

UNDERSTANDING THE MEANING OF THE
LIVED EXPERIENCE OF ADOLESCENTS
IN TREATMENT FOR CANCER

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DEDICATION

This dissertation is dedicated in loving memory to

Frank L. Seleny,

my husband and best friend,

whose wise counsel and enduring love were always with me

in spirit through this long journey

and to

my parents, Mary and Edward Fochtman,

who instilled in me the values and beliefs I treasure

and whose unconditional love and support sustained me

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ABSTRACT

The increased intensity and complexity of cancer treatment has an impact on the lives of the adolescents undergoing such treatments. Living with cancer is a distinct experience for them which include physical, psychological, spiritual and social dimensions. The cancer experience comprises more than the measurement of symptom occurrence, frequency, duration and severity, or the ratings of quality of life. The meanings of the lived experience from the adolescent's perspective and self-report can give a more accurate, holistic picture of the nature and scope of the experience. Practitioners need to know and understand the meaning of the experience from the adolescent's perspective in order to design appropriate interventions to prevent or relieve distress in these patients.

The purpose of this study was to describe the meanings of the lived experience of having cancer for adolescents undergoing treatment. Phenomenology was the qualitative research methodology used. As outlined by Patricia Munhall, this methodology seeks to understand the meaning of lived experiences.

Seven adolescents, 14 to 18 years of age, in treatment for cancer were interviewed. Six males and one female participated in this study. Six were receiving treatment for acute lymphocytic leukemia and one for a solid tumor. All participants were of Pacific Island origin; two live in Hawaii and five were temporary residents. The audio taped interviews were transcribed and analyzed to understand the meaning of the cancer experience. The essence of the experience for the individual adolescent was described and a composite interpretation of the meaning derived.

Recommendations to healthcare providers for improving communication with adolescents in treatment for cancer are provided, including discussing death and dying early in the illness trajectory. The interdisciplinary concept of care is stressed, as well as the importance of a thorough physical examination. The importance of social support and techniques to potentially strengthen and increase this support are outlined. Solutions to the problems of school reintegration are introduced.

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CHAPTER ONE

INTRODUCTION

Chapter One presents the background for this study, the research question and problem statement, purpose, and the significance of the study.

As a clinician I have been practicing in pediatric oncology nursing for over 30 years, both as a clinical specialist and as a pediatric nurse practitioner. I have been present for the most human of experiences, both tragic and joyful, for patients, family, and staff. I have shared their laughter and their tears and bore witness to their suffering. I have developed nursing interventions based on assessments of both the physical and psychosocial condition. The physical assessment was learned through training and experience. The psychological assessment was often based on intuition and experience. However, intuition is not enough if we want to understand the meaning of the experience to the individual – patient, family or staff – and experience is only gained over time. To truly understand another human being we must investigate how they perceive the experience.

Survival rates for childhood cancer have increased over the past two decades, due in large part to the increase in the intensity and complexity of the treatment modalities used. The increased intensity and complexity have an impact on the lives of adolescents undergoing such treatment. The impact of cancer treatment is more than just the measurement of symptom occurrence, frequency, duration and severity. The experience of enduring treatment needs to be defined and measured by self-report (as opposed to parent or staff report) to gain an accurate, complete holistic picture of the nature and scope of the

adolescent's experience. Knowledge of how adolescents experience this treatment would enable practitioners to design appropriate interventions. The focus of this study is adolescents' perceptions of the lived experience of having cancer. Adolescents were chosen as subjects because they comprise a single developmental stage (though with several interdevelopmental stages) and are more apt to be able to articulate their experiences than the younger child.

As a nurse practitioner assessing adolescents with cancer I found myself looking for the presence or absence of individual symptoms such as pain, nausea, and fatigue. Quantitative measures are often used (e.g. rate your pain on a scale of 1 to 10, or, in the last week how often have you been nauseated?) and often using the assessments of others, such as parents and staff. I surmised that we were not really listening to the adolescent or asking the right questions. To understand what is important or distressing to the adolescent with cancer we have to elicit their perceptions of the experience.

A brief exemplar can be used to illustrate the necessity of understanding from the adolescent's point of view:

Julie is a 13y/o Japanese American girl with recurrent ALL. She is in the midst of her second 2 ½ yr course of chemotherapy. Therapy is frequent, intensive and varies between inpatient and outpatient. Part of the triage/assessment each time she comes to clinic is "Do you have any pain?" Each time she has to stop and think before she answers. Her answers vary: "no"; "Well, I was nauseated yesterday and I couldn't go out with my friends"; "My knee hurts sometimes";

“Why does this (the mucositis) keep happening to me?”; “Well, I was constipated, but no more”; “I couldn’t go to school Tuesday cause my foot hurt”; “I really didn’t feel like eating all day yesterday”.

The query was in regard to her pain. Her answers cover a broad range of symptoms and their meaning. She is telling me that the meaning of having leukemia is more than just the measurement of one symptom. It is obvious that the leukemia and its treatment have produced physical, psychological, social, and perhaps spiritual symptoms. One or more changes in normal function, sensation or appearance are causing physical discomfort, mental anguish, or distress. We are not “getting at “or measuring the meaning of the experience by only asking her if she has pain.

Background

A review of the United States Cancer Statistics 1999 to 2005 Incidence and Mortality Report reveals the scope of childhood cancer today (U.S. Cancer Statistics Working Group, 2009). In the United States in the year 2005, 13,137 children between the ages of 0 and 19 years were diagnosed with cancer which included 2549 between the ages of 0 and 14 and 4372 between the ages of 15 and 19 (U.S. Cancer Statistics Working Group, 2009, Table A.5.1). The incidence of cancer in children 0 to 19 years was 16.5/100,000 persons (age-adjusted to the 2000 U.S. standard population) with an incidence of 12.7/100,000 in 0 to 14 years and 21.6/100,000 in 15 to 19 years (U.S. Cancer Statistics Working Group, 2007, Tables 1.2.5.1 and 1.2.6.1). Trends in the five-year relative survival rates for children under age 15 in the United States from 1975 to 2004 have shown an improvement from 58% for patients diagnosed in the period 1975 to

1977 to 80% for those diagnosed in the period 1996 to 2004 (Jemal, Siegel, Ward, Hao, Xu, Thun, 2009, Table 16). The five-year relative cancer survival rate for children diagnosed in the period 1996 to 2004, adjusted for normal life expectancy and based on follow-up of patients through 2005, is 80% for all sites. This survival rate is as high as 88% for acute lymphocytic leukemia in children under 15 years of age, a change from the rate of 58% in the period 1975 to 1977. The increase in survival rates is for the most part due to the more intensive treatment regimens used.

More intensive therapy has increased the number and intensity of side effects that adolescents may experience and has increased the complexity of care. These side effects have produced symptom distress which has added to the difficulty of dealing with the diagnosis and treatment. Hinds, Quargnenti, and Wentz (1992) defined the concept of symptom distress in adolescents as “an individual’s report of his or her awareness of one or more changes in normal function, sensation, or appearance that cause him or her some degree of physical discomfort, mental anguish or suffering” (p.84).

Assumptions

Symptom distress is the discomfort produced by each symptom and can be physical, psychological, social and spiritual. It is assumed that adolescents experience both positive and negative outcomes when they are treated for cancer. One or more changes in normal or usual physiological, psychological, social, and/or spiritual functioning leads to different meanings to the individual.

To define the meaning of the experience in adolescents with cancer, other assumptions are made:

1. The meaning has many dimensions, including physical, psychological, social and spiritual
2. Adolescents with cancer have varying degrees of positive and negative experiences as a result of the disease and treatment, especially with the more intensive therapies
3. Measurement of the meanings is more than symptom occurrence, frequency, duration and severity
4. Self-report is necessary for an accurate, complete holistic picture of the nature and scope of the adolescent's experience

The study proposed here defines adolescents as patients 13 to 19 years of age in treatment for cancer. Adolescents were chosen as participants because of their availability as subjects and because they comprise a single developmental stage and are more apt to be able to articulate their experiences than the younger child. Previous studies designed to measure quality of life in children and adolescents with cancer are not comprehensive enough to capture the scope of the adolescent's experience. This study seeks a more comprehensive, in-depth understanding of what the experience means to the adolescent.

Research Question

What is the meaning of having cancer to adolescents 13 to 19 years of age?

Statement of the Problem

Survival rates for cancer in adolescents have increased over the past two decades due to the increase in the intensity and complexity of treatment modalities used. It can be assumed that this increase in intensity and complexity has produced increased distress or suffering (physical, psychological, social and spiritual) for the adolescent undergoing

treatment for cancer. Studies of adolescents often focus on the assessment of distress or suffering from the care-givers' perspective. We need to know how the adolescent perceives the cancer experience. Without these perspectives conceptual and empirical research on adolescents with cancer is incomplete and may contribute to measurements that are insensitive or inaccurate.

Statement of Purpose

The meaning of the experience of having cancer needs to be defined and measured by self-report from the adolescent to gain an accurate, complete, holistic picture of the nature and scope of the issues. Further research is needed on the experience of adolescents with cancer. A qualitative study of the lived experiences of these adolescents with various cancer diagnoses, at various adolescent ages, and at various points on the cancer illness trajectory using phenomenology will contribute to our understanding of this population. Knowledge of how adolescents find meaning in this lived experience will enable practitioners to design interventions to prevent or ameliorate distress.

Definition of Terms

Adolescents – participants 13 to 19 years of age without developmental disabilities

Lived experience – “the reciprocal relationship between the respondent and the environment as he or she sees it” (Munhall, 2007, p.102) or “an act of consciousness” (Smith, 2006).

Phenomenology -- the study of the individual's life-world, as experienced rather than as conceptualized, categorized, or theorized. Phenomenology aims for a deeper understanding of the nature or meaning of everyday experiences (van Manen, 1984).

Symptom distress – “an individual’s report of his or her awareness of one or more changes in normal function, sensation, or appearance that cause him or her some degree of physical discomfort, mental anguish or suffering” (Hinds, Quargnenti, & Wentz, 1992, p.84)

Significance of the Study

Adolescents face many developmental tasks. Having cancer adds another challenge. How adolescent patients perceive this life experience can affect their willingness to participate in and comply with treatment and ultimately their future outlook and approach to life. Understanding the lived experience of adolescent patients receiving treatment for cancer is vital to the development of interventions to help these teenagers meet these challenges. Listening to the adolescents describe the experience and the meanings in their own words “can result ultimately in both enhanced treatment and management of their symptoms and related distress and more accurate diagnostic differentials. Successful management of symptoms and the distress they cause can help develop a more trusting relationship between adolescent patients and their health care providers. Improved diagnostic differentials can result in better treatment tolerance and improved outcome of therapy” (Hinds, et al., 1992, p.84).

Summary

- The cure rate for adolescents with cancer has improved over the past two decades. This is in large part due to more intensive treatment. The increased intensity and complexity of these treatment modalities have an impact on the lives of the adolescents undergoing such treatments. The impact of cancer treatment is more than the measurement of symptoms in the adolescent or relying on the report of caregivers. The meaning of the

experience needs to be defined and measured by adolescent self-report to gain a more accurate, complete, holistic picture of the nature and scope of the adolescent's experience. The focus of this study is adolescents' perceptions of the lived experience of having cancer. Knowledge of how adolescents experience cancer and its treatment would enable practitioners to have a deeper understanding of the adolescent undergoing treatment and design appropriate interventions to prevent or relieve distress.

CHAPTER TWO

LITERATURE REVIEW

Chapter Two presents the literature review of the theories of adolescent development, defining adolescence, adolescents with cancer, adolescents as research subjects, measurement of adolescents' perceptions of the meaning of the cancer experience, qualitative research and the use of phenomenology.

Adolescence

Adolescence is a developmental stage filled with many physical, cognitive, psychological and social changes. It is a complex and tumultuous period between childhood and becoming an independent adult. It “brings much excitement, discovery and achievement”... [but also presents the challenges of the] “multitude of physiologic, cognitive, emotional, and social processes [that] are incorporated in the transcendence from childhood to young adulthood” (Neville, 2000, p.3). During adolescence the young person will go through puberty and the completion of growth, take on sexually dimorphic (male and female) body shape, develop cognitive skills such as abstract thinking and increased verbal abilities, develop a clearer sense of personal and sexual identity, and develop a degree of emotional, personal and financial independence (Christie & Viner, 2005).

Theories of Adolescent Development

Several models or theories of development have described adolescence as a “stage” of development. Freud (1905/1962) focused on psychosocial development as the individual goes through the stages of life from infancy through adolescence which he

described as oral, anal, phallic, latency and genital. He believed that a single motive, the desire to satisfy biological needs and therefore discharge tension, was the motive that governs all human behavior. He described the preadolescent or “latency” period (7 to 11 years) as a time when the individual develops a balance between the ego (the self) and the id (primitive drives and instincts). For him adolescence (12 to 18 years) was the “genital” stage of development where the individual is bombarded with instinctual impulses that disrupt this balance. The ego is torn between the strong impulses of the id and the restrictions of the superego (conscience) which makes this a time of tremendous stress and turmoil (ReCAPP, 2007; Christie & Viner, 2005).

Piaget (1969) defined the stages of development in terms of the cognitive abilities of the individual which he defined as the sensorimotor period (birth to two years), the concrete operational period (2 to 7 years) where children master independently acquired skills and are able to form mental representations of objects and imagine actions related to them, and the concrete operational period (7 to 11 years) where children are capable of logical thinking. Adolescence is defined as the formal operational period (12 years to adulthood) during which the individual develops the ability to reason abstractly. There is a movement from concrete to abstract thinking and a decrease in egocentric thought (Stroufe & Cooper, 1988; ReCAPP, 2007).

The concept of egocentrism is derived from Piaget’s theory of cognitive development. Egocentrism can be defined as a lack of differentiation between a person’s own point of view and the point of view of others (Muuss, 1996). In adolescence egocentrism “is an adolescent’s false belief that others are just as interested in his or her

own actions, behaviors, assets, weaknesses, and appearance as the adolescent is” (Neville, 2000, p.5). Thus the adolescent thinks that he or she is the focus of interest of other people. This belief that they are the center of attention contributes to self-consciousness, especially among peers.

The adolescent is moving from the earlier concrete operational stage to the formal operational stage. The development of formal operational thought allows the adolescent to review the evidence using abstract thinking and hypothetical reasoning before coming to a logical conclusion (Jarvis, 1996). Abstract thinking and logical reasoning lead the adolescent to think about and assess family values and beliefs. They can contemplate future possibilities beyond the present reality and mentally form ideals (Neville, 2000).

Erikson (1963) developed a psychosocial theory of development that places importance on the social and cultural components of the individual’s developmental experiences. At each stage the individual is “confronted with a unique problem requiring the integration of personal needs and skills with social demands and cultural expectations. Erikson refers to the individual’s efforts to adjust as a crisis... Each psychosocial stage has two components, the favorable and unfavorable aspects of the core conflict...” (Wong, 1995, p.121).

Birth to one year of age is the stage of basic trust vs. mistrust where trust is learned or mistrust develops when trust-promoting experiences are deficient or lacking or when care is inconsistent. One to three years of age is the stage of autonomy vs. shame and doubt where children learn to be self-sufficient in mastering tasks and become increasingly able to control their bodies, themselves and their environment or they are made to feel

unimportant and self-conscious and doubt their abilities and their capacity to act on the world.

Three to six years of age is the stage of initiative vs. guilt where children explore the physical world with all their senses, initiate play with peers, accept responsibilities, and develop a conscience. Sometimes these activities are in conflict with others which create guilt. If the guilt is excessive it can inhibit their initiative. Seven to 11 years of age is the stage of industry vs. inferiority where children must master increasingly more difficult skills such as social interaction with peers and academic performance. Competition, cooperation, and achievement are important aspects of the development of a sense of mastery and self-assurance. Feelings of inadequacy and inferiority develop if too much is expected of them or if they feel they cannot measure up to the standards set for them by others.

The fifth stage of Erikson's developmental model, from 12 to 18 years, is the adolescent stage of identity vs. inferiority. Here the individual builds on all the earlier stages to develop a sense of self-identity. Adolescents struggle to find their place among peers, define their role, integrate their concepts and values with those of society, and come to a decision about their future occupation. Failure to reach the goal of self-identity may cause confusion in sexual identity, the choice of occupation, and the roles they are to perform as adults (Wong, 2005; ReCAPP, 2007; Stroufe & Cooper, 1988). Confusion is expected as the adolescent struggles to develop an ego identity amidst the myriad of bodily changes and libidinal urges (Muuss, 1996).

All of these models depend on clear cut “stages” in defining the progression of development. “A more useful model is the biopsychosocial approach, which acknowledges that adolescence has biological (puberty and sexual development) as well as psychological and social elements” (Christie & Viner, 2005). Adolescents do not proceed through this developmental process in a step-wise fashion. Some may advance rapidly, others more slowly. Regression can occur, particularly when success in one area is not achieved, or feelings of self-worth are undermined, or when an event such as injury or illness occur. The primary challenges of adolescence include “the achievement of biological and sexual maturation, the development of personal identity, the development of intimate sexual relationships with an appropriate peer, [and] the establishment of independence and autonomy in the context of the sociocultural environment” (Christie & Viner, 2005, p.301).

Defining Adolescence

The concept of adolescence is therefore an elusive one to define. The World Health Organization (WHO) defines adolescence as the period of life between the ages of 10 and 19 years of age (WHO, 2008). They recognize the overlapping definitions of youth, adolescents and young people and “to eliminate confusion on these definitions, WHO clearly defines adolescence as the period of life between 10-19 years, youth as between 15-24 years and young people as those between 10-24 years. Problems of interchanging the definition of youth and adolescence has also been countered by accepting that dynamic transitions of this stage of life have as much to do with biological aspects as

with socio-cultural conditions. Therefore, the health of both groups, youth and adolescents, are often taken together” (WHO, 2008, p.1).

The Centers for Disease Control (CDC) in a summary of health statistics for US children in 2006, defined adolescence as 12 to 17 years (Bloom & Cohen, 2007). The Association of Maternal and Child Health Programs and the National Network of State Adolescent Health Coordinators in a collaborative project on adolescent health define adolescence as 10 to 24 years (Fine & Large, 2005). The National Initiative to Improve Adolescent Health by the Year 2010 defines our nation’s “youth”, i.e. adolescents and young adults, as aged 10 to 24 (Healthy People 2010, 2008). The Grantmakers for Children, Youth and Families (GCYF), a membership association of grantmaking institutions, defines the “youth” population as those within the “commonly accepted definition of adolescence, i.e. ages 9 to 24” (Large & Skillicorn, 2007). They recognize that four distinct subgroups of “youth” exist:

1. Preteens – age 9 to 12
2. Early teens – age 13 to 16
3. Late teens – age 17 to 19
4. Young adults – age 20 to 24 (p. 2-3)

Grantmakers for Children, Youth and Families (GCYF) also acknowledges that the definition must encompass both chronological age and the developmental tasks and emotional benchmarks that characterize the progression from childhood through adolescence and into adulthood. That window has traditionally been equivalent to the teenage years. However, with puberty arriving earlier and financial dependence lasting

longer, it seems as though the length of adolescence has been extended (Penner, 2008). Research methods “must address the needs of youth according to their physical and chronological age in tandem with their developmental and emotional needs” (Large & Skillicorn, 2007, p.3).

Crockett and Peterson (1993) identify three distinct subphases of adolescence:

1. Early adolescence (11 to 14 years) characterized primarily by the physical changes of puberty and the individual’s responses to those changes
2. Middle adolescence (15 to 17 years) characterized by transition to a dominant peer orientation, with all the preoccupations with music, appearance and dress, language and behavior
3. Late adolescence (18 to 20 years) characterized by transitions into adulthood, including taking on adult work roles and developing adult relationships (Wong, 1995)

During each of these subphases the changes, opportunities, pressures, skills, and available resources differ.

Adolescents with Cancer

Studies have shown that physical appearance contributes to overall levels of self-esteem in the normative adolescent population (Coleman & Hendry, 1999; Harter, 1999). All treatments for cancer - surgery, radiation and chemotherapy – have an impact on the adolescent’s appearance. “An aspect that has been overlooked in existing research is the effect the disease and its treatment has on adolescents’ appearance and how this impacts on their lives” (Wallace, et. al., 2007). Reiter-Purtill and Noll (2003) reported that

adolescents with cancer whose treatment affected their central nervous system or their physical appearance were at greatest risk for difficulties in relationships with peers. Puukko, et al. (1997a; 1997b) found that adolescent female survivors of childhood leukemia had a poorer body image than control groups. Varni, et al. (1995) studied adolescents nine months after the diagnosis of cancer and found that a more positively perceived appearance predicted lower levels of depression and social anxiety mediated by self-esteem. Eiser (1998) noted that even in long term survivors of childhood cancer alopecia was the most distressing aspect of cancer treatment.

Gibson, et al. (2005) conducted a phenomenological study of fatigue in eight adolescents undergoing treatment for cancer. Their findings indicated that these adolescents found fatigue to be overwhelming, affecting them physically and mentally. Fatigue was embedded in a cluster of symptoms and emotions associated with the illness itself and with treatment. “Fatigue had a significant effect on physical, psychological, and social well-being, placing an extra burden on adolescents who are striving for normality” (p. 651).

Emotional social support in the lives of adolescents is recognized as a significant factor in their psychosocial response to the experience of cancer and its treatment. Ritchie (2001) identified two major sources of emotional support for adolescents with cancer – their mother and their friends. Adolescents often form friendships with other teens that have cancer and thus often have both healthy and ill friends. However, emotional social support from friends who are healthy appears to differ from that of illness peers because healthy peers cannot fully understand the meaning of cancer (Ritchie, 2001; Enskar,

Carlsson, Golsater, & Hamrin, 1997). Katz and Varni (1993) conducted a critical review of the literature on social support, psychosocial development, and coping among pediatric cancer patients. They concluded that social competence, the perceived ability to be accepted by one's peers, is a major determinant of one's overall self-esteem. Those children who have limited support systems are at risk for long-term psychosocial maladjustment. Therefore, social support and social competence are key factors in coping and adjustment for children with cancer.

The diagnosis of cancer presents some unique difficulties and challenges for an adolescent. In addition to the physical changes of puberty, for the average adolescent there are the goals of achieving a stable self-image, increasing autonomy and independence from family, dealing with a growing awareness of sexuality, and developing the ability to think in abstract terms (Roberts, Turney, & Knowles, 1998). The cancer diagnosis adds dealing with a potentially life-threatening illness, adjusting to the treatment and side effects, and coping with the disruption these cause and the consequent physical changes (Wallace, Harcourt, Rumsey & Foot, 2007).

Adolescents as Research Subjects

In the past adolescents have largely been treated as passive research subjects while those charged with their care spoke for them (Pole, Mizen & Bolton, 1999). Adolescents were perceived as lacking the cognitive skills necessary to contribute to decision making about their lives (Neal, 1995), or not fully responsible for themselves (Gecas & Seff, 1990), or generally providing untrustworthy responses (Frank, 1997). The voices and views of adolescents are lacking in research on the family (Eder & Fingerson,

2002). However, because their perspective often differs significantly from those of adults, it is important to find ways to improve qualitative research in this population.

In general adolescents participate in research studies less often than younger or older populations. Adolescents do not frequently appear in the samples of either adult or pediatric research studies related to nursing to nursing or symptom management (Erickson, 2003). Although at least 70% of children with cancer are enrolled in clinical trials, fewer than 3% of adolescents with cancer participate in clinical trials (Barr, 1999).

Engaging adolescents in qualitative research is a challenge. Basset, et al. (2008) found “recruitment of the teens, locating a quiet space for interviews, the silencing effects of the tape recorder, and asking about abstract concepts to be constraints on adolescents’ conversational abilities”(p.119). It can often be difficult to get adolescents to express themselves beyond monosyllabic responses. Because adolescents are not a homogeneous group, challenges may vary across social differences such as age, gender, ethnicity, culture, and socioeconomic status. .

Because the majority of adolescents with cancer will survive to adulthood, they deserve age-specific support throughout all aspects of the experience with cancer and its treatment. This will help them achieve the developmental milestones of the adolescent stage of development, maintain some semblance of normal teenage life, and resume meaningful and functional lives after cancer (Erickson, 2003).

Measurement of Adolescents’ Perceptions of Meaning

The adolescent’s perception of all the domains of the cancer experience is rarely measured. “Hearing patients speak has a profound effect on the way we

understand....Listening for gaps in the patient's story and allowing it to unfold at a pace determined by the patient is more likely to result in the opportunity to become a partner in care" (Harrison, 2001, p.69-70). To relieve distress, health care providers must understand the multiple dimensions of the person who is experiencing the distress (Kane, Hellsten & Coldsmith, 2004, p.180). Qualitative studies from the adolescent's self-report are needed. These may give us an accurate, complete, holistic picture of the nature and scope of the adolescent's experience and provide critical information about what nursing interventions can be designed to prevent or relieve distress.

Measurement of symptoms may be one indicator of distress. Nursing interventions to treat symptoms require that one know what the symptoms are, including intensity and frequency, and how much suffering they cause (Docherty, 2003). "Without the means to comprehensively measure symptoms, the epidemiology of symptoms in childhood cancer is poorly characterized and symptom intervention trials (other than antiemetics) are lacking" (Collins, Byrnes, Dunkel, Lapin, Nadel, Thaler, et al., 2000, p.364). Some researchers measure each symptom as an isolated part of the whole person. Quantitative studies measuring physical symptoms in children and adolescents with cancer have been conducted (Linder, 2005). The child and adolescent's perceptions of separate symptoms such as pain (Sutter & Miaskowski, 1992), nausea and vomiting (Zeltzer, LeBaron, Richie, Schoolfield & Prihoda, 1988; Tyc, Mulhern, Fairclough, Ward, Relling & Longmire, 1993; Tyc, Mulhern, Jayawardene & Fairclough, 1995; Mehta, Reed, Kuhlman, Weinstein & Parsons, 1997) or fatigue (Hockenberry-Eaton, Hinds, Alcoser, O'Neill, Euen & Howard, 1998; Hinds, Hockenberry-Eaton, Gilger, Kline, Burlison, Bottemley, et al., 1999;

Hockenberry, Hinds, Barrera, Bryant, Adams-McNeill, Hooke, et al., 2003) have been studied.

Several studies have included physical symptoms as part of a larger measure of cancer-related symptoms. Phipps and colleagues (1994) developed the Behavioral Affective and Somatic Experiences Scale (BASES), a nurse-report instrument, to assess behavioral, affective and somatic outcomes in the acute phase of bone marrow transplant. Five subscales were labeled Somatic Distress, Compliance, Mood/Behavior, Interactions, and Activity. Parent and child self-report versions have also been developed (Phipps, Dunavant, Jayawardene & Srivastiva, 1999). Collins and colleagues (2000) used the Memorial Symptom Assessment Scale (MSAS) for adults and adapted it for use in children 10 to 18 years old to determine symptom prevalence, characteristics and distress. Analyses of data supported the reliability and validity of the MSAS 10-18 subscale scores as a measure of physical, psychological and global symptom distress. Collins and colleagues (2002) further evaluated the reliability and validity of a revised MSAS in patients aged 7 to 12 years as an assessment of symptoms in young children with cancer. The focus was on multiple symptoms and physical and psychological symptom distress. The MSAS (7-12) assesses only 8 symptoms while the MSAS (10-18) assesses 30 symptoms.

In either case with the MSAS instruments there may be symptoms that children are experiencing that are not captured with these instruments. For example, the tool asks about “irritability” but does not cover anger and assesses how “I don’t look like myself” but not the idea of “fitting in” with schoolmates or friends. These tools to measure symptom distress seem to lack the richness of expression found in children and adolescents

with cancer, especially in regards to social and family interactions and the meaning of being ill. As with other quantitative instruments, there also may be other obstacles to using these tools for measurement in children, such as limitations related to children's attention span, language and reading skills and understanding of conventional rating scales. These scales are designed to measure symptoms and they may measure symptom distress but they do not measure the meaning of the experience in adolescents with cancer.

Other studies have tried to measure the elusive concept of "quality of life" in children with cancer (Varni, Katz, Seid, Quiggins, Friedman-Bender & Castro, C.M., 1998; Varni, Rode, Seid, Katz, Friedman-Bender & Quiggins, 1999; Watson, Edwards, von Essen, Davidson, Day & Pinkerton, 1999; Bhatia, Jenny, Bogue, Rockwood, Feusner, Friedman, et al, 2002; Varni, Burwinkle, Katz, Meeske & Dickinson, 2002). Some have included physical symptoms as part of the measurement. "These instruments conceptualized physical symptoms as contributing to the overall quality of life both during and following completion of treatment for cancer" (Linder, 2005). Quality of life instruments have made an important contribution to the understanding of how children and adolescents cope with cancer. "However, the bases of these instruments have not included first-hand reports from the patients; thus, these instruments may be conceptually incomplete" (Hinds, Gattuso, Fletcher, Baker, Coleman & Jackson, 2004). Hinds and colleagues (2004) developed 3 questions on quality-of-life to directly solicit the perspectives of children and adolescents receiving treatment for cancer. One patient's response prompted the addition of a fourth question related to the meaning of the illness experience. The quality of life domains were defined as: symptoms, usual activities,

social/family interactions, health status, mood and the meaning of being ill. Their findings support the feasibility of accurately assessing the quality of life of a child or adolescent receiving treatment for cancer by directly asking the patient.

Naar-King, Ellis, and Frey (2004) have recently compiled a handbook of measures to assess children's "well-being". This work seeks to provide an interdisciplinary guide to screening instruments for clinicians and researchers who work with pediatric populations. Only quantitative measures with some evidence of adequate psychometric properties are included. Though some may be applicable to adolescents with cancer, none are specific to the meaning of the experience.

Hinds and colleagues (1992) feel that symptom distress varies in intensity and across situations, individuals and disease status, and that measurement of symptom distress comprises more than symptom occurrence, frequency, duration, or severity. The child or adolescent experiences many more symptoms related to the disease and treatment, physically, psychologically, socially and spiritually, and the symptoms tend to be not isolated, but clusters (Dodd, Janson, Facione, Faucett, Froelicher, Humphreys, et al., 2001) that produce distress. "A meaning-centered approach in which researchers seek to understand children's experiences as they are lived and grounded in the children's meanings and interpretations is missing" (Woodgate & Degner, 2003a, p.480). A qualitative research study of the adolescent's perceptions of the overall feelings and the meanings they attach to lived experiences related to cancer and its treatment can define the distress. These overall feelings are related to one or more changes in normal function, sensation or appearance that cause physical discomfort, mental anguish, or distress.

In the past, defining the meaning has been mostly anecdotal or relating of experiences, observations or opinions (Bearison, 1991; Berde & Wolfe, 2003; Cassell, 1999; Dangel, 2003; Hinds, Quargnenti & Wentz, 1992; Kane & Primomo, 2001; Woodgate, 1999; Woodgate & McClement, 1998) or relied on reports from parents or family members (Hickman, Tilden & Tolle, 2001; Lillrank, 2002; Lobchuk, 2003; McMillan & Moody, 2003; Theunissen, Vogels, Koopman, Verrips, Zwinderman, Verloove Vanhorick, et al., 1998; Vance & Morse, 2001) and/or health care providers (Hedstrom, Haglund, Skolin, vonEssen, 2003; Wolfe, Klar, Grier, Duncan, Salem-Schatz, Emmanuel, et al., 2000). For example, Wolfe and colleagues compared physicians' and parents' perceptions of the degree of suffering in the last month of life in terminally ill children. They found that the majority of parents felt that their children suffered "a lot" or "a great deal" from at least one symptom in the last month of their life and parents were significantly more likely than the physician to report their child's symptoms. Only physical symptoms were studied.

Only a handful of studies published between 1978 and 2008 have been conducted to gain insight into the child and/or adolescent's perception of the experience related to the cancer and its treatment. In a classic, early study, Bluebond-Langner (1978) looked at how terminally ill children know they are dying of leukemia and how they conceal this knowledge from others. Aamodt and colleagues (Aamodt, 1986; Aamodt, Grassl-Herwehe, Farrell & Hutter, 1984) used ethnography to study the cultural knowledge that guides the behavior of children when they lose their hair from chemotherapy. Hinds and Martin (1988) used grounded theory to study how adolescents help themselves to achieve

hopefulness during their cancer experience. Woodgate (2005), as part of a larger study, described the impact that cancer and its symptoms had on adolescents' sense of self.

Woodgate (2001) has studied the perceptions of children, parents and siblings in a lengthy study of symptom distress in children with cancer and their families. Using grounded theory and illness narratives in formal and informal interviewing and participant observation the researcher conducted a qualitative longitudinal study based on the philosophy of interpretive interactionism in an attempt to understand the cancer experience from the child and family's perspective. The original intent of the study was to focus on the child's cancer symptoms, but the children and families could not easily separate their cancer symptom experiences from the whole cancer experience. (Woodgate & Degner, 2003a, 2003b). Thus the total experience or the overall meaning from the adolescent's point of view must be defined before interventions can be proposed. As Woodgate, Degner and Yanofsky (2003) have observed:

“When families, physicians, nurses and other health professionals approached children's symptoms solely as side effects (e.g., nausea) or singular physical and psychological states, children provided minimal description of what they were actually experiencing. However, a greater understanding was achieved when the symptoms were approached as dynamic, multidimensional experiences that occurred within a particular context. Children experienced symptoms as feeling states. Critical to children's feeling states were the meanings that children and their families assigned to the symptoms. Viewing cancer

symptoms in the context of assigned meanings has implications for how symptoms are assessed and managed.” (pp. 800-801)

The majority of those studies that have tried to define the experience from the child’s point of view have primarily measured the child’s perceptions in predominately middle-class, Caucasian populations. Although Dr. Ida Martinson has studied childhood cancer in Chinese populations (China, Taiwan, Hong Kong), her studies have been primarily of parents (Martinson, 1989; Martinson, Chiang & Liang, 1997; Martinson, et al., 1999; Martinson, Su, & Liang, 1993; Martinson & Yee, 2003) or siblings (Wang & Martinson, 1996). Only one article (Martinson & Liang, 1992) looked at the reactions of Chinese children who have cancer.

Qualitative Research

My particular area of interest is how the adolescent perceives the experience of having cancer (Fochtman, 2006). The basic premise of my research is that we do not know or understand the meaning of having cancer for adolescents. We rely too much on the reports of others and do not listen or cannot hear the perceptions of the adolescent. Although quantitative research is necessary and valuable, it does not adequately deal with perspective of the individual experiencing the phenomenon. To describe the phenomenon in detail and capture the multiple dimensions and realities of that phenomenon, a qualitative paradigm is necessary (Charmaz, 1990). Qualitative research can create a more comprehensive understanding of the adolescents’ experiences and their personal meaning (Patenaude & Kupst, 2005; Ritchie, 1992). It will identify problems that cannot be

discerned by questionnaires alone (Eiser, Hill & Vance, 2000) and provide participants with the opportunity and freedom to express their own views (Eiser & Twamley, 1999).

There are many different ways of classifying or categorizing qualitative research studies, but unfortunately there is no readily agreed-on classification for the various approaches (Polit, Beck & Hungler, 2001). The tradition used by the researcher should be clearly defined if the clinician is to understand the findings and conclusions and apply them to nursing practice. Three commonly used traditions can be identified, although there are others; these include phenomenology, ethnography and grounded theory.

Phenomenological research, with its roots in philosophy, is designed to answer questions of meaning, to understand an experience as those having the experience understand it.

Ethnographic research, a branch of human inquiry associated with the field of anthropology, explores phenomena within cultural contexts from the perspectives of the members of the cultural group involved. It focuses on the culture of a group of people, trying to understand their world view. Grounded theory research is designed to inductively develop theories and theoretical propositions grounded in the observations of the world of selected people.

All of these methodologies “share a similar goal in that they seek to arrive at an understanding of a particular phenomenon from the perspective of those experiencing the phenomenon” (Woodgate, 2000a, p. 194). Although they share the major characteristics of seeking to understand the human experience and inductively deriving concepts from coded data, they do differ with respect to their assumptions and purposes (Baker, Wuest & Stern, 1992). Woodgate (2000a, 2000b) has provided a comprehensive overview of qualitative

research related to children's experiences with cancer. Since my purpose is to understand and describe the experiences of adolescents living with cancer, I have chosen to use the methodology of phenomenology.

Phenomenology

Phenomenology is both a philosophy and a research methodology. Any attempt to understand it must consider both perspectives. "Phenomenology is the study of human experience and of the ways things present themselves to us in and through such experience" (Sokolowski, 2000, p.2). Phenomenological research, with its roots in philosophy is designed to answer questions of meaning, to understand the experience as those having the experience understand it. Phenomenology is concerned with the lived experience, the lived world. Its major assumptions are that "perceptions present us with evidence of the world – not as it is thought to be, but as it is lived... [and] human existence is meaningful and of interest in the sense that we are always conscious of something" (Morse & Richards, 2002, p.45).

The phenomenological method of research developed from a philosophical movement with many perspectives and thus multiple interpretations (Dowling, 2004). The roots of phenomenology go back to early-recorded history, to Plato, Socrates and Aristotle, as philosophers struggled to understand phenomena. Actions, behaviors, physical changes, and so on, could be observed and recorded, but what was the meaning of these things to the subject? Rene Descartes (1596-1650), a French philosopher and mathematician, developed the model of the mind and the mind-body split that became known as Cartesian

duality, offering a mechanistic view of the person (Koch, 1995). Early phenomenologists basically rejected this notion of duality.

After Descartes the development of phenomenology can be seen as complex and intricate with many interlinking connections. Phenomenology can be divided into separate, but overlapping, philosophies – descriptive phenomenology and interpretive phenomenology. The following discussion is based on the original works of philosophers, including Husserl's *Logical Investigations* (1900/1970), *Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy* (1913/1983) and *Cartesian Meditations* (1931/1967), Heidegger's *Being and Time* (1927/1962), and Merleau-Ponty's *Phenomenology of Perception* (1945/1962).

The beginnings of phenomenology as a philosophy can be seen in the works of Edmund Husserl (1859-1938), a German mathematician later turned philosopher. Husserl (1913/1983) introduced the concept of the “life world”, one that is not readily accessible because it constitutes what is taken for granted. Every day experiences involve preconscious perceptions that shape the meaning of the phenomenon to the individual. The task of phenomenology is to return to “taken-for-granted” experiences and to re-examine them in an intentional manner that brings to light the “essence” (meaning) of human experience.

Three important concepts of Husserl's (1913/1983) phenomenology are intentionality, essences and phenomenological reduction. The mind can be directed toward objects, which may be physical objects, thoughts, concepts, or feelings. This directedness is called intentionality. Being within our environment, we have precognitive perceptions

of the meaning of phenomena. By intentionally bringing these preconscious perceptions into consciousness, we can discover meaning. Phenomenological reduction, or *epoche*, also referred to as “bracketing”, is the process of setting aside all previously conceived beliefs about the phenomenon and all assumptions about the causation, consequences and wider significance.

Maurice Merleau-Ponty (1906-1961) introduced an original and enduring post-Husserlian phenomenology in France. He believed that phenomenology is not only a transcendental philosophy (a philosophy based on intuition or innate belief rather than experience), but “also a philosophy for which the world is always ‘already there’ before reflection begins...” (Merleau-Ponty, 1945/1962, p.vii). “Merleau-Ponty’s overall aim was to uncover ‘the roots of rationality’ using the methods of Husserlian phenomenology. He saw the function of philosophy as the reawakening of an understanding of the original acts whereby humans come to awareness in the world” (Moran, 2000, p.401). “All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view or from some experience of the world... The world is there before any possible analysis of mine...” (Merleau-Ponty, 1945/1962, pp.ix, x). Merleau-Ponty rejected the notion of reduction described by Husserl. “The most important lesson which the reduction teaches us is the impossibility of complete reduction” (Merleau-Ponty, 1945/1962, p.xv). We cannot completely suspend our own awareness of the world.

Martin Heidegger (1889-1976) was a fellow professor and, briefly, a personal assistant to Husserl who went on to develop his own tradition in phenomenology, referred to as existential or interpretive phenomenology. Heidegger’s method of inquiry focuses on

what humans experience rather than their perceptions or what they consciously know. Heidegger (1927/1962) challenged Husserl's construction of phenomenology as purely descriptive. "The meaning of phenomenological description as a method lies in *interpretation*" (p.61, italics in the original). "Thus 'phenomenology' means... to let that which shows itself be seen from itself in the very way in which it shows itself from itself... [or] 'To the things themselves!'" (p.58).

Heidegger (1927/1962) proposed that the individual ("Being") lives in an encompassing world context ("Being-in-the-world"). In phenomenology, *world* has a different meaning from our common understanding of world as environment, or nature, or the sum total of everything in our life. "*World* is the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture... World is the shared skills and practices on which we depend for meaning and intelligibility" (Leonard, 1994, pp.46-47).

Through our "being-in-the-world" our "Being" is constructed by the world we live in. At the same time our "Being" is constructing this world from our own experiences and background. The person and their world co-constitute each other (Koch, 1995). Any description, either in the way the phenomenon is described, or the way that it is recorded, or the way it is retold, cannot take place without interpretation by the person doing the description. (Heidegger, 1927/1962; Benner, 1985; Koch, 1996; Mackey, 2005).

Hans-Georg Gadamer (1900-2002) carried further the philosophy of Heidegger. He proposed that language, history, understanding and interpretation are inextricably linked (Gadamer, H-G., 1975). Language reveals the *Being* of Heidegger (Maggs-

Rappaport, 2001). Our preconceptions or “horizons of meaning” are part of our linguistic experience and make understanding possible (Dowling, 2004). Interpretation is wholly dependent on historical time and we can only understand through our own contemporary comprehension. Only when our horizon of meaning and that of the participant “fuse” in a common understanding, is interpretation possible.

Hermeneutics” is a term often used in the literature. Essentially, hermeneutics involves cultivating the ability to understand things from someone else’s point of view. Hermeneutics interprets or inquires into the meaning of phenomena through understanding the perspective of the participant in the phenomena. This process of understanding the meaning as a whole involves understanding the individual parts of that meaning. Neither the whole, nor any individual part can be understood without reference to one another; thus the term “hermeneutic circle”. The circle may also refer to the interplay between our self-understanding and our understanding of the world. “Hermeneutic phenomenologic method... requires an ability to be open, reflective, insightful, sensitive to language, and constantly open to experience” (van Manen, 1997, p. xi).

A review of the literature on phenomenology was undertaken to understand how phenomenology has been used in pediatric cancer nursing research over the last ten years (1996-2006). The review process was conducted using Academic Search Premier (EBSCO) and CINAHL to capture articles that dealt with pediatric oncology nursing research. The rationale for using these databases was accessibility to pediatric oncology nursing research. The keywords used were “phenomenology”, “hermeneutics”, “children”, and “nursing research”. Articles selected for analysis were those that stated

“phenomenology” or “hermeneutics” as a methodology, had at least one nurse researcher, and focused on the child or adolescents’ perspective. Articles excluded were those that dealt only with the experiences of caregivers (staff or parents) and those that dealt with siblings of children with cancer or children of parents with cancer.

Only two articles clearly stated that phenomenology was used as the research methodology. Hicks, Bartholomew, Ward-Smith, and Hutto (2003) asked childhood leukemia patients to describe their quality of life in their own words. Their methodology was based on Merleau-Ponty and Munhall. Gibson, Mulhall, Richardson, Edwards, Ream, and Sepion (2005) interviewed adolescents to describe their perceptions of fatigue, well-being and ability to maintain normal activities. Their research approach was based on Husserl’s transcendental phenomenology as modified by Moustakas. Presumably there are many more nursing research articles in pediatric cancer research that used phenomenology as a methodology. However, these researchers have not identified the theoretical basis of their methodology.

Woodgate (2000b) reviewed qualitative research related to children’s experiences with cancer prior to 1998 and outlined when phenomenology was used as a methodology. Haase and Rosted (1994) used Colaizzi’s (1978) steps for data analysis, but “children were only interviewed once which is not in keeping with phenomenology” (Woodgate, 2000b, p.212). Hockenberry-Eaton and Minick (1994) used phenomenology to understand the experience of school age children with cancer. “A limitation of the study was that each child was only interviewed once... [and] the interview was too structured, again not in keeping with Phenomenology” (Woodgate, 2000b, p. 213). Rechner (1990) used

phenomenology to describe and understand the experiences of adolescents living with cancer. “Data were detailed resulting in clear, concise, and congruent themes” (Woodgate, 2000b, p. 215).

Several articles on research of children’s perceptions of their cancer experience were cited in my concept analysis of suffering in children and adolescents with cancer (Fochtman, 2006). These included research from the child or adolescent’s perspective (Hinds, Gattuso, Fletcher, Baker, Coleman, Jackson, et al., 2004; Woodgate, 2005). However, further review of these articles indicated that phenomenology was not the methodology used in these research projects. Hinds et al. (2004) do not define the methodology used, though they do state that “all transcribed responses were entered into the qualitative software program ETHNOGRAPH... and analyzed by using a semantic-content method” (p. 763). Woodgate (2005) clearly states that the methodology for her research was grounded theory, not phenomenology. As she states, “I do not solely use one specific qualitative method as it depends on the question” (Woodgate, personal communication, 2007).

Summary

Living with cancer is a distinct experience for the adolescent that takes place at the level of the whole person and varies across situations, individuals, and disease states. The measurement of the meaning of the experience comprises more than symptom occurrence, frequency, duration and severity, or the rating of quality of life. The lived experience includes physical, psychological, spiritual, and social dimensions. The overall feelings and meanings attached to the lived experience of cancer in the adolescent may be related to one

or more changes in normal function, sensation or appearance that cause physical discomfort, mental anguish or distress. The question is: What is the lived experience of the adolescent with cancer? A qualitative methodology is needed to define the meaning from the adolescent's perspective. Phenomenology, which seeks to understand the meaning of lived experiences, is one such methodology. A phenomenological study from the adolescent's self-report may give us an accurate, complete, holistic picture of the nature and scope of the cancer experience in this population and provide critical information about what nursing interventions can be designed to prevent or relieve the distress.

CHAPTER THREE

METHODOLOGY

Chapter Three presents the methodology for conducting this study which seeks to understand the meanings of the lived experience of adolescents with cancer. This chapter includes a description of phenomenology as a research methodology and its use in nursing research, the research design, setting and sample, protection of human rights, the research procedure, including data collection, and data analysis.

Phenomenology as a Research Methodology

If the clinician is to understand the research and the results and design interventions based on that research, then the researcher must be clear on the methodology used. The research question developed must be congruent with the methodology, and the methods to be used to conduct the research and the methods for data analysis must be defined. As Munhall says, we must learn to live phenomenologically to understand the meaning in the experiences of our patients (Munhall, personal communication, 2007), but we must also choose a qualitative research methodology that “fits” with our research question (Woodgate, personal communication, 2007).

Scholars in disciplines other than nursing have operationalized the philosophy of phenomenology. For example, Colaizzi (1978), as a psychology graduate student, developed a set of seven procedural steps for analyzing data phenomenologically. He cautioned that these steps should be viewed “only as typical, and are by no means definitive” (p. 59). Both the listed procedures and the sequence should be viewed flexibly and freely “so that, depending upon his [the researcher’s] approach and his phenomenon,

he can modify them in whatever ways seem appropriate” (p. 59). Colaizzi’s “steps” have been widely used in nursing.

Perhaps the best known and most comprehensive design of phenomenological research in education, the health sciences, and psychology comes from Max van Manen, a Professor of Education. His theory combines both descriptive and interpretive phenomenology. “...we may say that phenomenological text is descriptive in the sense that it names something. And in this naming it points to something and it aims at letting something show itself. And phenomenological text is interpretive in the sense that it mediates... It mediates between interpreted meanings and the thing toward which the interpretations point” (van Manen, 1997, p.26).

Thus for my research phenomenology does not ask “How do these adolescents cope with cancer?”, but it asks, “What is the nature or essence of the experience of having cancer?” so that I can now better understand what this particular experience is like for these adolescents. “A phenomenological description is always *one* interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complimentary, or even potentially *richer* or *deeper* descriptions” (van Manen, 1997, p.31, italics in the original).

Moustakas (1994) developed a phenomenological research design and methodology for use in the human sciences. Using the major concepts of Husserl’s transcendental phenomenology he constructed a design for defining and collecting data “that explicates themes, meanings, and essences of human experience” (Moustakas, 1994, p. xiii).

Giorgi (1997) has outlined the criteria necessary for a qualitative research study using phenomenology in a descriptive Husserlian sense. His approach to the phenomenological methodology includes the three interlocking steps of reduction, description and the search for essences. For research in other disciplines (psychology, sociology, nursing), modifications, if they are made, should not sever the tie to the philosophy. Each of the five steps of qualitative research (collection of narrative data; reading the data; breaking the data into some kind of parts; organization and expression of the data; synthesis or summary of the data) can be adapted to a phenomenological perspective (Giorgi, 1997).

Schultz and Cobb-Stevens (2004) advocate the use of Husserl's theory of wholes and parts as a guide in the selection of phenomenological research methods in nursing. This differentiation of parts into 'pieces' and 'moments' was viewed by Husserl (1900/1970) in the following manner. 'Pieces' are independent parts of the whole that can be isolated. 'Moments' are not independent and cannot be detached, presented or studied apart from the whole (Sokolowski, 2000, p.23). Phenomenology looks at the relationship between the human mind and the universe. The mind is not an independent 'piece', it cannot "be separated from the worldly content to which it naturally and essentially belongs... Furthermore, if we can begin to understand the nature of the mind as a more abstract, nonindependent 'moment' of the world, we can begin to understand the nature of the mind as a more abstract, nonindependent 'moment' of the whole human being" (Schultz & Cobb-Stevens, 2004, p.220). For example, cancer can be understood as a 'piece' of the individual and suffering or distress as a 'moment'.

Debate continues over how to operationalize phenomenology in nursing. In the 1980's nursing scholars developed phenomenology in their own work in a Husserlian tradition (Oiler, 1982; Omery, 1983; Parse, 1981; Parse, Coyne & Smith, 1985; Ray, 1985; Cohen, 1987; Reeder, 1987). Other researchers introduced the Heideggerian philosophy into nursing as grounding for phenomenological research (Benner, 1984; Benner & Wrubel, 1989; Benner, Tanner & Chesla, 1996; Chesla, 1995; Dickelmann, 1992, 1993). Benner and Wrubel (1989) adopted Heideggerian philosophy in their study of caring in nursing. Lopez and Willis (2004) identify critical differences between descriptive and interpretive approaches to phenomenological research and present nursing research studies that illustrate how each approach is operationalized. Steeves and Kahn (1995) guide the researcher through the process of inquiry using a hermeneutic or interpretive process with Steeves' study of bone marrow transplant patients.

Benner (1994) edited a collection of essays and studies to “collectively demonstrate the power of Heideggerian or Interpretive phenomenology for areas of study related to lifeworld, meanings, skilled know-how, clinical knowledge and everyday skillful ethical comportment” (p vii). Her objective was to “reflect the work of a scholarly community who have worked out what interpretive phenomenology has to offer nursing science, nursing practice, the lived experience of health and illness, and health care ethics and policy” (p. xiii-xiv).

Paley (1997; 1998), in a more critical vein, argued that nurse researchers largely misunderstand the phenomenological concepts of Husserl and Heidegger “and, as a result, their version of ... philosophy bears little resemblance to the original... while the methods

used in 'phenomenological' nursing research may still have some legitimacy, they cannot achieve what they are alleged to achieve..." (Paley, 1997, p.187).

Johnson (2000) maintains that there is a place for Heidegger's philosophy within phenomenological research in nursing. "Hermeneutical phenomenology can remind us that both the problems we are trying to solve and our understanding of these are grounded in situational, cultural and historical contexts that can be brought to the fore... an increased understanding of the situational, cultural and historical contexts could potentially lend insight into the solution of problems that plague nursing " (p. 144).

Giorgi (2000a, 2000b) argues that phenomenology can be operationalized in nursing research if the researcher is clear on the philosophical basis of the research. Difficulties are encountered because consensus on how to employ the phenomenological method in the social sciences does not exist (Giorgi, 2006). Confusion arises when nurse researchers do not clarify their understanding of the theories of phenomenology found in philosophy. "Those who really understand phenomenology are the philosophers, and as they articulate the genuine meaning of phenomenology they do it *as a philosophy*" (Giorgi, 1985, p.46; italics in the original). If phenomenology is to be used in nursing research one must "mediate between the philosophical method and a legitimate scientific version that is equally scientific and phenomenological" (Giorgi, 2000b, p.12).

In *Revisioning Phenomenology: Nursing and Health Science Research*, Munhall (1994) describes phenomenology as the study about the meaning of being human. "Being-in-the-world, being here, being there, being present, coming into being are all viewpoints... the structural concept of phenomenology is the study of lived experience...

we are studying human beings experiencing something or being something” (p. xv). “Just as phenomenology was once thought of as a reaction to logical positivism, this search for meaning today may be a response to the advance of technology, the changes in power structures, the vacuum left by discredited materialism, and the need to balance scientism with compassion, care and understanding” (p. xvi). An avid movie fan, Munhall uses popular movies, songs, and a phenomenological experience to illustrate how phenomenology is always present in our every-day lives. She advocates that we learn to *live* phenomenologically in order to understand the meaning of the lived experiences of others.

“The four existential life worlds are other dimensions from which we need to process phenomenological material to give meaning a perspective that tells us more about it” (Munhall, 2007, p.194). These are spatiality, corporeality, temporality and relationality. Munhall (2007) states that “the natural sciences investigate objects *from the outside to the inside*, whereas the human sciences [including nursing] depend on a perspective from the *inside to the outside*. The most important concern in the human sciences is that of meaning” (p. 10, italics in the original). Two of her most powerful beliefs are “that our phenomenological research *is* significant and that *we can demonstrate* its significance not by numbers, but by stating the implications for change that emerges from the interpretation we glean from our participants on the meaning of various experiences” (p. 154, italics in the original).

The debate continues over the bridge between the phenomenology of philosophers and the use of phenomenology in nursing research. Crotty (1996) contended that North

American nurse researchers are missing the intent of phenomenological research. “It could be said that in being transplanted to the North American continent, phenomenology experienced significant mutations” (p.2). If nurse researchers wanted to continue in the direction he believed they were going, then they should call their work the “new” phenomenology because it did not follow, from his perspective, the original intention of phenomenology. After reflecting on Crotty’s analysis, Munhall (2007) felt that his critique could actually assist nurse researchers in furthering their endeavors in phenomenological research. A critical element that nurse researchers were not including in phenomenological studies had to do with Crotty’s (1996) assertion that “the goal of phenomenological inquiry goes beyond identifying, appreciating and explaining current and shared meanings. It seeks to critique these meanings” (p.5). Munhall (2007) believes that it is essential that we “heed the initial aim of phenomenology, which is a *social critique* with an imperative for improving the social fabric of human life” (p. 27, italics in the original).

Research Design

The research design for this qualitative research study uses a phenomenological approach described by Munhall (1994, 2007). The research was conducted from an emic perspective, recognizing the participant as the authority. Munhall’s (2007) stepwise approach guided the methodology with the knowledge and understanding that phenomenological research does not always conform precisely to a stepwise or linear progression and that some “steps” may occur concurrently (Munhall, 2007)

Setting and Sample

Subjects consisted of a convenience sample of seven adolescents, 13 to 19 years of age, who were receiving treatment (chemotherapy) for cancer at a major pediatric cancer treatment center. The number of participants recruited was “determined by the quality of the participants’ experiences [and] the ability of the participants to reflect on and report their experiences” (Morse & Richards, 2002, p.199). Interviews of approximately one hour were conducted in the participants’ place of residence. A second interview was conducted as needed to expand on material from the first interview and validate the findings.

Protection of Human Rights

Approval of the research project was obtained from the Institutional Review Board (IRB) at the University of Hawaii at Manoa. A waiver of jurisdiction for the IRB review and continuing oversight of the research study to the University of Hawaii Institutional Review Board was granted by the Western Institutional Review Board on behalf of Hawaii Pacific Health and Kapiolani Medical Center for Women and Children. Informed consent was obtained from all adolescents and from the parent or legal guardian of the participants under 18 years of age.

Research Procedure

Potential participants were identified by the medical and nursing staff from the inpatient and outpatient pediatric oncology units. The research study was briefly described to the adolescents and the parent by the physician and permission was obtained for contact by the researcher. The researcher contacted the parent, explained the research study, answered any questions, and scheduled the interview visit. Consent was obtained from the

parent of all patients younger than 18 years of age and from the adolescent. Participants answered a few demographic questions. Interviews were scheduled at the convenience of the participant and conducted over a seven month period. A second interview was conducted as necessary to clarify the meaning of the experience of the participant.

Data generating questions were based on the study by Hinds and colleagues (2004) which begin with “When getting treatment for cancer, some days are good days, and some days are bad days”.

1. What makes a good day for you?
2. What makes a bad day for you?
3. Are there some things you like to do that you cannot do now?
4. What is the meaning of having cancer to you? (alternative – How has being sick been for you?)

Other probing questions were then asked to further elicit the meaning.

Data Analysis

Assumptions of the investigator were identified and, as much as possible, set aside. Recognition of further assumptions continued throughout the interviews and analysis. Interviews were taped and transcribed and the investigator’s field notes included for each interview. Data analysis was ongoing throughout the research process.

Techniques for data analysis in phenomenological research have been identified (Colaizzi, 1978; Giorgi, Fischer, & Murray, 1975; Spiegelberg, 1976; van Kaam, 1969). These techniques may differ somewhat, but there is a general procedure of moving from

the participants' description to the researcher's synthesis of all the descriptions. The steps generally include:

1. Total immersion in the data with thorough reading and re-reading, setting aside assumptions and pre-suppositions, of the entire transcript of the participant's description of the meaning of the experience of having cancer.
2. Identification of shifts in participant thoughts resulting in division of the transcription into thought segments.
3. Specification of the significant phrases in each thought segment, using the words of the participant.
4. Distillation of each significant phrase to express the central meaning of the segment in the words of the researcher.
5. Grouping together of segments that contain similar central meanings for each participant.
6. Preliminary synthesis of grouped segments for each participant with a focus on the essence of the phenomenon of having cancer as an adolescent.
7. Final synthesis of the essences that have surfaced in all the participant's descriptions, resulting in an exhaustive description of the lived experience.
8. Identification of the meaning of this experience. (adapted from LoBiondo-Wood & Haber, 2002).

Summary

This study was conducted using phenomenological methodology on a sample of seven adolescents, 13 to 19 years of age, undergoing treatment for cancer. The purpose

was to describe the lived experience of having cancer and to interpret the meaning of the experience. Consent was obtained and the data was collected from taped interviews and the investigator's field notes. Data was analyzed with a thorough review of the transcripts.

CHAPTER FOUR

RESULTS

Chapter Four presents the results of this study to understand the meaning of the lived experience of adolescents in treatment for cancer. For each individual participant there was total immersion in the data followed by a division of each into thought segments. Thought segments with similar central meaning were grouped together to form patterns or themes illustrated in the participant's own words. The final composite is a synthesis of the patterns or themes of all the participants in describing the adolescent cancer experience.

Description of the sample

Ten adolescents and their parents agreed to phone contact from the researcher to explain the study. Three were excluded because of a complex social situation, a language barrier, and residence off island with infrequent clinic visits. A total of seven adolescents ranging in age from 14 to 18 years participated. All were undergoing treatment for cancer at the major referral and treatment center for childhood cancer in the Pacific. Time in treatment varied from four months to 10 years with four in treatment for one year or less, two in treatment for two to three years, and one in treatment intermittently for 10 years.

Only one of the seven participants was female. The preponderance of males was consistent with the population eligible for study which roughly consisted of 14 males and four females. All but one participant had acute lymphocytic leukemia (ALL). One was being treated for a sarcoma.

All of the participants were Pacific Islanders. Two were part-Hawaiian, three were Samoan and two were Chamorro. The reasons for this finding are not clear. The incidence

of childhood cancer is not clearly defined in Pacific Islanders since statistics are calculated for “Asian Pacific Island” as a group. However, this group as a whole does not appear to have an increased incidence of childhood cancer. The healthcare institution is the major referral center for childhood cancer for the entire Pacific Region and this may account for the number of participants of Pacific Island origin. It did provide an opportunity to study the lived experiences of a minority population. Only the two Hawaiian males had permanent residence on Oahu. The other five participants were living in Honolulu temporarily for treatment. These five participants were bilingual with English as a second language. The interviews were conducted at the place where the participant was living.

Individual Descriptions of the Cancer Experience

The interviews from each participant were analyzed to understand the meaning of having cancer to the individual adolescent in this study. Only pseudonyms are used throughout.

Alea

Alea is a 15 y/o female American Samoa, a US territory located about 2300 miles from Hawaii. American Samoans are US nationals, but not citizens.

Alea was diagnosed with acute lymphocytic leukemia in March, 2008. In Samoa she lives with her parents and many of her extended family. While in Hawaii she and her mother live with relatives in a large, multi-family home. Both interviews were conducted in an outdoor area of this home.

Being home in Samoa is very important to Alea. When asked what she looked forward to every day she stated “I just want to go back home”. At this stage of her treatment she and her

mother are able to go home more often, a freedom they did not have in the beginning months of her therapy. The focus of her time in Hawaii is to get her treatment so she can go back home.

Though most Samoans are bilingual, English is not their first language. When English is a second language, some may have difficulty understanding the meaning of words or phrases. For example, Alea did not appear to understand what was meant by “a good day”. The use of pronouns can also be confusing for some.

“He’s a minister” (Life revolves around the ministry)

Alea’s father is a minister. The life of his family is deeply rooted in his ministry and the Church. Alea has love and respect for her parents. It makes her happy to be with them and to help them with tasks. She likes to “hang out with my Daddy and..., help, help my parents to clean...I like to do”. She feels her struggle with cancer is for her parents’ sake. She has the will to live and survive because of her parents’ love and support. She fights the cancer because she is too young to die and wants to live.

But I can’t stop like drinking my medicine... that’s all I do. I can’t cause I love my parents so much. I just live for them...And also I can...like, fight for it ‘cause I wanna stay home with my parents ‘cause I, cause I’m still young.

“I miss my Dad...he just makes me calm” (Father/Minister)

Alea literally “lights up” when she talks about her father. He seems to be the most important person in her life. She speaks with him every night when she is in Hawaii, “I like to share with him”, and she is aware of how concerned he is about her. When she was first diagnosed he was so worried and now that she is in remission he is happy to see her well again.

Sometimes he's worried because of me, if something happen like go to the hospital and he don't know why, what happened to me...he don't know what to do, he just sitting and thinking [worrying]... the first time he saw me but I can't walk, I can't, I can't do anything, I just sitting, watch TV and that's it...[After my heavy treatment was done] I didn't feel like sick... My Dad was so happy, cause he seen me like I could do whatever I want, walking around...

When she is worried or upset her father is able to provide comfort and encouragement. He is able to soothe her and thus make her calm. If she has pain (suffering, distress) he makes her laugh so she can let go of the feelings. If she is worried he provides reassurance that no harm will come.

So, if I cry, like, I am so painful, so he can make me laugh, or...Just make me laugh, so I can release all the pain. That he make do to make me calm, and like, if I nervous he just...he just say, "no, it's nothing, there's nothing come", like that...He just makes me calm...

Both Alea and her father seem to be able to separate his roles as minister and as father. As a minister Alea believes that her father is a "helping person".

It's [his role] like, helping people, and make a speech for the youth, helping the youth so they won't touch that drugs...And help old people to make them feel better, like very sick...And he pray for them...He go visit all the church members on Sunday...like old people they can't come to church...

However, she feels that he can separate his roles. For example, when she was diagnosed it was so stressful for him to be in both roles (minister and father) that he set aside the minister's

role to just be a father. “The first time, he found out, that’s what the time that he is so stressed. It’s hard for him to like, put it together, so he just leave the minister and just be a dad”. In the normal course of events he can play either role, except at certain times when the demands of being a minister predominate.

The Church has also recognized the stress in this dual role of father and minister and sent the family on a two month vacation. They told him to take two months off and not think about being a minister, not think about the church and not to worry about anything, just go for two months and have fun. “So they all talk and the tell my dad you have to go on vacation for two months, then you come back... they just let my dad go like, go vacation, have fun, no more stress for the Church stuff...”. Without the worries and concerns inherent in the ministry, the whole family can relax and enjoy the vacation. Most of all her father, free of the stress of being a minister, can relax and enjoy life.

Like every time I call him he say, “oh, I’m at the golf course”. Like every time, every time [laughs]...He just, he just told my mom, “ohhh, this is better....better”. It’s like, he knows like he have relaxing, like, there’s nothing like, off his mind, it’s stressing, it’s just normal... It’s just like free...Free his mind, go out, go around...

“I can share with her...” (Mother/Minister’s Wife)

Alea’s mother is a warm, cheerful woman who seems to live the role of minister’s wife. She is outgoing and caring and occasionally came out to provide tea or food during the interview. Alea takes direction from her with obedience. Outside of the interview her mother speaks of her daughter with pride and love.

Alea sees her mother as the quiet support, the parent she can share her feelings and concerns with. Her mother is always concerned about her and does whatever she can to relieve Alea's distress and make her feel better. "She do whatever I want. Like she do, and she always see if I like pain, it's, it makes me feel better and better".

"Just don't give up, just fight and be brave...fight for life" (Cancer as a battle)

Alea sees the cancer experience as a struggle and visualizes her desire to be cured and survive as a "fight". She has to be strong. During the first intensive part of therapy she felt weak, but as her treatment gets less intense she feels strong. "[The first] 9 months was so hard. I just think I can't do anything...like, that was normal like I was get cancer...This month, so I feel like the first time like...I didn't feel like sick. I just feel strong".

Alea is encouraged by her father in this fight. "I have to fight for him, that's what he say, I have to fight for him...". She feels that if she does not fight hard enough she will "let him down".

Alea feels that her father wants to cry at times but he holds it back so he can "be strong" for her. Her father also uses the analogy of cancer as a battle and he encourages her in the fight. "I crying [why me?], that's it, call my dad, see my dad...So he say get strong, fight...He just say don't cry, don't cry, just fight...". Her prayers are directed at seeking help in the fight. "If I pray it can help me with the fight, to pray, so He can help me too...".

She would advise a new patient with leukemia to "don't give up, just keep it up, don't give up...just fight...fight and be brave. Just think that you'll stay strong, it will pass". Perhaps reflecting on her own feelings and coping, Alea would also advise a new patient not to think of themselves as "sick" and to think "positive". "[I would] just say to them...don't think about it,

this sick, or he or she thinking about it we have one leukemia cancer, just think positive like you're strong, you're strong...".

Alea knows that once an adolescent no longer feels "sick" from the leukemia they may be tempted to stop taking their treatment. The struggle for survival continues even when she feels well and she must continue to "fight" the battle.

Alea feels that her own strength can be an example to others and if they want to survive as she has, they must be strong like her and fight. "Just look at me, I'm strong now cause I was sick too so I didn't give up...so just tell them if they wish to be for me they can...fight, fight for life". She is aware of another patient who did not finish her therapy and apparently is now in relapse. She encourages the family to keep up the fight, the struggle with cancer, even in the face of relapse.

I met another woman with his child, with her child, she didn't pau with his, her daughter's treatment so they came back for their treatment 'cause the leukemia is coming back to her daughter. So I just tell them, "don't give up, just fight for it, for your daughter's life".

"Keep praying to God...that he can make you calm" (Spirituality)

Separate from the fact that her father is a minister and the family is very involved with his congregation, Alea has a deep sense of spirituality. Talking to God in prayer is very much a part of her life and her being. Her mother shares in prayer with her - "Me and my mom pray every night", and she knows that her mother is often quietly praying for her. "She always feel for me and always pray for me. Like just sometimes when I'm sleep she - I hear her pray, like every night that's what...".

This is Alea's first experience with cancer and she does not have any theories about what caused it or where it came from. "This is my first time I had cancer...I never did heard back in Samoa, like cancer...but now I just get it..., just happened". She does not see cancer as a punishment and is emphatic that God did not "cause" her cancer. However, He does help her cope with the disease and her struggle. "If I pray it can help me with the fight, to pray, so He can help me too...".

Alea does sometimes ask the "Why me?" question and finds that prayer helps her with these feelings. "Sometimes when I was like suffer about there's something pain on me, like I always cry and 'why me?' I just talk to myself...why me, tell God, why me getting this?...so I just stay inside the room and pray God...I just praying...pray...pray...". Praying makes her calm and helps her to be brave. This belief seems very strong and not just the expected response of a minister's daughter.

She would advise a new patient "keep praying to God so that He can help you... and making calm...". She believes that if one is sick or suffering they just have to pray that God will make them feel better and He will answer their prayers. "Keep praying...Just to pray you can do it. There's nothing can do for it, just the praying. God can give you more, like make you feel better and better, so He can answer your prayer..."

Perhaps because she is the minister's daughter, Alea's struggle with cancer has generated prayers for her by many others. They have seen her with very physical evidence that she is sick (weak, hair loss, nausea, weight loss) and now see her as an attractive, active teenager. As evidence of the power of prayer, they say she is a "miracle".

Every member, church member back home, they always say I am a miracle, like every day... They tell me that every day if they see me, yeah. They say, 'oh you're so pretty, you're so miracle'. I say 'thank you'. Yeah I just thank them for their prayers, like every day, every day.

Alea is humble in her response. She is grateful for their prayers, but perhaps reluctant to fully accept the "miracle" concept since she continues with treatment and the fight against cancer.

"I won't do that...like keep feelings inside" (Feelings)

Alea does not keep her feelings "inside". If something is bothering her she talks to her family who provide comfort and support. This is the only time she mentions her brother as a source of support. Talking with them helps her to cope. Once again the analogy of cancer as a "fight for life" is given.

I won't do that...like keeping feelings inside me. I talk to my mom, or my dad or my brother. I always tell them. I don't know, you don't tell them to release every, like, bad things, bad things, so they just keep telling me don't even care...just go ahead and don't make care...They just, they like, they...'you're fighting for, fight for your life', say 'okay', I just come there and I just tell them, and I will share with my parents and my brother...

When she is concerned or worried about something she usually talks to her mother so she can gain information and understand. "If there are worries about something I just talk to my mom, just my mom, tell, tell her so she can explain everything to me".

Tears can be an expression of sadness, or fear, or concern. Her father was worried about her very survival when she was first diagnosed, but she feels he could not let her see him cry because to do so would frighten her.

Yeah, I think [he was scared] cause he never...showed it to me, like crying or sad, the first time he knows I'm diagnosed with leukemia cancer...He never cried, I know he was...even when I cry, but he can't cry cause, he just, he would let me down...

When asked what her mother did that made her happy she talked about her mother crying. Perhaps this provided evidence to her how much her mother loved her and worried about her.

When I first got the leukemia and she found out, she can't stop crying. Like night, morning...so the first day, we'd be like, sitting together, face-to-face, so she cried and she hold that back and "aw, I'm gonna...." Yeah. And so, she tried to be...stop crying, so I won't see her cry.

Sometimes she herself just needs to cry. She tries to hold it in but that does not always work for her. "I'm holding it inside, but I can't hold it [laughs] and then I cry... I did cry...". She uses distraction to not think about "bad" feelings or things. "[Sometimes] I just take a nap, just forget all those things...I just, listen to music, that's it...or just look around so I won't think about it...".

Her friends cried when they first saw her after she was diagnosed. She was so sick and looked so different (pathetic). "[They cried] just the first time, like...they just saw me like sick, real sick. I had no hair, no eyes, my eye lashes and it's like, I was like different that time, so

they cry”. They cried when she left to go back to Hawaii, perhaps fearing that they would not see her again. Now that she is physically better they are “happy”. Now she looks better and she is not “sick”. Alea feels that they do not cry now because they do not want to make her cry. “So what right now they saw me, I’m back again. They were so happy. They don’t wanna see like crying in front of me, so it’s like I’m gonna cry too, that’s why”. Both she and they may all be still thinking of the possibility that she will not survive.

“Hanging out” with friends and family makes her happy. She wants them all to be happy and to come together and have fun. Alea has many friends who help her through the troubling times. They are always offering to get something for her, go someplace with her, keep her busy. They care about her and are very much a part of her life.

They always cry if they see me cause...they say they don’t know why I came with this, this kinda illness...So they like, if I come back home so they always come, come by my house...sleep over, do whatever I want...they help me... Sometimes they like, “you wanna go somewhere?, You wanna drink soda? You want chips?” They always say that.

Because she is the minister’s daughter, most people at home are familiar with her diagnosis and treatment. She also is open about her condition with people who do not know, like classmates in Hawaii. She does not appear to seek some kind of reverse status or benefit from sharing with them other than friendship and understanding. “My other friends they didn’t know I had leukemia so I shared with them, so I just explain to them, share with them, so I can...I don’t want to hide anything”.

She also inevitably meets other people who do not know about her leukemia. “But sometimes if I go, it’s like some, some of the people, ‘oh I hear you’re from somewhere’, and I say, ‘hospital?’ they say yea, I...then they say, ‘why are you there, like every, like every time?’. She finds it best to be honest with them, “oh I have leukemia, I just tell them” because her mother has taught her to be honest with others. “My mom said if someone told [asked] you something, just like, release that to them, share, share with them”. When they then ask how she is doing she reassures them that she is well, but must continue with her treatment. “They say, how it goes, How...? I just say ‘I’m good now, I’m fine thank you. Now I’m fine right now, but I’ll be, I’m still have treatment, yeah”.

On the other hand, she does long to be a normal teenager and not let others know. Part of being happy for her is feeling normal, blending in with normal teenagers so she does not feel different. “I like to go out like, go out like, there’s like, um, the normal kids, like normal teenage, so like nobody know that. I just wanna...”.

Being home in Samoa is a different life for her, one where she can forget that she has cancer and just enjoy going out and living life. She can release all her thoughts, fears and concerns about cancer. In Hawaii the focus is so much on treatment.

It’s [home] like, a lot different from here, and...and I, like, if I go back home it’s, like just go out like. Don’t stay here where I have to make treatment. So I can, release all this stuff so I can, make, think like you’re not sick, I’m not sick...

She sees the role of medical staff as asking her about the physical effects of cancer and its treatment, not the feelings or emotions that are generated. She wants to understand the “feeling” of pain, not the “feeling” of sadness. “I just want them ask them, I kinda, like having pain that is

really bad, having pain or something like that so I understand what it means, I just want to know cause they don't make me worry or something happens...". She wants to know about a specific symptom so she can understand why it is occurring and if it is something to worry about. Alea wants information about her leukemia so she can understand what is going on with her body. "I just want to tell me that everything, like about cancer leukemia...so I can understand".

"So I can help them much to make them calm and be brave" (Helping others)

Alea feels that if she can understand her cancer then she can do a lot to help other kids and families to understand and be brave.

I just want to understand so I can help, help the other kids have leukemia and cancer...So I can help them and tell them, explain them... You know what I feel too, they like I was getting this cancer... so I can explain to the family or anyone that's worried about, so I can help them much to make them understand, what a cancer means, leukemia...to make them calm and be brave...

Alea is comfortable with sharing the fact that she has leukemia with others. Some day these people may get cancer and they can remember that she had it too and she got better. "Cause I'm better now and I like to share with them, like, we don't know like, some day or when they grow up they have leukemia, so they have to think about me. Remember everything...".

She can be an inspiration and source of hope to others. She has an auntie who needed a transfusion, but was afraid to get blood from another person. "She go to see the doctor and she afraid to transfuse. Remember like, people are like, their blood, they had to take their blood to transfuse them, so she say she didn't know like, she didn't know that person, like their blood...".

Then this aunt thought about Alea and was inspired by her. Others can find hope from Alea and continue with their “fight” against illness.

So she think about me right? “Oh if Alea can do it, so can I do it too”. Cause she knows like me, I had low counts, so they make me, transfuse me, so she can now, so she fight for it and she told me. If I [Alea] can do it, she can do it too.

Keoni

Keoni is an 18 y/o Hawaiian/African-American/Chinese male who lives with his mother and sibling(s) in a housing project. Both interviews were conducted in the living room area of this multi-room, two-story apartment. Keoni was diagnosed with acute lymphocytic leukemia in March, 2006. The first interview was conducted while he was receiving therapy and looking forward to the completion of his treatment. The second interview was conducted several months after he completed therapy.

“You know what I mean?” (Striving to be understood)

Keoni was eager to tell his story and be understood. He frequently asked rhetorically “you know what I mean?” at the end of his statements of how he felt and often added “that’s how I feel” (with emphasis on the “I”). There are many troubling phrases in our language that we use without considering their full meaning simply because they have been accepted into common usage. Keoni absolutely hates when anyone (staff, family, friends) say “I know what you mean” – THEY DON’T! He just wants people to listen to him, and if they don’t want to listen, just say tell him that. Even if they have cancer, they don’t know how he feels. His feelings are unique to him and define him as an individual. He expresses his anger and resentment about this many times throughout both interviews.

Don't be saying "I know where you're coming from" or "I know what you mean". Don't say that to greet me, make me feel good, 'cause you're really not... When people tell me that I feel like it's disrespectful because you don't know what it feels like... Choose your words carefully... Don't be telling me 'oh, I know how you feel, because they don't. I don't care if you don't like listen, just tell me. Or if you don't know what to say, just don't say nothing, just nod. Don't just listen the whole time and right when I finish or something then you go "I know what you mean". They are just trying to make you feel better, but they have no idea what they're talking about. They don't know all the stuff you gotta go through, they don't have to give up stuff. And then you're trying to bring up one time in your life... I know your experience is probably bad to you, but does it even relate to the problem I'm telling you? It's like I'm talking oranges and some people talking bananas – two different stories.

"I'd rather hold em in" (Holding feelings in)

In contrast to wanting others to listen to him and understand, Keoni does not like to share his thoughts and feelings with others. He feels if he talks about his problems with anybody they will not understand him and just think he's complaining. He is concerned that maybe his fears or concerns may worry others, particularly his mother. If he does not reveal his thoughts and feelings everyone will think he is "OK".

I don't like to talk over my problems with anybody...I just keep em in. If I did talk about my problems maybe there would be some drama or they would think I was making a big deal out of something small...'Cause they can be listening and

they can be saying “yeah, yeah, yeah”, but I just think they’re saying “oh, this guy, he should just stop complaining and just be happy”. But I’m not complaining, I’m just telling you guys how I feel. Don’t blame me if I feel like that, that’s how I feel... To me, if I hold everything in, then nobody else is going to stress about it ‘cause they’ll think I’m OK and all that... That’s why I hold everything in, kinda like nobody worry.

He does not seem to have any close friends, though he says “only a few friends know that I had cancer, only like the close ones”. He lost friends when he was diagnosed just from lack of contact, but feels that was a good thing because they were a bad influence. He does not talk about his illness with friends, “it’s none of their business... I don’t like nobody to know”. He has made new friends, but “I don’t really like to tell them about that I have cancer, I don’t like them to treat me differently... Automatically when people find out you have cancer, they treat you super different, like you’re handicapped or something. I mean like, come on, I still got all my limbs!” He feels that to tell anyone would make him “different” and he doesn’t want to be treated differently or it would create an insincere relationship.

On chemo I couldn’t always hang out with my friends because I had doctor’s appointments or whatever. When people heard that often enough they started asking questions and then I’d have to tell them my story and then they treated me differently – they were all “nice”, best friend kind, you know what I mean? The best thing [about coming off therapy] is that I don’t have to tell anybody anymore, nobody even talks about it.

Keoni does not find it helpful to talk to other kids with cancer because “we’re all different. I mean we may have gone through the same experience, but we’re looking at them in two different ways”. That is why he does not go to the oncology camps and does not seek relationships with other patients.

Keoni found talking to a psychologist was very helpful because she listened. “She was cool cause she just listened and at least she never go like, ‘oh, I know what you mean’. She didn’t even ask me about my family problems. She just listen to my stories and asked me what do I think it’s from and maybe it could be this...”. This illustrates his need to be heard, for someone to listen and for someone to help him work out his problems. However, he later felt betrayed when she took him to another hospital to be in front of a whole group and discuss his feelings. He did not understand the purpose of this venture and expected only a few people, not a whole crowd. “They kept asking me questions like I was one guinea pig or something... I felt like I was one lab rat”.

He was quite angry with the psychiatrist he was referred to because instead of talking about the “crazy dreams” he was concerned about, the psychiatrist wanted to know about his relationship with his mother and his father. He considered these questions to be irrelevant to his problem. He never kept further appointments with this psychiatrist and is still angry with him.

He was just asking me some off the wall questions. He’s asking me “what’s going on?” so I told him I was concerned about my dreams. And then for no apparent reason he just asked me “how is your relationship with your mother and father?” What the hell does that have to do with this? I’m not telling you I feel paranoid from them. Oh, I just wanted to hit him in the face for real. To me he

was just talking all BS. Felt like he wasn't even trying to help me, but just cause problems. 'Cause why the hell I telling him about paranoia when I'm alone, and he's asking me what is the relationship status with my family? That's pretty stupid. I never tell him I had any problems with them, so why was he asking about that?

Keoni found participation in the interviews for this study to be very helpful to him – “it felt good to talk about it, real good...you just listen. It's hard to hold everything inside and sometimes it feels good to just let everything out and just talk about what I'm feeling”. He does not like to talk to people about his feelings, but then he has nowhere to go with the questions that are bothering him, e.g. why am I having these crazy dreams? The interviewer had proven to be someone who mostly just listened and never said “I know how you feel”.

“I always thought that cancer means you're going to die” (Death and dying)

At diagnosis Keoni was convinced that he had six months to live, even though nobody told him that. He cannot say where he got this idea, and he never told anybody that's what he was thinking. Towards the end of that time period he thought “it could be any day now”. When he passed the six month mark he began to hope that maybe he did have a chance to survive.

In the beginning you don't know if you're going to make it or not...I always thought cancer means you're going to die. It's running through my mind. I thought I was going to die. I thought I only had six months to live... That's what I thought so I was just rolling through...After I hit toward November I was thinking, “oh, yeah, it could be any day now, could be any day”. Then December

came and I was like, “oh, OK, that’s six months gone, so I do have a chance to survive”. Then as each month went by, then I guess I got confidence.

His previous experience with movies and the deaths of famous people from cancer may have been the basis for these ideas. He never asked if he was going to die, as if to voice his fears would make them a reality (don’t ask, don’t tell).

I didn’t want to ask because I was scared, scared to ask and find the answers and then one day it might happen...I never like know... You no like know if you’re going to die... I think I heard the doctor say if 20 guys on a football team had leukemia, 18 of us would’ve survived, something like that. He was trying to use like sports terms and all of that. I was thinking “OK, 18 that’s pretty good of a chance, but you still got 2 people...” Who knows, I coulda been one of those two, but good thing I wasn’t. So I never like ask.

Keoni seems to believe in “signs”. A contemporary of his died from cancer and he felt this was a “sign” that he would die too. “I had one friend who just passed away from melanoma. Now I’m scared, I feel like it is just one sign...for is me next”. This scares him that the cancer will come back and he will die, even though the type of cancer (melanoma) was completely different from his. He could not even go to the funeral because he was so concerned about the death.

He is afraid that if the leukemia comes back he will ultimately die from it – an idea that he expresses often. “Scared the thing will come back...and I don’t know what’s next after that...In my head right now I think I’m going to end up dying...”. But he is afraid to ask about it, as if to voice the thought would make it come true. “I’m scared to ask the questions and find

out the answers, and then one day it might happen”. He is afraid that “if it comes back, it’s going to be more aggressive probably”. He asks hopefully about whether there is treatment for relapse in leukemia, including bone marrow transplant, but is convinced that if it does come back he will ultimately die from it. Even though he has hope and wants to live he still fears that he will die. “Only just knowing that you like live, that’s what helps... but you still got one chance that you can die or something”.

As with the six month timeframe to dying in the beginning, Keoni puts a timeframe on relapse. He believes that his risk for relapse is highest in the first nine months after completing treatment. Whether he was told this or not is not relevant, that’s what he heard and he continues to worry about the possibility. When the nine months has passed he may worry less, but he will continue to worry about the possibility of relapse.

Stopping medications, that’s kinda like, like what if the thing come back? Some days I can just wake up and just think in my head ‘you just gotta remember you still got a chance of the thing coming back one day so don’t get too relaxed’. I mean until the day I stop taking medicines and the time after that I don’t know what to expect. Who knows what’s gonna happen? Make me kinda like worried, little bit.

Keoni is concerned about recent recurring “crazy” dreams which seem to revolve around death – “my dreams take place in different places and have different people, but they are always about dying – usually me dying or my mom dying... Sometimes I even got stuff in my dreams - the devil... It’s in my dream, there’s always talk about him”. He is not clear how often he has these dreams, but recently they seem to be fairly frequent.

Once, apparently early in his treatment, his dreams made him “paranoid” and he believed people were hiding in the house and out to get him. About two years ago he had dreams again and was told they might be from the medications (steroids). He is not on medication now, worries about the cause of these dreams, and searches for meaning. “Is it the chemo? Or did the chemo like mess up my head? Or is it just me?”. The dreams frighten him. “And sometimes I get scared, not really scared scary... but like when I wake up I feel scared...”. He feels he cannot talk to anyone about these dreams because they will think he is making it all up, or he is “crazy”, or they might think the events are something he “actually wants to happen to them”. “I don’t like tell anybody about them because they might think I was lying or joking around so I don’t say anything...I tried to tell my mother when they first started again, but her answer was I needed to go to Church. I don’t think that will help”.

Keoni readily accepts the suggestion that perhaps holding fears and feelings inside may be the cause of the dreams. “I’d rather just hold everything in, on anything, but sometimes it’s not good, to hold everything in cause when I hold everything in too much, start getting like funny kind dreams, crazy dreams, coming in”. In the interview he begins the process of working out for himself what may be the basis for the dreams with some suggestions, such as maybe it’s your thoughts buried during the day, coming out in dreams. “That sounds true. Maybe I don’t like to think about them by day, but they are so much on my mind that I think them in my sleep”.

“Leukemia was part of my blueprint in life” (Spirituality)

His spirituality does not involve organized religion. “I don’t go to church, but I believe in God and everything”. And he does pray, “I pray every day, thankful for everything, thankful

for one second chance in life and everything”. He believes that his path in life is predetermined. Leukemia was just part of God’s plan for him, “all of this happened for one reason”.

Maybe getting leukemia was my blueprint in life or something... You know, like making a house. You get blueprints like where you’re going, what you’re going to do and all that...I felt like it was my path to play football...but maybe it wasn’t meant for me...The military, that’s the one I really, really wanted to do...and then I got turned down...Maybe that wasn’t planned for me too, like football and stuff...

“Before I got cancer I was one punk you know” (Punishment)

He sees God as a punishing God and his leukemia as punishment for past transgressions. He was not a “criminal” (“I did some pretty bad stuff, not like super bad”) but he did a lot of “bad things”, e.g. got in a lot of fights, broke a teacher’s hand, and got arrested. Having leukemia changed his attitude and his anger reactions and he feels it was a message, a “sign”, from God to change his ways. He believes it was a punishment from God because “that’s what I was taught”. “When something really bad happens, that’s when people ask - am I getting punished and stuff? That’s how come I felt like that, but nobody understands”. Leukemia provided him with a “second chance” to lead a good life.

I used to always get in trouble, all kinds of fights, got kicked out of school, suspended...then I got cancer and I felt like, sorta like I got punished for all the stuff I did..I got punished for everything I did wrong...To me, if I didn’t have cancer I would still be the same kid doing trouble and stuff... [having cancer] gave me a second chance to shape up.

Now he is determined to stay out of trouble because his actions may have caused his leukemia. “Stay away from that already. ‘Cause to me that’s what got me here”. He questions if he gets in trouble now will God punish him further and the leukemia will come back?

Now before I do stuff [bad] I always think “you better not do that because the cancer will come back...”. Sometimes I think, “what if it was a punishment” and I go back to my old ways? Then the punishment will be ten times worse maybe because I didn’t learn my lesson.

Keoni continues his search for meaning in his dreams, particularly the meaning of the devil or evil. Does the presence of the devil in his dreams mean that he is going to return to his old evil ways?

But the only thing is about the devil, that’s the problem...I don’t ever think about that, but it always pops up in my dreams...In my dreams people say that I am the devil. Does that mean I’m going to do something really bad?...Maybe my dream is like telling me “beware”, maybe I might commit a crime or something... I’d just like to know why I’m having these dreams...now there’s the devil... Where does it come from?

Although he believes that the leukemia is a punishment, he struggles with the question of “Why me?”. In the beginning this question was more intense (“real, real tough... you just wonder”), less so later in therapy, but still there. After the three years or so since he was diagnosed with leukemia he thinks it should not bother him anymore “because I’ll never know the answer”, but it does.

“I was robbed of my teenage years” (Loss and Grief)

Having cancer meant a loss of hopes and dreams for Keoni. Before he got leukemia his whole life was defined by football. He saw the game as his path to achievement, recognition and success. When he could not play because of his leukemia he lost that dream and he was sad and hurt. He is filled with questions about what could have been, the “what if’s”. He did not aspire to be a professional football player. He just wanted the possibility of being a high school star and maybe getting a college scholarship.

I feel like everything was taken away. The main thing in my life was gonna be football, football was my life, my path to achievement. I was looking forward to high school football so long, and then finally when the time came it’s taken away...and then there was a detour...I was so hurt and sad...When I was in the hospital and I watched our high school game on TV, watched all those others living my dream, I cried...I was so hurt and still to this day I’m kinda sad, but not like hurt as before, still sad... I just wanted a chance to play and I’m always going to have the “what ifs” – what if I played, would I have been good? Would I have played, or would I have been benched? Could I have been good enough to get a college scholarship? I just wanted to experience it... Maybe I wouldn’t have been the best, but at least I could have tried and experienced it...I will always wonder what could have been and now I’ll never know.

Another dream he had for the future was to join the Army and make it a career. He was sad and felt rejected when he was told his history of leukemia made fulfillment of this dream impossible. Cancer had once again robbed him of his hopes for the future. “Another big disappointment was the Army. I went to talk to one recruiter – straight rejection you know...The

military, that's the one thing I really, really wanted to do and then they turned me down because of my medical history they said".

He seldom talks about being angry. When asked if having cancer made him mad he reported that his feelings were more of frustration than anger. "I felt frustrated, real frustrated. I just wanted to be like everyone else, like, normal, and go out and do whatever my friends were doing...". He relates any feelings of anger mostly to steroids which produced irritation or paranoia. "I feel really, really irritated at the smallest thing. I feel like just punching you in your face".

"Then I got cancer and the whole way I looked at life changed" (Resilience/Hope)

Although his thoughts frequently return to his regrets about not being able to play football, Keoni looks to a different future. He accepts what has happened to him because of cancer and the loss of his plans for the future. He is ready to make new plans, to move on with his life.

I'm not gonna be stuck on this my whole life, instead just move on. I'm passed that... Football could have been my ticket into college. But now, it's just like now I'm going into something else. I'll still go to college but it's not gonna be off a scholarship or something. It's gonna be off financial aids and stuff. It's alright. Maybe it wasn't meant for me, yah? So just keep trying to move on. That's how I feel. Ever feel like that? When stuff not happen for one reason, you just shrug it off? That's how I feel right now.

Keoni feels that having cancer made him grow up and mature. Before he got leukemia he felt invincible. Having cancer changed the way he looks at life, made him more aware of and careful in his actions, and increased his wisdom about life.

I used to feel untouchable and then I got cancer and the whole way I looked at life changed...Now I better be careful of what I do, my actions....Having this cancer made me feel like I know more about stuff, about life and all kinds of stuff, than all the people my age now...It changed everything, my whole outlook on life, what I am going to do when I grow up and all kinds of things...I got cancer and I guess I grew up from that...

Keoni is resilient. He feels he learned to accept the cancer as part of his life and get through the hard parts of the experience because he is “mentally strong”. He is able to see positives things in having cancer and he no longer questions why it happened to him and feels lucky to be alive.

Now it’s like just roll with the punches... After awhile you just live with it, you just accept it already...To me having cancer is just all a mental game. You gotta be mentally strong to take this...this is hard...[But] it’s a good experience going through this...I feel like I got more knowledge now from this. That’s a positive. I never regret having this no more. All of this happened for one reason. Before I used to be, how come me? Now I say it’s alright...At least I’m still here, it’s a big plus. Only just knowing that you like live, that’s what helps it.

Even though he does not particularly want to talk to other kids with cancer, Keoni does find hope in seeing cancer survivors.

I always thought cancer means you're gonna die and all that. Then I went to my first Relay for Life, and I seen everybody with the survivor bands. And I was thinking, man, there's a lot of survivors. That's one other thing made me feel good, like that's another one to give hope. Now I go to that every year. It's, I don't know, makes me appreciate everything, especially when they light up all those little light up bags and all that. Makes me appreciate everything, all the survivors.

Of note is the fact that "those little light up bags" are luminarias, usually created in memory of someone who died from cancer and placed around the track at Relay for Life. He has created his own meaning for them, one that gives him hope.

Toa

Toa is a 14 y/o Samoan male who was diagnosed with acute lymphocytic leukemia in March, 2009. While in Hawaii for treatment he and his mother are living with a family from Church. The interview was conducted in the living room of this small apartment in a crowded housing development. The issue of confidentiality was explained, but his mother still wanted to be present for the interview. She reluctantly went to another room when Toa said he would do it alone. Members of the host family were occasionally in and out of the room during the interview.

As much as possible Toa tried to confine his replies to one-word answers. If English is not their first language, some may have trouble understanding the meaning of words used. For example, Toa defines a "good" day as "afternoon". Why? "Because it's almost nighttime...or evening". He says afternoons are "nice" because nighttimes or evenings are good. He defines a

“bad” day as “morning”. For him, good and bad are defined in terms of time of day. This may be cultural, or he may be similar to other teens who are not “morning” people. It is an interesting definition and reflects a different understanding of the meaning of “a good day”. The use of pronouns can also be confusing for some. When asked if he ever thought “why me?” he was confused and said “why you?”.

“There is some cancer you can’t cure” (Death and dying)

Toa feels “bad” about having cancer because “there is some cancer you can’t cure”. He only “guesses” that it cannot be cured and declines to say what it means if it cannot be cured, i.e. that death will occur. When pressed to say what will happen if they cannot make a cancer go away, he softly replies “someone will die”. When questioned he admits that he is worried about this and that the thought is “scary”. However, he is convinced that this will not be the outcome for him personally, “I’m not gonna die”. He was not willing to speak about his own death or dying or any of his fears about this during the interview and one can understand that he does not choose to discuss death at all with anyone and respect that desire.

“I have cancer, it’s kind of...sad” (Feelings)

When asked how cancer makes him feel “inside”, in an effort to discover his feelings, he said “nothing”. He may not understand “feelings” or it may be that he does not discuss feelings. He will admit that cancer makes him feel “sad... because it’s cancer... I have cancer, it’s kind of...sad...And sometimes bad...yeah, that’s it [that’s all I want to say about having cancer]”. When he is scared about something he can talk to a “friend” who goes to school with him. This friend is willing to listen but he does not elaborate on the relationship. He has friends back home in Samoa, but apparently has had no communication with them since he left home.

He also can talk to his mother about his fears and concerns. He is not afraid to talk with her and feels that he can bring up anything without disturbing her. She is looking out for him and deals with his problems.

Toa finds that the nurses help him also, but he defines help from them as “taking care” of him. They watch out for him, give him advice, and help him stay on course. The nurses and his mother work together to help him. He apparently was noncompliant with taking his oral medication. “When my mom tell them, I didn’t drink my pills at home, they say to drink my pills”, although he never tells the staff himself about his noncompliance. He feels the staff help him feel better inside “by talking”, but he is clear that it is them talking and him listening. It is getting advice from them, not discussing his feelings. The thing he most wants to hear from them is “that I’m gonna, the cancer’s gonna heal...off me”.

He misses home but does not clarify if this is a real longing for home or just a part of life as it is right now. He thinks he has to be here for treatment for three years, but maybe can go back and forth for treatment after six months.

He is not apprehensive about seeing the doctors and feels he has the right doctors and they are doing the right things. Being admitted to the hospital does not make him apprehensive, although he does admit that sometimes it does make him angry. He says his brother makes him “mad”, presumably in normal sibling relationship.

“What I think made me get cancer...I don’t know” (Cancer)

Toa knows one person at school who has cancer because he recognizes the stigma of cancer. “It’s bald head...and he has...um, I don’t know what’s in back of his head...It’s

cancer”. However, he does not define this fellow student as a friend. He wants to know other kids with cancer, but cannot define how this might help him.

He has some interaction with other cancer patients, but it is not clear who, what or where this occurs. “We hang around with, with other people, with another cancer,...um, we go camp. Yeah, that’s what we do, when...um”. This was confusing. He had actually not been to any of the camps, but thinks “that’s fun”. When it was suggested that maybe he was looking forward to going to camp he said “no”, but he may not have understood the concept of “looking forward to”.

Toa does not know if he ever thought about “why did I get this?” or does not want to think about it. He does not have thoughts about where cancer came from, but considers that maybe there’s a genetic factor.

I don’t know what to say, I don’t know where that cancer came... What I think made me get, get cancer... I don’t know. I don’t know what...maybe my family, my family, my relatives...I think maybe that’s where I got it.

Toa feels that having cancer has changed his life only because he cannot play football. Sports for males can be an all-consuming passion. This is particularly true of football in the Samoan culture. About 30 ethnic Samoans currently play in the National Football League and more than 200 play NCAA Division I college football (Pelley, 2010). It could be construed that having cancer destroyed his dreams of future fame and glory.

Toa did not report any problems with school. He was diagnosed shortly before the end of his school year in Samoa and was attending high school, although he may not have actually started since the interview was conducted in August.

“What else helps?...I don’t know...pray” (Spirituality)

Besides help from his mother, the nurses and his friends, Toa finds that praying helps him. “What else helps?...I don’t know...pray”. He says he prays often and goes to Church every Sunday and he gains strength from that. Praying “makes me feel good”.

Ethan

Ethan is a 14 y/o Chamorro male from the island of Saipan in the Commonwealth of the Northern Mariana Islands. The Chamorros are the native people of the Commonwealth with their own unique culture and language that is greatly influenced by the Spanish, German, and Japanese who occupied the territory over the years (Aldan, accessed 2010). The language is a mix of Chamorro, Spanish, Japanese and English. Ethan said he could understand English, but sometimes had difficulty in expressing himself. “I can say, actually understand you, but I... to say it, it’s hard for me. It’s in 3 different things, and it’s long for understand and it gets hard to put into words”.

Ethan was diagnosed with acute lymphocytic leukemia in June, 2009, and has been living with his mother in a hotel since that time. Both interviews were conducted in this studio apartment. The first interview was conducted shortly after he had been hospitalized for an intensive course of chemotherapy, the second several months later when he was in a less intensive phase.

“I wish it’s a not...but it could happen to me” (Fear of Dying)

Ethan knows people die from cancer and there are no “100% guarantees” he will not die. He hopes it will not happen to him and he does not want to think about the possibility. “Having leukemia is scary though, ‘cause it’s not 100% gonna pass...or live... It’s like when I see my

parents and the doctor talking like separate from me, it scares me 'cause I know they are really talking about... And it's like they are hiding it from me".

His previous experience with a teenage relative who died adds to his apprehension. Although he had not yet been diagnosed with cancer at the time of her death, he still thought at the time that this could happen to him and he was "scared". He avoids using the words "death" or "dying" and uses euphemisms (i.e. "negative things") or "it" to refer to dying. He seems to find reassurance in the fact that her cancer was "more rare" and therefore not the same as his and the outcome for him will be different.

Another thing that really make me scared of too 'cause I have a niece and she passed away...from cancer. And she was my age too... It's scary, could happen to me...I wish it's a not...but I...I didn't know she went to Hawaii for treatment 'til she came back and then she was good and...saw her later, infection came... and then just kind of took...I was there when that happened. I was there when she took her last breath...Couldn't sleep like, 3 days... I was scared... I know she didn't have the same thing as me... And I'm still scared 'cause it's, it's my first time to hear this kind of sickness... Before I was thinking about that and the doctor was talking to me one time, and he tell me, "Don't worry about that", it, that's one sickness was more rare than me.

His niece ultimately died from progressive disease, but he relates that she had an infection. When he had infections during the first part of his therapy, he associated infection with dying. "Getting an infection again, that's a bad day... Like I always shiver and fever... I was thinking negative things... ". However, he believes that her infection, from which she died,

was different than his infections because her cancer was different than his. In addition, he feels that since he does not get infections anymore he does not have to worry about dying.

As the chemotherapy regimen has become less intensive he is feeling better and is convinced he will survive. "I know I'm gonna make it, it's really much easier... I know I'm gonna make it 'cause it's like, it's getting easier". One of the more difficult things about having cancer though is that sometimes he cannot help thinking that he's not going to survive. "There's sometimes you can...just comes in your mind if you, you think negative, like you're not gonna survive...".

Meeting survivors of childhood cancer during his experience at Family Camp helped him believe that he can be a survivor. "Yeah, I met a lot of, cancer survivors in the family camp. So I kinda believe in myself, I can make it yeah... It helps a lot. When I see lots of survivors, can, can do it".

"Feeling normal is when I feel like...feel like just me" (Physical symptoms)

Ethan equates good days or bad days with how he feels physically. The intensive chemotherapy in the initial part of his treatment was very hard for him. He was far from his family, he felt nauseous all the time, and he did not feel like eating. As a consequence he felt weak and could not "think straight". Feeling "normal" to him is the absence of physical symptoms, feeling physically well with no nausea and the ability to be active.

A good day is when I can get my chemo and everything and come back home and feel normal. I really hate feeling, like, having that bad feeling... First stage was really hard, very hard... far from my family and my medicine make me feel nausea, I don't feel like eating, cannot think straight and so weak... I got more

than like eight medicines and oh, that is just so, a lot. And after that it's been a lot of vomiting and things... "Normal" is when I feel like... feel like just me [laughs].

Like I can do anything already. I can run, just do things like, sports...

Receiving chemotherapy now only once a week has made him feel physically better. Specifically he does not feel nauseous or vomit anymore and though he may still feel somewhat weak, he is still able to get out and walk around.

Ethan reports physical, but not psychological, symptoms to the medical staff and equates being strong with being physically well and not being in the hospital. "I always tell them after I feel something... I always tell... just when I have body aches or the like... when I feel something different that I haven't felt before I would let them know... Yeah I'm being strong and fighting the sickness. I haven't been inpatient for how long already? "

"Our family's not complete" (Family)

In the Chamorro culture families and family members are very important to each other (Aldan, 2010). They watch over each other and help one another out in time of need. In Saipan Chamorro families live close to each other and there is a sense of security when family members are around. Though not everyone is related to each other, they think of themselves as family.

Ethan and his mother have been separated from family for almost a year. He talks to his father every night, worries about his father alone in Saipan, and longs to see him. He feels the family is divided, separated, not complete, because he and his mother are here for his treatment. If they were together they could look out for each other, take care of each other.

A good day is talking to my family, 'cause I don't really have family here... I talk to my dad every night... I tell my dad I really want to see him and tell him

things how I feeling... I worry about my Dad. He's always by himself, in the house, back home... He's an old guy already. He's really old and I feel sorry for him 'cause no one's helping him, he's on his own. I do have family sometimes [coming in], but he's always by himself... We're sometimes worried about... 'cause he's alone... Our family's not complete.

His father expresses his concern for his son and emphasizes the family value of being strong to overcome adversity. "He ask me if I'm, if I'm in good condition already... He tells me that [be strong] every single night". It sounds as if Ethan expects this and it may be reassuring to him. He can discuss some feelings with his mother, "when I'm scared I can talk to my mom", but relates little else regarding his relationship with her. Perhaps it is taken for granted that his mother is there to help him and he can rely on her.

His 21 year old brother visited briefly in September on leave after a tour of duty in Iraq. Ethan looked forward to the visit and expected that seeing his brother would "cheer me up" because he had not seen him for a year. However, when his brother came he was sick. "That time he came I wasn't feeling good. I couldn't enjoy a lot." Ethan misses his extended family in Saipan and wishes he could communicate with them. However, he is willing to be patient since he feels the end of the separation is in sight.

Frequent family get togethers are part of the Chamorro lifestyle and fiestas are celebrated often (Aldan, 2010). Ethan was unable to go home for Christmas. "I wanted to go to Saipan Christmas but we didn't have enough money to go there". This illustrates the financial burden or the "hidden costs", the ones that are not calculated in providing cancer care to families, especially for foreign (i.e. non-Hawaii residents) patients and families.

“I don’t really make new friends easily. I really not lucky... (Friends)

Ethan misses his friends back home, but is able to communicate with them to some extent via email. “I miss my friends back home a lot, but, I’m okay with it now I visit them online every, once a week... I use the Net Café down Ala Moana. Just to check if they’re alright”.

Sometimes he just needs to talk to a peer and Ethan has been fortunate to find a friend to share his experience. Casey is a 16 y/o from Saipan who is also staying at the hotel and undergoing treatment for leukemia. Casey has become like a brother to Ethan. He is from the same island, helps Ethan keep active and out in the world, and helps him cope with his disease. He and Casey are on a similar trajectory toward maintenance therapy.

My mother helps, she helps a lot, but you know sometimes you just have to talk to people my age too... We [he and Casey] always look things around, walk around and exercise...He helps me think ‘cause he’s from my island, feels like family. Without him I’d, I’ll just be staying in this room doing nothing... so he’s like a brother to me already... You know, like he always tells me just to, like when I think about my sickness and I tell him that, he say I should be strong... and just fight the sickness...

Even with Casey’s help, Ethan finds it hard without his friends from back home. He is about to start school here in Hawaii and is concerned that he will not have any friends at school. “I don’t really make new friends easily. I really not lucky...”. He faces many new challenges in this regard, starting freshman year in a new school in the middle of the school term.

Ethan did attend Family Camp in November, but group and individual activities, developed to have fun and deal with issues, did not appeal to him and he did not participate,

perhaps in an effort to appear “grown up”. “It’s kind of OK, but I... I don’t know, I’m not that kind of... person who plays a lot... kinda more mature person... I just watch”.

“ I’m nervous ‘cause...now it’s kind of harder for me to think” (School is a major challenge)

Ethan identifies school as one of the major challenges he faces. He is due to start high school and he is apprehensive because he “does not know anyone”. Casey is also starting at the same high school, but Casey is older and probably two grades ahead. Ethan is starting a new school in a school system different from his home school. He is starting freshman year in the middle of the school year, having missed the entire first half of the year. He is also apprehensive about entering unfamiliar territory where everybody else knows what they’re doing and where they’re going. “And I don’t really know the place. I don’t know the buildings”.

He did not have problems with learning before he had cancer, but now he fears that he has forgotten some of the basics he once knew. He is worried that having cancer will affect his school performance or may have affected his brain.

I’m nervous about it, about the schoolwork. Ever since, I got this sickness... things go out of my mind already. Now it’s kind of harder for me to think... so it’s going to be tougher for me if I start, ‘cause I really didn’t [have problems] all along already... It’s really tough... Some things fade already, like they just fade away. Like I forgot so many things...I don’t know if I’m gonna remember stuff, ‘cause I lost a lot of things from my head already. Like times tables are kind of hard to... to get ready for... And forgot how to do a lot of things.

He worries that he will not keep up with his friends and classmates in school back home and he will fail. “Yes, I’m still worried about it... Really worried about it ‘cause I really don’t

want to fail... And, yeah, I want to see my friends again back home.. I don't want to be behind". When he first started treatment he did not feel physically well and could not really do school work. Now that he is physically better he believes he can do it. "I have not done any school work since I've been here. I always feel some...not really good. But now, yeah...". He has confidence in his abilities. "For sure if I go to school, just one month then I'll remember some things...".

"All of a sudden this sickness just come to me" (Fate)

Ethan does not appear to question why or how he got cancer. "Cancer comes from cells, yeah, the cells...but I don't know already, I forgot... I don't really care about it [the cause]. Just ignore it...It doesn't really bother me anymore...I was so active and things like that and then all of a sudden ...this sickness just come to me. It's kind of weird. And that's, I don't know how you say, that's weird... I don't know how this happened."

Spirituality does not seem to be a big part of his life. He refers only to his family praying for him and he is unsure about that. "All my family is praying for me, I hope, I guess. I don't know what's happening down there in my island".

"I don't want people to know I have cancer. I want em to treat me like, just normal, a real person". (Cancer does not define who he is)

On the one hand Ethan feels people with cancer, including him, are special people. "One [good] thing I like about it [cancer] is they give me all... people give me whatever I want... You know cancer people are, are special people so they get what they want...". At the same time he does not, in general, want people to know that he has cancer for fear of being different. He wants to be normal, a real person, not "that boy with cancer". He feels that other teens at school

and elsewhere can be cruel to those who are different and create “drama” (e.g. pity, gossip, negative feelings).

And I really hate it when people talk about that (cancer). I don't like it when people ask me if I have cancer. I don't want people to know I have cancer... I want em to treat me like, just normal, a real person... [When I go to school] I don't think, I don't think go like in there...like some are there and talking about me, ‘You know that boy with cancer’. I don't like that. I hate it when people behind my back... Some people are like...some parents too, they don't understand it. Teenagers, you know teenagers how they sometimes, talk about each other. They start dramas...

He has not expressed his concerns about starting school to the counselor, but he may not have had the opportunity to do so. In the busy, overworked school system will there ever be the opportunity?

“I just hold in, hold it in myself that's...I don't let it out” (Holding feelings in)

For the most part Ethan does not want to express his feelings or emotions. “If I'm worried about something I just hold it. I'm not like letting my feelings out... Just keep it in”. He says this is not because he is male, not because of his culture (as he sees it), it is just the way he feels.

He does believe in positive thinking and the value of a positive attitude. He does not know what advice he could give to a new patient except to “think positive” and “be brave”.

What I could do is just keep him company or something like that, and just tell him, like how I felt the first time I came here, the things that I have been through.

I would tell him don't give up. I went through it and it wasn't easy. You really have to be brave and just whatever medicine you get, just take... Think positive and... you can make it, you can get through it.

One of the developmental tasks of adolescence is the quest to achieve autonomy and independence. Adolescents with cancer may demonstrate this desire for some control over their lives by demanding to be included in all discussions and decision-making in regard to their illness and treatment. Ethan wants to know everything that is going on with him, even when it is bad news. He does not like it when the staff does not tell him things or talk to his parents instead. "I hate it when they hide things from me".

Casey

Casey is a 16 y/o Chamorro male from Saipan who was diagnosed with acute lymphocytic leukemia in December, 2008. He has been living at a hotel since he was diagnosed, initially with his parents and two young siblings, now with an aunt and uncle from Guam. Both interviews were conducted in this two-room hotel apartment. A concerted effort was made to try and understand his island and the Chamorro people prior to the second interview, including bringing a small map of Saipan.

Casey is concerned about confidentiality in the interview process. "Have you shown, have you make people hear what I said, or...?" He is reassured by a description of anonymity and how a composite of all the interviews would be the final product, but continues his search for what the final product will be. "And what do you do with it? And where do you put it? Like where do you show, yeah?" He appears to be satisfied with the description of a dissertation defense and publication in a nursing journal.

“Like what makes me happy?” (Components of a good day are environment, friends, and absence of physical symptoms)

Environment

The physical environment, the weather, helps to define a “good” day for Casey. When it is sunny he is happy. A rainy day makes him bored and sleepy, but not sad or depressed. “I don’t like it when it rains... [It doesn’t make me sad] I just think can be boring. You see when it rains makes you sleepy”.

Friends

“I like the day when I can spend time with my friends”. Casey describes “fun” as being with friends and going new places. He has been fortunate to share the experience here with another patient from Saipan, Ethan, who is also staying at the hotel. Casey has been here over a year and arrived six months before Ethan. He is two years older and obviously assumes a leadership role in their relationship. Ethan understands him, “he should because we are going through the same thing”. He and Ethan “go around” together and plan adventures “so we won’t be bored. Just stay at the hotel doing nothing. So we like make plans where we go...”.

Casey says he misses friends back home, but does not seem overly concerned. He does not mention any efforts to communicate with them, perhaps because he has been away from them for over a year. He has made new friends here, but, other than Ethan, it is unclear who these friends are, how or where he met them, or how old they are.

Absence of physical symptoms

Like other participants, Casey also describes a good day in terms of the absence of physical symptoms. Feeling “good” is equated with not feeling “sick”. Chemotherapy makes

him not feel good. However, he is creative and innovative and has developed his own unique way of coping with nausea which makes him feel “good” again.

Like I could feel good that day [the day he gets chemo] but around like three days later I can start feeling nauseous...Like sometimes you don't feel like eating, or sometimes you feel like throwing up...you feel nauseous...But when I feel those things I eat watermelon – it makes me feel good...it takes away the nauseous, it works for me.

Casey associates the hospital with feeling nauseated. “Every time I go to hospital, I feel nauseous...makes me sick”. Even if he is only at the hospital to get a blood transfusion he still feels nauseous, at least intermittently, during the visit. Even just talking about chemotherapy can make him nauseous.

He explores the use of “medical marijuana” for nausea during the second interview. He thought it might be OK for his nausea since it is “medical”, but worried that it might be “bad” for him by affecting his blood counts. He questions why marijuana has to be “legalized” when “it’s just herbal, it’s like its natural”. Despite a rather long discussion regarding addiction, he does not appear to understand the concept, and there was some difficulty in understanding his logic. “I don’t think it can addict... If I know its bad I don’t think it would addict me, the way I look at it... Just like McDonald’s – it’s so good, it’s not addicting”.

Casey is conscious of hair loss, but he finds humor in it. During the first interview his hair was quite thin on top, probably as a result of radiation therapy. “I think it’s funny. It’s like, see those old people in the front they don’t have hair...Some persons keep staring at you... It’s like an eye-catcher for them”. At one point he shaved it all off.

Casey misses the active sports he used to play. Fatigue does not appear to be a problem, but finding new physical activities has been a challenge. He participated in many sports before he was diagnosed, “back home I’m very active”, including baseball, basketball and soccer. He feels the only barrier to participating in sports now is the presence of the port.

Sometimes, like I wanna play sports, but like I forgot I have this, I can’t...I could play basketball but not rough, only shoot around like that... That’s all I can do. I can’t jump that high, because I can’t stretch because the port...And play baseball, I can only bat the ball.

Casey has found a new way to be active (biking) which demonstrates that he is innovative, independent and creative. “I do biking – me and Ethan... like we ride around”. He seeks to know the rules and regulations regarding biking – “I was reading that if you ride on the sidewalk you could get a ticket, especially riding in the sidewalk of Waikiki – you have to ride in the road...” However he does ignore a basic safety rule, wearing a helmet, with the sense of invincibility of youth. “No, I don’t wear a helmet...I always watch the cars, that’s why...I look before I go”.

He worries about his blood counts only because he might need a transfusion. He finds that whole process boring, but accepts it because it is a “have to” thing that will make him “feel better”.

Yes I worry [about counts] because...I don’t want to go to the hospital and get blood again...that’s boring... I know it’s a have to but you’re just gonna like sit there...keep receiving blood, but, of course I have to take it so makes me feel better and get more energy.

He was mystified by the occurrence of shingles because it did not hurt and he did not feel sick. At first he hesitated to tell the doctor because he did not want to be admitted, but later decided maybe it was something serious so he better reveal it.

Mine (shingles) didn't hurt at all... I had fevers but I wasn't sick...I was afraid to show the doctor 'cause I don't wanna stay in the hospital...but, I know that if I show him that I might be in bad condition, so I have to show him.

Casey is presently in the interim phase of therapy, the period between the intensive part of the treatment and the maintenance phase, which he aptly labels the "pre-maintenance" stage of therapy. He feels physically better and thus more "normal".

Not going to the hospital, not taking treatment – that's normal...See like...like me I take chemo like once every month. It's slowing down so it's better. 'Cause I'm in pre-maintenance. I'm only taking like chemo tablets, that's it.

"For me the thing is that there's always a 50/50" (Death and Dying)

Casey's fear of dying is influenced by the fact that his "second cousin", a young girl, died from leukemia. Her death occurred when he was about 10 years old. Knowing she died from leukemia made him more afraid of dying when he was diagnosed. He finds hope in believing that she had a different form of cancer, "but she had a intense cancer, right?...that's why. She had AML...the doctor told me AML..." and "I remembered that her leukemia was worser than mine".

Casey also worries about the possibility of relapse. "For me the thing is that there's always a 50-50. Sometimes you can come back, you don't know... I worried about it, something comes back...". He does not want to discuss the possibility that it might come back, "no, don't

say it”, as if saying it would make it come true or make it happen. He does not want to think about it. “I don’t wanna think like that. It’s gonna come back – no...I don’t think so”. He is convinced that if he faithfully takes his medicine the doctor has guaranteed that he will survive. “Sometimes just when I’m thinking, say it pop up in my head, like, how to avoid for making it coming back. The doctor told me just be [taking] your medicine when you go home...you’ll be OK”.

He feels his cousin did not take her medicine in maintenance therapy and that’s why she died. He is determined to always take his medicine as instructed so this will not happen to him, his leukemia will not come back, he will not die.

They told me that like she never took her medicine, that’s why [she died]. Like she never took her medicine back home, that’s why she, it came back. But me, I’m gonna take all my medicine to, not have like that...’cause I don’t wanna – I don’t want it to come back, that’s why [and I don’t want to die].

His cousin’s relapse occurred after she returned home to Saipan on maintenance therapy. He seems to be in no hurry to return home, perhaps fearing that the same thing will happen to him. “When it’s maintenance they...I think... I didn’t really ask the doctor that much but they said maybe summer”.

“Like seeing them... I know I could do it too...” (Hope)

Meeting survivors of childhood cancer at a Camp for teenagers was an important event for Casey. Seeing them made him less afraid of leukemia and dying and gave him more hope for the future. “Like seeing them, how they look after like treatment and everything. I mean like I know I could do it too. Like the way they look, they look good... Makes you like not, don’t be

scared 'cause you know...". Being "strong" was an important quality he saw in these survivors. "Cause I know a boy, at camp, my friend. He had cancer when he was five... He's 18 now, or like 19. His cancer never came back since he was five...He was cured all the way until now, his leukemia never came back...That's him - strong".

The purpose of this camp is not only to "have fun", but also to deal with issues for teenagers related to having cancer. For him, this was secondary to being able to actually see and hear from survivors. They might have visible, physical evidence that they once had cancer, but the important thing was that they were survivors, they were alive.

We just learn about...some things about cancer and they showed us, a live web chat with the survivors who had cancer...there's this one guy who had, he broke his arm then they found out there was a tumor growing in his arm...And there's this one lady who has only three fingers...She showed us in the video, was like that. That was weird...but it's good that she's a survivor.

He struggles with the contrasts – the hope in the survivors and his cousin who died from leukemia. Seeing the survivors decreased his fear and gave him hope. "I didn't have to worry that much, like how they cured like that. Like the people who has the same sickness as me".

"I miss my parents sometimes" (Autonomy, Independence)

Casey appears to be quite independent. In Saipan he lives in the mountains outside a major city with his grandparents and several members of his extended family (aunts, uncles, cousins). His parents live some distance away, but they visit every day and sometimes he stays with them. His parents and two much younger siblings were in Hawaii with him until they left to go back home, presumably to continue work and caring for siblings. They call him every night

and are concerned about his health, how he's doing in school and if he needs anything. He misses them "sometimes". His aunt and uncle from Guam now stay with him at the hotel. He sees them as his "escorts" rather than as his guardians. "They're watching me. Like they're my, they're my escort now".

Casey feels he does not have a lot of rules from his parents which he should not have because he's "older". "My parents don't have a lot of rules and they're not stricter 'cause now I'm older...they should understand, not treat me like a little boy". However, he did feel that his parents treated him differently after he was diagnosed with leukemia. They tended to do things for him that he would rather do for himself.

They treat me like I'm young...Ever since I've got cancer, they treat me more good, like they ask me if I want drink and they pour me drink...anything they would get, do. Like what I want to eat...That's it, that's a little boy thing... Like sometimes I want to cook it myself, 'cause they don't know how to cook it my way, how I want it to be cooked...

It appears that Casey had a fair amount of freedom to be out on his own in Saipan. To him Hawaii is less safe, perhaps because the population is larger and there is more crime. He recounted a recent crime near the hotel as an illustration. He told the story with little emotion and seemed to be more curious than frightened, as if it were entertaining, like watching a crime show on TV.

Casey actually seems to enjoy being in Hawaii and sees it as an opportunity for new adventures, things that are different from home. He is curious about things and innovative in finding ways to experience new things. For example, since he cannot participate in his usual

sports activities, he obtained a bicycle and uses that as physical activity and an opportunity to explore new places. He enjoys going to the mall because it is “really big” and so different from the mall back home. In typical adolescent behavior he cannot say what he likes about the mall or what he does there (like the often quoted adolescent response – “Where did you go – out. What did you do – nothing”). When his hair was thin Casey decided to shave his head and went out and bought the equipment to do this. Now that it has grown back he still shaves the “bolt” pattern on his head.

Casey sees himself as strong and seeks affirmation of this self-concept. He would advise a new patient to “just be strong...Me, I’ve always been strong...Do I look strong?... Active?”. He feels that having confidence in the abilities and skill of healthcare professionals is important and he would advise the medical staff “to take good care of the patients, make sure they’re in good hands...[good care] is like treating them with good chemotherapy...Like they...like know what medicine to give them”. He does not identify a primary physician, but seems comfortable with this. “I don’t know who’s my main doctor, but all three check me”.

Casey has returned to his school work now in high school. He does not describe the school work as cognitively difficult for him, but the volume of the work is the problem for him, lots more than he was used to in Saipan. “I’m suppose to be a junior, but I’m a sophomore again, ‘cause missing all those school. They know [I’ve been sick] but I don’t know. They just keep giving me work...”. His hardest subjects are physical science and health, not math or language.

“Sometimes sad...but, it’s normal” (Feelings)

Casey thinks that feelings like being sad, happy or mad are “normal” feelings. “Sometimes [I feel] sad... but it’s normal...I feel pretty normal”. When he is worried about something, or mad about something, or has a question, he discusses it with his friends.

Longing for home makes a bad day for Casey, “sometimes it’s a bad day ‘cause you’re gonna feel like you want to go back home”. However, over time this longing has lessened as he learned to live in the present and he is no longer constantly thinking about going home.

But right now I don’t really think about going. I don’t really think about home that much. I wanna go back home, but it’s not really in my mind anymore.

‘Cause I think I’ve been here so long already that, it’s not in my mind.

In the beginning he was concerned, but now he does not worry much about having cancer and tries to put it out of his mind rather than worrying about it. He can pretend that he does not have cancer and live “normal” if he does not think about it. He does not really deny that it is a reality; he just tries to put that reality back further in his mind.

Me, I don’t worry a lot. For me having cancer, the first time yes, I was scared, I cried. But when it got’s like, it’s like now...it’s like I don’t think I have cancer. I tell myself I don’t have that, but I know I have it, but for me, it’s like I don’t have it... Living normal...I don’t think about leukemia, so it can, go, get off from my head.

A sense of humor on the part of staff is important to him. “Sometimes I play jokes with them”. He gives a lengthy description about how he “tricked” one of the doctors with a shocking flashlight and she reacted appropriately. He does not identify any particular qualities that make nurses “okay” and does not identify any specific nurses. When talking about the nurses he went

immediately to nauseousness - perhaps a mental connection between the nurses who give him his chemotherapy and the feelings of nauseousness that result.

Casey does not recognize that there might be a healthcare professional to help him deal with feelings regarding the cancer experience. He interprets that he once saw a psychiatrist just because he was away from home and he thinks he can handle this himself.

This one time they gave me a psychiatrist...They just gave me that because all the things I'm going through, like I'm missing back home...that's why they gave me a psychiatrist doctor... but I didn't need those...I could just handle it myself, waiting to go home.

"I don't want to know how I get it" (Medical)

Casey seems to confuse the word "remission" with "cure". "How do you say that when a person is like not, no more in treatment – remission?". It was explained to him that "remission" means when there is no more leukemia, when they perform a bone marrow test they cannot find any leukemia cells. He replied, "I've been here already a year and two months" as if to say "I've been here so long I should be cured".

Casey does not have any theories about how he got cancer. "Yeah, I have thoughts like 'how did I get this', but I don't want to ask. I don't want to know how I get it". He then asks for reassurance - "You think there's a lot of survivors nowadays? Is leukemia curable?" He does worry about the possibility that cancer is genetic, that there are "family genes" that caused both his cancer and his cousin's and that he might pass it on to his children.

The doctor said it's, it's not a...it's not genes, right? Could cancer be passed by genes or not?...It's like [my cousin], like genes...family genes, cannot right?...but,

can you ever, my kids, like me having cancer – like if you have kids in the future, could they have?.. I don't wanna make my baby sick... I don't wanna make it suffering you know.

He refused sperm banking at diagnosis because he thought his sperm was “no good” and has decided that he must wait for five years after his therapy is completed before he has children.

Before you have a baby you have to wait, like after treatments, yeah, you have to wait like five years 'cause your sperm is like no good..That's what they said, I think. That's what the doctors say. That's why before I started treatment the doctor asked if I wanted to save my sperm. I said no...I want to wait until my treatment's done, then wait like five years later...

“It helps...its good to pray” (Spirituality)

Casey says his family “they always pray, pray”. And he himself also prays “yeah, it helps... it's good to pray...”. He prays not only at Church, but also “we've even gotten prayer inside prayer book”. He asks about the interviewer's religious faith, reminding her that it is Ash Wednesday and where she can go for the Catholic rituals related to this.

Casey does question why he was the one to get leukemia and if the leukemia is a punishment for something wrong that he did. “I like why me?... Like, why not, them? Like the one that's – like those terrorists? Why not them... Like, why me, what did I do?...Did I do something wrong like that?” He feels he is basically a good person and he got leukemia. If he had been bad would he not have gotten it? “Sometimes you wonder like, it I did die, you think that couldn't have been me [I'm good]?... See, right, I'm a good person. If I be bad you think

I'm not have that?...See there's bad people like...they don't really have those sickness. But that doesn't make me want to be a bad person”.

Sione

Sione is a 15 y/o male from Samoa. He was diagnosed with a non-osseous Ewing's sarcoma of the chest wall in October, 2009. He is being treated with intensive chemotherapy prior to surgical resection of the tumor. English is a second language and he tends to do a lot of “eyebrow talking”, a trait common among Pacific Islanders. While in Hawaii for treatment he and his mother are living with his aunt and other extended family members in a small apartment in a housing project. The interview was conducted in a small room of this apartment.

“They say that before but I, I didn't think it was cancer” (Avoidance/Denial)

A clue to the coping mechanism used by Sione and his family was evident in the consent process prior to the interview. Although his mother quickly signed the consent form, Sione's body language and “eyebrow talking” indicated he was reluctant to participate. His aunt asked to explain it more to him in Samoan and then indicated that “we only were told he had a tumor, not cancer”. She was expressing what the family chooses to believe – he has a tumor, we don't talk about cancer.

He did agree to participate and his understanding that he did have cancer was validated early in the interview. He had been told he has cancer but chooses not to believe it, or at least to avoid saying it. “[They never said that?] No...I...they say that before but I, I didn't think it was cancer”. He never used the word “cancer” during the interview, though it was liberally used by the interviewer. His avoidance may account for some of the vague answers to questions which referred to cancer. He often nodded in agreement, or replied, “yeah” or “I don't know”,

reflecting not poor understanding of the question, but an unwillingness to consider it and his feelings about it.

Even his complicated story of how he was eventually referred to the treatment center avoids the cancer diagnosis. Initially he said he came to Hawaii for school, only adding cancer treatment as an afterthought – “I came here to come school...go to school and now...and for treatment”. He recognizes that “in Samoa they don’t do the...this kinds, only maybe outside over here Hawaii”, but he avoids saying that the treatment is for cancer. “[The orthopedic hospital] didn’t accept me as their patient, they tried to contact me at another hospital, the Samoans, but I decided to come here instead. So when I first came here I go to one hospital, then they transferred me to this hospital. That’s how they found out”. “Found out” is a way to avoid saying “diagnosed with cancer”.

Sione knows that he has a “tumor”, that it is a “sarcoma”, and that it is in his chest. The “chest wall” as the site of his tumor is perhaps difficult for him to conceptualize. He can identify that the tumor is not in his lung, it is in an area of his left chest, and it is “under the skin”. He refers always to “it” or the “tumor”.

He cannot talk about his feelings regarding cancer because he does not want to acknowledge that he has cancer. He has lots of friends “back home” that he likes to be with, “we go hang out sometimes”. They know he has been sick but he does not talk to them about being sick or what it is like for him. How can he if he is unwilling to say he has cancer?

If he does not think he really has cancer it is difficult to describe how he has been changed by it. He feels “maybe” having cancer has changed his life. “Change means, cause like I’m missing my family back home”. It has changed his physical location; he is no longer in

Samoa. He has had physical changes as a result of the side effects of chemotherapy, “Like, my body...Like it’s kinda...It’s like every day I’m kinda feel sick”.

He has no advice for a new patient and laughs at the suggestion that he might. Sione has met another teenager with cancer, but they do not seem to have shared with each other. “Yeah... I have a classmate from Samoa...she got cancer. She’s over there on Samoa, back home. She’s back home for vacation... that’s my classmate, same grade...”. This is the only time he actually used the word “cancer”. What he fails to mention is that he actually belongs to the congregation where her father is the minister. He has not shared any feelings about the experience with her and his attitude seems to convey that this would be a ridiculous idea. He looked askance and only laughed when asked if he found it helpful to talk to her. Her diagnosis is a well-known fact in Samoa. Relating to her, or anyone else with cancer, would mean he would have to acknowledge his cancer diagnosis so he avoids it. It is not clear if he has tried to talk to any other teenagers with cancer or if this would help him - “Like somebody that’s going through cancer? No...I don’t know. [laughs]”. Most likely he has not wanted to and therefore has not “tried” it. He would have to admit that he has cancer.

“Nauseous, yeah, that’s the worst thing for anyone” (Resilience)

Seeing his disease as a “tumor” enables Sione to face the effects of treatment as a challenge. He can endure the treatment as something that is temporary, time-limited. The effects are not so bad when he thinks of it as a temporary set-back and does not consider the life-threatening nature of the illness.

He is familiar with his somewhat complicated chemotherapy schedule. “Like...I, I’m breaking this week, then next week I’m going back like three days, then come back home like

next week Wednesday...three days and then the other week off, then another week all six days, two Saturdays”. Things are not so “bad” because he knows there is a schedule and a time-frame. If there is a concrete plan and an end in sight to his treatment for a “tumor” then he does not have to think about all the potential possibilities of having cancer, like not surviving. He knows his treatment is for 43 weeks and that his surgery for the tumor removal is scheduled. “They’re doing the chemo to, shrink it... [in surgery] they’re gonna bring it out – the tumor”. He believes the chemotherapy is working because he feels better.

How he perceives his illness affects how he reacts to the effects of treatment. He tries to convey the attitude that he regards the treatment as just another bump in the road that he can deal with. The “worst thing” becomes aspects of dealing with the “tumor”, not facing the possibility of dying. The “feeling” he gets (nausea) is the hardest thing for him. “It’s just a...like the feeling...It’s like you’re...acting, acting like you want to throw up...nauseous, yeah, that’s the worst thing for anyone”. Hair loss was another challenge he overcame without undue anxiety. “[Laughs] I cut it...’cause they said I’m gonna lose my hair, so I got it bald”. Although he had pain when he was initially diagnosed he does not perceive that pain is the “worst thing”, perhaps because the pain is now gone.

Weakness and fatigue are inherent in the chemotherapy regimen Sione is on, but he is reluctant to admit any lack of energy. He would agree that he may not have as much energy as he had before and gets tired more often. He attributes this to lack of exercise, not to the cancer or the side effects of therapy, not to the fact that he even has cancer. Before diagnosis he could workout and play sports so he could stay in shape. Now the presence of a venous access device is what prevents him from doing this.

'Cause the first time I like...every time I like, I work like, I go hang out and play sports more often so, it's kinda like my...I kinda have workouts every day... But now, no more [softly]...It's because of the thing they said don't play with it...the PICC line. It's a PICC line...the IV thing. They say if I play...play with it, then it's gonna messed up...

Although he sees “don't play with it” in terms of playing football or working out, the staff may have meant “just don't mess around with it”.

He is not afraid of the surgery because he knows from his previous experience that he will be asleep. Anesthesia will take away the fears.

[laughs] Not scary. 'Cause I get go, go to sleep. I thought...I...like it was scary the first time. They did my biopsy, my biopsy under the arm, I thought I was gonna be scared...but they just make me sleep. After all I did, then I didn't, I thought I didn't have surgery. But when I move my arm it hurts. Then I realized that I did, I did realize that I did have the surgery...So I was surprised [laughs]. Like they just put me on the bed and they stuck in the medicine, on the IV, I was on it, I passed out...

He will be asleep. He does not have to “see” or visualize the concrete reality of the presence of cancer. When he wakes up it will be physically gone.

Sione's only career desire is to play professional football. This might have been a realistic dream before he got cancer since “it is estimated that a boy born to Samoan parents is 56 times more likely to get into the NFL than any other kid in America” (Pelley, 2010). He has the size and perhaps the talent, but the fact that he has cancer now makes such a career doubtful.

The site of his tumor (chest wall) would seem to preclude his playing football in the future. He does not appear to have considered the fact that having a malignant chest wall tumor, even if it is successfully treated and goes away completely, may prevent him from ever playing football again.

“Family...just spending time with them” (Family)

Sione describes a “good day” for him as when “I come back home” after receiving chemotherapy and “spending time with family”. He misses family and friends back home, ‘cause it’s all Samoans”. Being part of the larger culture makes him more comfortable.

He does not have a friend to confide in while here in Hawaii, but he does feel he can talk to his mother. “Yeah, my mom...She...yeah, she helps a lot...”. She does the things that need to be done and she knows everything he needs to know. “Like she does everything what does...and she knows it”. She knows both his physical “feelings” (symptoms) and his psychological feelings as well “like she knows my feelings”. This is the only indication that he ever talks to anyone about his feelings.

Sione does not mention his father. This may be attributed to the belief in the Samoan culture that the mother is responsible for the health and well-being of the children (Braginsky, 2010). The father is the one to go out to work and support the family. The mother’s role is to be with the children and take care of the family’s health.

Being with family makes Sione happy. “Family...just spending time with them...family here and family back home...”. He is the youngest of four siblings. All have careers or are pursuing higher education.

Four [siblings]...My older sister is at Alaska. And my older brother, the older, the old one is my brother – he’s back home. He’s a doctor...He’s like into x-ray thing... Third one go to school.

His sister is attending a university and he appears to go back and forth between her home and the housing project apartment, perhaps reflecting a cultural practice of children “living” in many “homes” as they are growing up, going back and forth freely between dwellings.

Sione feels that as the youngest he is spoiled. It may be common to “spoil” the youngest in the family. In his culture however, this stops as the child matures. When it no longer occurs it is a sign that the child is growing up, becoming an adult.

Treat me, yeah, like spoiled...sometimes I don’t wanna get spoiled...It’s not good...I don’t know why...That’s what we believe in Samoa...It’s like when somebody’s the youngest, it’s always get spoiled...but in Samoa we don’t ...we kind of like...we, Samoan people don’t let their kids like spoiled...it’s like you’re spoiled from when you’re a baby, but when you like grow up, you’re starting grow up...

He admits that he is still spoiled “yeah, sometimes they still do it [laughs]”, even before he was diagnosed with cancer. Much as he might enjoy it, he sometimes wants it to stop so in the eyes of everyone he will be seen as “grown up”.

Sione does not define what a “bad day” is for him. “[What makes a bad day?] I don’t know”. Although he may not understand the concept of a “bad day”, it is more likely that he does not want to admit to any negative feelings, or he defines it only in terms of longing for home. “[Are there bad days?] No...just like...days that I want to come home...”

“They let me play games over there” (Medical staff)

Sione says the doctors and nurses help him by allowing him to play the video games at the hospital – “they let me go play games over there”. However, this is not really fun for him because “it’s not cool play by myself”. The nurses let him play the video games but he does not feel they sit and talk to him. “[Do you feel like they know you?] I don’t know [laughs]... Maybe...”. The physicians are “good” because they could diagnose and treat him. “They’re good... ’cause everyone that go there and they...I wouldn’t, wouldn’t know my diagnosis, like...”. Without their expertise he would still be in Samoa and not treated. The phrase “my diagnosis” avoids using “cancer”.

He does not feel he can ask questions of the medical staff because he does not have any questions. “I just didn’t want to ask them... ’cause there’s nothing to ask”. It may be that he does not ask because he does not want them to give the answers (don’t ask, don’t tell).

Death and dying

When he was told he had cancer Sione says “I thought I was gonna die” and he admits that was “scary”. When asked what changed his mind about this idea he hesitated, became thoughtful and “forgot the question”. “[Do you still think you’re going to die?] No [laughs]... ’cause now it’s getting better...” He claims that none of the doctors or other staff talked about dying at all. He thinks “maybe” [with a nervous laugh] the cancer will go away forever. He has never asked the doctors if death was a possibility. “[You never asked, am I gonna die?] [laughs] No. Nope.”. The nervous laugh may have been to cover his discomfort with this question. He seemed to say, “Why would I ask that? No I definitely never asked that”. It was suggested that some teens did not ask the question because they did not want the answer

and he nervously laughed again and did not respond. The lack of response to this statement, and his laugh may indicate “I won’t go there, I won’t ask and you (or others) won’t tell”.

Sione was in high school in Samoa and has not returned to school in Hawaii. “Sometimes” he did well in school but school does not seem to be a major concern for him. He maybe planned on going to college if he could play football. His spirituality is expressed only in terms of prayer. He does pray – “yeah, when I go to sleep...”.

Jared

Jared is a 17 y/o Hawaiian/Portuguese male with acute lymphocytic leukemia. He was initially diagnosed in April, 2000, at about age 7 years of age. He relapsed in March, 2006, at about 13 years of age, approximately 2 ½ years after completing his initial therapy. He has been receiving further therapy since that time. Essentially he has been in treatment for the last 10 years. He lives with his mother and teenage sister in a small one-bedroom house. His father died unexpectedly from heart disease in 2006. The interview was conducted in the living room of this small home.

“It’s like an everyday thing practically” (Cancer as a way of life)

As a teenager treated for cancer for over half his life, Jared provides rare insight into how cancer can be integrated into the core of what defines the person. Living with cancer has become an integral part of his life. “It’s like...it’s like an everyday thing practically”. He would not have chosen it, but now it is so much a part of his existence that it is taken for granted. Taking it in as part of who he is makes it possible for him to cope with it. He sees himself as the same person as he would have been without it. This makes it possible for him to go on with life and

avoid the constant stress of thinking of cancer as separate from himself. Cancer has become a “normal” part of his existence.

I mean, I think the cancer thing is okay, it's just that I wouldn't ask for it... It's like, you could deal with it but...like you, you wouldn't ask for cancer, but you would...If you deal with it, it turns out better. I mean it turns out, that it's just like the same thing as not even having it... Yeah, its like [sighs]... it seems like...it's just, it's just normal to do all the time, everything...

It may be hard for him to describe the cancer experience as a separate entity because it has been such an integral part of his life for so long. “Yes [laughs] it's kinda like...there's no problem with it, just...having it, just doing it...”. Jared would agree that he has a lot of inner strength which he attributes to learning to live with cancer. “It's cause I learned from all the cancer and stuff, like how to deal with things”.

His memories of the early days of his disease are vague. “It's basically...I don't remember most of it”. He does remember what he describes as a “small thing” – the day he was diagnosed:

Only small things, like when I...'cause that was during school and, I got took to the hospital. I just remember [laughs] that. I used to be a bad student like, so I had to sit in this corner place next to the student teacher. And I was kinda like, getting like lightheaded and I...I just went and I just kinda turned and laid on the ground like. And then the teacher was all like, “Ahhh, oh you just don't...don't pay attention to him, he's not really listening” and then he's like, “Um, could you check on...?” Asked the student teacher if she could check on me and then,

they're like..."Are you OK?"...So my auntie was working there at the time...they called the ambulance and she came with me to the hospital...oh, to the clinic up the street... that's all I remember [laughs].

This was 10 years ago when he was 7 years old. He remembers the image of himself as a "bad student", the physical sensations (lightheadness), the sense of frustration (no one took him seriously), and the excitement of an ambulance ride. He does not recall the trip to the hospital, the bone marrow aspiration and spinal tap, the IV, and the shock, fear and grief of the diagnosis. He was quite young. This is now 10 years later and cancer has become part of the fabric of his life. He remembers details of when it "came" to him, when he first encountered it.

Since the cancer came back he has learned that it can be successfully treated again and the relapse does not seem to concern him much. It is a continuation of cancer as a part of him. "Cause I kinda understand it already. It's just basically the same thing again [laughs]". Realistically a relapse increases the risk of eventually dying from the disease. However, the fact that it occurred after the completion of his previous treatment and that it has been successfully treated over the last few years may mean that he has a reasonable chance for long-term survival.

He feels that having cancer has changed his life by making him a better person. He believes that through his experience he has matured beyond the self-centeredness of adolescence. He has learned how to relate to others, to empathize and understand how people cope with the problems of life.

I could say yeah...I would say it changed my life because...it's...I think it made me a better person...To learn like, how...other people deal with it and ...people

have problems too, not just the leukemia...[I learned this] just by experiencing it myself, and, talking with others at the hospital...

To describe the other changes in his life brought about by having leukemia is difficult for him. He has been in treatment for over half his life and it is hard to separate the cancer experience from his life of growing up. He can describe some physical changes that are perhaps attributable to cancer. "I get joint pains sometimes...I'm a lot more tired, basically during the week of chemo...". His therapy has always involved taking steroids, but he does not report any of the psychological problems related to steroids (irritability, mood swings), it "only makes me hungry a lot...But the other one, vincristine, that one gives me joint pains...I get it in my jaw, a lot...". He does not know if cancer has affected the way he looks because he does not know what he would look like without cancer. "I wouldn't know [laughs] if...for real...I think I would have been taller [laughs]...a little taller [laughs]".

"Yeah, you have to strong and you need your family too" (Family)

Jared lives with his mother and sister. He agrees that one has to be strong to get through the cancer experience, but "you need your family too...it's just comforting that they're there and hoping you feel better". With family to help him he does not feel like he is alone or isolated. They make it a lot easier. He has a typical adolescent male relationship with his sister - sometimes she's helpful, sometimes she's not.

His mother has helped him get through it all but it is a collaborative relationship where the whole family helps each other. "We all helped each other get it, through it". This includes "getting through" his father's death. He feels it was a lot easier for all of them before his dad died. "It was a lot easier when my Dad was around...during my first...". The whole family

could cope with the cancer experience. Now the family is incomplete and the survivors not only must deal with the cancer, but also with the loss of a part of the whole.

“He died about five years already...he died like right before I relapsed, or, yeah, I think about right before...” Even though over 5 years have passed since his father’s death he obviously misses him and still grieves. The death was sudden and unexpected and he described the events before he died.

He was like a...a heart complication or something...something about his heart..., he was sick for a couple days and so we were wondering if we were gonna take him to the doctors but then...we were gonna take him the next day, but then, he started not to respond or anything, so we called the, ambulance and stuff.....

He stopped at this point and did not describe the events that followed. He does not express any guilt, but certainly his sadness is evident.

“I mean I talk to them, but we don’t really talk about me being sick” (Friends)

A good day for Jared is almost any day and it is being with friends. “Um...good day... would be like almost every day, I guess...I don’t know what makes it good...it’s being around people, talking with friends and stuff”. He relates to kids with cancer much as he would with other kids. They do not sit around talking about cancer. Mostly they “play around” and talk and relate to each other like normal friends would do outside of this situation. “Like, well mostly just play around and stuff. It’s not like...it’s like normal, like you talk with them, normal friends...” However, he does feel they do understand better what he is going through. “Yeah, I would say they do [understand better]...Talking to people who know about it, and stuff like, who are familiar with it...”

His friends outside the hospital are quite familiar with his diagnosis, but they do not really talk about his disease, perhaps because it has just been a part of who he is for so long and he does not want to talk about it. “[My friends outside the hospital] yeah, they understand it too. I mean I talk to them, but we don’t really talk about me being sick very good...”. Talking to them would not be appropriate, meaningful or helpful to him. He does not feel he has lost friends because of the leukemia. In fact, he thinks he has gained new friends, not because of the leukemia, but in the normal course of growing up. “I wouldn’t say I lost, but I gained more [laughs]... Not because of it, but...ah, but I say ah...” He had a tutor and was not in school for at least two years, but friends still kept in touch and visited. “And they’re...they still say hi and stuff...” He still saw them and maintained friendships.

“It’s all better in the end, if you just stick with it” (Resilience)

Jared has gone from the “bad student” that he describes at diagnosis 10 years ago to a high school senior taking difficult math courses. Keeping up with school was a challenge for him over the years, more so after his relapse. He was diagnosed when he was seven years old. At that time keeping up with school was not a problem.

Yeah, [I got] chemo...seven, eight, and that...I had it during third grade. But then that wasn’t so hard, ‘cause then I went back to school during fourth grade. ‘Cause I kinda finished the third grade already, it’s like at, during the end. So I went back to school, to fourth grade. So it was all basically during the summer.

His therapy became less intense in maintenance, he was seen for follow-up after completing that therapy, and then he relapsed. “About...when I was eleven it started getting

slower and then...it was like every four months so I had to go back and check on this thing...and thirteen it came back, yeah”. School became more of a problem in relapse.

’cause I got it in eighth grade and then, I didn’t start going back to school til my junior year...I had a tutor during junior year [junior high] and, um...I think it was like during my freshman year and sophomore year I had a tutor. My junior year I kinda did it myself.

He found that a tutor was actually easier for him than attending class because he had a good tutor and could concentrate on what had to be done. “The tutor? It’s easier, [laughs] a lot easier cause he was a good tutor...It’s basically what I had to do...”. He is now back in the classroom as a senior.

To Jared a “bad” day relates to doing badly on a test in school. This has nothing to do with having cancer; it is a bad day similar to a bad day for any adolescent. He knows when he “messed up” and did badly on a test and he accepts responsibility.

I wouldn’t...like say it was a bad day, but like say...if I get a test and I know I didn’t do good on it or something like that, yeah, [laughs] that’s like a bad day. That’s, that was my Thursday...I had two tests and I knew I was gonna mess up [laughs]...well I stayed after school for one, but the other test was kinda just like, that’s what it was and I messed up [laughs].

Jared has received many intrathecal injections throughout his courses of treatment. Medically one could anticipate consequent cognitive problems, particularly with math. Jared is in fact taking trigonometry. He actually likes math and, though he sometimes finds it hard, he seems to be quite good at it.

Although he is now a senior in high school, Jared has only vague plans for his future. Some adults would say that a senior in high school should be making plans for their future career goals, but this is often not the case, even with healthy adolescents. For Jared there is the added uncertainty of his future with cancer. “[Are you making future plans?] [laughs] Not yet...well, [laughs]... deciding still [laughs]...Deciding what I’m going to do...” He does not feel that the cancer would change his goals, his future, or what he wants to do. He might consider being a surveyor, but he does not seem to have pursued this very seriously, if at all. “I’m willing to being a surveyor...’cause that’s, like after...so I’m trying to learn a trade [laughs]...In some places I think [you can get a degree], but I don’t know about around here in the island”.

Jared’s resilience is evident in the advice he would give to a patient newly diagnosed with leukemia. He would tell him to persevere and keep moving forward, because things will get better. “Just try to pull through and, um...it’s all better in the end. If you just stick with it, just keep, pushing and you can get better. Everything will be fine”.

“Talk to them more often...ask them how they feel” (Listen to me)

Jared believes that staff should really listen to the patient. If someone is quiet (like him) they should talk to them more often, not just “give up” and not make any further effort. Eventually the quiet one will trust and “open up”. “I can say like they, if they talk to them [the quiet patients] more often, they’d start to open up. Um, ‘cause I, I was quiet. I didn’t speak... [laughs] Yeah, I was kinda real quiet....”.

Jared feels the medical staff should approach patients by “like, asking them how they feel today”, not just the symptoms they have, but also their feelings. “Yeah, how do you feel about like everything. Like talk with them and like...get to know them so you understand them...”

However, he has some boundaries. “The [clinic] nurses do that a lot. They really get in your... Yeah, well they’re annoying [laughs]. They’re like...um...’so I heard you had a girlfriend?’ [high-pitched imitation voice] That’s so annoying [laughs]”. He does not answer these inquiries, but his sister may interfere in annoying ways. “I don’t [answer them] [laughs] It’s none of their business. Well my big-mouth sister too...telling everyone”.

“Cause I kinda understand it already” (Death and Dying)

It was hard for Jared to define when, or if, he actually thought about dying from leukemia. “I think before, um I...before my second relapse, oh, not before but during my first time, like...not during [the beginning]... like when I was eight, nine. Because I...” He then interrupts the train of thought to clarify that the interviewer understands that he is being treated after a relapse. “This is my relapse right? I just wanted to say it”. He then digresses to his school attendance.

Jared did not worry about dying when he first found out he had cancer (at age 7) because he did not really understand cancer. He does not worry about it since his relapse because now he knows that it can be treated even if he relapses so he does not have to think about it.

[In the beginning I didn’t worry about dying] ‘cause I didn’t really understand what it was yet. But then, now that I, I get to know how, what it is, like...I can basically see, like...oh, they can even use those to make it better and everything...[I didn’t worry about it since relapse] ‘cause I kinda understand it already. It’s just basically the same thing again [laughs].

Jared thought about the interview before it occurred. He thought about “everything”, but did not think of “anything”. “I don’t know [if there is anything else to tell you] I was kinda

thinking about everything before you came...but, I didn't really think of anything [laughs]...I was kinda thinking about my math..." There are perhaps concerns he thought about and did not want to reveal. It is more likely that his most immediate concern was his math homework, not his experience of having cancer.

Composite Description of the Cancer Experience

The following description of the meaning of having cancer is an aggregate of the seven adolescents of Pacific Island origin undergoing cancer treatment in 2009 who shared their experience in this study.

Cancer, the Disease

Physical symptoms define a good day or a bad day for the adolescents in this study. A good day was the absence of physical symptoms. The most troublesome symptom was nausea. Anticipatory nausea also occurred. Some of these teenagers associated the hospital or the nursing staff with feelings of nausea. Fatigue, or at least lack of energy, which prevents activity, exercise, or playing sports was also problematic. This predominately male group seemed less willing to admit to fatigue and tended to attribute their lack of exercise to the presence of a central venous access device (port or line). Hair loss was not a major concern in the population studied, who were predominately male. Although it may attract some attention (an "eyecatcher"), several of the males felt comfortable shaving their head. Joint pains and steroid side effects, such as increased appetite and irritability, did occur. The irritability led to rage and paranoia in one of the participants.

These adolescents wanted good medical care and expected their physicians to be knowledgeable and skilled in the care of teenagers with cancer. They wanted them to know their

disease and the treatment and to know what chemotherapy to give. Those from outside Hawaii were aware of the deficiencies in care where they lived and were grateful that medical care was available to them.

A few of these adolescents seemed reluctant to disclose symptoms or physical problems. They either thought the problem was not a major issue or feared that the symptom might indicate serious disease. All of these teens perceived that the chemotherapy was working when they felt physically better. This is the point where they might be tempted to stop taking their medication.

Some of the adolescents worried about what caused them to get cancer. A few worried about heredity and genetics, particularly when there was a family history of pediatric cancer. Some perceived the occurrence of cancer as fate, while a few feared it was a punishment from God for past transgressions. They also worried about whether they would pass the disease on to their own children.

Cancer as a Part of Me

All but one of the participants saw cancer as a temporary, time-limited event in their life, another bump in the road. They planned to get their treatment, endure the side effects, survive and go on with their life. At the extreme one adolescent chose to cope with cancer by denying that he had it and using euphemisms such as “tumor” or “it”. Several others tried to pretend that they did not have it and put it out of their mind, especially when they were physically feeling well. It was not that they denied it, but they tried to “forget” that they had it. Of course this was sometimes difficult to do when they were frequently receiving chemotherapy.

The adolescent who had been receiving chemotherapy for a long period of time incorporate the cancer into his persona. Cancer becomes an integral part of his life, woven into

his existence, part of who he is as a person. When cancer treatment starts at a young age the adolescent has literally grown up with it, cancer becomes a part of the fabric of his life. He could not imagine what he would be like without it.

Regardless of whether they see cancer as a part of them or a separate entity, cancer has changed their lives. Some felt that the struggle with the disease had made them a better person. They gained maturity, became less belligerent, were more caring of others, and wanted to help others more.

Death and Dying

All the adolescents were concerned about death when first diagnosed with cancer or leukemia, though they may not have voiced these fears to others. “Cancer” was equated with death. This belief was strongly reinforced by past experience with cancer, most profoundly when a relative or friend died from cancer. The two participants with close family members who died from childhood cancer reassured themselves by believing that their cancer is different, with a better prognosis than the fate of their relative. The teenagers in this study think about death a lot or a little, but they all thought about it. They often did not talk about their concerns with staff or parents, as if to talk about them would make the possibility more real – “if I don’t ask, then they won’t tell me”.

Some adolescents in this study coped with the threat of death by denying that it is a possibility or wishing that it would not happen. They may avoid using the word, referring to such thoughts as “negative thoughts” or “negative feelings”, or “it”. If they deny even having cancer, thoughts of dying are pushed away. Once the more intensive part of therapy was completed and they felt physically better, thoughts of death become more remote. At this point

they seemed to become convinced they would survive and did not worry as much about the possibility of dying.

Fear of relapse causes their fears to periodically surface again for some of them. Unless they had the knowledge and experience of successful treatment for recurrent disease, relapse to them meant certain death. They looked for guarantees that they would not relapse, e.g. “if I take my meds I won’t relapse”. Some refused to even talk about the possibility of relapse.

Expressing Feelings

Even healthy teenagers are hesitant to express their feelings, fears and concerns. The adolescents with cancer in this study were perhaps even more reluctant to talk about their feelings. Sometimes they answered questions about how they felt with one word answers, shrugs, or grunts. This may be a normal adolescent response, but also could be due to an unwillingness to talk or think about their feelings. They could not talk about the feelings because they did not want to acknowledge them. Cultural beliefs and gender may also play a part. Some cultures may not encourage children to express their feelings and in many societies it is much more acceptable for females to express feelings. The only female participant in the study freely discussed her feelings and concerns with others and she was the only participant who admitted to tears. Females may have more of a tendency and freedom to express their feelings, especially in regard to tears and crying.

The adolescent participants in this study saw little value in talking with staff from Behavioral Health or had learned to mistrust these healthcare providers. They perceived a referral to a psychiatrist or psychologist as an admission that they were “crazy” or had severe mental health problems. They did not perceive that the emotions and feelings inherent in having

cancer are troublesome ones that can be helped by someone experienced in Behavioral Health. Some believed that feeling sad or mad are normal when one has cancer.

Support

Unfortunately some adolescents found very little support in their struggle and relied mainly on their own inner resources which can lead to feelings of isolation and loneliness. However, most found support from family and friends. As part of a family they had the sense that they were all in it together, they all helped each other. Some felt they could talk to their parents, particularly their mother, about their thoughts and feelings and this provided comfort and reassurance. They felt their mother knew all about their disease and could help them understand. She knew what to do about physical symptoms and how to care for them. This is consistent with the Pacific Islander view of the mother's role. Fathers were less frequently mentioned, except in the case of the minister's daughter. Most often the father encouraged their son or daughter to be strong and fight the cancer.

For those from outside Hawaii there is separation from significant family members, particularly the father, which produces a sense that the family is not complete. The adolescent worried about family back home and missed their presence. Often they are living in cramped or crowded quarters in a busy city. Separated from family and friends they felt lonely and isolated.

Adolescents from outside Hawaii often experienced social isolation. They had only limited, if any, contact with the teenagers back home who had been such a big part of their lives and they missed these friends. Some had concerns about trying to make new friends. School reintegration was often a slow process which decreased their exposure to opportunities for making new friends. English as a second language may also have been a barrier.

Most of the adolescents in the study were reluctant to share their diagnosis with their friends. They feared that they would be seen as different at a stage when they most wanted to fit in with everyone else. Hospitalizations, treatment, and dealing with the side effects of therapy interrupted their school attendance and their interactions with friends.

Resilience

These adolescents demonstrated resilience in facing the challenge of having cancer and living with the disease and treatment. Several saw it as a battle that must be fought and won. They have to be strong and fight the disease. They had hope and wanted to think positively and maintain a positive attitude. They found hope in seeing and hearing from others that had survived the struggle, especially in the oncology camps.

These teenagers with cancer learned to live in the present and enjoy the good days. A good day was one spent with family and friends. They did not seem to be future-oriented, perhaps because the future is so uncertain. They all wanted to succeed in school and struggled to overcome the barriers to this goal. They wanted respect and expected staff to listen to them and get to know and understand them.

Cancer had changed their lives and they struggled to find new direction, purpose and meaning. Career choices tended to be vague and unplanned, a trait of even healthy adolescents. For some their dreams for a future playing football or joining the Army had been thwarted and they had to cope with the feelings of anger, grief and loss, and search for a different goal.

Adolescence is a time for the development of autonomy and independence. For the adolescent with cancer this developmental task becomes even more difficult. Because of their own fears and concerns parents may be overprotective. These adolescents wanted to be a part of

their care and treatment. They did not like it when parents and physicians left them out of discussions. They took pride in being knowledgeable about their chemotherapy schedule.

Most of these adolescents wanted to continue with their schoolwork but they faced many barriers. Initially they were actually too ill to attend school. Once they did feel well enough to physically attend school they were often very far behind and school reintegration presented many problems. The system presents many obstacles which they had to overcome. Some were also concerned about cognitive problems. Problems with school were even greater for those from outside Hawaii. These teenagers were attempting to transfer to a new school, often in the middle of the school year, where they had no friends and even the physical layout of the school was unfamiliar territory.

Spirituality

The spirituality of the adolescents was congruent with the beliefs and practices of the family. Most prayed, but the quantity and quality varied. Prayer was a source of strength for some. To some it was a part of their life, to others a ritual only sometimes observed.

For one participant the cancer was seen as a part of God's plan for him, a sort of blueprint for his life. Some teens asked, "Why me?" and sought to know what they did to "deserve" this illness. Some saw it as a punishment for past transgressions. Others wondered what they had done that was so "bad" as to deserve this.

Summary

Seven adolescents, 14 to 18 years of age, in treatment for cancer were interviewed. Six males and one female participated in this study. Six were receiving treatment for acute lymphocytic leukemia and one for a solid tumor. All participants were of Pacific Island origin,

two live in Hawaii and five were temporary residents in Hawaii for cancer treatment. The audio taped interviews were transcribed and analyzed to understand the meaning of the cancer experience. The essence of the experience for the individual adolescent is described and a composite interpretation of the meaning presented.

CHAPTER FIVE

IMPLICATIONS AND RECOMMENDATIONS

Chapter Five discusses the implications of the findings and recommendations for change. The limitations of the study and the recommendations for further research are outlined.

Recommendations for Practice

The litmus test for all nursing research is the answer to the question, “So what?” (Munhall, 2007). Simply describing the meaning of the adolescents’ experience fails to call into question the implications of the findings. It reports only on “what is” and not “what might be” if the teens are to be heard. “The goal of phenomenological inquiry goes beyond identifying, appreciating and explaining current and shared meanings. It seeks to critique these meanings” (Crotty, 1996, p.5). Phenomenological research is significant and “we can demonstrate its significance...by stating the implications for change that emerges from the interpretation we glean from our participants on the meanings of various experiences” (Munhall, 2007, p. 154).

Communication

Communicating with Teens

Communicating with adolescents is often difficult. They may try to confine their replies to one-word answers, answer questions with “I don’t know”, or answer with shrugs, grunts or a blank stare. It is important to recognize nonverbal communications, like the “eyebrow talking” of the Pacific Islander. Caregivers should listen for what they do not say as well as the words they use.

Adolescents with cancer want to be heard. They want staff to listen to them and get to know and understand them. Taking the time to build rapport is vital to communicating

effectively with them (Deering & Cody, 2002). This requires sitting down, listening with an open mind, and putting aside assumptions. They often have difficulty trusting that adults will treat them with respect and listen to them in a nonjudgmental manner. Listen more than talk. To facilitate discussion, caregivers should use open-ended questions, such as “Tell me about (your thoughts, feelings)”, rather than asking for specific knowledge (Decker, Haase, and Bell, 2007). When you do talk, heed the advice of one of the participants and choose your words carefully. There are many “pat” responses that we use to convey empathy simply because they have been accepted into common usage, such as “I know what you mean”. The adolescent believes that others cannot really know what he means; the meaning is unique to him. Watch for clues about how they want to approach an issue, e.g. the participant who wanted to refer to his disease as a “tumor” and did not want to use the word “cancer”. It is important not to make promises that cannot be kept or that may be misunderstood, like the adolescent who believed he would survive if he took his meds.

When discussing cancer or its treatment with the adolescent, talk about other aspects of their lives as well. This guidance is consistent with the research of Hinds (2004) that showed that a conversation that focuses only on the illness aspect of their lives puts the illness in the foreground of their thinking. When other aspects of their lives are discussed, it allows them to focus on themselves as a person and not as a diseased body. “A distancing from the illness occurs, and in its place is a focus on the emotional, spiritual, and social aspects of life” (Hinds, 2004, p.283).

An important finding in this study, unreported in earlier literature, is that cultural influences were an important part of the meaning these adolescents found in the cancer

experience, particularly those from outside Hawaii. It is unclear how the institutional classification of ethnicity is determined, i.e. whether it is self-report from the patient or is from another source. In addition, the classification of “Asian/Pacific Islander” gives little information about ethnicity and may not always be accurately recorded. In Hawaii, and specifically in this study, “Pacific Islander” included a multiplicity of different cultures – Samoans, Chamorro and Hawaiian. Taking the time to learn about the adolescent’s home and culture increases understanding. Even just learning the geography is important. To understand the adolescent’s experience healthcare providers must be knowledgeable about specific cultural beliefs and practices and education to increase their knowledge and understanding must be provided. The adolescents themselves have much they can teach if one takes the time to listen and learn.

Discussing Death with Adolescents

Another important finding in this study was that all the adolescents were afraid that they were going to die when they were told that they had cancer, whether they voiced this concern at the time or not. Sometimes their fears were unrealistic, like the participant who thought that having leukemia meant he had only six months to live. Sometimes their concerns were based on past experiences, like the two participants who feared they would die because their relative had died from childhood cancer.

The issue needs to be faced from the very beginning days of the diagnosis, a factor not considered in most of the literature. While acknowledging the reality of death, the issue can be approached with optimistic honesty and with attention to cultural nuances. The connection between cancer and death can be brought up in a general way by saying that most people make this connection in their mind and yes, some people do die from cancer. They may even have

heard or know someone who died from cancer. However, great progress has been made in the treatment of childhood cancer. Today, in fact, most teenagers will survive their cancer and go on to lead a normal life.

The teenager needs to know that for most adolescents with cancer the prognosis is reasonably good and it is an expectation that they will survive. Statistics are probably not helpful at this point, like the participant who “heard” that he had a 50-50 chance of surviving. They need to know that everyone’s efforts are directed toward that goal. Life will be difficult for awhile and the going will be rough, but everyone will be working toward helping them overcome the cancer. If the prognosis is less optimistic the adolescent needs to know this, with emphasis on the efforts to help them. The teenager needs to know that if the expectation for survival changes or becomes less hopeful they will be told. All communication must be based on trust and honesty.

The Medical Team

The Team Concept and Roles

Implications for practice can sometimes be gleaned from what is not reported by the participants as much as what they report. The omission of any understanding of receiving care from an interdisciplinary team of healthcare professionals seems relevant. The teenagers described here seemed to think of their medical care only terms of the competency and skill of the physician who is treating their disease. They had no concept of the multidisciplinary nature of a team responsible for their care. Only one participant identified a nurse by name. Explaining this team concept and identifying team members and their roles, and then practicing as a team would improve the care of the adolescent with cancer.

The role of Behavioral Health was not defined for these adolescents. They often saw referral as a sign that they were “crazy” or could not cope. Behavioral Health should be presented as an integral part of the team’s care. Coping with cancer is difficult for all adolescents, therefore they are all routinely seen by Behavioral Health at the time of diagnosis.

An interesting question for further research would be to discern if the team concept in practice is important or relevant to adolescents with cancer.

Physical Care

A thorough physical examination is an important part of the medical care. Teenagers may not be aware of the significance of changes that are occurring, like the presence of skin lesions. Or they may be afraid to mention symptoms, fearing that they indicate something very seriously wrong. They may be tempted to not mention things. A thorough physical exam may reveal undisclosed problems that require attention.

Sharing with Family and Friends/Strengthening Support

As with healthy adolescents, teenagers with cancer may be reluctant to share their feelings, fears and concerns with others. In this study this may also be related to gender differences or cultural beliefs. Social support systems for each individual must be identified, reinforced and expanded. This finding reinforces practice guidelines based on other studies which showed that the objective is to identify gaps in their support systems and reinforce existing ones (Ritchie, 2001b). Identify key individuals in their lives, be aware of cultural practices and beliefs, create opportunities for them to talk about their feelings and encourage their sharing with family and friends (Ritchie, 2001a). Teenagers who report more social support also report less psychological distress and higher coping scores (Neville, 1998; Nichols, 1995).

Unfortunately some adolescents in this study found very little support in their struggle and relied on their own inner resources. The teens described here who did share feelings and concerns most often identified sharing with family, particularly their mother. This is consistent with research that has found that mothers are the most significant source of support for adolescents with cancer (Enskar, Carlsson, Golsater & Hamrin, 1997; Hockenberry-Eaton & Minick, 1994; Hokkanen, Eriksson, Ahonen & Salantera, 2004; Ritchie, 2001a). The adolescent's mother may need more factual and practical knowledge and guidance in fulfilling this role. Since the adolescent often relies on the parent to "interpret" medical information, the mother must fully understand the disease, treatment and home care. If a language barrier is suspected, use an interpreter as needed. Request an interpreter in a way that is not demeaning but seeks to ensure that complete and comprehensive information is received. Prepare the parent for potentially difficult questions from the adolescent and how to respond.

Seeking family support is contrary to the developmental task of adolescence which seeks to increase independence (Stegenga, 2009). It is important to recognize that adolescents do not exchange their existing social circle to exclude parents but expand it to include peers (Ritchie, 2001a). Most adolescents seek support from peers, but this is not always possible for the adolescent with cancer, especially if they choose not to share their diagnosis with their peers or they are physically separated from those peers. Appropriate peer support may mitigate the experience for adolescents with cancer.

Teens are divided in their desire to share information about their diagnosis and treatment with friends and peers. Some feel quite comfortable in sharing their story with friends, especially close friends. Others fear being labeled as "the kid with cancer" and losing friends.

This stage in life is characterized by a need to feel accepted by one's peer group (Conger & Galambos, 1997). Feeling different is a particular concern to the adolescent with cancer (Stegenga, K. & Ward-Smith, P., 2009). Adolescents are afraid that if others know about their illness they will "pick on" them, gossip about them, and not want to be friends with them (Yeh, 2001). If they keep their condition a secret, they can avoid having to deal with others' negative reactions.

The choice to share their illness with friends must be theirs to make. One can only relate the advantages other teens have found in being open and honest with friends. It may be helpful to rehearse potential social situations with the adolescent. While many of the adolescents described here felt that healthy friends could not fully understand the experience of living with cancer, those who chose to share their experience were comforted by having them listen and be emotionally present for them. An important care strategy is to provide opportunities for the adolescent to have sustained contact with peers by encouraging phone calls, email, and visits and providing the needed privacy for peer-to-peer interaction. With the adolescent's consent, a "group" session may be held to provide information to the teen's friends and teach them how they can help. School visits with classroom presentations on the disease and treatment for students and teachers may be helpful.

Teens from outside Hawaii greatly miss their friends and family from back home. Face-to-face contact and interactions become impossible and other mean of communication are necessary. Telephone contact can be sporadic and expensive. E-mail communication can be effective, but most participants lacked the resources for this. It seems unfortunate and cumbersome that one participant had to use the Net Café at a local mall and only once a week to

communicate with his friends by email. With due consideration of the impact on resources, it would be beneficial if the hospital could provide this communication with home and friends through the Internet. Access to a computer and the internet could also provide an adjunct to treatment and a welcome diversion during treatment.

Survivors of childhood cancer may provide support. Participants who attended an oncology camp found hope and inspiration in talking to survivors of childhood cancer. Caregivers should encourage attendance at camp and support participation. Survivors could also be enlisted as mentors for new patients. Not only is it a chance for the teenager to gain support, it is also a chance for the survivor to “give back” (Stegenga, 2009).

School Reintegration

A focus on attaining educational goals is a developmental task of adolescence. This finding is consistent with a recent study of adolescents with cancer that reported that when they are diagnosed with cancer adolescents have to face the stressful situation of dealing with the illness and their goals change to a focus on caring for their illness (Wu, Chin, Haase & Chen, 2009). Initially, many are too sick to return to the classroom or to keep up with school work. In the beginning these adolescents abandoned their efforts to achieve academically and focused on tolerating their treatment.

As their physical condition improved these adolescents were able to refocus on their academic goals. School reintegration is a major problem for all the adolescents. Tutors, if available, do not have flexible schedules that adapt to the needs and abilities of the teenager. Anxiety increases as the teen gets further and further behind classmates. Total disinterest in school may result. Even when school attendance is possible, the teen with cancer is ill-prepared

to rejoin the classroom. Problems are even greater for the teenagers temporarily living in Hawaii during treatment. These adolescents are confronted with transferring to a new school where they have no friends and even the physical layout of the school is unfamiliar. Lack of knowledge about the educational system and language problems by both the teen and the parent may also be barriers to school reintegration.

The educational system seems unwilling and/or unable to provide the services these teens need. The medical institution must provide the help if these teens are to be successful in school and to become successful adults in the future. A full-time designated school liaison staff position is needed to meet the needs of the teen and the school system. Such a person could design flexible tutoring schedules both in and out of the hospital that meet the adolescents learning needs while at the same time recognizing the periods of illness when the adolescent is unable to participate in school work. The liaison could work with individual schools and teachers to provide for a seamless re-entry into the classroom.

Recommendations for Future Research

Further research is needed regarding the issues related to treatment of adolescents from outside the geographic area of the cancer center. Relevant factors related to the general issues of displacement, separation, finances and housing need to be defined, particularly as they relate to the unique factors of culture and care in Hawaii.

Nausea was the most problematic symptom for these adolescents and it had an impact on their quality of life. Particularly while receiving the intensive chemotherapy the feeling permeated their lives, often for days at a time, and they were unable or unwilling to eat. Nausea is a subjective sensation and awareness of the urge to vomit which is difficult to assess and does

not always result in vomiting. Effective treatment for nausea must begin prior to the first dose of chemotherapy. Antiemetics are more effective in preventing nausea than alleviating it once it is established. If not effectively treated in the beginning, anticipatory nausea will occur. This is a learned or conditioned response to previously uncontrolled nausea and may be associated with taste, odors or the hospital/clinic environment. Studies of nausea and vomiting have been conducted as new antiemetic medications have been developed. Although these teens were likely receiving the most evidence-based treatment for the nausea, they still complained of acute, delayed and anticipatory nausea. Research is needed on the most effective regimens of antiemetics for the individual patient and the use of behavioral techniques, such as desensitization and hypnosis, and complimentary therapies to prevent nausea.

Peers can be an important component of adolescent coping. Many previous studies identify the needs for peer support and interaction (Haase, 1987; Neville, 1998; Ritchie, 2001b; Woodgate, 2006; Woodgate & Degner, 2003b), but no literature has been identified specific to peer support interventions for the adolescent with cancer. Research is needed on how to help the adolescent find this peer support and how to help these “well” individuals to provide the support. How can “well” peers be included in providing support and engaged in a potentially meaningful way?

The one participant treated for an extended period of time described leukemia as an integral part of who he was, woven into the very fabric of his being. The others tended to view cancer as an entity apart from themselves. When, why, and how does cancer become a part of ones being is another topic that should be studied.

Limitations

Six of the seven participants were male and therefore the meanings that emerged from these data may not fully capture the experience of females. Five of the seven participants reside in another geographic area and their experiences may be different from those who reside in Hawaii. They present some interesting phenomena unique to their situation that needs further study. All participants were of Pacific Island origin which may influence the meanings described. They do represent a unique population and cultural issues need to be further explored. Phenomenology does not seek generalizability as its aim but rather seeks to generate meanings that can be further tested and may provide insight into the lived experience of others.

Summary

Recommendations to healthcare providers for changes in or expansion of current practice includes techniques for communicating with adolescents and discussing death and dying with teens with cancer from the time of diagnosis, the interdisciplinary team concept of care, and the importance of a thorough physical exam. The importance of social support and techniques to potentially strengthen and increase this support are outlined. Solutions to the problems of school reintegration are introduced. Directions for further research include study of the effects of ethnicity on the meanings experienced by adolescents with cancer, the physical effects of treatment, methods to foster peer support, and how the lived experience of having cancer becomes incorporated into being. The limitations of this study are defined.

APPENDIX A: PERMISSION TO CONTACT

Parental Permission to Contact
Dianne Fochtman

Dr. _____ has told me that I may be interested in allowing my teenager to participate in a research study to understand the meaning of cancer to the adolescent. This study will be an opportunity for people caring for teens with cancer to better understand how the teens themselves perceive their cancer experience.

I agree that Dianne Fochtman, RN, MN, an experienced pediatric oncology nurse who is now a graduate student in the doctoral program at the University of Hawaii at Manoa School of Nursing may contact me to discuss the study.

First name(s)

Phone number(s)

Date

Older Adolescent (18 & 19 years) Permission for Contact
Dianne Fochtman

Dr. _____ has told me that I may be interested in participating in a research study to understand the meaning of having cancer. Research has been done with adults on this, but there is little information about how teens think about their cancer experience. Talking with me will allow Dianne to begin to tease out what are the similarities and what are the differences between teens and adults. This knowledge will help the oncology team deliver teen-specific support to teens who are going through the cancer journey.

I agree that Dianne Fochtman, RN, MN, a nurse who has worked with teens with cancer for many years and is now a graduate student in the doctoral program at the University of Hawaii at Manoa School of Nursing, may contact me to discuss this study.

First name

Phone number(s)

Date

APPENDIX B: PARENT INFORMED CONSENT

Agreement for My Teenager to Participate in a Study of Adolescents with Cancer Dianne Fochtman Primary Investigator

This research project is part of a dissertation for a doctoral degree in nursing. Teenagers with cancer are being asked to participate because the researcher believes that healthcare professionals need to hear from the teenagers themselves exactly what the experience is like. The purpose of the project is to understand the meaning of living with cancer for adolescents who are actually living it. You are being asked for permission for the investigator to contact your teenager and explain the project and your consent for your teenager to participate if he or she wants to participate.

At the most, 12 adolescents will participate in the project. Participation will include filling out a brief form with information about the teenager and two interviews with Dianne Fochtman. The brief information will be **anonymous** and will not include any information that would identify the participant. The interviews will last one to two hours, and will be conducted four to five weeks apart with the participant alone in a private place of their choice outside the institution. The interview content will focus on what it's like to live with cancer. Because the purpose is to hear what the teenager has to say, only a few general questions will be asked to guide the interview. The interviewer may take some notes during the discussion. Interviews will be audio recorded and transcribed, and reviewed only by Dianne Fochtman and her Professor, Dr. Lois Magnussen, at the University of Hawaii at Manoa School of Nursing.

It is anticipated that the adolescent's participation in this project may help doctors and nurses understand the experience better and therefore it may help other teenagers who are experiencing cancer now and in the future. Discussing the experience may help your teenager to understand his or her own experience. There may be a small risk of psychological pain. The investigator has had over 30 years experience in working with adolescents with cancer and helping them work through psychological distress. Referral to appropriate Behavioral Health specialists will be offered if necessary.

All information will be kept confidential to the extent allowed by law. Agencies which supervise research, such as the UH Committee on Human Subjects, have the authority to review research data. All research records will be stored in a locked file in the researcher's home for the duration of the research project. Audio tapes will be destroyed following review and transcription. All research records will be destroyed when the project is done.

Participation in this research project is completely voluntary. The teenager is free to stop at any time during the project. If you don't want your teenager to participate, or your teenager does not want to participate or decides to stop at any point, this will not in any way affect his or her medical or other health care. The information shared during the interviews will not be shared with healthcare providers in any way that identifies the participant.

If you have any questions regarding this research project, please contact the researcher, Dianne Fochtman, at .

If you have any questions regarding your teenager's rights as a research participant or your rights in parental consent, please contact the UH Committee on Human Studies at (808)956-5007, or uhirb@hawaii.edu.

Parent:

I have read and understand the above information and agree that my teenager may be given information about this research project and may participate if he or she wants to do so.

Name (printed)

Signature

Date

Child's Name

APPENDIX C: ADOLESCENT INFORMED CONSENT

Agreement to Participate in a Study of Adolescents with Cancer Dianne Fochtman Primary Investigator

This research project is part of a dissertation for a doctoral degree in nursing. You are being asked to participate because you are a teenager with cancer. The purpose of the project is to understand the meaning of living with cancer for adolescents who are actually living it. You have been asked to participate because your doctor, and your parent if you are under 18 years old, thought you might be interested.

At the most, 12 adolescents will participate in the project. Participation will include filling out a brief form with information about you and two interviews with Dianne Fochtman. The brief information form will be **anonymous** and will not include any information that would identify you. The interviews will last one to two hours, and will be conducted four to five weeks apart with you alone in a private place of your choice outside the institution. The interview content will focus on what it's like to live with cancer. Because the purpose is to hear what you have to say, only a few general questions will be asked to guide the interview. The interviewer may take some notes during the discussion. Interviews will be audio recorded and transcribed, and reviewed only by Dianne Fochtman and her Professor, Dr. Lois Magnussen at the University of Hawaii at Manoa School of Nursing.

It is anticipated that your participation in this project may help doctors and nurses understand the experience better and therefore it may help other teenagers who are experiencing cancer now and in the future. Discussing the experience may help you to understand your own experience. There may be a small risk to you of psychological pain if you participate in this project. If this should occur, referral to appropriate Behavioral Health specialists will be offered.

All information will be kept confidential to the extent allowed by law. Agencies which supervise research, such as the UH Committee on Human Subjects, have the authority to review research data. All research records will be stored in a locked file in the researcher's home for the duration of the research project. Audio tapes will be destroyed following review and transcription. All research records will be destroyed when the project is done.

Participation in this research project is completely voluntary and up to you. You are free to stop and drop out of the study at any time during the project. If you don't want to do it or you decide to stop at any point, this will not in any way affect your medical or other health care. The information shared during the interviews will not be shared with your healthcare providers in any way that identifies you.

If you have any questions regarding this research project, please contact the researcher, Dianne Fochtman, at 942-5375.

If you have any questions regarding your rights as a research participant, please contact the UH Committee on Human Studies at (808)956-5007, or uhirb@hawaii.edu.

Participant:

I have read and understand the above information, and agree to participate in this research project.

Name (printed)

Signature

Date

APPENDIX D: DEMOGRAPHIC DATA SHEET

Demographic Data

Date: _____

_____ Name: _____

Phone #: _____ Ethnicity _____

Parent name: _____

Present Permanent

Address: _____ Address: _____

Gender: _____ Age: _____ BD: _____

Diagnosis: _____

Date of diagnosis (month/year): _____

Present treatment:

_____ chemotherapy frequency: _____

_____ radiation therapy

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