the literature reviewed directly related to this population. This treatment protocol outlined the clinical signs and psychological reactions that patients would exhibit with specific objectives of occupational therapy interventions. Based on this original protocol which consisted of mild and graded activities affording mental stimulus, making bed rest as pleasant as possible, activities designed to eliminate apprehension, and having parents allow their children to participate in normal daily activities as long as possible, patients had little input to their own care.

In implementing an Occupational Adaptation model of intervention, focus is on occupational goals determined by the patient, regardless of what diagnosis would be developed based on the initial evaluation. In order to foster autonomy and change, patients would actively choose activities which they find meaningful and would address their goals. In choosing their own tasks and activities it allows them to control the therapy process thus enhancing occupational performance. The therapist will make suggestions and recommendations as needed in order to develop an environment where change can occur in occupational performance. Patients would have the opportunity to evaluate themselves on their perceived progress in addition to whatever evaluations the therapist conducts. The patient is involved not only in goal setting, but also in assessing the outcome of intervention as he/she experiences it.

In terms of psychosocial aspects of occupational therapy intervention, no studies were located related directly to this population. As mention above, an AOTA 1958 protocol was located suggesting general intervention strategies when working with this population. Based on the results of this study, a major theme was the impact of changes in appearance on social participation as participants all shared how these changes impacted their lives. In planning an occupational therapy plan for these participants, a community-based program would offer them many opportunities to increase social participation where the focus is on “doing” rather than being judged on appearance.

A service group working in a church food pantry would focus the participants away from their problems and be an outlet for coping with their illness. They would experience social participation without the stress of others being judgmental, as this would be a church-based program where individuals would be less critical of appearance. This group project is meant to foster interaction with others, build self-esteem through engaging in meaningful altruistic tasks, and develop appropriate social skills. In essence they are doing a job that would be meaningful, yet they are in an environment which would foster social interaction.

This program would follow an Occupational Adaptation model as the occupational therapist is setting the environment to foster the internal change of the participant to overcome challenges in the environment. One of these challenges may be to interact more with others in order to help people who are less fortunate. In the end, with the focus being on a service model, the participants are also gaining a sense of empowerment.

This study has other clinical applications including the need to further develop occupation-based interventions related to the adolescent oncology population which are client-centered. The use of phenomenology-based research provides occupational therapists with the opportunity to see the experience of others and relate this to the way they practice. Findings from phenomenology studies, such as this one, facilitates occupational therapists' awareness of patients' perceptions, and the responsibility therapists have in influencing the care and experience of these young adults. In this way, phenomenology can meaningfully inform practice by providing valuable evidence on which to base occupational therapy practice.

Utilizing both qualitative and quantitative methods, outcome measures can provide rich and true experiences and insights into the type of services that may be important in these clients' lives and the factors to be considered when providing OT services. Additionally, during the last decade, evidence-based practice (EBP) was integrated into the medical community and has become a staple in the health care environment, which includes occupational therapy. EBP directly affects how OT services are provided, as it shapes clinical practice through ever changing knowledge. The primary goal of EBP is to examine the care of each individual the profession services in a conscious and reflective way, allowing for more accurate treatment which supports and guides OT intervention (Holm, 2000; Law, 2002b; Sackett, Rosenberg, Muir-Gray, Haynes, & Richardson, 1996; Slawson, 1997).

Based on the results of this current research, many young adults appear to be on intensive treatment protocols when diagnosed with cancer. With these protocols come the psychological and physical effects which impact everyday life. Adolescents undergoing cancer treatment are usually connected with large hospital facilities, with an initial inpatient stay which seeks to bring about a remission. This is then followed by 2-3 years of outpatient therapy. Although the medical model of chemotherapy, radiation, and lab reports are vital to a patient's care, it may not acknowledge the patient as an occupational being. The experience of being on chemotherapy with the abrupt loss of familiar routines and daily occupations, as reflected in this study, resulted in a lived experience of loneness and isolation.

The development of programs which are occupation based and client-centered can be implemented at the initial diagnosis of cancer during a patient's inpatient stay. Application of this program would first involve an occupational therapist gaining an understanding of the patient's present occupations and routines, taking into consideration any environmental factors. Therapeutic intervention might focus upon helping patients develop occupations across a broader range of pursuits. The primary goal is to help patients in planning and initiating realistic occupations that are meaningful and focus upon creating various avenues of socialization. In essence, creating an environment which promotes personally satisfying occupations, while encouraging peer interactions and increasing self-esteem. This internal change, based on the OA model, would be a result of their adaptive process including mastery of new skills and challenges which would continuously unfold in their environment.

Development of such a program would require both the support of the oncology department and the hospital administration. An occupation therapist can spearhead advocacy in this area demonstrating the need to examine the occupations and routines of these adolescent patients beyond the hospital walls. In developing such a program, outcome measures can support occupational therapy services and provide scientific based information that services are effective in meeting the expectations of patients (Cusick & McCluskey, 2000; Holm, 2000; Unsworth, 2000).

Outcome measures for this program may be determined through the use of the Canadian Occupational Performance Measure (COPM). The COPM is an individualized measure of a patient’s self-perception in occupational performance and is designed to be used in client-centered practice (Law et al., 1994). In utilizing the COPM, patients retain an active role with their therapist in determining problems, goals, and outcome measures from their own perspective (Baptiste & Rochon, 1999). Comparisons of outcome measures between initial baseline information and reassessment will be a vital part in supporting the usefulness of this program to administrators and financial supporters.

Finally, the significance of this study to the profession of occupational therapy supported some previous research done in the area of survivorship, while highlighting new findings such as the importance of spirituality in the lives of these young adults. It expanded the field of knowledge by adding the dimension of understanding how cancer treatment impacts occupation(s) as shared from those who are living the experience. It also contributes to the present literature important issues or concerns which can be addressed by occupational therapists.

Implications for Further Research

This study will assist in filling the void in the occupational therapy literature as it explored both the past and present lived experience of these young adults. Certainly, further study is indicated to investigate diversity between young men and women, an expanded age range, and different socioeconomic classes. This would expand the scope of knowledge into a further dimension of the cancer experience. Since the adolescent cancer population is not a homogeneous group, nor are the side effects of different treatment protocols, the impact of social participation may differ. Therefore, further research by age, gender, or socioeconomic class can build a new body of knowledge related to occupation, specifically social participation. Since this study consisted of four participants from the same geographical area of New Jersey, expanding the numbers of participants and area would further assist in understanding social participation.

Another area of study to consider would be the role of religion or spirituality in these participants' lives. Within this study, participation in religious rituals was one of the central themes mentioned by most participants as being important and meaningful in their lives. Participants described how religion, God, or an increased awareness of their own spirituality helped them in the recovery process. Further research on the importance of religion or spirituality within this population is congruent with the *Occupational Therapy Practice Framework* (2nd ed., AOTA, 2008). Qualitative research, specially focused on the adolescent population and religion, may serve as secondary tool for treatment beyond the mechanical approach and as a method to train rehabilitation professionals about religious issues.

Religion and spirituality are widely mentioned in the literature as an important coping strategy for persons with disabilities. Research studies (Johnstone et al., 2007; McColl et al., 2000; Weaver & Flannelly, 2004) have concluded that religion and spirituality are linked to positive physical and mental health outcomes when associated with individuals with chronic diseases. Religion was also found to assist individuals with disabilities to help them adjust to their impairments and to give new meaning to their lives. Although these studies were helpful in understanding the importance of religion in the general disabled population, further studies focusing on the adolescent population could better reflect the role of religion in these young lives.

On a global scale, increased research in social participation from a cultural viewpoint will enlighten the profession to the norms and expectations of that culture in terms of social participation. As substantiated in the literature review, culture is a vital component in building a young adult’s beliefs and behavioral standards (Moore, 1996). Occupational therapy is responsible for developing treatment interventions considered by persons of different ages, genders, or cultural backgrounds (Pierce, 2001). In identifying cultural differences occupational therapy can develop specific interventions accordingly to meet the needs of these young adults with cancer. Additionally, studies would also support practice guidelines outlined by AOTA (Moyers, 1999), which called for occupation-based and client-centered intervention protocols.

Outside of occupational therapy, further research would support the WHO's National Cancer Control Programs, Policies and Managerial Guidelines (WHO, 2008), which is intended to provide new knowledge and evidence-based related information on adolescent oncology from a humanistic viewpoint.

Furthermore, based on the small amount of research to date, additional qualitative research in the area of social participation would build a comprehensive understanding of how adolescents are impacted by their cancer experience. In utilizing qualitative research methods for further exploration in this area, participants are given the opportunity to express themselves openly detailing their experiences, which can be emotional or sensitive at times. These experiences may not be captured in quantitative methods, where questionnaires or surveys are sometimes utilized alone.

Additionally, research in this area would also support the mission of the Adolescent and Young Adult Oncology (AYAO) Progress Review Group (PRG), a public-private partnership with the LIVESTRONG organization. As a well known organization, founded by Lance Armstrong, it funds programs for patients with cancer and has become a clearing house in assessing the state of research in adolescent and young adult oncology (LIVESTRONG, 2010).

Through additional phenomenological research, which describes these individual's lived experiences, it provides LIVESTRONG the tools needed to put a "human face" on the problems of adolescent oncology patients (LIVESTRONG, 2010). Capturing the attention of local, state, and national media outlets, their efforts can communicate with decision makers in understanding the needs of these young adults. Advocacy at this level can illuminate how participation in occupation, can add to these patients' overall health and well-being, thus becoming productive members of society.

Limitations and Delimitations

After reflecting on this research endeavor, many limitations need to be discussed. First, the challenge of utilizing phenomenological reduction or bracketing within this study was a limitation. However, bracketing was an important aspect of this method, as I had a similar experience as the participants in my youth. In light of this, another method such as hermeneutic phenomenology, could not have addressed this study, as bracketing is not a key concept in this research design. Second, this study was based on the lives of four individuals that were currently undergoing treatment for various types of cancer. This small sample size may not accurately represent the larger general population nor is it expected to in phenomenology. Identifying this limitation does not reduce the lived experiences of my participants.

Third, of the four participants, three were male, which may reflect a gender bias in the findings. Additionally, three were being treated for Acute Lymphoblastic Leukemia and the fourth for Anaplastic Large Cell Lymphoma. This is important to note as treatment protocols may differ, revealing another dimension to the issues surrounding treatment and the impact on occupation. These participants also varied at age of diagnosis and time since treatment was initiated, so the intensity of treatment at the time of the interviews may vary. Finally, the pool of participants was limited to those being treated at a major metropolitan university hospital, which may not be a reflection of the general socioeconomic class.

Summary

In summary, the present study offered a different perspective as it sought to explore the experience of four young adults living with cancer. The focus was to illuminate the impact of cancer treatment on daily occupation and social participation. A major benefit of this was that participants were able to talk about being on treatment for cancer, an aspect of experience poorly addressed in the literature. Being actively on treatment was found to have a significant impact in these participants' lives.

This phenomenological study examined the research question, "What is the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically social participation?" Results of the study are within the profession's domain of concern and offered unique insights into the occupations of these young adults in the treatment process of cancer.

The literature reviewed explored the many aspect of survivorship, of both the adolescent patients and adults who were treated for cancer during their adolescences. Although useful in nature from the standpoint of understanding the long-term impact of cancer post treatment, it did not reflect the lived experience of these individuals. From the reviewed literature, concepts related to psychological distress among cancer survivors, the impact of quality of life, poor self-esteem, the barriers of returning to school, and coping, were well represented.

In order to understand the lived experience of these participants, a phenomenological methodology structured the research process. The research addressed the essence of these four young adults' experiences through in-depth interviews, exploring the impact of cancer treatment on daily occupations. The focus of the questions pertained to lifestyle changes, their own perception of having cancer, influences of daily decision making, social participation with family and peers, and the role of occupation in their lives.

Results of this phenomenological research has illuminated how occupation and social participation were affected when a young adult is undergoing cancer treatment. The themes which evolved from this study included: (a) change of lifestyle (b) exploring new occupations, (c) reconnecting with family, and (d) living with cancer isn't easy. These themes reflect significant statements and meanings that describe the experience of being in the treatment process of cancer.

It is essential to note that while some of the interpretations for this study echoed previous research in survivorship, this study differs as it highlighted the present lived experiences of these adolescents. In addition, this study did not attempt to capture the entire field of adolescent oncology, but rather paint a picture of the lived experience, specifically related to the participants in the study.

In closing, the research question posed "What is the lived experience of adolescents with cancer in relationship to their occupational engagement, specifically social participation?" has been answered. A greater understanding of the complexity of these participants' lived experiences without occupation(s) and the influences on social participation have been discussed. Furthermore, the findings generated through this research study have implications in the areas of occupational therapy practice and research.

Appendix A: Individual Interview Guide

1. What thoughts stood out for you when you were told you had cancer?
2. What is the experience of being in the treatment process (chemotherapy, if applicable) of cancer like?
3. If I was to stand in your shoes describe what would I see?
4. How has cancer treatment (chemotherapy, if applicable) affected your daily routines?
5. (Follow up question: How do you feel about this?)
6. What is daily life like for you?
7. What is different now in your life?
8. How has what you are doing changed?
9. What do you think influences the decisions you make on a daily basis?
10. Describe the activities most important to you and why?
11. How does your illness affect the types of activities you engage in?
12. How is this experience affecting significant others in your life?
13. Describe the experiences you most enjoy with your family, friends, and peers.
14. What was the experience of returning to school like?
15. Describe your relationship with your classmates/friends?
16. How is your participation in school affected by your illness?
17. How do you feel your classmates see you?

Additional question to be asked at 1 month follow-up:

1. What has changed for you in the last month?

Appendix B: Hackensack University Medical Center Informed Consent Form

HACKENSACK UNIVERSITY MEDICAL CENTER

Consent Form

Note: This consent form is used for both minors under 18 years of age as well as young adults who are 18 years or older. The word **you** in this consent form signifies **you or your child**.

Title of Protocol

The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations

Who is conducting this study?

Co-Principal Investigator: Carlene Cord, RN, APN, C.
Co-Principal Investigator: Gary Grimaldi, MA, OT/L, ATP

Sponsors: Tomorrow's Children's Institute/Nova Southeastern University

Why have I been asked to take part in this research study?

You have been asked to take part in this study because you are an adolescent in the treatment process of cancer and are between the ages of 13 – 19 years old and you continue to attend school in a traditional setting vs. home schooling. It is up to you to decide whether or not to take part in this study. Please read this entire consent form. This consent form may contain words that you do not understand. Please ask the investigators, to explain any words or information that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

Why is this study being conducted?

You are being invited to participate in this research study to help determine what impact cancer treatment has on enjoying activities you like to do. In other words, we will be looking at how cancer treatment influences the activities that you chose to engage in. These activities are important and valued in your life. We will specifically being looking at the way you see yourself and what issues, if any, interfere with engaging in activities that are meaningful to you.

What other treatment options are there?

N/A – This study is qualitative in nature and does not examine treatment or interventions.

How will information about me be kept private?

Your identity and participation are confidential to the extent permitted by law. In addition, the sponsors Hackensack University Medical Center's Tomorrow's Children's Institute & Nova Southeastern University, representative of the sponsors, the Director of Research or Designee, or the Institutional Review Board will be granted direct access to your original medical records for verification of clinical trial procedures and/or data without violating your confidentiality to the extent permitted by applicable laws and regulations. By signing this consent you or your legally acceptable representative is authorizing such access.

Records identifying you will be kept confidential to the extent permitted by applicable law. If the results of the trial are published your identity will remain confidential. All data will be secured in a locked filing cabinet. Your name will not be used in the reporting of information in publications or conference presentations. The investigators will not use any other information that identifies you, except age and other background information, which may be useful later. Upon completion of the study, the investigators will destroy the audio recordings and keep the written transcripts in a locked cabinet. Additionally, the investigators will destroy all contact information of the participants in the study. The transcriber and the investigators will have access to the verbatim transcription of the interview data. The transcriber will not keep the interview data on the hard drive of the computer used for word processing. Furthermore, the IRB and regulatory agencies may review research records. By signing this consent you or your legally acceptable representative is authorizing such access.

What are the costs?

There is no cost for participation in this study. Participation is voluntary and no payment will be provided.

What are my rights as a research participant?

Your decision to take part in this study is voluntary. If you decide not to participate or if you choose to withdraw after beginning the study, you will not lose any benefits associated with your medical care. You are encouraged to ask questions before deciding whether you wish to participate and at any time during the course of the project. Your participation may be terminated by the investigators or sponsor without regard to your consent.

You will be told of any new findings that may influence your decision to continue to participate in this research project. If information becomes available that may influence your decision to take part in this study you will be asked to sign a revised consent or consent addendum. This will be at the discretion of the Institutional Review Board.

In the case of physical injury resulting from participation in the study, treatment determined by a physician will be made available to you. This care will be billed to you/your insurance company in the usual and customary manner. There will be no monetary compensation by Hackensack University Medical Center.

How many people will participate in this study?

This study is limited to 4-5 adolescent patients between 13-19 years of age who are in the treatment process of cancer. Participants may be male or female and presently being treated at Tomorrows Children's Institute at Hackensack University Medical Center (HUMC).

What is involved in this study?

If you agree to participate, you will be asked questions about yourself regarding your personal experiences while in the treatment process of cancer and the impact cancer treatment has had on tasks and activities you enjoy doing. The interviews will be recorded on audiotape and then typed into a written format.

How long will I be in the study?

The total time commitment from you would be 4 hours over time (2 interviews 1 month apart and a third meeting to review the analysis of the interviews for accuracy prior to the final submission of the study). Any changes needed to be made will be corrected.

What are the risks involved in this study?

There no risks associated with participation in this study except inadvertent disclosure of information. A pamphlet with contact information will be provided to you, if necessary, to discuss uncomfortable issues which may arise in the interview, with trained health care professionals. If you have any concerns about the risks or benefits of participating in this study, you can contact the investigators at the numbers indicated above.

Are there benefits to taking part in the study?

Although you may not benefit directly from participation in this study, you have the opportunity to enhance knowledge necessary to improve treatment options available to occupational therapists that work with adolescent patients with cancer.

Who can I call if I have questions or problems?

For questions concerning this research project and/or research subjects' rights, you should call The Human Subjects Protection Board at 201-996-2255. In the event that medical assistance is required, you are instructed to call Carlene Cord, RN, APN, C. at (201) 996-5437/Gary Grimaldi, MA, OT/L, ATP.

Financial Disclosure

The Co-Principal investigators are not receiving payment from the study sponsor for their participation in this protocol. If you have questions about the disclosure please call the Department of Research at (201) 996-2879.

Consent

- I have read or it has been explained to me and I understand the information in this consent form. All my questions have been answered to my satisfaction. I consent to participate in this study.
- I understand that I will receive a signed and dated copy of this consent form for my records.
- By signing this consent form I have not waived any of the legal rights which I otherwise would have as a participant in a research study.

I hereby consent (to have my child/ward consent) to participate.

____

Person Obtaining Consent

____________________________________ ________________

Signature of Person Obtaining Consent **Date**

____

Subject's Name

____________________________________ ________________

Signature of Subject (If participant is 9 years old or older) **Date**
Or Signature of Legally Authorized Representative

____

Parent/Guardian's Name if Participant is a Minor or Legally Authorized Representative

____________________________________ ________________

Signature **Date**

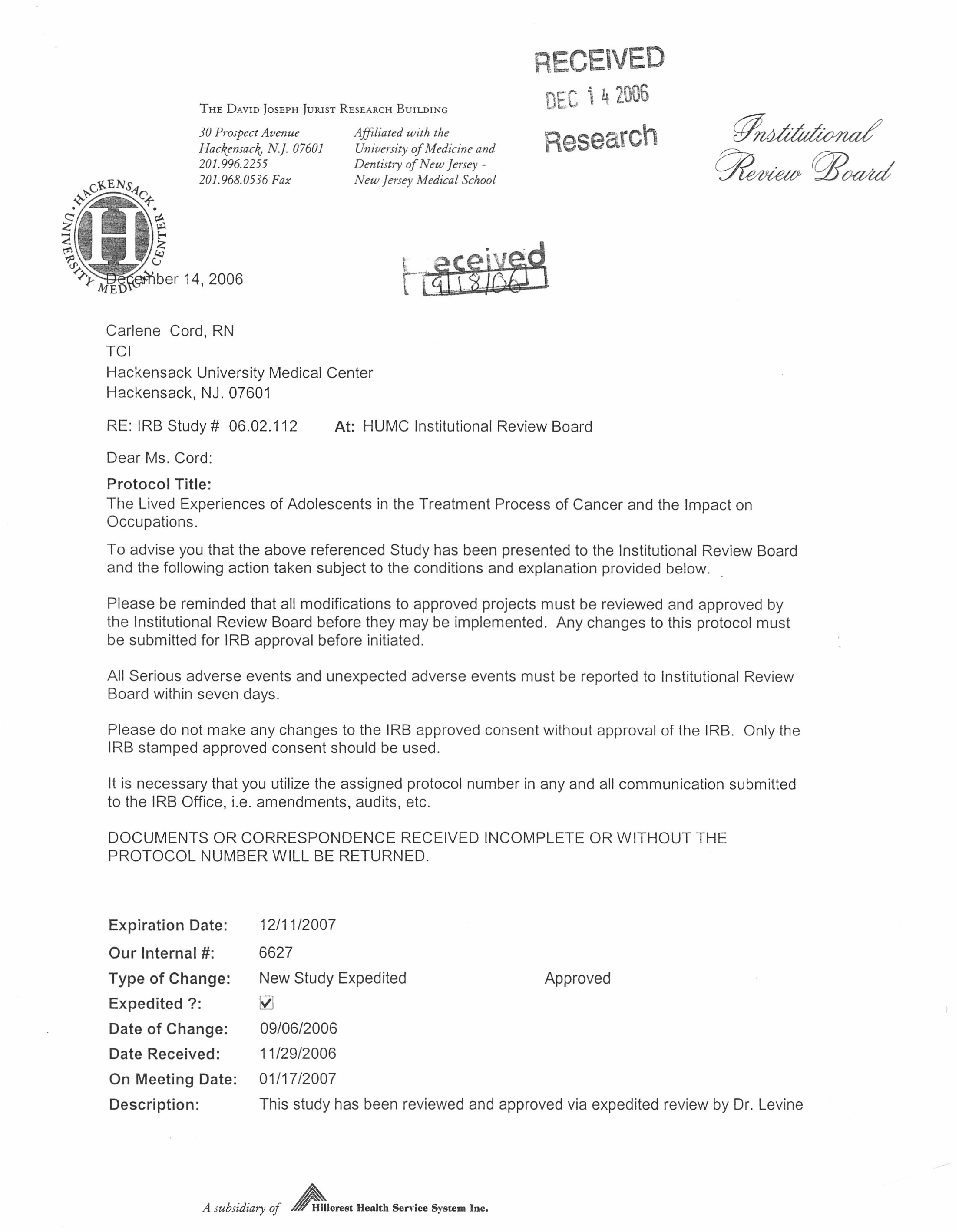
A witness is someone who has no connection with the clinical trial. A witness is only required in cases where the subject cannot read or is not able to understand the consent document. By signing the consent form, the witness attests that the information in the consent form and any other written information was accurately explained to and apparently understood by the subject or the subjects legally acceptable representative and that the informed consent was freely given by the subject or the subjects acceptable representative. In cases where this does not apply N/A should be placed in the witness section.

Witness *(someone not connected to this research project)* _____________***Date:***_____

Witness Identification*: (nurse, friend, receptionist, etc.)* ________________________

If the assent of the child, age 9 or older is not obtained, the reason should be stated below or attached to this consent form.

Appendix C: Hackensack University Medical Center IRB Approval



RECEIVED
DEC 14 2006
Research

THE DAVID JOSEPH JURIST RESEARCH BUILDING

30 Prospect Avenue
Hackensack, N.J. 07601
201.996.2255
201.968.0536 Fax

Affiliated with the
University of Medicine and
Dentistry of New Jersey -
New Jersey Medical School

Institutional Review Board

Received
9/18/06

December 14, 2006

Carlene Cord, RN
TCI
Hackensack University Medical Center
Hackensack, NJ. 07601

RE: IRB Study # 06.02.112 **At:** HUMC Institutional Review Board

Dear Ms. Cord:

Protocol Title:
The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations.

To advise you that the above referenced Study has been presented to the Institutional Review Board and the following action taken subject to the conditions and explanation provided below.

Please be reminded that all modifications to approved projects must be reviewed and approved by the Institutional Review Board before they may be implemented. Any changes to this protocol must be submitted for IRB approval before initiated.

All Serious adverse events and unexpected adverse events must be reported to Institutional Review Board within seven days.

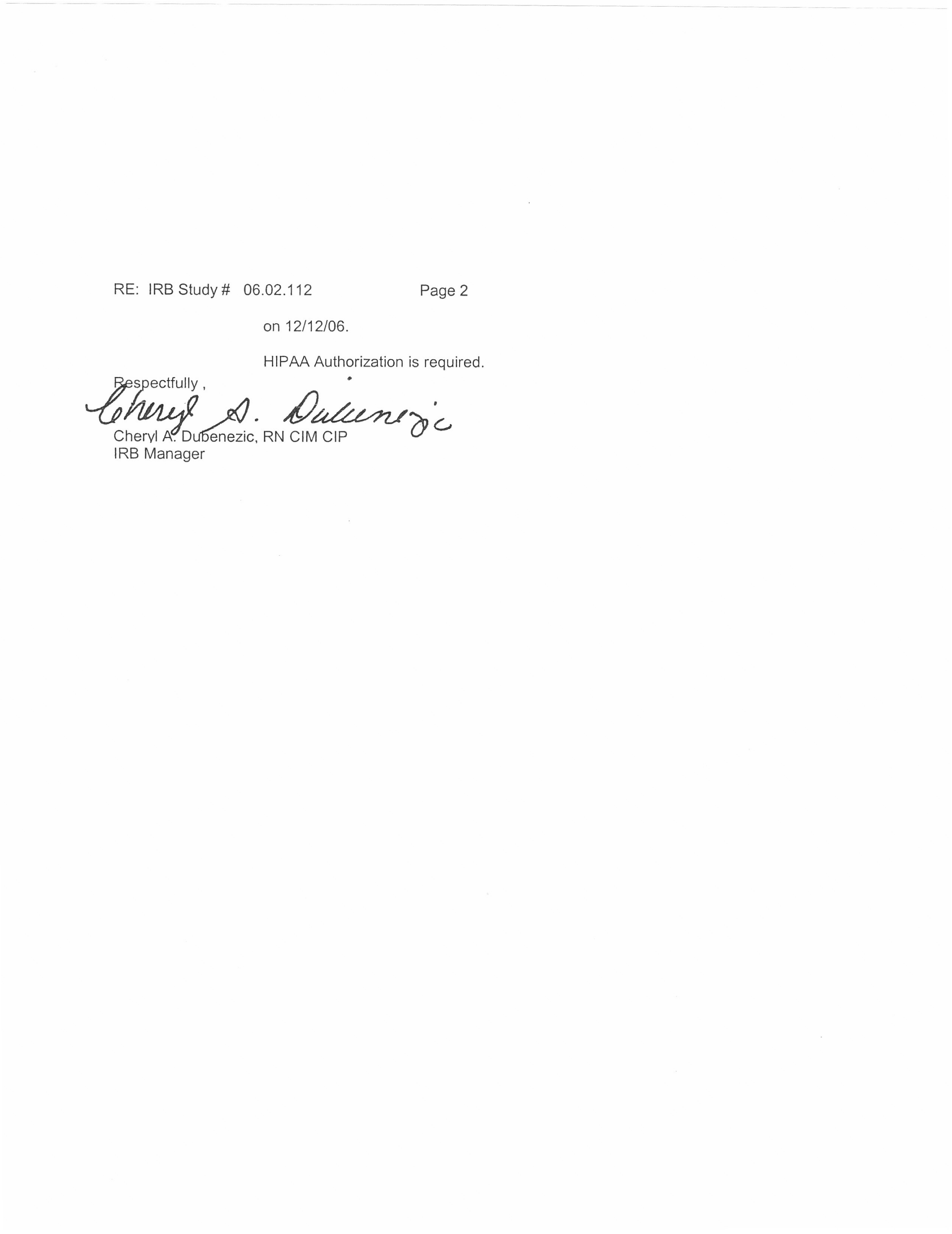
Please do not make any changes to the IRB approved consent without approval of the IRB. Only the IRB stamped approved consent should be used.

It is necessary that you utilize the assigned protocol number in any and all communication submitted to the IRB Office, i.e. amendments, audits, etc.

DOCUMENTS OR CORRESPONDENCE RECEIVED INCOMPLETE OR WITHOUT THE PROTOCOL NUMBER WILL BE RETURNED.

Expiration Date:	12/11/2007	
Our Internal #:	6627	
Type of Change:	New Study Expedited	Approved
Expedited ?:	☑	
Date of Change:	09/06/2006	
Date Received:	11/29/2006	
On Meeting Date:	01/17/2007	
Description:	This study has been reviewed and approved via expedited review by Dr. Levine	

A subsidiary of Hillcrest Health Service System Inc.



RE: IRB Study # 06.02.112 Page 2

on 12/12/06.

HIPAA Authorization is required.

Respectfully ,

Cheryl A. Dubenezic

Cheryl A. Dubenezic, RN CIM CIP
IRB Manager

Appendix D: Nova Southeastern University Informed Consent Adolescent Assent Form

NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Allied Health and Nursing
Occupational Therapy Department
International Institute for Leadership
In Occupational Therapy

ADOLESCENT ASSENT FORM

Assent for Participation in the study: The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations

IRB approval #:

Principal Investigator:
Gary Grimaldi, MA, OT/L, ATP
43-59 160th. Street
Flushing, NY 11358
E-Mail: grimaldi@nova.edu
Phone: 718-463-3691

Co-Investigator:
Sandee Dunbar, DPA, OTR/L
Nova Southeastern University
Health Professions Division
Occupational Therapy
3200 S. University Drive
Fort Lauderdale, FL 33328
E-Mail: sdunbar@nsu.nova.edu
Phone: 954-262-1222

Institutional Review Board
Nova Southeastern University
Office of Grants and Contracts
(954) 262-5369/IRB@nsu.nova.edu

Description of the Study:

You are being invited to participate in this research study to help determine what impact cancer treatment has on enjoying activities you like to do. In other words, the researcher will be looking at how cancer treatment influences the activities that you chose to engage in. These activities are important and valued in your life. The researcher will specifically be looking at the way you see yourself and what issues, if any, interfere with engaging in activities that are meaningful to you. You are being invited as a participant based on being an adolescent between 13-19 years of age, presently receiving cancer treatment, and you continue to attend school in a traditional setting vs. home schooling. If you agree to participate, you will be asked questions about yourself, which will be recorded on audio tape, regarding your personal experiences while on chemotherapy and the impact cancer treatment has had on tasks and activities you enjoy doing. The total time commitment from you would be 4 hours over time (2 interviews 1 month apart and a third meeting to review the analysis of the interviews for accuracy prior to the final submission of the study). Any changes needed to be made will be corrected. The interviews will be recorded on audio tape and then typed into a written format. On your request or the request of your parents/guardians research questions may be reviewed prior to making a decision about your participation in the study.

Risks/Benefits To The Participants:

To the best of my knowledge, there are minimal risks associated with participation in this project. A pamphlet with contact information will be provided to you, if necessary, to discuss uncomfortable issues which may arise in the interview, with trained health care professionals. You would be financially responsible for this care. There are no benefits to you for participating in this study.

Initials: ____________ Date: _____________

Costs and Payments to the Participant:

There is no cost for participation in this study. Participation is voluntary and no payment will be provided. However, if the interview is completed at a location other than your home, taxi reimbursement will be provided to you.

Audio Recording:

"This research project includes audio recording of your voice. This audio tape will be available to the researchers and a paid transcriber. The tape will be kept securely locked in a file cabinet in the researcher's home office. All data secured in a locked filing cabinet in the researcher's home office will only contain pseudonyms. The tape will be kept for 36 months and destroyed after that time through cutting the tape, thus making it inoperable. Because your voice will be potentially identifiable by anyone who hears the tape, your confidentiality for things you say on the tape cannot be guaranteed although the researcher will try to limit access to the tape as described above."

Confidentiality and Privacy:

Please understand that no one else will know that you have participated in this study except for the researcher's advisor and your parents. Your name will not be used in the reporting of information in publications or conference presentations. The researcher will not use any other information that identifies you, except age and other background information which may be useful later. The transcriber will not keep the interview data on the hard drive of the computer used for word processing, but rather on a flash drive, which will also be locked in a file cabinet in the researcher's home office. The transcriber will transcribe the data into a written format in a private room in her home utilizing headphones to maximize confidentiality. Additionally, the transcriber will take an oath of confidentiality. All information obtained in this study is strictly confidential unless disclosure is required by law. Furthermore, the IRB and regulatory agencies may audit research records from this study. All information related to this study will be reported in aggregate.

Participant's Right to Withdraw from the Study:

You have the right to refuse to be part of the study or stop participating. If you decide to not participate or quit the study, it will not affect how you are treated at Hackensack University Medical Center. All data collection materials related to this study will be destroyed upon your request unless prohibited by state or federal law.

Other Considerations:

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you by the researcher.

Initials: ____________ Date: _____________

NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Allied Health and Nursing
Occupational Therapy Department
International Institute for Leadership
In Occupational Therapy

Voluntary Consent by Participant:

I have read the preceding consent form, or it has been read to me, and I fully understand the contents of this document and voluntarily consent to participate. All my questions concerning the research have been answered. I hereby agree to participate in this research study. If I have any questions in the future about this study they will be answered by Gary Grimaldi. A copy of this form has been given to me. This consent ends at the conclusion of this study.

Participant' Signature: ______________________________ Date: _________
Witness's Signature: _______________________________ Date: _________

ACKNOWLEDGEMENT OF PARENT OR GUARDIAN
I have read the preceding and give consent for my child to participate in this research project. A copy of this form has been given to me.

Parent/Legal Guardian's Signature ___________________________ Date: _________
Witness's Signature: _____________________________________ Date: __________

Protocol Title: The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations

Appendix E: Nova Southeastern University Informed Consent – Parent/Guardian

NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Allied Health and Nursing
Occupational Therapy Department
International Institute for Leadership
In Occupational Therapy

PARENT/GUARDIAN INFORMED CONSENT

Parent/Guardian Consent for Participation in the Study: The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations

IRB approval #:

Principal Investigator:
Gary Grimaldi, MA, OT/L, ATP
43-59 160th. Street
Flushing, NY 11358
E-Mail: grimaldi@nova.edu
Phone: 718-463-3691

Co-Investigator:
Sandee Dunbar, DPA, OTR/L
Nova Southeastern University
Health Professions Division
Occupational Therapy
3200 S. University Drive
Fort Lauderdale, FL 33328
E-Mail: sdunbar@nsu.nova.edu
Phone: 954-262-1222

Institutional Review Board
Nova Southeastern University
Office of Grants and Contracts
(954) 262-5369/IRB@nsu.nova.edu

Description of the Study:

You are being asked to give permission for your child to participate in a research study. This research study is designed to help determine what impact cancer treatment has on enjoying activities your child likes to do. In other words, the researcher will be looking at how cancer treatment influences the activities your child chooses to engage in. These activities are important and valued in his/her life. The researcher will specifically be looking at the way he/she sees himself/herself and what issues, if any, interfere with engaging in activities that are meaningful to him/her. Your child is being invited as a participant based on being an adolescent between 13-17 years of age, presently receiving cancer treatment, and continues to attend school in a traditional setting vs. home schooling. If you agree to participate, your child will be asked questions about himself/herself regarding his/her personal experiences while on chemotherapy and the impact cancer treatment has had on tasks and activities he/she enjoy doing. The total time commitment from your child would be 4 hours over time (2 interviews 1 month apart and a third meeting to review the analysis of the interviews for accuracy prior to the final submission of the study). Any changes needed to be made will be corrected. The interviews will be recorded on audio tape and then typed into a written format. On your request or the request of your child research questions may be reviewed prior to making a decision about your participation in the study.

Risks/Benefits:

To the best of the researcher's knowledge, there are minimal risks associated with participation in this project. A pamphlet with contact information will be provided to your child, if necessary, to discuss any issues which may arise in the interviews, with trained health care professionals. You would be financially responsible for this care. There are no benefits to your child for participating in this study.

Costs and Payments to the Participant:

There is no cost for participation in this study. Participation is voluntary and no payment will be provided. However, if the interview is completed at a location other than your home, taxi reimbursement will be provided to you.

Audio Recording:

"This research project includes audio recording of your child's voice. This audio tape will be available to the researchers and a paid transcriber. The tape will be kept securely locked in a file cabinet in the researcher's home office. All data secured in a locked filing cabinet in the researcher's home office will only contain pseudonyms. The tape will be kept for 36 months and destroyed after that time through cutting the tape, thus making it inoperable. Because your child's voice will be potentially identifiable by anyone who hears the tape, your child's confidentiality for things he/she say on the tape cannot be guaranteed although the researcher will try to limit access to the tape as described above."

Initials: ____________ Date: _____________

Confidentiality and Privacy:

Please understand that no one else will know that you have participated in this study except for the researcher's advisor and your parents. Your name will not be used in the reporting of information in publications or conference presentations. The researcher will not use any other information that identifies you, except age and other background information which may be useful later. The transcriber will not keep the interview data on the hard drive of the computer used for word processing, but rather on a flash drive, which will also be locked in a file cabinet in the researcher's home office. The transcriber will transcribe the data into a written format in a private room in her home utilizing headphones to maximize confidentiality. Additionally, the transcriber will take an oath of confidentiality.

All information obtained in this study is strictly confidential unless disclosure is required by law. Furthermore, the IRB and regulatory agencies may audit research records from this study. All information related to this study will be reported in aggregate.

Participant's Right to Withdraw from the Study:

You have the right to refuse or withdraw your child in participating from this study at time. If you decide not to participate or quit the study, it will not affect how your child is treated at Hackensack University Medical Center. There will be no consequences to your child or yourself as a result of the withdrawal from this study. All data collection materials related to this study will be destroyed upon your request unless prohibited by state or federal law.

Initials: ____________ Date: _____________

NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Allied Health and Nursing
Occupational Therapy Department
International Institute for Leadership
In Occupational Therapy

Other Considerations:

If significant new information relating to the study becomes available which may relate to your willingness to have your child continue to participate, this information will be provided to you by the researcher.

Voluntary Consent by Participant:

I have read the preceding consent form, or it has been read to me, and I fully understand the contents of this document and voluntarily consent for my child to participate in this study. All my questions concerning the research have been answered. I hereby agree to have my child participate in this research study. If I have any questions in the future about this study they will be answered by Gary Grimaldi. A copy of this form has been given to me. This consent ends at the conclusion of this study.

Child's Name: ____ Date: _________
Parent/Legal Guardian's Signature ___________________________ Date: _________
Witness's Signature: _______________________________________Date: _________

Protocol Title: The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations

Appendix F: Nova Southeastern University General Informed Consent

NOVA SOUTHEASTERN UNIVERSITY
Health Professions Division
College of Allied Health and Nursing
Occupational Therapy Department
International Institute for Leadership
In Occupational Therapy

ADULT/GENERAL INFORMED CONSENT

Adult/General Informed Consent for Participation in the Study: The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations

IRB approval #:

Principal Investigator:
Gary Grimaldi, MA, OT/L, ATP
43-59 160th. Street
Flushing, NY 11358
E-Mail: grimaldi@nova.edu
Phone: 718-463-3691

Institutional Review Board
Nova Southeastern University
Office of Grants and Contracts
(954) 262-5369/IRB@nsu.nova.edu

Co-Investigator:
Sandee Dunbar, DPA, OTR/L
Nova Southeastern University
Health Professions Division
Occupational Therapy
3200 S. University Drive
Fort Lauderdale, FL 33328
E-Mail: sdunbar@nsu.nova.edu
Phone: 954-262-1222

Description of the Study:

You are being invited to participate in this research study to help determine what impact cancer treatment has on enjoying activities you like to do. In other words, the researcher will be looking at how cancer treatment influences the activities that you chose to engage in. These activities are important and valued in your life. The researcher will specifically be looking at the way you see yourself and what issues, if any, interfere with engaging in activities that are meaningful to you. You are being invited as a participant based on being an adolescent between 18-19 years of age, presently receiving cancer treatment, and you continue to attend school in a traditional setting vs. home schooling. If you agree to participate, you will be asked questions about yourself regarding your personal experiences while undergoing cancer treatment and the impact cancer treatment has had on tasks and activities you enjoy doing. The total time commitment from you would be 4 hours over time (2 interviews 1 month apart and a third meeting to review the analysis of the interviews for accuracy prior to the final submission of the study). Any changes needed to be made will be corrected. The interviews will be recorded on audio tape and then typed into a written format. On your request research questions may be reviewed prior to making a decision about your participation in the study.

Initials: ____________ Date: _____________

Risks/Benefits:

To the best of the researcher’s knowledge, there are minimal risks associated with participation in this project. A pamphlet with contact information will be provided to you, if necessary, to discuss uncomfortable issues which may arise in the interview, with trained health care professionals. You would be financially responsible for this care. There are no benefits to you for participating in this study.

Costs and Payments to the Participant:

There is no cost for participation in this study. Participation is voluntary and no payment will be provided. However, if the interview is completed at a location other than your home, taxi reimbursement will be provided to you.

Audio Recording:

“This research project includes audio recording of your voice. This audio tape will be available to the researchers and a paid transcriber. The tape will be kept securely locked in a file cabinet in the researcher’s home office. All data secured in a locked filing cabinet in the researcher’s home office will only contain pseudonyms. The tape will be kept for 36 months and destroyed after that time through cutting the tape, thus making it inoperable. Because your voice will be potentially identifiable by anyone who hears the tape, your confidentiality for things you say on the tape cannot be guaranteed although the researcher will try to limit access to the tape as described above.”

Confidentiality and Privacy:

Please understand that no one else will know that you have participated in this study except for the researcher’s advisors. Your name will not be used in the reporting of information in publications or conference presentations. The researcher will not use any other information that identifies you, except age and other background information which may be useful later. The transcriber will not keep the interview data on the hard drive of the computer used for word processing, but rather on a flash drive, which will also be locked in a file cabinet in the researcher’s home office. The transcriber will transcribe the data into a written format in a private room in her home utilizing headphones to maximize confidentiality. Additionally, the transcriber will take an oath of confidentiality.

All information obtained in this study is strictly confidential unless disclosure is required by law. Furthermore, the IRB and regulatory agencies may audit research records from this study. All information related to this study will be reported in aggregate.

Participant’s Right to Withdraw from the Study:

You have the right to not participate or quit at any time, without penalty. If you do withdraw, it will not affect how you are treated at Hackensack University Medical Center in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless prohibited by state or federal law.

Other Considerations:

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you by the researcher.

Initials: ____________ Date: _____________

Voluntary Consent by Participant:
I have read the preceding consent form, or it has been read to me, and I fully understand the contents of this document and voluntarily consent to participate. All my questions concerning the research have been answered. I hereby agree to participate in this research study. If I have any questions in the future about this study they will be answered by Gary Grimaldi. A copy of this form has been given to me. This consent ends at the conclusion of this study.
Participant' Signature: ______________________________ Date: _________
Witness's Signature: ______________________________ Date: _________

Protocol Title: The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations

NOVA SOUTHEASTERN UNIVERSITY
Office of Grants and Contracts
Institutional Review Board

NOVA SOUTHEASTERN UNIVERSITY
Office of Grants and Contracts
Institutional Review Board

MEMORANDUM

To: **Gary Grimaldi**
Health Professions Division – College of Allied Health and Nursing
43-59 160th Street
Flushing, NY 11358

From: **Josephine Shallo-Hoffmann, Ph.D.**
Chair, Institutional Review Board

Date: **October 13, 2006**

Re: ***The Lived Experiences of Adolescents in the Treatment Process of Cancer and the Impact on Occupations –***
Research Protocol No. HPD-ALL09200605Exp.

I have reviewed the above-referenced research protocol by an expedited procedure on behalf of the Institutional Review Board of Nova Southeastern University. Please make the following corrections and resubmit them to the Office of Grants and Contracts for review by me. Please note that research is not to commence until final approval has been given. Also note that corrections must be submitted within six months or full resubmission will be necessary. Please direct all corrections to: Institutional Review Board, Office of Grants and Contracts, 3301 College Ave., Fort Lauderdale, FL 33314.

Submission Form, page 3

F. Is the $25 - $50 / person only for the taxi fare?

Consent Forms

Description of the Study:

There is a typo on all three forms in the approximately 4th sentence: "The researcher will specifically be looking.... i.e., change "being" to be."

Please place the title of the study on the last page of the consent forms to insure that no one else will use the signatures for another purpose.

Add a sentence to invite the subjects and parents/guardians to review the questions before making a decision about the study.

Please include a cover letter with your revisions which detail the exact changes which were made in response to the points cited in this letter.

cc: **Dr. Teri Anne Hamill**
Dr. Diane Whitehead
Dr. Patrick Hardigan
Jaime Arango

3301 College Avenue • Fort Lauderdale-Davie, Florida 33314-7796 • (954) 262-5369
Fax: (954) 262-3977 • Email: *irb@nsu.nova.edu* • Web site: *www.nova.edu/cwis/irb*

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