

MEANING AND PURPOSE OF LIFE IN ADOLESCENT
CANCER PATIENTS

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We hereby recommend that the Thesis prepared under
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CHAPTER 1

INTRODUCTION

Cancer has long been recognized as one of the major health problems in this country. In the 1950s, a child or adolescent who was diagnosed as having cancer was considered terminally or fatally ill. The advances in therapy over the last 25 years have been impressive. Children and adolescents with cancer have been given a chance to live an ever-lengthening life. With the increased survival rate, a touch of hope has been brought to this group of individuals. Research efforts now have gradually come to focus on issues relative to life and quality of life rather than to concerns of death. The challenge now is to ensure that these young people inflicted with cancer can pursue life to the fullest.

Whether these young people live or die, it is not without a struggle. The adolescent with cancer is an example of the determination and the will to live even against overwhelming odds. These adolescents have the fight for life and a most powerful weapon, the will to live life fully in the face of death. One of mankind's greatest attributes is the will to survive. The very

birth of our civilization comes from mankind applying the mind and human potential to survive through time and history (Spinetta & Spinetta-Deasy, 1981). Health professionals have a responsibility to assist these young people to help "maximize coping and adaptation efforts to obtain the fullest possible life within the physical limitations imposed by their cancer process" (Spinetta & Spinetta-Deasy, 1981, p. 8) and help them to attempt self-mastery over their illness in a realistic manner.

Nurses have long been concerned with assisting ill patients to cope and live with their chronic diseases. Often, it is the nurse who looks beyond medical intervention and departs from the traditional way of viewing a sick person and his circumstances to alternate strategies for helping the chronically-ill person.

Existentialism as a source of understanding can offer many insights to the health professional interested in providing necessary psychosocial and physical support to the oncologic patient. Perhaps the knowledge gained through direct feeling of experience, as illustrated in existential literature, can provide a framework in which adolescents too can experience a fuller, richer life. The specific focus of this research was to study whether or

not adolescents with cancer experience their illness with meaning and purpose in their life.

Problem of Study

The problem of this study was to determine if there is a difference between the meaning and purpose in life of adolescent cancer patients receiving active treatment when compared to the meaning and purpose of life in healthy adolescents.

Justification of Problem

The justification of this study stems from a three-fold need: (a) a personal interest derived from work experience with adolescent cancer patients, (b) a lack of systematic written information regarding the therapeutic effects of existential nursing therapy in meeting the psychosocial needs of the cancer patient, especially the adolescent cancer patient, and (c) a thrust toward moving back to basics in nursing with the goal of guiding an individual in exploring human values for sources of meaning in understanding the relationships of life's experiences. In a society that strives for happiness, health, and an everlasting life, there are life events such as cancer that do not lend themselves readily to

explanation. Adults cannot explain the event of cancer to themselves, thus, the adolescent would not be expected to understand the meaning of having cancer. It is difficult to fit the phenomena of cancer into a simplified biological construct. Often, one utilizes beliefs and myths to understand (Spinetta & Spinetta-Deasy, 1981). Van Eys (cited in Spinetta & Spinetta-Deasy, 1981) stated that cancer is not an invader but a behavior of the body; it is better "to be with cancer than to have cancer" (p. 30) and, therefore, something to be acknowledged and dealt with. The concept of the disease determines the outcome as much as the actual facts do. "Psychological support of the patient often focuses on the present crisis, but the need is to focus on the optimization of outcome predicated on knowledge and experience" (Spinetta & Spinetta-Deasy, 1981, p. 33).

Indeed, cancer is a handicapping and chronic illness. Van Eys (cited in Spinetta & Spinetta-Deasy, 1981) strongly urged that the highest priority be to prepare the cancer patient psychologically, educationally, and socially for it is the attitude, self-image, and adjustment to reality that must be stressed. "How patients feel about the experience and themselves determines the cure

more than does the physical reality" (Spinetta & Spinetta-Deasy, 1981, p. 36).

Cure is not the ultimate goal. Cure is an attitude as well as a biological reality. Yet, if biological cure fails, then psychological cure must be adjusted and generated. A cure does not mean that the disease is forgotten, rather reality of the disease is incorporated in the life of the child or adolescent, the reality of being. This process must begin early in the cancer experience. "One must generate an attitude toward the reality of cancer that allows an adolescent to grow and develop normally and on par with peers, with, not in spite of, cancer" (Spinetta & Spinetta-Deasy, 1981, p. 37).

Logotherapy, an application of existential philosophy developed by Viennese psychiatrist, Viktor Frankl, "aims at helping individuals to face crisis situations wherein a radical change in status has created a loss of personal identity and purpose in life" (Crumbaugh, 1972, p. 418). Knowledge is gained about one's self through direct feeling of an experience and the subjective reflective self. The concept of self implies that an individual at a turning point in his life can explore his possibilities, choose his actions and goals, and create his values with a

sense of meaning and purpose. "Meaning cannot be given; meaning must be found by oneself, by one's own conscience, so as to foster the meaningful fulfillment of one's being" (Frankl, 1972, p. 88). The nurse, therefore, views the individual as a whole person. The nurse ministers to the individual with the goal of achieving autonomy under altered conditions (Gulino, 1982) while looking to alternate strategies for promoting a level of wellness in the cancer patient. Nurses are often the health professionals who have the closest and most frequent contact with the patient. Consequently, nurses are in a prime position to assist the patient in understanding the meaning and purpose of living with cancer.

It is important that nurses recognize that existentialism can move one to more critically examine a particular situation, although it does not provide specific answers to specific problems. This philosophy allows the nurse to examine the many patterns of knowing, the different approaches, and different perspectives while yielding insight into the complex nature of man and rewarding one with more of an appreciation of the individual meaning of experiences for the adolescents (Guilino, 1982). As nurses begin to assist the adolescent in incorporating the experience of cancer into their lives,

perhaps nurses could assess the degree to which logotherapy could accelerate or impede the patient's progress toward a functioning level of wellness. A portion of the assessment could be completed by having the adolescent complete a purpose-in-life test, which is reflective of logotherapy concepts. The results could provide the nurse with objective data concerning the presence and degree of sense of meaning and purpose in adolescents with cancer, thus providing a focal point in which the adolescent's feelings of self and sense of identity could be enhanced.

The purpose of this investigation was to provide some answers to the following question: Do adolescents with cancer, because of the effects of the disease, the intensive treatment, and management of the disease, develop a meaning and purpose in life different than the healthy adolescent who is not enduring a life-threatening illness? No studies have been found which investigated this phenomena in the adolescent.

Theoretical Framework

Frankl's (1962) theory of meaning in life served as the framework for this study. Frankl stated that man's search for meaning is the primary force in man's life. His theory consists of principles of existential

philosophy, and he referred to his therapy as logotherapy. "Logos" is a Greek term denoting "meaning." Therefore, logotherapy is an application of existential principles to clinical practice.

Frankl (1962), a Viennese psychiatrist, conceptualized his theory as a prisoner in the concentration camps during World War II. In the concentration camp, he learned what a human being does when he realizes he has "nothing to lose except his so ridiculously naked life" (p. x). Frankl lost every possession, every value; suffered hunger, cold, frugality, and was stripped to his core--"How could he find life worth preserving?" Frankl's view of existential is stated in the following: "to live is to suffer, to survive is to find meaning in the suffering. If there is a purpose in life at all, there must be a purpose in suffering and dying" (p. xi).

Existential analysis is particularly concerned with making one conscious of responsibility to the self and the existence of that self. Such responsibility implies a sense of obligation which can only be understood in terms of meaning, especially in meaning of human life (Frankl, 1962). According to Frankl, the "how" one lives has application to not only meaning of life but also meaning

in death, suffering, love, and work. Frankl studied the meaning of life in the old and young, the prisoner, the terminally ill, the mentally retarded, and the healthy. From this perspective, Frankl found that a person answers to life by answering for his own life. Man's purpose in life represents a basic motivating spiritual force. In logotherapy, the person is usually confronted with and reoriented toward the meaning of his life and made to be more aware and conscious of this. Logotherapy considers man as a being whose main concern consists of fulfilling a meaning and actualizing values. What matters, however, is not meaning of life in general but rather the specific meaning of a person's life at a particular moment in time. Furthermore, this task is unique and specific as man answers for his own life (Frankl, 1962).

If man's search for meaning is not successful, then man's will becomes frustrated. Frankl (1962) identified this as existential frustration. This can result in noogenic neurosis, one of Frankl's coined terms. Noogenic neurosis pertains to the spiritual core of personality. Spiritual, in this sense, refers to a human dimension, not a religious one. Noogenic neurosis arises largely as a response to complex emptiness and lack of purpose in life

in which conflicts develop between various values and human dimensions. Logotherapy seeks to combat existential frustration and noogenic neurosis. If neither of these are successfully dealt with, then an existential vacuum can occur in which a feeling of total meaninglessness, lack of awareness of what to live for, and an experience of inner void is experienced. This phenomena is created by a vacuum of perceived meaning in personal existence and manifested by a symptom of boredom and meaninglessness (Crumbaugh, 1968).

Crumbaugh (1968) contributed to Frankl's theory. It was he who "psychometrically analyzed" Frankl's existential philosophy and theory by developing a tool to measure perceived meaning or purpose in life. The instrument, Purpose in Life (PIL), was developed and utilized to operationally define the concept of purpose in life, and, hence, support Frankl's noogenic hypothesis.

In practical terms, logotherapy functions by "helping individuals to face crisis situations wherein a radical change in status has created a loss of personal identity and purpose in life" (Crumbaugh, 1972, p. 419). Bearing in mind these facts, it would seem that as the adolescent is struggling to seek and define his identity as well as

strive for independence, meaning, and purpose in life, that the concepts of logotherapy and Frankl's theory on meaning in life could be applicable as a means of support in the cancer experience. Conceivably then, adolescent cancer patients whose lives have and will experience many changes can find purpose in their lives and meaning in their cancer. The question at this point is whether their experience of meaning in life is different from that of the general population of healthy adolescents.

Assumptions

The following assumptions applied to this study.

1. Cancer is a threat to the adolescent and demands new coping styles.
2. It is desirable for adolescents to have meaning and purpose in their lives.
3. Frankl's (1962) theory is applicable to adolescents.

Hypothesis

The null hypothesis for this study was: There is no significant difference between the meaning and purpose in life of adolescent cancer patients when compared to the meaning and purpose in life of healthy adolescents as measured by the Purpose in Life Test (PIL).

Definition of Terms

For the purposes of this study, the following terms were defined.

Meaning in life and purpose in life--unique primary instinctual drive specific to an individual, each individual answering for his own life by being responsible. Meaning can be experienced by (a) doing a deed, (b) experiencing a value, and (c) suffering. Meaning is not given but personally discovered (Frankl, 1962). Purpose in life is the individual significance one places on experiencing a meaning in life. This concept is operationalized by the Purpose in Life test, which is an attitude scale designed to measure the degree to which a person experiences a sense of meaning and purpose in life (Crumbaugh, 1968).

Adolescent cancer patients receiving active cancer treatment--adolescents aged 14-19 years who have a confirmed diagnosis of cancer and are presently receiving radiation, chemotherapy, immunotherapy, or any combination as treatment for cancer. The cancer patients are enrolled in junior and senior high school.

Healthy adolescent population--adolescents aged 14-19 years who do not have any perceived disturbance in

physical, psychological, or social well-being, and who are enrolled in junior or senior high school.

Limitations

The following limitations applied to this study.

1. The sample size was small and nonrandomized.
2. The study used a tool which has not been utilized with adolescent cancer patients before.
3. The available literature pertinent to the study was minimal.
4. There was no control over the amount of support the subjects received from significant others, family, peers, and health professionals.
5. There were variations in the type and stage of cancer and type of cancer treatment.
6. There were different levels of knowledge about the disease and treatment among the subjects.
7. There was no control made for the number and types of developmental and cognitive tasks that had been achieved by the subjects.
8. There was no control made for age, sex, and different life experiences.
9. Subjects may have been uncomfortable with the type of personal questions asked in the questionnaire.

Summary

The problem of this study was to determine if there is a difference in the experience of meaning and purpose in life in actively treated adolescent cancer patients when compared to healthy adolescents. Adolescence is a complex stage of life that all individuals experience. Cancer is a universal disease without bias. Singularly, adolescence and cancer are life events that pose many psychosocial difficulties and stresses. When these events occur concomitantly, the adolescent experiences compounded physical, psychosocial, and social changes that affect the adolescent's sense of identity and experience of meaning and purpose in life.

The adolescent cancer patients, therefore, deserve reasoned approaches to assist them in adjusting and mastering the experience of cancer. Traditionally, nurses often have the closest contact with the patient and have often shown concern for quality of life. Nurses, as health professionals, therefore, have a responsibility to assist these young people to maximize coping and adaptation efforts in their experience with cancer and crisis situations and likewise assist them in the discovery of meaning while experiencing difficulty by

exploring their feelings. Hence, due to the lack of empirical research and standardized measures of this phenomena in the adolescent age group, it is necessary that further investigations of this concept be made.

Chapter 1 introduced and justified the study, presented a theoretical base, and stated a null hypothesis. The study was planned to compare healthy and nonhealthy adolescents based on the score of the Purpose in Life test (Crumbaugh, 1968) and to reveal that meaning and purpose in life is a psychologic dimension present in the adolescent.

CHAPTER 2

REVIEW OF LITERATURE

This chapter presents a review of literature. The purpose of the study was to determine the presence of meaning and purpose in life of adolescent cancer patients compared to the meaning and purpose in life of healthy adolescents. A review of literature was performed in order to investigate the following areas: (a) normal adolescent psychosocial development, (b) adolescents' development and the relationship to cancer, and (c) existential concepts of meaning and purpose in life. While the literature search revealed considerable information concerning adolescence, psychological/ emotional adjustments of adolescents with cancer/chronic illness, and the existential concept of meaning and purpose in life, no single article or study was found which explored all of these variables. The literature review addressed each of these areas as it applies to the adolescent cancer patient coping with cancer and the otherwise healthy adolescent.

Normal Adolescent Psychosocial Development

This section examines the adolescent as an individual person who is distinguished from others by his special position in the natural developmental process and his unique characteristics and style. Knowledge of the developmental process of adolescence, particularly the notion of identity as it applies to the area of developing life's goals, provides a baseline and framework from which a better understanding of the concept of meaning and purpose in life can be applied to the adolescent population.

In America today, there is a period of time during which young people are adolescents. Blos (1967) saw adolescence as a "second individuation process," (p. 162) as one stage with many themes running through it, some being prominent at one moment and some at another. The exact age range is variable, depending on biological, emotional, and sociocultural factors; but generally the chronological age span is between 12 and 20 years. Adolescence is a pivotal time of significant physical growth, and it is also a time when the major psychosocial developmental task is mastery of one's identity and the development of a strong self-concept in relation to the

world at large. Adolescence is coming to know who one is, what one values and believes in, and what one wants to accomplish and get out of life.

Erikson (1959, 1963, 1968), a leading developmental-stage theorist, postulated his eight stages of man. His was an approach to the development of individuals in terms of stages. His highly regarded theory consisted of clearly defined stages through which an infant, child, and adolescent pass in sequence. The attainment of one stage is dependent upon the completion of the previous one. One can anticipate if there is significant difficulty or incompleteness in one stage, then a problem could develop in a later stage.

Simplistically, life begins with trust; the premise being that the infant will establish a trusting relationship with his primary caregivers. Secondly, the child begins to establish a sense of autonomy as an outgrowth of self as he exercises increased mobility and freedom. In the third stage, the child develops initiative as he curiously establishes a sense of responsibility and adjusts to new roles. Industry, the fourth state, is characterized by the child who learns new skills and contemplates goals. The antithesis of each of these

stages are mistrust, shame and doubt, and guilt and inferiority, respectively. The stage that follows, and one which is the critical issue of adolescence, is identity. Again, Erikson (1968) theorized that identity develops gradually out of the successive identifications of childhood; an integration of all that has occurred in previous years. These identifications may be through parents, peers, teachers, groups, events, or cultural categories. According to Erikson, in order for the adolescent to grow, develop, and master his identity and/or role, he must have trust in himself and in his significant others; yet all the while, he does not want to appear too trusting to anything or anybody. Paradoxically, he would rather act shamelessly in the eyes of his elders rather than be forced to do something that is not in conjunction with his sense of identity. Finally, if during the process of maturing, the adolescent maintains a desire to do something and does it well, then such a choice assumes significance. Thus, for this reason, some adolescents would rather not work at all than be forced into a career or position that might offer success without any satisfaction. In this respect, the adolescent begins to establish a sense of self and identity with new roles.

Clearly from Erikson's (1959, 1963, 1968) view, a background of love, trust, and understanding from parents and significant others is fundamental in attaining a reasonably happy and positive self-image and sense of identity.

Erikson's (1963, 1968) element of identity, which the adolescent ideally attempts to master, and likewise the processes through which identity is often defined, includes the following tasks: (a) independence from parents, (b) establishing and integrating a mature sexual identity and body image, (c) establishing meaningful and workable peer relations with both sexes, (d) delineating educational, occupational, and career work goals, and (e) establishing a sense of self with goals congruent with societal norms. The challenge of accomplishing these tasks is not without difficulty and stress. The many physical, psychological, and developmental changes in the adolescent occur at an uneven rate. The process of attaining one's identity is not always positive, some of it is inherently negative. It is when the teenager attempts to cope with the demands of adolescence and finds his sense of identity is lacking or empty, then too often he is faced with diffusion and crisis (Erikson, 1963).

Manaster (1977) agreed with Erikson (1963) that identity also means an individual's personal uniqueness. Manaster (1977) recognized Erikson's (1968) "identity crisis," and suggested that identity crisis falls within the realm of normal coping processes for the adolescent, as life presents with its upsets and crises. Likewise, it is also feasible for the adolescent to see himself with some perspective as a separate and distinct individual, integrating his needs, motives, and patterns of responding into a "self" that can deal with the phenomena of life's everyday ups and downs (Conger, 1977; Erikson, 1968). Unfortunately when an adolescent has not learned to delay gratification and tolerate frustration, exercise discriminating control over his actions, feel comfort in exploration and assumption of appropriate sex roles, and feel pride in his accomplishments as established in earlier years, he then may enter adolescence demanding gratification, doubting his abilities, failing to achieve sexual identity, and feeling inferior to peers. The resultant behaviors may reflect truancy, depression, meaninglessness, obsessive/compulsive behaviors, hysterical symptoms formation, and academic underachievement (Leichtman & Friedman, 1975).

The meaning and mastery of identity in the adolescent also includes the understanding that cognitive and intellectual development are also important in increasing the adolescent's ability to deal with his sense of self and individuality. Over time, the adolescent hopefully achieves a balanced and consistent state of reasoning and abstract thought to make his sense of identity more rich and formal. Piaget (1969), a major contributor in the field of developmental child psychology, hypothesized on this subject for over 50 years. Piaget, as did Erikson (1959, 1963, 1968), viewed cognitive and intellectual development as occurring in a series of stages. In Piaget's clinical work and writings, he researched how the child understands the world surrounding him. Piaget's (1969) understanding of the adolescent centered around how the adolescent intellectually copes with problems, how he experiments, and how he reasons observed data (Inhelder, 1962). The development of cognition through formal operations vastly increases the adolescent's ability to deal with himself and world as well.

Piaget (1969) also contended that as the adolescent learns about the world and himself, he further achieves an advanced state of equilibrium, which enables him to adapt

effectively to a variety of problems. This new awareness in intellectual thinking begins to affect the adolescent's approach to himself. His problem-solving is not limited to just scientific or practical areas but to social and emotional concerns in regard to his values, his feelings about peers, his parents, and his own egocentrism (Pulaski, 1980). Piaget theorized that through the passing of each cognitive stage (early sensormotor--0-1 year, late sensormotor--1-2 years, the operational--2-6 years, and stage of formal operations--6-12 years), cognitive maturity will likely be present to some degree during adolescence (Inhelder, 1962). As abstract thinking and conceptualization continues to develop, the concept of identity will then be implanted in the adolescent in a meaningful, interrelated way. Piaget maintained that the advancement of cognition, and thus identity, occurs as a function of appropriate neurological development, a proper social environment (home and school) experience, and internal cognitive reorganization (the child's own activity) (Inhelder, 1962). Hence, Piaget (1969) indicated through such a developmental process, cognitive and intellectual achievement are sustained in the adolescent and a sense of identity becomes formalized.

In order to continue to understand the process by which an individual masters the tasks of adolescence and strives to assume adult roles, it is important to understand that adolescence is divided into three substages. Early, middle, and late adolescence provide the general and practical, though often indiscrete, outline by which adolescence evolves (Daniel, 1977; Leichtman & Friedman, 1975; Mercer, 1979). These categories are also points referenced later in the review in the context of which the adolescent with cancer or any other handicapping disease is discussed.

Early adolescence may roughly be considered the period of puberty--ages 12-14 years. During this time, physical growth and sexual changes are occurring rapidly and acceptance of the physical self and establishing a realistic body image are of utmost importance (Daniel, 1977; Mercer, 1979). Unreasonable requests, peer comparisons, confusion, off-color humor, and fascination with pornography and masturbation are often quite evident. Privacy, setting limits, and being available for talking to reaffirm their feelings of normality are important (Leichtman & Friedman, 1975).

Middle adolescence, the period of identification, includes the ages of 15-17 years: the young person is now preoccupied with bodily changes and the seeking of independence from parents, thereby permitting peer relations and establishing individual identity and value systems. Fantasies, drama, creativity, narcissism, and mood swings are prevalent and vacillate from moment to moment (Blos, 1967; Mercer, 1979). In this stage, deductive reasoning, problem solving, and debating are developing. The adolescent is also concerned with academic achievement, finances, and philosophical issues of moral responsibility (Liechtman & Friedman, 1975).

Late adolescence spans from 17 years until adulthood: this is the period of coping and mastery of one's environment. During this time "parents and society increase their demands on the teenager to achieve self-sufficiency and to assume responsibility for independent living, career choices and consolidation of identity" (Mercer, 1979, p. 188). The young person also attempts to achieve and maintain stable relationships, maintain respect of self, and stabilize mental functioning capacities to safeguard his integrity. Cognitive

functioning is fairly stable and problem solving is more comprehensive and less sporadic.

Knowledge of normal psychosocial development is important and valuable for nurses and other health professionals who are involved in caring for healthy adolescents or adolescents with cancer, or other chronic/handicapping conditions. A life-threatening illness, such as cancer, presents the adolescent with many limitations that vastly complicate the process of mastering normal developmental tasks and also compounds the effects of a chronic illness. Since the main goals of rehabilitation of the adolescent with cancer are to cure the disease and to close the gap between the physical limitations and psychological maladaptations, it is wise for the professional to have a baseline knowledge to maximally support the adolescent with cancer and in the context of this study, better understand and promote feelings and attitudes relative to positive meaning and purpose in life during hardship.

The Adolescent with Cancer

When an adolescent has a life-threatening chronic illness, such as cancer, whether it is acquired or recently diagnosed, the issues and problems of adolescence often become even more complicated. This situation is

intensified by the fact that a teen must learn to cope and live with a malignant disease as well as undergo the normal stresses of adolescence. Advances in therapy in the last 25 years have allowed adolescents to live with their malignancy and grow toward maturity. However, helping these teenagers to cope and adapt to their life-threatening illness is not an easy task. It is generally expected that different persons with different types of malignancies will cope with their situation differently at various times. Many factors influence the adjustment of an adolescent to a life-threatening disability. However, with anticipatory guidance, support, sensitivity, and baseline knowledge of human development, it is possible that these teens can continue to proceed with the normal developmental tasks of establishing their own identity and self-concept and gain mastery and control over their own lives on target with other healthy teens (Fochtman, 1979; Mercer, 1979).

As referenced earlier in the text, the stage of development that the adolescent is in is a factor that influences adjustment. In the early adolescent stages (12-14 years), acceptance of growth and a changing body image is of extreme importance. This realization of body

changes, whether it be with healthy adolescents or during a time of sickness or disfigurement, often causes panic, uncertainty, and anxiety. Often, teenagers balk at the side effects of therapy required for treating their malignancy. They may lose their hair, lose a limb, experience pubertal delay and growth retardation, and experience other side effects of therapy which can be devastating (Holton, 1980). Young adolescents who are faced with an illness may also face the dilemma of becoming dependent on parents for medical reasons and feel a sense of helplessness from which they may see no future relief. Such a feeling of hopelessness about ever achieving mastery over their body and environment may lower their self-concept and overall coping abilities at an early stage of their adolescent development (Mercer, 1979). During middle adolescence (15-17 years), when independence from parents, peer relations, and fuller efforts toward establishing identity and values are important, a chronic illness at this time interrupts these processes. Peer relationships are affected because of rejection by their healthy friends who themselves are uncertain about their own adequacy and feel threatened by limitations seen in others. Such a lack of acceptance by peers often produces great emotional distress to the ill teenager and, therefore, is an issue

to be dealt with to prevent further lowering of self-concept and identity formation. Likewise, constant relying on parental support for necessary physical and emotional assistance, binds the teenager to the parent at a time when he wants freedom and independence. Such a conflict can result in antagonistic behavior toward a parent or other authority figure and likewise lead to coping and attitude problems concerning their illness. A life-threatening or chronic illness during the late adolescence stage (17 years and up) threatens many of the goals of adult living. To achieve self-sufficiency and assume responsibility for independent living and choose a career and consolidate one's identity requires alterations of plans, often increasing the young person's frustrations, hostility, and feelings of hopelessness. The forced passivity and loss of autonomy can be humiliating. The greater the degree of and the more prolonged the limitation of activity and isolation, the greater the regression toward dependence and maladaptive coping responses (Morrow, 1978).

From a psychological point of view, the emotional needs and responses of the adolescent with cancer will depend upon the specific nature of the cancer, the site,

the treatment, and the course. These will determine to what extent and how the patient and his significant others must adjust (Tiedt, 1975). With the adolescent, it is more often "the symptom than the life expectancy that provokes the behavioral responses and arising needs of those involved" (Plumb & Holland, 1977, p. 57). The perception of the symptom dictates for patients their mood and hope. Therefore, it is important to "take into account the power of the presenting symptom and the patient's interpretation of it throughout the clinical course" (Tiedt, 1975, p. 265). If such concern is not addressed, the illness may further "isolate the adolescent from meaningful peer relationships, deprive him of control over himself or his environment, foster dependence and apathy and impede the transition to responsible, meaningful self-actualization" (Fochtman, 1979, p. 27).

The meaning of the illness to the patient, the reactions to the illness, and the defensive maneuver for handling underlying psychological distress are issues of concern in chronically-ill persons. Although each person generally looks upon his illness in a unique manner,

basically the person perceives the illness as a threat to his bodily integrity. Thus, how the patient accepts this loss becomes of prime importance. Secondly, the illness affects the interpersonal aspects of life and his

relationship with the world about him. (Abram, 1972, p. 659).

This transition is often a crisis period for the adolescent sustaining the diagnosis of cancer. Given the limitations of current treatment modalities for long-term diseases, such as cancer, adolescents must cope with the physical, social, and psychological manifestations of their illness. Adolescents must modify daily activities and routines, rearrange their environment, and revise patterns of interaction with others. "In essence, they must redesign their lives and circumstances to compensate for, circumvent, or surmount the difficulties they face" (Reif, 1973, p. 261).

In perspective, adolescence is a period of breaking ties with parents, facing up to one's life, and becoming autonomous. Anything that has to do with separateness has to do with loneliness. Loneliness likewise borders with levels of meaninglessness, aimlessness, purposelessness, and bored behaviors. This is a naturally occurring phenomena in today's society of healthy teenagers (P. Chesmore, personal communication, February 21, 1982) and an issue of concern.

In contrast, what does the adolescent with a chronic disease such as cancer experience in terms of meaning and

purpose in life? No studies were found that related directly to meaning and purpose in life in either healthy or ill adolescents. A few related psychological research projects were reviewed which tested for the effects of illness in adolescence in terms of anxiety, self-esteem, locus of control, impact of illness, and coping styles.

In a study by Kellerman, Zeltzer, Ellenberg, Dash, and Rigler (1980), 349 healthy adolescents were compared with 168 adolescents with various chronic or serious diseases on a standardized measure of trait anxiety, self-esteem, and health locus of control. No differences in anxiety or self-esteem were found between healthy and ill groups or between various ill groups. Patients with oncologic, renal, cardiac, and rheumatologic disorders perceived significantly less control over their health than did healthy adolescents and patients with cystic fibrosis or diabetes mellitus.

Kellerman et al. (1980) suggested that there is doubt that chronic or serious disease inevitably leads to psychologic disturbance in adolescents. This is unlike other studies which suggested psychologic maladjustment associated with a variety of chronic diseases (Mattson, 1972). The study by Kellerman et al. (1980) presented a pattern of normal attitudes and psychologic adjustment

among adolescents regarding control over health. There was marked similarity between healthy and ill adolescents on measure of self-esteem and trait anxiety. This result is consistent with previous findings in which life stress was found to be related to anxiety in healthy children but not in those with chronic disease (Bedell, Giordani, Amour, Tavormina, & Boll, 1977). This suggests that for the healthy child, stress is seen as a disruption and change produces anxiety. For the chronically-ill child, he has learned to live with varying degrees of disruptions, developed more tolerance for stress, and generated effective coping mechanisms.

Bedell et al. (1977) stated that evaluating the effects of serious disease upon day-to-day functioning and living with the disease is more important than emphasizing psychologic problems. Kellerman et al. (1980) also suggested that further work be done to determine if treatment modalities that emphasize self-help techniques (i.e., self-hypnosis, autogenic techniques for pain control) have an effect upon locus of control and subsequent adjustment. A study by Tavormina, Kastner, Slater, and Watt (1976) suggested that chronically-ill children's functional strengths and coping abilities outweighed any of their perceived weaknesses.

In a follow-up study, Zeltzer, Kellerman, Ellenberg, Dash, and Rigler (1980) designed a project to relate the adolescent's perception of the influence of illness upon body image, autonomy, relations with peers, family interaction, sexuality, future aspirations, and education. Total impact of illness (e.g., leukemia or colds) did not differ significantly between ill and healthy respondents, and the nature of adolescent concerns was similar for both the healthy and diseased adolescents. Zeltzer et al. postulated that since healthy adolescents are usually well, any disruption of daily routines is perceived as significant, unlike the chronically-ill adolescent who frequently undergoes numerous disruptions and may tend to underplay any but the most major illness as a disruption.

Likewise, restriction of freedom was seen as the major disruption brought about by illness. Other areas of impact that affected them included relations with peers, siblings, and parents. Of significance was the fact that the adolescent cancer patients were most likely to view treatment as highly disruptive and expressed greatest disruptions of body image secondary to disease and treatment. Zeltzer et al. (1980) hypothesized that the word cancer is so emotionally laden and frightening that

the label itself was enough to traumatize the family dynamics and disrupt interpersonal relations. Also of significance was the finding that most patients in all samplings perceived the treatments as worse than the disease itself.

Katz, Kellerman, and Siegel (1981) demonstrated in their study that a large percentage of pediatric and adolescent cancer patients were highly anxious regarding bone marrow aspirations and lumbar punctures and that repeated procedures do not necessarily lessen anxiety on subsequent occasions. Zeltzer et al. (1980) found that females in all groups reported more impact of illness on physical appearances than did males. This difference was greatest in adolescents with cancer, rheumatologic disease, and cystic fibrosis. Also, Zeltzer's et al. (1980) data supported the notion that chronically-ill adolescents (diabetes mellitus, cystic fibrosis, cancer, cardiac, renal, and rheumatologic diseases) are a psychologically healthy population. Such normalcy suggests that psychologic explorations may not be as useful as psychosocial rehabilitation aimed at learning to cope with specific disease and treatment-related problems as well as learning to attain a general hopeful and

meaningful positive outlook regarding their pursuit of autonomy.

Based on this review of literature concerning adolescents and cancer, one must have an understanding of the normal developmental milestones of adolescence and subsequently relate these tasks directly to the situation at hand with the adolescent cancer patient. Since the symptoms, side effects of treatments, and disruptions of body image are often identified as having the greatest impact, then it might stand to reason that anticipatory guidance, education, and supports aimed at assisting the individual to live with these discomforts might help to offset any psychologic distress and maintain a positive goal-oriented future.

Meaning and Purpose in Life

What is the meaning of life? What is the nature of an individual's experience of his life as meaningful? What are the conditions under which an individual will experience his life as meaningful? These are questions that Battista and Almond (1973) asked as they analyzed the theoretical phenomena of meaning in life. With the quality of human experience becoming a growing concern both in health and in disease, these questions have often

been discussed and debated (Lipowski, 1970). Today more than ever, persons in good and bad health and young and old are complaining of a sense of futility and emptiness, a feeling of meaninglessness.

According to Frankl (1959), the essence of human motivation is to realize a meaning in life; if this does not occur, then existential frustration occurs. This meaning is unique and specific in that it must and can only be fulfilled by the individual himself. Frankl believed that people who are diseased, in pain, or suffering can be happy in the face of tragedy and in spite of suffering if there is meaning and if it is realized. "An appeal to continue life, to survive the most unfavorable conditions can be made only when such survival appears to have a meaning. That meaning must be specific and personal, a meaning which can be realized by one person alone" (Frankl, 1959, p. 23). Frankl felt there is a healing force in meaning.

Dickinson (1975) stated the spirit needs a human relationship; man's present search for meaning needs integrating into everyday life in a spiritual sense, not necessarily once a week in a church, temple, or synagogue. The search for meaning is a ministry; "especially during

illness, where one's mode of living is called into question, character, commitments of the heart, and answers to the ultimate question of what it means to be alive are of supreme importance" (Dickinson, 1975, p. 1978).

Dickinson stated that the importance of man's search is the "difference between being happy or sad. Experiencing trouble or pleasure in this existence depends on whether or not a person has found meaning" (1975, p. 1790). If whatever we are doing or suffering has meaning to us, we are at peace. But, if it is meaningless to us, we are desperately unhappy.

Travelbee (1971), who wrote extensively on the interpersonal aspects of nursing, noted that the human being is motivated by a search for meaning in life experiences and that meaning, too, can be found in the experiences of illness, suffering, and pain. When such meaning is found, the individual is able to achieve self-actualization. This sense of spirituality, therefore, is the central core of man, a distinctively human phenomenon which causes one to search for meaning and purpose in life, meaning in terms of responsibility, commitment in terms of total response to responsibility, sense of direction (where am I going?) and a sense of identity (who am I?).

The role of hope has been consistently tied to man's quest for meaning. Korner (1970) defined hope as "an essentially positive phenomenon necessary for healthy coping, its key purpose being the avoidance of despair, with the secondary function of permitting the individual psychologically to bypass ongoing unpleasant or stressful situations" (p. 134). Today, there is much recognition in the power of hope to make life under stress tolerable; previously hope had been largely ignored by health practitioners since there were practically no controlled observations on the effectiveness of hope as a coping defense mechanism. This was due to the widely-held belief that hope was virtually a mixed blessing in a spiritual sense.

Vailliot (1970) combined these concepts of spirituality and meaning in life by stating that the spirit is "the quality of those forces which activates us or the essential principles influencing us" (p. 272). Vailliot was an advocate of the existential philosophy of nursing, meaning a "philosophy of commitment" (1970, p. 500). Like most existentialists, Vailliot (1966) believed that the task which confronts each of us is to pass from existence to being. This is actualized through commitment. Vailliot

stressed that the worth of the individual is through the freedom of "becoming" and acceptance of one's life.

Orem's (1980) self-care theory also stressed the meaning of a person's life, emphasizing the individual's own efforts to establish his role and place and to give meaning to life and death. The concept of self-care implies that the individual learn to explore his possibilities, choose his actions, and create his values with the potential for achievement.

Orem (1980), Travelbee (1971), and Vailliot (1966) utilized existential concepts to view man and his relationship with health care and in particular to operationalize nursing. Vailliot (1966) viewed the nurse as the one health professional who meets the needs of the patient in a multi-dimensional sense. Vailliot believed that the nursing profession is unique in its role in assisting people to find meaning in life.

Lange (1978), in her writing, described six nursing actions to assist a patient in coping, maintaining, and restoring hope. The sixth and final coping skill was "finding a general purpose or pattern of meaning in the course of events of a crisis, illness, treatment, and/or outcome" (Lange, 1978, p. 189). The corresponding nursing

action was that "the nurse recognize the complexity of any given illness situation and respect how individuals differ in their responses" (Lange, 1978, p. 189). This challenge was based on the belief that nurses, because of their philosophical and multidimensional level of understanding and awareness can assist the patient and his family to experience meaning in different situations where hope is vital.

Oftentimes a nurse is the one person who can help a patient and his family come to an understanding of what the patient has experienced and why. The availability and the consistent presence of a nurse in a therapeutic relationship during time of sickness and despair can enrich the patient by helping him mobilize his own internal strengths and responses (Dickinson, 1975). Leininger (1977) stated "caring . . . is the most essential and critical ingredient to any curative process" (p. 200). The function of the nurse

is to care for the patient to help create an environment in which recovery is swift . . . it is important that nurses help release any untapped potential . . . and create a climate in which faith may grow, a climate that can be achieved by listening, supporting, emphasizing and encouraging. (Peck, 1981, p. 159).

This challenge may be difficult in the case of cancer patients who are actively receiving treatment.

Feelings of hope often fall by the wayside when cure is not a reality. The concern for the quality of life remains a major theme of intervention for the cancer patient. The recent attitude is to promote a positive side to active treatment and likewise have a genuine interest in the patient as a human being (Peterson & Kellogg, 1976).

"In my personal practice, my experience of over 25 years has made it obvious to me that one cannot predict the precise course or outcome of cancer." The old adage 'He will be dead in six months' or 'I will give him a year to live' is an unforgiveable statement for a physician to make; unforgiveable because there are no valid grounds to make so rigid a prognosis. One can never tell. This uncertainty about the future introduces a ray of hope, however small, for both patient and family. Do not misunderstand me. I am merely emphasizing that the course and alternate outcome can only be determined by day-to-day observation. No matter how grim the situation, there is always room for hope." (Dunphy, 1976, p. 314)

Measurements of quality of life in chronically-ill and/or cancer patients has never fully been established or standardized. Likewise, only a few studies have researched the particular notion of meaning and purpose in life.

Meaning or purpose in life has been studied using the Purpose in Life (PIL). Crumbaugh and Maholick (1964) designed this test to measure the degree to which a person

experiences Frankl's meaning and purpose in life. In one of his studies, Crumbaugh (1968) sampled 230 healthy businessmen and professionals and compared their PIL scores to a sampling of psychiatric patients and alcoholics. In Crumbaugh's study, the healthy group ($n = 230$) averaged a score of 118.9 on the PIL, while the psychiatric patients ($n = 225$) scored lower. Outpatient neurotics averaged 73.3; alcoholics averaged 85.4; and the mean score for schizophrenics was 96.7. These findings were similar to Yarnell's (1971) study which compared Air Force men ($n = 40$) and male schizophrenics ($n = 40$). The scores on the PIL were 110.03 and 81.88, respectively. In another study concerning undergraduate students, 27 marijuana users were compared to 28 nondrug-using students via the PIL. Mean PIL scores for the control was 98.39, while regular marijuana users had a mean of 88.47 ($SD = 1.97$, $p < .001$). Results indicated that drug users scored significantly lower on the PIL.

In another study, Meier and Edwards (1974) examined age and sex differences in healthy subjects with respect to meaning in life and PIL scores. The mean PIL score of the 13-15 age group differed significantly from the mean PIL score of the 17-19 ($p < .01$), 45-55 ($p < .01$), and 65

and over ($p < .01$) age groups, utilizing a fixed effects, two-way analysis of variance. Using the same statistical test, it was found that there were no significant sex differences in PIL scores ($p < .05$). A further analysis related differences in educational level and religious affiliation to PIL scores. Final results being that age groups, through ANOVA, were found to differ in PIL scores, but no sex differences or age/sex interaction were found. The two youngest age groups, 13-15 and 17-19 years (each with $n = 220$), were found to score significantly lower than three older age groups.

Research with the meaning and purpose in life concept has often attempted to relate the PIL to measures of personality and psychopathology. Phillips (1980) inspected the relationship between the PIL and measures of depression and locus of control among 134 healthy college students (mean age 19 years). After administering the PIL, the Self-Rating Depression Scale, and the Internal-External Locus of Control Scale, it was found that the PIL does measure more than absence of depression and internalized perceived locus of psychological reinforcement. Raw scores revealed consistent increase in PIL scores from depressed to nondepressed and from external to internal

locus of control, thus possibly inferring that the PIL items could predict depression and locus of control.

Only one specific study was located which compared cancer patients with healthy individuals on the PIL; this study involved adults. Grant (1980) found a significant difference in the experience of meaning and purpose in life in cancer patients ($n = 64$) receiving active treatment when compared to that of the normal population as measured by the PIL ($p < .001$). Ages ranged from 32 to 80 years; the mean score of the healthy sample was 119.9 ($SD = 11.3$). The mean score of the cancer sample was 107.3 ($SD = 15.73$). The findings of Grant's study also indicated that although the actively treated cancer sample scores were not as low as the psychiatric population scores in other studies, the scores were lower than most samples of normal populations. The question at hand is whether the variable of living with cancer is responsible for the differences in scores between the control group and study sample.

Kennedy, Tellogen, Kennedy, and Havernick (1976) studied adult cancer patients and found that in cancer patients experiencing an apparent cure, their attitude about life was subsequently very positive. It is very

difficult to separate the effects, feelings, and experience of the cancer from the effects related to the specific treatments on a day-to-day basis. A frequent comment stated in the literature by adolescents responding to questioning concerning their ability to cope with cancer is the fact that they often do not think of themselves as sick. They attempt to go on living and not dwell on their disease. They learn what to expect, and they share information and support each other. The teens learn to understand how they feel and why and relate to other people without feeling different all the time. The adolescents related that it is important to prepare for the future academically, socially, and personally; share your own life with others meaningfully; yet remembering you are a person first and secondly you have cancer. It is in this respect that the adolescent comes to terms with the meaning of his/her disease.

No findings in the literature search revealed any differentiations between the role and use of logotherapy in counseling adolescent patients, whether healthy or inflicted with a disease. Although the literature continually advocated the role of the health professional, especially the nurse, in assisting an individual to find

meaning and purpose in time of illness, pain or hardship, such a research study was not found. Certainly efforts to research these phenomena would be warranted.

Summary

A review of literature was completed to research the psychosocial development of adolescent, review adolescent's development in relation to cancer, and review the concepts of meaning and purpose in life. Adolescence was presented as a unique stage in life with the central developmental task being to develop a sense of identity and subsequently a meaning in life congruent with the individual's own needs and congruent with society's norms. The adolescent who is handicapped by chronic disease, such as cancer, often finds these tasks very difficult to accomplish.

Bedell (1977), Kellerman et al.(1980), and Zeltzer et al.(1980), in their related studies of healthy and diseased adolescents, found no significant differences between the healthy and sick subjects on a variety of psychological reactions. The nature of adolescent concerns were similar for both healthy and diseased adolescents.

Frankl's (1959) theory relative to life stated that realizing meaning and purpose in life is essential and that meaning in life can be found during times of sickness, suffering, pain, and discomfort. A related concept to meaning in life is hope. Likewise, hope, and meaning can be found in the most desperate of situations.

Bearing these facts in mind, the role of nursing is to assist the patient and his family to discover meaning during times of difficulty. Of paramount importance when working with adolescents is to understand the basis of their growth and development and incorporate Frankl's (1959) concepts of existentialism so that the adolescent's experience with cancer will allow him/her to live life with his/her greatest degree of normalcy and wellness, recognizing the limitations and confines of the disease.

CHAPTER 3

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

This investigation was a descriptive, comparative study. The study was designed to determine the degree to which adolescent cancer patients receiving active treatment experience a sense of meaning and purpose of life compared to healthy adolescents' sense of meaning and purpose in life. The data were obtained by administering a questionnaire, the Purpose in Life Test (PIL), to adolescent cancer patients receiving active treatment in a clinic and healthy adolescents in a social setting.

Polit and Hungler (1983) stated that descriptive investigations observe, describe, and often classify phenomena. Descriptive research has been used frequently in nursing research to describe behaviors and attitudes. Research of a descriptive nature can lead to tentative relationships between phenomena.

Setting

The data were collected in two settings. The adolescent cancer patients were selected from one pediatric oncology clinic which is a regional referral center for pediatric and adolescent oncology patients.

The clinic is located in a large southwestern metropolitan city. The healthy adolescents were obtained from an organized youth group located in the same southwestern metropolitan area.

Population and Sample

An accessible population was used in this study. "An accessible population is the aggregate of cases which conform to the designated criteria and which is accessible to the researcher" (Polit & Hungler, 1983, p. 428). The subjects for both groups were selected by convenience or accidental sampling. This method of selection was used to obtain the sample subjects who were most readily available (Polit & Hungler, 1983). Ten adolescent cancer patients comprised one group. This group was compared to a group of 10 healthy adolescents. The PIL was administered to each group.

The criteria required for the adolescent with cancer to participate in the study included (a) confirmed diagnosis of cancer; (b) active treatment of cancer (chemotherapy, radiation, immunology, or any combination); (c) willingness of the individual to participate; (d) parental consent; (e) between the ages of 14 and 19 years; and (f) able to read, write, and comprehend English.

Protection of Human Subjects

In compliance with the current rules and regulations of the Texas Woman's University Human Research Review Committee, the following steps were taken for the protection of human subjects.

1. Prior to the initiation of the study, permission was obtained from Texas Woman's University Human Research Review Committee (Appendix A) and from the Graduate School (Appendix B).

2. Prior to the collection of data, permission was obtained from the agencies at the proposed locations of data collection (Appendix C).

3. Prior to the administration of the questionnaire, written consent was obtained from participating adolescent cancer patients and one or both parents/guardians (Appendix D). In the case of the healthy adolescent population, one or both of the parents/guardians of the students gave permission. Attention was given to the following:

a. The subject read and received a verbal explanation of the procedure (Appendix E) in the form of an introductory letter explaining the nature of the study.

b. The subject read and received a verbal description of the associated discomforts and risks.

c. The subject read and received a verbal description of the benefits to be expected.

d. The subject was asked to respond to the questions and words on the questionnaire. There was no alternative procedure or treatment to offer the subjects.

e. The subject received a verbal offer to answer any questions concerning the procedure.

f. Each subject was informed that his participation was voluntary and that he was free to withdraw from the investigation at any time without penalty. Care of the adolescent cancer patient was not altered by participation or refusal to participate in the study.

4. In order to assure confidentiality and anonymity, the subject was asked not to use his name on any form. Data were reported as group data so that an individual was not identified. Subjects were advised of their right to withdraw from the study at any time with no penalty.

Instrument

The instrument utilized in the study were the Purpose in Life Test (PIL) (Appendix F) developed by Crumbaugh and Maholick (1964). The PIL instrument was developed and tested prior to publication in 1964. In this study, the instrument was used to measure the degree to which adolescent cancer patients receiving active treatments and healthy adolescents experienced a sense of meaning and purpose in life.

Permission to use the PIL was received from Crumbaugh (Appendix G). The cost of each questionnaire was nominal.

The PIL is an attitudinal, Likert scale consisting of 20 items composed of self-ratings. Each item is a 7-point scale, which has specific feelings associated with the numbers on a continuum. The scale was specially designed to evoke responses believed related to the degree to which an individual experienced "purpose in life." The statements and associated numbering systems are scored so that positively-worded statements and nonendorsement of negatively-worded statements are assigned a higher score. The direction of magnitude was randomized for the items in

order that position preference and the "halo" effect might be minimized (Crumbaugh & Maholick, 1964). The subject's total score is determined by adding together individual item scores. The PIL consists of 20 items rated from 1 (low purpose) to 7 (high purpose). The total scores range from 20 to 140. A high score reflects a positive attitude while a low score reflects a lack of meaning and purpose in life.

To support the notion of construct validity, the PIL was able to distinguish between patient and nonpatient populations on a consistent basis; therefore, differentiating the purpose in life phenomena from other psychopathology. One study of 225 subjects comprised five subpopulations: Group I, 30 nonpatient Harvard summer school graduate students; Group II, 75 nonpatient undergraduate college students; Group III, outpatients of various cooperating psychiatrists in private practice; Group IV, outpatients of a private psychiatric clinic; and Group V, hospitalized alcoholic patients. Findings resulted in a significant discrimination between patients and nonpatients, and a progressive decline in mean score from Groups I through V, both for the total scores and for

most of the individual items (Crumbaugh & Maholick, 1964).

The study of concurrent validity in correlating the test scores with therapists' ratings of "purposefulness" in patients yielded only modest success. The Frankl Questionnaire (FQ), which was developed by Frankl (1962), demonstrated his thesis by utilizing an informal series of questions to evaluate and determine clinically the "existentially frustrated" individual. In this instance, there was a high relationship between the PIL and the FQ, indicating that the instrument describes Frankl's (1962) "existential frustration" and may be presumed to represent Frankl's effort to define operationally what he was talking about.

The low relationship between the PIL and the Minnesota Multiphasic Personality Inventory supported Frankl's hypothesis of a new type of neurosis and, therefore, different from the usual measure of clinical psychopathology. The low relationship between the PIL and the Allport-Vernon-Lindzey Scale of Values (A-V-L) suggested that the purpose or meaning in life was not just another name for values in the usual sense. Frankl (1962) believed that purpose in life represents a basic

motivating force best described as spiritual. Robinson and Shaver (1969) summarized the reliability and homogeneity of the PIL by stating that a split-half correlation of .85 was reported for a sampling of 120 subjects.

Normal and psychiatric samples were originally studied by Crumbaugh and Maholick (1964). The normal population consisted of businessmen and other successful professionals, college undergraduates, older-aged persons, and indigent hospital patients. The psychiatric group consisted of neurotics, alcoholics, schizophrenics, and psychotics. Since that time, the instrument has been utilized by other researchers in determining meaning and purpose in life in adult cancer patients (Crumbaugh, 1972).

Permission was granted by Crumbaugh (Appendix G) to utilize the tool and to make minor adjustments in the wording to meet the cognitive level of adolescents. In question 7, the words "after retiring" were changed to "after high school." Other adjustments altered only words while maintaining the central thought and weight.

Prior to the main data-gathering event, the instrument was sent to two panels of experts, who participated

in its evaluation in order to determine content validity and appropriate use of language in accordance with the adolescent's cognitive and developmental understanding. One panel consisted of three individuals: a registered and certified nurse practitioner, a social worker, and a psychologist, all of whom worked in an adolescent clinic. The second panel was comprised of two adolescents, a 15-year-old male and a 17-year-old female. Both panels agreed that the instrument was appropriate for use with adolescents.

Data Collection

The procedure for the collection of data used in this study follows. The sample for the investigation was obtained with the cooperation of the administration and staff of the pediatric oncology clinic and the youth group leader of the healthy subjects.

To enlist voluntary participation from the healthy adolescents (Group I), they were approached by the researcher in a youth group meeting or on an individual basis via home visits. During the home visits, the teen and a parent or legal guardian were present. The interested subjects read and received standardized verbal instructions (Appendix E) and an explanation of the

purpose of the study. Confidentiality and privacy of the responses were emphasized. Approximately 10 minutes was needed for completion of the instrument. Those students who volunteered obtained consent from their parents or legal guardians before completing the instrument. When the explanation was completed and consent obtained, the subjects were given the PIL and demographic sheet to complete.

Agency permission (Appendix C) was given to obtain the adolescent cancer patients. Data on available subjects who met the criteria were obtained from the nursing staff of the pediatric oncology clinic. In order to contact the subjects, the investigator made phone calls and home visits to enlist their voluntary participation. Interested subjects and their parents or legal guardian read and received the standardized verbal approach (Appendix E) explaining the purpose of the study. Confidentiality and privacy were emphasized. Those subjects who volunteered obtained consent from their parents or legal guardians (Appendix D) before completing the test. When the consent was obtained, the subjects were given the PIL and demographic sheet to complete.

Treatment of Data

The PIL consists of 20 items rated from 1 (low purpose) to 7 (high purpose). Total scoring ranges from 20 to 140. The score of each participant was determined by adding the numbers of each response together for a total sum. Data were analyzed by means of a two-tailed t-test. The t-test is a parametric procedure used when the researcher wants to compare group means. This statistical test was consistent with Crumbaugh and Maholick's (1964) statistical procedures. The level of significance was set at 0.05. The results of the computational procedures determined whether or not a difference in scores existed between the cancer group and the healthy group.

CHAPTER 4

ANALYSIS OF DATA

A descriptive, comparative study was conducted to determine the degree to which adolescent cancer patients receiving active treatment experience a sense of meaning and purpose in life when compared to healthy adolescents. This chapter describes the results of the data collected through the use of a questionnaire, the Purpose in Life Test (PIL) (Crumbaugh, 1968). This instrument was administered to an adolescent cancer group and a group of healthy adolescents. A t-test was the statistical measure used to analyze the data. The discussion of the data analysis follows.

Description of Sample

Twenty adolescents participated in the study. The subjects were a convenience sampling between 14 and 19 years of age consisting of 10 healthy adolescents and 10 adolescent cancer patients actively being treated. The group of healthy adolescents were between the ages of 15 and 18 and all attended junior or senior high school on a regular basis. Six (60%) were male and 4 (40%) were

female. The mean age was 16 years, and the median was 15.5 years. Of the 10 healthy adolescents, 2 (20%) were 18 years, 1 (10%) was 17 years, 2 (20%) were 16 years, and 5 (50%) were 15 years. The ages of the adolescent cancer patients ranged from 14 to 19 years. Ten (100%) attended junior or senior high school regularly. There were 7 (70%) males and 3 (30%) females. The mean age was 14.7 years, and the median age was 14.5 years. Of the 10 cancer subjects, 5 (50%) were 14 years, 4 (40%) were 15 years, and 1 (10%) was 17 years. None of the subjects fell in the 16- or 18-year-old bracket. All of the healthy adolescents were Caucasian. Eight (80%) of the cancer patients were Caucasian, one (10%) was Black, and one (10%) was Latin American.

The adolescent cancer patients were at various stages in their treatment. Ten (100%) of the cancer patients were receiving chemotherapy; of these 10, 5 (50%) were also receiving radiation as an adjuvant treatment. The length of time from diagnosis to the present varied from 3 months to 5-1/2 years. The mean length of time from date of diagnosis to the present was 18.2 months, and the median was 10 months. Eight (80%) of the adolescent

cancer patients were in remission, while 2 (20%) were not in remission or had relapsed at the time of the testing.

The following are the types of cancer found in the adolescent cancer patients: Acute Lymphoblastic Leukemia (ALL) three (30%); Acute Myelogenous Leukemia (AML), one (10%); Hodgkin's Disease, three (30%); Ewing's Sarcoma, one (10%); Burkett's Lymphoma, one (10%); and Medulloblastome, one (10%). The type of religion among the cancer patients varied. Nine (90%) were of the Protestant faith; three (30%) were Baptist; two (20%) were Methodist; one (10%) was Christian; one (10%) was Lutheran; one (10%) was Church of God; one (10%) was Pentacostal; and one (10%) was Catholic. All (100%) of the healthy adolescents were of the Protestant faith; five (50%) were Christian, three (30%) were Methodist, one (10%) was Lutheran, and 1 (10%) was Baptist. Five (50%) of the healthy adolescents had never been hospitalized prior to this testing, while five (50%) had been hospitalized for reasons, such as tonsillectomy and adenoidectomy (20%), head injury (10%), pneumonia (10%), and myringotomy (10%).

Findings

When examining the profile of the overall group scores and the age and gender of the groups, two patterns were found regarding the distribution and frequency of the PIL scores. Figure 1 displays the patterns of scores for the two groups.

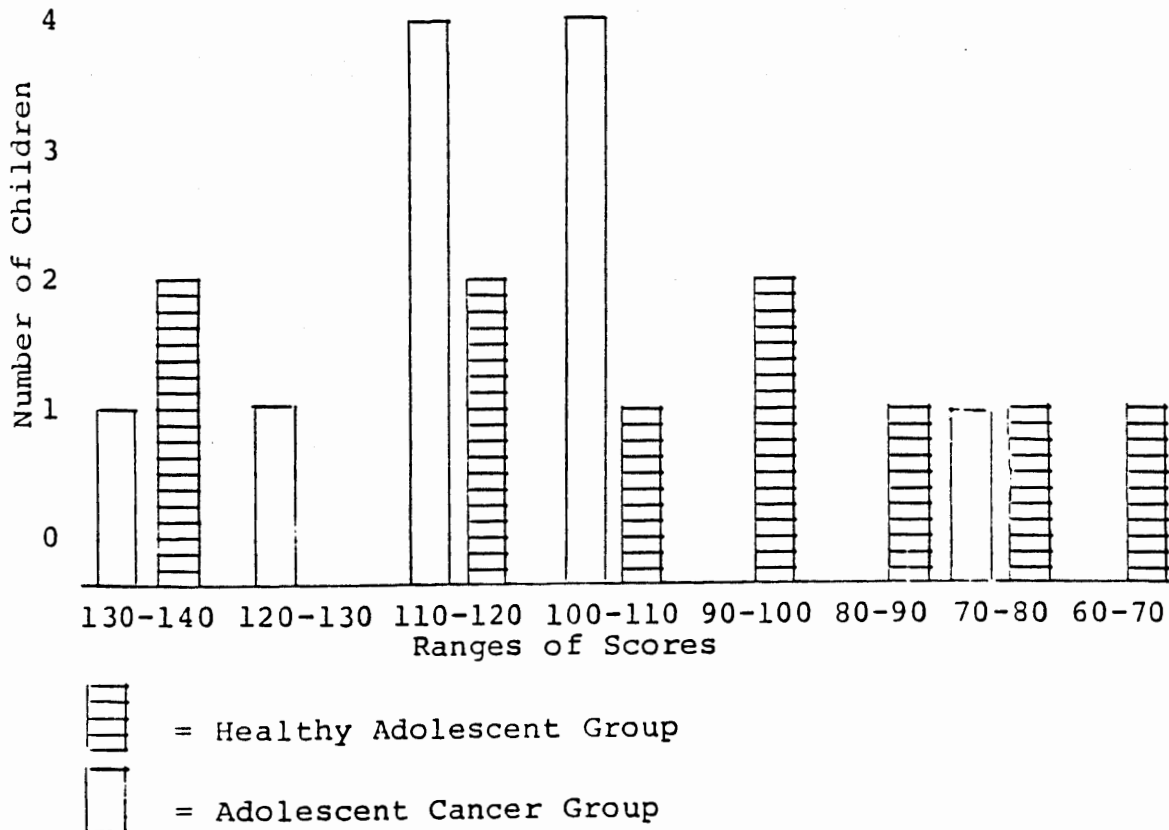


Figure 1. Group distribution and frequency of PIL scores

Among the healthy adolescents, 6 (60%) of the 10 subjects were male; their mean score was 100.33 with a range of 65-131 on the PIL. Likewise, the female group comprised 40% of the sample with a mean score of 102.25 and a range of 76-118 on the PIL.

The age range of the males was 15 to 18 years. Three of the five 15-year-olds were males. One of the 15-year-old males scored the lowest on the PIL. There were two 16-year-olds, one male, one female; again the male scored lower on the PIL. There was one 17-year-old female, and two 18-year-olds: one female and one male; the male scored higher on the PIL.

From these descriptive data, the female subjects in the healthy group scored slightly higher on the PIL according to the mean (mean = 102.25) and had a relatively smaller range of scoring on the PIL at 76-118 as compared to the male group. Also, according to Crumbaugh and Maholick (1964) "the PIL raw scores from 92 through 112 are in the indecisive range, scores above 112 indicate the presence of definite meaning and purpose in life; scores below 92 indicate the lack of clear meaning and purpose" (p. 4). Therefore, according to this reference, both the male and female subjects in the healthy adolescent group

would fall within the 92-112 indecisive range. The females scored only slightly higher than the males.

In the control group, 5 (50%) of the 10 subjects were 15 years old. The mean PIL score of the 15-year-olds was 92.2 with a range 65-130. In the 16-17-year-age range, the mean PIL score was 110 with a range of 86-131. Thus, it might be inferred that within this small sample, the healthy adolescent, regardless of sex or age, is indecisive regarding his meaning and purpose in life and that one's concept of self at this point in his life does not include a full awareness of one's actions, goals, values, and identity in exploring human values for sources of meaning in understanding the relationships of life's experiences.

Among the adolescent cancer patients, 7 (70%) of the 10 subjects were male; their mean score was 110.57 with a range of 101-125 on the PIL. The females comprised 3 (30%) of the 10 subjects with a mean score of 96.3 and a range of 75-110. The age range of the males was 14-17 years. Three of the five 14-year-olds were males and two were females. One of the 14-year-old females scored lowest on the PIL. There were four 15-year-olds; all were males. The 17-year-old was a female subject.

In comparing the two groups, the female adolescent cancer patient's mean score was relatively lower than the healthy adolescent, 96.3 and 102.25 respectively, but both groups had a similar raw scoring range of 75-110 and 76-118 regardless of age subcategories. In the case of the males in both groups, the male cancer group's mean PIL score was relatively higher at 110.57 compared to the healthy adolescent score of 100.3. The range was substantially different with the adolescent male cancer group's raw score range being 101-125 and the healthy male subjects' score being 65-131. Table 1 displays the summary of the cancer and control groups in terms of PIL raw scores, age, and gender. Mean scores of males and females and the range of scores is found in Table 2.

When further comparing the descriptive data of both healthy and cancer patient groups in terms of overall PIL scores, frequency, and distribution of scores, there is a distinct difference. Although the mean scores of both the cancer group and the healthy group are near equal, the adolescent cancer patient was heavily tailed with two extreme scores, while the healthy adolescent group had a flat scoring range. In the healthy adolescent population, three (30%) had a raw PIL score that indicated lack of

Table 1

Summary of PIL Scores, Ages, and Gender of Cancer Group
and Healthy Group of Adolescents

Subject	Cancer Group			Healthy Group		
	Score	Age	Gender	Score	Age	Gender
1	75	14	Female	65	15	Male
2	105	14	Female	76	15	Female
3	110	14	Male	92	15	Male
4	116	14	Male	98	15	Male
5	125	14	Male	130	15	Male
6	100	15	Male	86	16	Male
7	101	15	Male	110	16	Female
8	108	15	Male	105	17	Female
9	114	15	Male	118	18	Female
10	110	17	Female	131	18	Male

Table 2

Means and Range of Scores for Males and Females

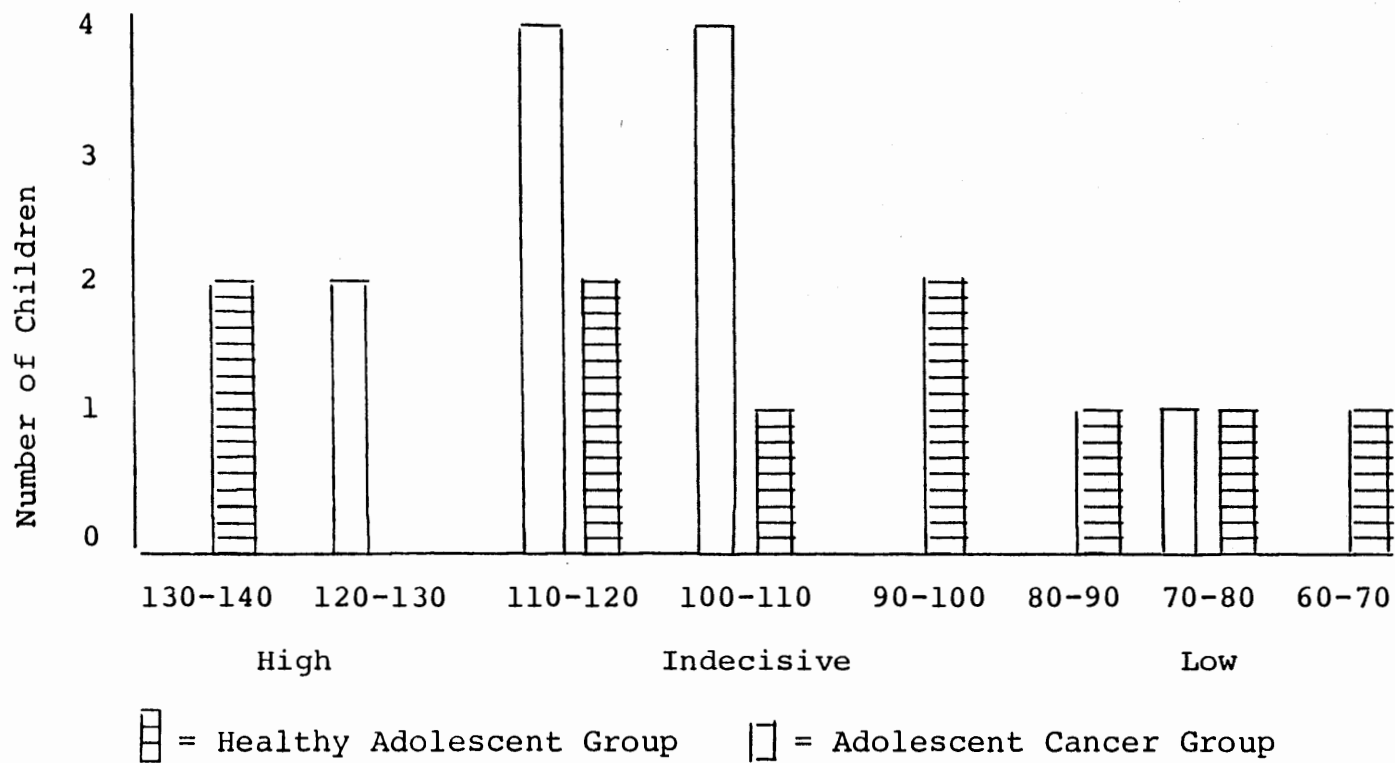
	Cancer Group		Healthy Group	
	Males	Females	Males	Females
Mean	110.57	96.3	100.33	102.25
Range	101-125	75-110	65-131	76-118

Note. Possible scoring range 20-140.

clear meaning. Two of these subjects were 15-year-olds, one male and one female, and a 16-year-old male. Four (40%) fell in the indecisive range: two were 15-year-old males, one a 16-year-old female, and another 17-year-old female. In the high range of meaning and purpose in life three (30%) were in this category: one 18-year-old female, one 18-year-old male, and one 15-year-old male.

In reviewing the dispersion of Group II, the adolescent cancer patients, one (10%) 14-year-old female fell in the range of low meaning and purpose in life. Six (60%) fell in the indecisive range: one 14-year-old male, one 14-year-old female, three 15-year-old males, and one 17-year-old female. In the high range of meaning and purpose in life, three (30%) fell in this area; this included one 14-year-old male, one 15-year-old male, and one 14-year-old male.

Based on this breakdown of raw PIL scores, it appears that, overall, the adolescent cancer patient subjects scored higher and, therefore, appear to have a tendency for experiencing a greater meaning and purpose in life. Figure 2 summarizes the data concerning PIL raw scores, distribution, and frequency, and Table 3 shows group percentages on the PIL.



Score ranges: 92--lack of clear meaning and purpose in life; 92-112--indecisive range; 112--definite meaning and purpose in life.

Figure 2. PIL raw score distribution and frequency

Table 3
Group Percentages on Purpose in Life Test

Group	Low	Moderate	High
Healthy adolescents	30% (3)	40% (4)	30% (3)
Adolescent cancer patients	10% (1)	60% (6)	30% (3)

The hypothesis of this study was: There is no significant difference between the meaning and purpose in life of adolescent cancer patients when compared to the meaning and purpose in life of healthy adolescents as measured by the Purpose in Life Test (PIL). The PIL was scored by using the approach advised in the instruction manual for the Purpose in Life Test (Crumbaugh & Maholick, 1964). The hypothesis was analyzed by utilizing the independent t-test, a basic parametric procedure for testing differences in group means. This statistic was congruent with Crumbaugh and Maholick's (1964) statistical procedures on their projects.

The mean score of the healthy adolescents was 101.1, with a standard deviation of 22.02. The lowest score was

65, and the highest score was 131. The mean score of the cancer group was 106.4, with a standard deviation of 13.26, $n = 10$. The lowest score was 75, and the highest score was 125.

The hypothesis was treated by utilizing the independent t -test for analyzing the differences in the group means. The null hypothesis was accepted; there was no significant difference in the means of the two groups as measured by the Purpose in Life Test (PIL), $t(18) = 0.65$, $p = .523$. Additional statistical testing was applied to the hypothesis. The t -test assumes that the variances of the two groups are equal. Using Bartlett's test, it was found that the variances were statistically equal ($p = .147$). However, this result indicated a tendency for the variances to be unequal. Therefore, the nonparametric counterpart to the t -test, Mann-Whitney U, was also performed. The results from the Mann-Whitney U agreed with the previous findings. No significant difference in the groups' PIL scores was shown ($U/10,10 = 4.25$, $p = .571$).

The inference for this sample is that the cancer and healthy subjects had a similar degree or level of meaning and purpose in life. Table 4 shows the difference between

the PIL scores in the healthy adolescent group and the adolescent cancer patient group.

Table 4

Differences between the Purpose in Life Test (PIL)
Scores in the Healthy Adolescents and the
Adolescent Cancer Patients

	Healthy Adolescents	Adolescent Cancer Patients
<u>N</u>	10	10
Mean	101.10	106.40
Standard Deviation	22.02	13.26
Variance	$(22.02)^2$	$(13.26)^2$
Minimum Score	65	75
Maximum Score	131	125

Summary of Findings

The findings of this study can be summarized as follows.

1. According to the descriptive data, a frequency distribution graph of PIL raw scores revealed that the adolescent cancer patients, regardless of age or sex, had

a more heavily tailed scoring range when compared to the healthy adolescent.

2. According to the descriptive data, 14-15-year-old males and females in both groups scored lower on the PIL, indicating lack of clear meaning and purpose in life and indecisiveness about meaning and purpose in life in that age category.

3. The mean score for the healthy group was 101, while the mean score for the cancer group was 106.

4. There was no statistically significant difference in the experience of meaning and purpose in life in adolescent cancer patients when compared to the control group of healthy adolescents as measured by the PIL.

CHAPTER 5

SUMMARY OF THE STUDY

A descriptive, comparative study was the methodology used to determine if there is a difference between the meaning and purpose in life of adolescent cancer patients when compared to healthy adolescents. A null hypothesis was tested which stated there is no significant difference between the meaning and purpose in life of adolescent cancer patients when compared to the meaning and purpose in life of healthy adolescents. This chapter reports a summary of the study, discussion of findings, conclusions, implications for nursing practice, and recommendations for further study.

Summary

The study was conducted to determine the experience of meaning and purpose in life in actively-treated adolescent cancer patients when compared to healthy adolescents as measured by an instrument labeled the Purpose in Life Test (PIL). This questionnaire was devised by Crumbaugh and Maholick (1964) to validate and quantify Frankl's (1962) existential concept of meaning and purpose in life.

The study was conducted in a large southwestern metropolitan area. Home visits were made to each of the 20 adolescent subjects. The adolescent cancer patient population was selected from a pediatric oncology clinic, which is a regional referral center for pediatric and adolescent oncology patients. The healthy adolescents were selected from an organized youth group located in the same southwestern metropolitan area. Since the method for selecting the participants was by convenience or accidental sampling, those subjects who met the criteria for selection and who voluntarily agreed to participate were utilized. The healthy adolescents and the adolescent cancer patients each had written parental consent prior to the administration of the questionnaire. All patients received a written letter explaining the study and copies of the consent forms. Adolescents in both groups received a standardized oral presentation explaining the study.

Data treatment consisted of the t-test which tested the difference between the means of the two groups. The statistical treatment of means indicated no significant difference between the two groups regarding the adolescents' experience of meaning and purpose in life.

Discussion of Findings

The study sample between the ages of 14 and 15 years were similar to the 13-15-year-olds in PIL scores in the study by Meier and Edwards (1974). The results of the Meier and Edwards' study showed that the 13-15-year-olds scored lower than the 17-19-year-olds.

Crumbaugh and Maholick (1964) found a difference between patients (alcoholics and schizophrenics) and nonpatients with nonpatients scaling higher on the PIL. The findings in the present study with adolescents do not agree with Crumbaugh and Maholick's study, indicating that adolescents and adults may differ in their purpose and meaning in life.

Grant (1980) studied adult cancer patients and nonpatients (healthy adults) using the PIL. Her results showed higher scores in the nonpatient subjects, thereby supporting Crumbaugh and Maholick's (1964) study. In this study, adolescent subjects' scores differed from both of these studies, which were done on adults. However, Grant (1980) noted that her subjects stated that overall they believed their cancer did not influence their general view of life, as did the majority of the adolescent cancer patients.

The present study supports the findings of research of Bedell et al. (1977), Kellerman et al. (1980), and Zeltzer et al. (1980). Although their research focused on other psychological variables concerning adolescents and chronic disease, no differences were found between the healthy and diseased adolescents when comparing these two groups.

Insights gained by the investigator upon making home visits may indicate other variables which may have influenced selected subjects' scores on the PIL. With two of the subjects, possible variables may have been financial difficulties, single parenting, child abuse, and housing difficulties.

Conclusions and Implications

One conclusion for this sample is that the cancer did not make a difference in the adolescent's life regarding meaning and purpose in life. The implication for nursing care points to no major change in the nursing process, whether dealing in the primary mode with relatively healthy adolescents or in the secondary mode with cancer patients. However, if a low score on the PIL was found with a 16-19-year-old cancer patient, the nurse might wish to initiate special nursing actions, specifically anticipatory guidance and support relative to the

logotherapy principles. The meaning of the illness to the patient and the patient's reaction to the illness might be explored with a focus on principles of loss of personal identity and responsibility to the self in deriving a meaningful existence.

The second conclusion relates to the PIL scores achieved by the youngest teens. The scores for all early adolescent subjects in both groups were lower than those of the 15-19-year-old adolescents. The implication here is that perhaps the early adolescent group needs to be studied as a separate group.

Recommendations for Further Study

Based upon this study, the following recommendations are made.

1. The study should be replicated with an increased number of subjects and include patients who are not receiving active treatment, though diagnosed with cancer.
2. The study should be replicated with controls for variables such as race, age, and socioeconomic and religious levels.
3. A study should be done in which the PIL is administered to adolescents and their parents to determine a possible relationship of PIL scores within the family.

4. A study should be conducted in which the PIL is administered to adolescents dying of a terminal illness.

APPENDIX A

TEXAS WOMAN'S UNIVERSITY
Box 23717, TWU Station
Denton, Texas 76204

1810 Irwood Road
Dallas Irwood Campus

HUMAN SUBJECTS REVIEW COMMITTEE

Name of Investigator: Jill Dougherty Center: Dallas

Address: 5423 Parker Date: 2/3/83

Omaha, Nebraska 68104

Dear Ms. Dougherty:

Your study entitled Meaning and Purpose of Life in Adolescent
Cancer Patients

has been reviewed by a committee of the Human Subjects Review Committee and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health, Education, and Welfare regulations typically require that signatures indicating informed consent be obtained from all human subjects in your studies. These are to be filed with the Human Subjects Review Committee. Any exception to this requirement is noted below. Furthermore, according to DHEW regulations, another review by the Committee is required if your project changes.

Any special provisions pertaining to your study are noted below:

Add to informed consent form: No medical service or compensation is provided to subjects by the University as a result of injury from participation in research.

Add to informed consent form: I UNDERSTAND THAT THE RETURN OF MY QUESTIONNAIRE CONSTITUTES MY INFORMED CONSENT TO ACT AS A SUBJECT IN THIS RESEARCH.

The filing of signatures of subjects with the Human Subjects
Review Committee is not required.

XX Other: Please make your statement to the parents that they are not
not obligated to participate stronger on both the letter and
the consent form.

 No special provisions apply.

Sincerely,

Estelle D. Kuntz

Chairman, Human Subjects
Review Committee

at Dallas

i.e., the hospital authorities have given permission for
me to approach you but please note that you are not
obliged to participate in any way and your care will
not be affected if you do or do not participate.

- underline voluntary statement on consent form.

PK/sml/3/7/80

APPENDIX B



Texas Woman's University

P.O. Box 22479, Denton, Texas 76204 (817) 383-2302, Metro 434-1757

THE GRADUATE SCHOOL

July 5, 1983

Ms. Jill Dougherty
5423 Parker
Omaha, NE 68104

Dear Ms. Dougherty:

Thank you for providing the materials necessary for the final approval of your prospectus in the Graduate Office. I am pleased to approve the prospectus, and I look forward to seeing the results of your study.

If I can be of further assistance, please let me know.

Sincerely yours,

A handwritten signature in dark ink, appearing to read "Robert S. Pawlowski".
Robert S. Pawlowski
Provost

ec

cc Dr. Helen Bush
Dr. Anne Gudmundsen

APPENDIX C

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____

GRANTS TO Jill Dougherty
a student enrolled in a program of nursing leading to a
Master's Degree at Texas Woman's University, the privilege
of its facilities in order to study the following problem.

The problem of this study will be to determine if there
is a difference between the meaning and purpose in life
of adolescent cancer patients when compared to the
meaning and purpose in life of healthy adolescents.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative ~~or~~ administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: _____

Jill Dougherty
Signature of Student

Signature of Agency Personnel

Helen A. Bush Ph.D., R.N.
Signature of Faculty Advisor

*Fill out & sign three copies to be distributed as follows:
Original - Student; First copy - Agency; Second copy - TWU
College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Children's Medical Center

GRANTS TO Jill Dougherty
a student enrolled in a program of nursing leading to a
Master's Degree at Texas Woman's University, the privilege
of its facilities in order to study the following problem.

The problem of this study will be to determine if there
is a difference between the meaning and purpose in life
of adolescent cancer patients when compared to the
meaning and purpose in life of healthy adolescents.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Date: _____

Signature of Agency Personnel

Jill Dougherty
Signature of Student

Delia R. Bush Ph.D., R.N.
Signature of Faculty Advisor

*Fill out & sign three copies to be distributed as follows:
Original - Student; First copy - Agency; Second copy - TWU
College of Nursing.

APPENDIX D

Consent Form
TEXAS WOMAN'S UNIVERSITY
HUMAN RESEARCH REVIEW COMMITTEE

(Form A--Written presentation to subject)

Consent to Act as a Subject for Research and Investigation:

The following information is to be read to or read by the subject. One copy of this form, signed and witnessed, must be given to each subject. A second copy must be retained by the investigator for filing with the Chairman of the Human Subject's Review Committee. A third copy may be made for the investigator's files.

1. I hereby authorize Jill Ann Dougherty, R.N., B.S.N.
(Name of person(s) who will
perform procedure(s) or
investigations(s)
to perform the following procedure(s) or investiga-
tions(s): (Describe in detail.)

This is a study of adolescents and their personal sense of meaning and purpose in life. You are invited to voluntarily complete a questionnaire and data sheet. There are no right or wrong answers. You will be asked to respond according to how you feel and not according to how you think you should believe or feel. You will be asked to follow directions written on the questionnaire and data sheet. You will be allowed as much time as you need to complete each question.

Written consent to administer the Purpose in Life Questionnaire will be obtained from the parents/guardians of adolescents between 14 and 19 years of age. The parents/guardians will be asked to return the consent form. Upon return of the consent forms, the adolescents whose parents/guardians have granted permission for their son/daughter to participate in this study will be asked to volunteer for the study and complete the Purpose in Life Test and Demographic Data Sheet. The approximate time for completion of the questionnaire and demographic data sheet is 15-20 minutes. When participants have completed the questions, both forms will be collected by the researcher. No names will be used to identify the participants.

2. The procedure or investigation listed in Paragraph 1 has been explained to me by Jill Ann Dougherty.
(name)
3. (a) I understand that the procedures or investigations described in Paragraph 1 involve the following possible risks or discomforts.
(Describe in detail.)
 - (1) It will take a period of time to read and complete each test.
 - (2) Although measures have been taken to control data and maintain confidentiality and privacy, it is possible an improper release of data may occur.
 - (3) Completing the questionnaire may possibly cause some uncomfortableness/embarrassment in relation to the type of questions asked.
- (b) I understand that the procedures and investigations described in Paragraph 1 have the following potential benefits to myself and/or others:
Benefits:
 - (1) Help adolescents of this age, 14-19 years, identify their sense of meaning and purpose in life.
 - (2) This knowledge will provide adolescents with information which may encourage them to increase their understanding and application of meaning and purpose in life in times of difficulty, pain, illness, or suffering.
 - (3) This information could provide nurses and other health personnel who work with teenagers with knowledge to help the adolescent to grow to find clearer understanding and meaning in life in times of difficulty, pain, illness, or suffering.
4. An offer to answer all of my questions regarding the study has been made. If alternative procedures are more advantageous to me, they have been explained.

I understand that I may terminate my participation in the study at any time.

Subject's Signature

Date

(If the subject is a minor or otherwise unable to sign, complete the following.)

Subject is a minor (age _____), or is unable to sign because:

Father

Date

Mother

Date

Guardian

Date

Witness (one required)

Date

APPENDIX E

ORAL PRESENTATION TO ADOLESCENTS OF BOTH GROUPS

Hello,

My name is Jill Dougherty. I am a registered nurse enrolled in a Master of Science nursing program at Texas Woman's University, Dallas, Texas. My major area of interest is working with adolescents. To fulfill all requirements for my degree, a research study or thesis is required. I am conducting a study to determine how teenagers feel about themselves and their lives, and I would like very much to have you participate.

If you agree to voluntarily participate in this study, you will be informed of the following items: (a) one or both of your parents or legal guardians will give permission for your participation (this will require their signature and yours also); (b) no names will be placed on the questionnaire at any time during the study, all information will be kept confidential; (c) you will complete a short information sheet first, followed by your completing a 20-item questionnaire in which you circle the response that most clearly reflects how you feel and not according to how you think you should feel or believe. There are no right or wrong answers. Answering the questions should take you approximately 10-15 minutes, although you may take as much time as you need to complete each question.

You are probably wondering what benefits or risks your participation in this study has for you. By answering these questions, it might benefit you to think about your meaning and purpose in life and encourage you to increase your understanding and application of meaning and purpose in life in times of difficulty, illness, pain, or suffering. This information could also benefit nurses and other personnel who work with teenagers with added knowledge in helping you to come to find clearer understanding and meaning in life during times of difficulty, illness, pain, and suffering.

Possible risks during this study would be loss of your time, improper release of data collection, and loss of confidentiality. Completing the questionnaire may possibly cause some uncomfortableness/embarrassment in

relation to the type of questions asked. Your care/activities will not be affected by your participation or nonparticipation in this study. You may choose to withdraw from the study at any time. Please feel free to ask any questions that you have about the study. I will remain nearby and will be glad to answer them.

Thank you for your time, interest, and cooperation.

Sincerely,

Jill Dougherty, R.N., B.S.N.
Graduate Student
Texas Woman's University

EXPLANATION TO PARENTS OF HEALTHY ADOLESCENTS

Dear Parent or Guardian:

The purpose of this letter is to introduce myself, explain the purpose of my study, and ask your consent for your son/daughter's participation in my study.

My name is Jill Dougherty. I am a professional nurse enrolled in a Master of Science nursing program at Texas Woman's University, Dallas, Texas. My major area of interest is working with adolescents. In partial fulfillment for my degree, a research study or thesis is required. I have been given permission to talk to this group of adolescents by your director/leader. Please note that you are not obliged to participate in any way; your teenager's participation in the youth group activities will not be affected if he/she does or does not participate.

The research that I am conducting involves contacting adolescent males/females 14-19 years of age. The questionnaire to be administered has been completed by other adolescents. The approximate time for completion of the questions is 10-15 minutes. All information obtained will be kept strictly confidential. No names will be used in this study.

If you agree to allow your son/daughter to participate in this study, please read and then sign the enclosed form, Form A, at the bottom of the last page and return the form in the extra envelope. (The form includes a detailed description of my investigation, with instructions, benefits, and risks clearly delineated.) Your son/daughter may then volunteer to complete the questionnaire as described in the form when the youth group regularly meets or on an individual basis.

Your consideration in this matter is appreciated. If you should have any questions, please feel free to contact the youth group leader and, I likewise, will be

available to you if you should have any questions. Thank you.

Sincerely,

Jill Dougherty, R.N., B.S.N.
Graduate Student
Texas Woman's University

EXPLANATION TO PARENTS OF ADOLESCENT CANCER PATIENTS

Dear Parent or Guardian:

The purpose of this letter is to introduce myself, explain the purpose of my study, and ask your consent for your son/daughter's participation in my study.

My name is Jill Dougherty. I am a professional nurse enrolled in a Master of Science nursing program at Texas Woman's University, Dallas, Texas. My major area of interest is working with adolescents. In partial fulfillment for my degree, a research study or thesis is required. The hospital you attend and/or your physician has given me permission to talk with your son/daughter regarding this project. Care of your son/daughter will not be affected by participation or nonparticipation in this study.

The research that I am conducting involves contacting adolescent males/females 14-19 years of age. The questionnaire to be administered has been completed by other adolescents. The approximate time for completion of the questions is 10-15 minutes. All information obtained will be kept strictly confidential. No names will be used in this study.

If you agree to allow your son/daughter to participate in this study, please read and then sign the enclosed form, Form A, at the bottom of the last page and return the form in the extra envelope. (The form includes a detailed description of my investigation, with instructions, benefits, and risks clearly delineated.)

Your consideration in this matter is appreciated. If you should have any questions, please feel free to contact any of the nurses in the clinic (phone 920-2377), and likewise, I will be available to you should you have any questions. Thank you.

Sincerely,

Jill Dougherty, R.N., B.S.N.
Graduate Student
Texas Woman's University

APPENDIX F

PURPOSE IN LIFE TEST

A copy of this instrument may be obtained from:

Psychometric Affiliates

P. O. Box 3167

Munster, Indiana 46321

APPENDIX G

LETTER OF PERMISSION

From the desk of

JAMES C. CRUMBAUGH, PH.D

Ms. Dougherty:

This sheet will give you some helpful information.
Sorry that since retirement I can't send everything out
free under government franking privilege.

Will be most interested in your results.

Best of luck with your study.

A handwritten signature in cursive script, appearing to read "J. C. Crumbaugh", written in dark ink.

P. S. It's OK with me for you to change the PIL words to
suit your teen population if you note the changes in the
study.

REFERENCE LIST

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