ADOLESCENTS WITH CANCER: THEIR EXPERIENCE LIVING WITH A CHRONIC ILLNESS

By

MONA GALE RECHNER

B.S.N. The University of British Columbia, 1987

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING in

THE FACULTY OF GRADUATE STUDIES (The School of Nursing)

We accept this thesis as conforming to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

April, 1989

© Mona Gale Rechner, 1989
In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of Nursing

The University of British Columbia
Vancouver, Canada

Date April 1989
Abstract

This phenomenologic study was designed to understand and describe the experiences of adolescents with cancer living with a chronic illness.

The study was conducted with a sample of five adolescents, aged thirteen to seventeen who had received or were receiving treatments for cancer. Data were collected during audio-taped interviews and were analyzed for common themes.

The findings revealed that the adolescents' overall goal was to get on with life. The teenagers responded to cancer by experiencing the illness and determining that they were normal. They developed a philosophy of being positive and redefined their social world in order to get on with life. Understanding the manner in which adolescents with cancer experience living with this illness may enable health care practitioners to provide appropriate care to the teenager with cancer. Implications for practice, research and education are discussed.
# Table of Contents

Abstract.................................................................................................................. 11  
List of Tables.......................................................................................................... vi 
Acknowledgements.................................................................................................. vii  

CHAPTER 1  
INTRODUCTION ........................................................................................................... 1  
Conceptual Framework............................................................................................. 3  
Problem Statement and Purpose of the Study.......................................................... 8  
Methodologic Approach............................................................................................ 9  
Definition of Terms.................................................................................................. 10  
Assumptions............................................................................................................. 11  
Limitations................................................................................................................ 11  
Summary.................................................................................................................... 12  

CHAPTER 2  
REVIEW OF SELECTED LITERATURE ..................................................................... 14  
Adolescent Development.......................................................................................... 14  
Chronic Illness......................................................................................................... 18  
Effects of Cancer on Adolescent Development....................................................... 21  
Perceptions of Adolescents With Cancer About Their Illness............................... 26  
Summary.................................................................................................................... 32  

CHAPTER 3  
METHODOLOGY ...................................................................................................... 34  
Sampling................................................................................................................... 34  
Selection Procedure................................................................................................. 35  
Description of the Respondents.............................................................................. 36  
Ethics and Human Rights....................................................................................... 38  
Data Collection and Analysis................................................................................... 39  
Summary.................................................................................................................... 44  

CHAPTER 4  
PRESENTATION OF FINDINGS ............................................................................... 45  
Development of an Analytical Framework.............................................................. 45  
Getting On With Life............................................................................................... 48
CHAPTER 5
DISCUSSION OF FINDINGS..................................................89
Adolescent Development..................................................89
Chronic Illness...............................................................97
Normalization...............................................................101
Social Support...............................................................104
Summary........................................................................107

CHAPTER 6
IMPLICATIONS FOR NURSING AND SUMMARY OF THE STUDY........109
Implications for Nursing Practice........................................109
Implications for Nursing Research.....................................112
Implications for Nursing Education...................................113
Summary........................................................................116

References.......................................................................117
List of Tables

Table 1: Getting on With Life.................................................................48
Acknowledgements

I would like to thank the adolescents who so openly shared their personal experiences.

I wish to thank my committee members Judy Lynam (chairperson) and Marilyn Dewis.

Finally, I would like to express my appreciation to my family and friends who have supported and encouraged me.
CHAPTER 1: INTRODUCTION

Adolescents with cancer are a client population with special needs (Bru, 1985; Klopovich & Clancy, 1985). Adolescents have the cognitive ability to understand the implications of having cancer and undergoing the cancer treatments; however, they may not yet have developed the personal resources or experienced life events in their development from child to adult to contend with the problems associated with living with cancer (Farrell & Hutter, 1980). Many adolescents with cancer are therefore faced with the dilemma of dealing with their illness, while trying to achieve the developmental tasks of adolescence.

Prior to recent advances in treatment, a diagnosis of cancer in adolescents meant that they had to cope with dying. Because of the improved survival of these adolescents with cancer, this disease is now viewed by health professionals as a chronic illness (Gavaghan & Roach, 1986; Kellerman, Zeltzer, Ellenberg, Dash & Rigler, 1980; Klopovich & Clancy, 1985; Spinetta, Deasy-Spinetta, McLaren, Kung, Schwartz & Hartman, 1982; Zevon, Tebbi & Stern, 1987). Research suggests that adolescents perceive cancer differently from other chronic illnesses such as diabetes, heart disease and mental illness, and they associate intense negative feelings and stigma with cancer (Michielutte & Diseker, 1982). Additional studies of adolescents with chronic illnesses indicate that adolescents with cancer experience
their disease differently than these other adolescents (Kellerman et al., 1980; Zeltzer, Kellerman, Ellenberg, Dash & Rigler, 1980).

Many cancer treatments have side effects such as alopecia, nausea, vomiting, weight loss and fatigue. These visible and debilitating side effects may have an effect on adolescents' developing sense of body image and identity (Carr-Gregg & White, 1987). The treatments for cancer are viewed by many adolescents as worse than the disease (Cohen & Klopopich, 1986; Zeltzer et al., 1980). The adolescents now must cope with living with a disease that can require up to three years of intensive treatment, followed by long term follow-up and assessment, and possible treatment for sequelae from the treatment (Zeltzer, L., Zeltzer, P. & Le Baron, 1984).

Adolescents rely upon health care professionals to help them live with the chronic illness of cancer and the resultant treatments to enable them to continue to develop normally and become healthy, well-adjusted adults (Morrow, 1978; Nilsen, 1982; Spinetta et al., 1982). An understanding of adolescents' perceptions about their chronic illness and its treatment will increase the ability of health care professionals to provide effective care and support for adolescents. There is a need therefore to examine the experience of adolescents who have received cancer treatments to understand how they perceive this chronic illness and its treatment and how they perceive its impact on their lifestyle and normal development as adolescents.
Several conceptual frameworks for chronic illness have been developed by various theorists (Dimond & Jones, 1983; Lubkin, 1986; Miller, 1983; Strauss et al., 1984; Thomas, 1987). The conceptual framework chosen for this study is the "chronic condition framework for children" developed by Robin Thomas (1987). The term chronic condition as defined by Thomas includes physical, physiologic and developmental "impairment(s) that interfere with the individual's ability to function fully in the environment" (p. 5). The individual may experience stable periods interrupted by acute phases that require hospitalization or medical intervention. In Thomas' framework, these acute phases do not necessarily result in decreased functioning or a downward course of illness for the individual as proposed by others such as Strauss et al. (1984). The stable or positive concept of chronic illness in children in Thomas' framework is suitable for the study of adolescents living with cancer, such as many of those with Hodgkin's disease and leukemia, where the course of their illness is generally upward with a positive outcome.

Thomas' framework is concerned with the effect of a chronic condition on the day to day functioning of a child and is focused on the consequences to the child rather than on the specific disease condition. Thomas structured the conceptual framework into three sections: 1. Impairment, disability and handicap; 2. Handicapping factors: A, B, C; and 3. Stigma. The limitations or restriction imposed by the condition, the child and society and the effect that the
limitations and restrictions impose on the child and his/her family are described for each of these sections. Each section is further differentiated into different elements and for each element Thomas has outlined the consequences of the chronic condition for the child.

In Thomas' framework, "impairment" is considered to be the organic disorder or disease of the child. Diabetes, asthma or paraplegia are examples of "impairment" as used by Thomas. There are functional limitations experienced by the child that are a result of the "impairment" itself or the child's psychological response to the "impairment". These limitations are described by Thomas as the "disability". An example of Thomas' to illustrate this term is a child with asthma who is unable to participate in some activities such as running games or a child with paraplegia who decides not to participate in activities rather than risk rejection. There are also limitations on the child's social role fulfillment and the social responses of others that are a consequence of the "impairment" and resulting "disability". Thomas describes these social consequences as the "handicap". For example, a child may not be invited to join in social activities because of others' discomfort with this child with a chronic condition.

Thomas identified three factors that handicap the development of a child with a chronic condition as Handicapping Factors A, B, and C. These factors can limit the child's experiences in his/her social and physical environment which can restrict skill development and psychosocial adjustment necessary to become fully a integrated
individual in society. Social assumptions about a child with a chronic condition are held by individuals, including parents, within the child's world. Attention can be directed by others to the "impairment" rather than the child. The child's development is then impeded by the handicapping factors A, B, and C. The child with a chronic condition can also be stigmatized because of restrictive social perceptions of others. In this study, the experience of adolescents with a chronic illness, cancer, will be examined within the essential elements of the three sections of Thomas' framework.

Chronic illness is characterized by periods of varying degrees of sickness and wellness. This unpredictable nature of a chronic illness has been addressed in Thomas' definition of chronic illness. Thomas, however, has not identified the "impairment" to be dynamic and changing which is characteristic of a chronic illness. The changing nature of a chronic illness would result in variations in "disability" and "handicap" depending upon the state of the "impairment" for the child. The terms "impairment, disability and handicap" have different meanings in the general literature. It is therefore important that such terms be operationally defined and Thomas has done this. The use of these terms throughout the literature on chronic illness varies according to the definition given by the author (Dimond & Jones, 1983).

In Thomas' framework, the role of the nurse caring for the child and the family with a chronic condition is that of mutual participation. This approach for nursing care means that goals are
mutually negotiated, accepted and evaluated by the nurse, child and family. Within the scope of this study, the family will not be explicitly considered. Thomas' framework underscores the importance of understanding what children's perspectives are in order to foster active participation in their care. An understanding of the perceptions of adolescents is especially important because they have achieved the developmental maturity to be recognized and cared for as independent individuals in their health care.

The idea that it is important to understand the perceptions of individuals about health and illness was identified by Kleinman (1978). He described health care systems as cultural systems of health, illness, and health care related aspects. Within these health care systems there are three sectors: professional, popular, and folk (p. 86). The professional sector is composed of recognized health professionals while the popular sector is composed of the family and community. Members of each of these sectors have explanatory models (EMs) for sickness episodes. These "EMs contain explanations of any or all of five issues: etiology, onset of symptoms, pathophysiology, course of sickness and treatment" (Kleinman, Eisenberg & Good, 1978). Thus, the way in which sickness is experienced and reacted to within each of these three sectors may be different from each other and these differences may be a source of conflict between the sectors. In this model, Kleinman (1978) defined disease as a "malfunctioning in or maladaptation of biological and/or psychological processes" (p.88). Disease, which is synonymous with
Thomas' term "impairment" is commonly associated with the explanatory model of the professional sector. Illness on the other hand is usually associated with the explanatory model of the popular sector. Illness is defined as "the experience of disease (or perceived diseases) and the societal reaction to disease" (p. 88). The two parts of this definition are similar respectively, to Thomas' definitions of "disability" and "handicap". This experience can be described as "the way the sick person, his family, and his social network perceive, label, explain, valuate, and respond to disease" (p. 88).

Kleinman's conceptualization of the illness experience provides support for the use of Thomas' framework to understand the resulting disability and handicap for an adolescent living with the chronic illness of cancer. Similarly, Kleinman's identification of the importance of understanding the perceptions of individuals about their health and illness strengthens the idea of understanding the perceptions of adolescents about their illness within the conceptualization outlined in the first section of Thomas' framework.

This study will explore the perceptions of adolescents with the chronic condition of cancer about their illness and its treatments and the effect this condition has had on their day to day lives. Study of the perceptions of adolescents with cancer may enable the professional sector to base their clinical practice on an increased knowledge base and understanding of the adolescents' experience living with the chronic illness of cancer. By knowing the adolescents' perceptions about their chronic condition the nurse will be able to
understand more clearly how to be effective in her role as a mutual participant in the care of adolescents.

Problem Statement and Purpose of the Study

An important role of nursing is to help adolescents live with chronic illnesses and foster their achievement of developmental tasks (Klopovich & Clancy, 1985). How adolescents with cancer perceive the impact of their chronic condition and its treatments on their lifestyle and growth and development is not known. In order to provide care that is effective, nurses have a need to understand how adolescents perceive their experience of living with the chronic illness of cancer.

The purpose of this study was to determine how adolescents with cancer perceive living with this chronic illness. Aspects specifically explored included the adolescents' perceptions of cancer, its treatments, and the functional and social consequences of this illness on their lifestyles. The specific questions that directed this study were:

1. What are the perceptions of adolescents about their experience of living with, and being treated for, the chronic condition of cancer?

2. What are adolescents' perceptions of the "disability" or functional limitations and their psychological responses that are a result of the "impairment" of cancer?
3. What are adolescents' perceptions of the social limitations or "handicap" that are a consequence of the "impairment" of cancer and its resulting "disability"?

Methodologic Approach

A phenomenological study was done to discover the experience of the adolescent with cancer. Phenomenology is a research method and a philosophy and approach. Giorgi (1975) defined phenomenology as "the study of the structure, and the variations of structure, of the consciousness to which anything, event or person appears. It is interested in elucidating both that which appears and the manner in which it appears, as well as the overall structure that relates the 'that which' with its mode or manner" (p. 83).

The purpose of phenomenology is "to describe the total systematic structure of the lived experience, including the meanings that these experiences had for the individuals who participated in them" (Omery, 1983, p. 50). The use of phenomenology in this study enabled the researcher to understand the subjective meaning of cancer for adolescents with this chronic illness. This perspective also provided an understanding of the effect that cancer has on the lived experience of these adolescents. The qualitative analysis of the adolescents' descriptions provided an explanation of the adolescents' perceptions of their illness experience. It is hoped that this knowledge of adolescents' perspectives will provide nurses with an
understanding of the meaning and value that the experience of living with the chronic illness of cancer has been for a group of adolescents.

Definition of Terms

**Participant**: an individual, male or female, aged thirteen to eighteen with a diagnosis of cancer. This adolescent will have received or be receiving cancer treatments and will not be in an induction or terminal phase of treatment.

**Chronic condition**: "any anatomical or physiological impairment that interferes with the individual's ability to function fully in the environment" (Thomas, 1987).

**Impairment**: "an organic disorder or disease" (Susser and Watson, 1971).

**Disability**: "The functional limitations imposed by, and the child's psychological response resulting from, the impairment itself" (Susser and Watson, 1971).

**Handicap**: "The social consequences of the impairment and resulting disability that interferes with social role fulfillment and especially the social response of others in the individual's environment" (Susser and Watson, 1971).

**Phenomenology**: "The study of human experience from the actor's particular perspective" (Knaack, 1984, p. 107).
Assumptions

An assumption of a phenomenological study is that the researcher explicitly states her assumptions and preconceptions about the phenomena being investigated and then brackets or suspends these preconceptions. This bracketing allows the researcher to analyze and understand the experience from the participants' point of view rather than from her own (Knaack, 1984; Omery, 1983).

Another basic assumption in this study will be that the participants will tell the truth about their experiences. It will also be assumed that adolescents have the cognitive abilities to understand their illness and will be able to communicate their perceptions about their illness in an interview setting. Thus, the content of the interviews will reflect the true experiences of the participants.

Limitations

A limitation of this study is associated with the sample that was selected. The sample was restricted to adolescents who were accessible to the researcher. Consequently, this sample was only a part of the group of adolescents who received or are receiving cancer treatments as outpatients. There were more participants eligible to participate in this study outside the area accessible to the researcher. However, the cost and time to travel the long distances to other areas of the province to interview participants was prohibitive for this study.
The findings from this study cannot be generalized beyond this sample population. The participants studied were deliberately selected because of their experience with the phenomena and ability to speak of it. However, there are essential elements of these individual experiences that can be understood and applied to the group of adolescents with cancer as a whole (Morse, 1986).

Summary

Adolescents with chronic illnesses are recognized in the literature as a group having varying degrees of difficulty managing their illness and achieving the developmental tasks of adolescence. Cancer in adolescents is viewed by health professionals as a chronic illness because of improved survival rates. Research suggests that adolescents with cancer perceive and experience their illness and its treatments differently than adolescents with other chronic illnesses. The literature indicates that the differences experienced by adolescents with cancer may have an effect on their achievement of developmental tasks such as establishing an identity or a stable body image. Because there is a lack of literature describing adolescents' actual experiences of living with a chronic illness, cancer, a qualitative phenomenological study can provide significant data to further the understanding of nurses about the client population of adolescents with cancer.

The organization of study presentation will be outlined in the next five chapters. Chapter 2 will be a review of selected literature,
followed by the methods in chapter 3. Findings will be presented in
chapter 4 and discussed in chapter 5. Finally, a summary of the
research and implications of the study for nursing practice, research
and education will be presented.
CHAPTER 2: REVIEW OF SELECTED LITERATURE

In this chapter literature is reviewed in order to provide an understanding of why it is important to explore experiences of adolescents living with the chronic illness of cancer. Since there is a limited amount of literature specific to adolescents experiencing cancer as a chronic illness, the review will include research that included adolescents with chronic illnesses other than cancer. This literature is also relevant because research indicates that adolescents with cancer perceive and experience their illness differently than adolescents with other chronic illnesses.

To place the experience of adolescents living with cancer in the context of life span development, a review of the developmental stage and developmental tasks of adolescence will first be presented. An overview of literature on chronic illness will then be outlined. Next, cancer as a chronic illness and how it impacts on the achievement of the developmental tasks of adolescents will be described. Finally, the perceptions that adolescents with cancer have about their illness, its treatments, and its impact on the functional and social aspects of their day to day lives will be presented.

Adolescent Development

Adolescence is a developmental stage that has been described by many theorists as a period with identified developmental tasks to achieve (Garbarino, 1985). Developmental tasks are defined as
"skills, knowledge, functions, and attitudes that an individual has to acquire at a certain point in life; they are acquired through physical maturation, social expectations, and personal efforts" (Muss, 1982, p. 162).

Havighurst (1972) identified nine developmental tasks for the period of adolescence, drawing upon and combining concepts from the theories of adolescence of Williams, Rank, Adler, Freud, Blos, Erikson and Lewin (Muss, p. 163; Spinetta et al., 1982). The identification, number, and description of the developmental tasks of adolescence vary slightly among authors because of their differing theoretical perspectives. However, the essential developmental achievement identified by other authors is consistent with the tasks conceptualized by Havighurst.

Havighurst (1972) identified tasks as: accepting one's physique and a male or female role, developing peer relations with both sexes, gaining emotional independence from parents and other adults, achieving assurance of economic independence, preparing for an occupation, developing civic competence, becoming socially responsible, preparing for marriage and family life, and building values in harmony with the world. The achievement of these tasks by adolescents is an essential part of their development within the context of their overall life span.

A premise of developmental theory is that the stages are hierarchical and invariant and the tasks of one stage must be achieved to successfully progress to the next stage. Thus, it is important for
individuals to achieve the developmental tasks of adolescence to facilitate their progression to the next developmental stage of adulthood.

Several authors have categorized adolescence into three stages: early adolescence, middle adolescence and late adolescence (Gode & Smith, 1983; Mahon, 1983; Miller, 1974; Zevon et al., 1987). The age ranges for these three groups vary slightly among authors. However, their descriptions of the developmental tasks to be achieved in these three stages are similar and correspond to the tasks identified by Havighurst (1951). Early adolescence is characterized by the task of separation from the family and the establishment of a separate identity. The task of middle adolescence is to build new and meaningful relationships with peers of both sexes. The adolescent must also gain comfort with his/her sexuality and establish a sexual identity. Dating and the beginning of sexual experimentation begins within this period (Zevon et al., 1987). The middle adolescent also must begin to formulate ideas about career choices. Late adolescence requires the adolescent to maintain stable relationships and to begin to choose future life goals and tasks.

Adolescents who have a chronic illness such as cancer are challenged to achieve their developmental tasks and, at the same time, to manage their illness. Thus, the experience of living with cancer and its treatments may impede the adolescents' successful progression through these three developmental stages of adolescence.
Another important consideration in the developmental stage of adolescence is cognitive development. Piaget identified a final stage of cognitive development, formal operations, that is achieved during the adolescent period of development. Formal operations are "characterized by the use of propositional thinking, combinatorial analysis, and abstract reasoning" (Muss, 1982, p. 186). Theorists such as Selman (1977) and Elkind (1967) have developed stage theories of social cognition that are based on the cognitive development described by Piaget. In both of these social cognition theories a specific stage of development has been identified for adolescence. These stages are characterized by the concepts of "mutual perspective taking" (Selman, 1977) or the "adolescent egocentrism" (Elkind, 1967) of adolescents. Selman and Elkind use the concepts to describe the manner in which adolescents perceive themselves, others and how others perceive them in their social environment.

In summary, adolescence has been identified by various theorists as a unique and identifiable stage within human lifespan development. Theorists have identified developmental tasks that are necessary for an adolescent to progress to the next stage of development. There is also a new level of cognitive development, formal operations, that can potentially be achieved during adolescence. This cognitive development impacts upon the social development of adolescents and influences the achievement of their developmental tasks. Adolescents have developed the capabilities to begin to make independent decisions and take personal responsibility.
for dealing with life events. Successful progression and achievement in this stage of development for adolescents may be affected by individuals having a chronic illness such as cancer (Carr-Gregg & White, 1987; Hamburg, 1982; Zevon et al., 1987). In the following section, the literature on chronic illness is reviewed to understand the nature of chronic illnesses and their effect on individuals.

**Chronic Illness**

Chronic illness is conceptualized by several theorists. Strauss et al. (1982) developed a framework that provided a way to systematically look at the experiences, especially the social and psychological, of a person who was chronically ill. Strauss' framework outlined the key problems and the strategies and organization that individuals with chronic illness undertake to live their daily lives. A consequence for individuals, as conceptualized within this framework, is an illness trajectory that is generally downward and characterized by periods of acute episodes and remissions. The framework of Strauss et al. (1982) is less than ideal when conceptualizing the experiences of adolescents living with a chronic illness or condition because of the more positive trajectory of some adolescent chronic illnesses such as cancer.

Trajectory is also a concept that is found in Lubkin's (1986) description of a chronic illness; he expands upon the basic idea of trajectory described by Strauss et al. (1982). The illness trajectory has shape, duration, and movement. The outcome of the illness may be
Influenced by "shaping" which is the work done by the individual and others to manage the illness. Lubkin accounts for the individual's perceptions and uniqueness in response to the illness in the definition of biographies or social trajectories; he addresses the changing pattern in chronic illnesses through advances in technology. The person with a chronic illness may have multiple problems that have a negative effect on the predictability, shape and outcome of the trajectory. A strength of Lubkin's conceptualization of chronic illness is the importance accorded to the impact of the individual's perspective and response to the chronic illness. Trajectory is a concept that describes the course of the illness that in Thomas' (1987) conceptualization of chronic illness, is influenced by the handicapping factors rather than "shaping" as in Lubkin's (1986) conceptualization.

Another conceptualization of chronic illness has been described by Dimond and Jones (1983). A specific definition for chronic illness is not given; rather, three definitional perspectives are outlined. There are clinical, personal and social definitions that influence the ways in which individuals with a chronic illness and those individuals within their environment respond to the illness. Individuals' behavioral responses to the illness are influenced by the characteristics of the illness and also by the response of others to the illness. This idea about responses is similar to Thomas' (1987) description of disability and handicap where the psychological
response of the individual and the social responses of others to the illness affect the experience of living with a chronic illness.

Dimond and Jones (1983) also state that the response to the illness is affected by the point in the life span at which the chronic illness occurs. Gode and Smith (1983) and Thomas (1987) have focused on examining chronic illness within the developmental stage of childhood and adolescence. Thomas (1987) developed a parallel concept of chronic illness to Dimond and Jones (1983), Lubkin (1986) and Strauss et al (1982) in that the illness has an effect on the individual. Thomas (1987) however, identified that the child's response to the illness and development is compromised by handicapping factors.

Dimond and Jones outline three perspectives on chronic illness to understand the factors that influence individual's responses to the chronic illness. These perspectives are: the sick role, illness behavior and the at-risk role. Within the discussions of these perspectives, Dimond has incorporated the other perspectives of clinical, personal and social responses to chronic illness.

Miller (1983) developed a model of coping with chronic illness. Within this model, thirteen specific coping tasks of chronically ill individuals are identified. Some of Miller's tasks include: "maintaining a sense of normalcy; modifying daily routine, adjusting life-style; and maintaining a positive concept of self" (p 19). These coping tasks are described as challenges to be dealt with by persons with a chronic illness. The model includes strategies for coping with these tasks
and identifies criteria that are necessary for effective coping. Miller's comprehensive description of coping tasks is similar to the "work" associated with a chronic illness that was identified by Strauss et al. (1982) and Lubkin (1986).

The literature indicates that the conceptualization of chronic illness depends upon the perspective or emphasis taken by the author. The experience of living with a chronic illness is dependent upon differing factors such as the responses of the individual and others to the illness, the course of the illness, time of illness during the life span, and the work or coping to deal with the illness.

Advances in the management and treatment of childhood cancers has resulted in the improved survival of children and adolescents with cancer (Carr-Gregg & White, 1987; Zeltzer, Zeltzer & LeBaron, 1983). Because of this improved survival, cancer is now viewed as a chronic illness for an ever increasing group of individuals. In view of the significance of the point in time that a chronic illness occurs within the lifespan, an examination and review of literature to understand the impact that the chronic illness of cancer has on the achievement of developmental tasks of adolescence will be presented in the next section.

Effects of Cancer on Adolescent Development

Several studies have been conducted on the adolescent oncology population to evaluate how they are living with cancer. Many of these studies have investigated how their cancer and their ability to cope
with their illness have impacted on them as adolescents and on the achievement of their developmental tasks.

A study on the task of development of ego-identity was conducted by Gavaghan and Roach (1986) with an outpatient group (n=42) of adolescents with cancer and a matched control group (n= 42) of healthy adolescents. Both groups were administered an Ego-Identity Interview and completed the Ego Identity Incomplete Sentence Blank Questionnaire (EI-ISB). These tools were based on James Marcia's operationalization of the concept of identity in adolescents. The EI-ISB tools had been tested for validity and inter-rater reliability was established. The findings indicated that adolescents with cancer had difficulty achieving the developmental task of identity formation. There was no significant relationship between the ego identity variables and the severity of their illness.

In another study of adolescent outpatients, Kellerman et al. (1980) compared 349 healthy adolescents to 168 adolescents with various chronic diseases using reliable measurement tools such as the State-trait anxiety inventory, Rosenberg scale of self-esteem, and the Health locus of control scale. Thirty of the group of chronically ill adolescents were oncology patients from an outpatient clinic. The researchers found no differences in anxiety or self-esteem between the two large groups. However, results indicated that the smaller sub-group of adolescents with cancer perceived they had less control over their health. Thus, there are some differences between the oncology patients and adolescents with other chronic
diseases. Further study could explore why adolescents with cancer have different perceptions about their health than adolescents with other chronic illnesses.

Offer, Ostrov and Howard (1984) examined the self-images of groups of physically ill adolescents aged 13 to 19, with asthma (n=40); cancer (n=27), cystic fibrosis (n=28) as compared to the self-images of normal (non-patient) adolescents (n= 1385). Self-image was measured using the Offer Self-Image Questionnaire (OSIQ), a tool constructed of 130 items to evaluate adolescents' functioning in eleven content areas and five aspects of self, important to the adolescent. The categories were: psychological self, social self, sexual self, familial self and coping self. The male and female group means were calculated separately because of the assumption held by the researchers that physical illness might have different effects on males and females over and above differences in self-image by sex for normal groups of adolescents.

The findings of the study indicate that adolescents with asthma and cancer had normal self-images and the adolescents with cystic fibrosis had major difficulties with self-image. A comparison of the asthma and cancer groups indicate that both groups were aware of their physical condition but the adolescents with cancer were more worried about their health. Also, male adolescents with cancer had a low body image and were more sensitive to impairment to their bodies. Again, research findings indicate adolescents with cancer are able to develop a sense of identity and self-esteem but they still have
unique problems and concerns that need to be addressed. The use of Thomas' (1987) framework in this study can provide further explanation of how chronic illness influences development.

Sawyer, Crettenden, and Toogood (1986) compared the emotional and behavioral problems in children and adolescents treated for leukemia (n=42) with a control group from the general population (n=42) and a control group of the ill children's siblings (n=54). The Achenbach Child Behavior Checklist was completed by the parents of all subjects and the teachers of the leukemia and control groups. The Rutter B2 Behavioral Scale for Teachers was also completed by the teachers for these two groups. The Family Concept Inventory was completed independently by both parents and children over ten years of age.

Study findings indicate that leukemic children and adolescents had significantly more problems and less social competence, particularly in school related activities. The number of adolescents in the leukemic group is not specified by the authors, yet they indicate that the number was limited so statistical analysis of specific behavior scales was only completed for six to eleven year olds. There are also some discrepancies noted in the findings concerning the differences in responses from the teachers describing the performance in academic subjects and the expected behavior of the leukemic and control groups. The findings of this study indicate significantly more problems for adolescents with cancer than have
been identified by other researchers. These inconsistencies however, may be due to the limited number of adolescent participants.

A wide range of measurement tools have been used to measure the effect of cancer on adolescents' development. A study conducted by Rudin, Martinson and Gilliss (1988) was conducted to compare the responses of adolescents (n=7) to cancer using two different measurement tools: a semi-structured interview and the Thematic Appreciation Test (TAT). Results indicate that interview data provided information that was more problem-management focused and the TAT provided more emotion-focused information. These findings support the notion that data identifying the effect of cancer on adolescent development are at least partially dependent upon the tool used to assess psychosocial development of adolescents with cancer.

Another way to determine the effect of chronic illness on adolescents and on the achievement of their developmental tasks is to examine the perceptions of these adolescents about their actual experiences. It is important to assess adolescents' perceptions and their reasons for being different rather than simply whether or not they have achieved the developmental tasks of adolescence. By understanding the perceptions of adolescents with cancer, nursing and other health care professionals providing care for this group can realize a greater understanding of the impact cancer has on the day to day lives of this group of adolescents. In the following section, the author will review literature that has sought to understand the perceptions adolescents with cancer have about their experience
living with their illness and its impact on their psychological and social lives.

Perceptions of Adolescents With Cancer About Their Illness

In this section, an examination of the literature will be outlined to determine what has been learned about the perceptions of adolescents with cancer are about their illness, its treatments and the impact of this chronic illness on the functional and social aspects of their day to day lives.

Zeltzer et al. (1980) conducted a study using the same sample population as Kellerman et al. (1980) in order to determine adolescents' perceptions of the impact of their illness, the crucial issues for them, and their coping styles. A limitation of this study was that the researchers developed their own illness-impact questionnaire as there were no instruments available to comprehensively measure health concerns of adolescents. The authors gave no indication that the tool was tested for validity or reliability. However, the study showed that chronically ill adolescents had a repertoire of coping behaviors which resulted in a generally healthy, positive outlook. The oncology group perceived a greater disruption of activities and an overload on their coping abilities, possibly due to the amount of illness-related stressors they faced daily. Another finding unique to the oncology group showed that these adolescents perceived their treatments for cancer to be worse than their disease.
The perception by adolescents that the treatment is worse than the disease is also found in written self-reports from adolescents about their own personal experiences with cancer (Cohen & Klopovich, 1986). Wasserman, Thompson, Wilimas, and Fairclough (1987) also described similar perceptions in lengthy interviews of open ended questions with long term survivors (n=45) of Hodgkin’s disease. This retrospective study described the perceptions of the adolescent participants about their disease, the side effects of treatment, and the reactions of their family, schoolmates and friends.

Half the sample perceived that side effects of treatments such as nausea, vomiting and infections were the “worst part” of having cancer. The “worst part” about the illness also included feeling lonely and missing a phase of growing up.

Social relationships also changed. Forty percent of the subjects reported unpleasant experiences at school such as teasing, avoidance or ostracism by their classmates. Relationships with parents changed and almost half of the subjects felt spoiled during their illness. The study also showed that dating relationships changed.

Moore, Glasser and Ablin (1987) studied the late effects on psychosocial functioning resulting from childhood cancer and its treatments. The sample included subjects in grades three to twelve with the average being grade seven, who were long term survivors (five year post diagnosis) of acute lymphoblastic leukemia (n=19) and solid tumor (n=16). Subjects were divided into two groups with
diagnosis and treatments either before or after sixty months of age. The Deasy-Spinetta Behavioral Questionnaire (DSBQ) was completed by a parent and one of the subject's teachers. Subjects answered seven open ended questions about the impact of the previous cancer experience on relationships with family and friends.

Sixty percent of the subjects treated after sixty months of age felt different from their peers as a result of having cancer. Consistent with Wasserman et al. (1987) is finding subjects felt they missed out on a part of their childhood because of their inability to participate in activities with peers, feeling left out, or having grown up too fast.

A limitation of Moore et al.'s (1987) study is the method used to determine the subjects' perceptions. Qualitative responses were quantified to describe the experiences of the subjects; the researchers did not interview or follow up with the subjects to validate and expand upon the data collected from the open ended questions. The findings however are important because of their consistency with other research. Several researchers have attempted to study adolescents who have cancer using research methods that goes beyond simple exploration and description. The use of methods such as phenomenology can further expand the body of knowledge about adolescents' perceptions of the experience of having the chronic illness of cancer. Also, the use of an approach that explored the impact of chronic illness on development is warranted. This study
used Thomas' framework to explore how adolescents' experiences of living with cancer impacts on their development.

Tebbi and Koren (1983) investigated two groups of adolescents with cancer who were hospitalized for their treatments. One group (n=17) were admitted to an adult unit and the other group (n=29) to a special adolescent oncology unit. Findings from the self-reports of these two groups showed that the group from the adolescent unit had fewer worries and a better overall view of the future. However, both groups still had similar concerns in that they were both very worried about their ability to cope with the effect of their illness on their physical ability and appearance.

Another finding of this study was that nearly one-half of the adolescent patients had no one with whom they could discuss their problems freely and confidentially. This is consistent with the findings of Carr-Gregg and Hampson (1986) who discovered that the adolescents they studied had no one with whom they felt they could share their fears. The establishment of a peer relationships and a peer group is one of the developmental tasks of adolescence. Research indicates that cancer may have a negative effect on the achievement of this developmental task. The ability of adolescents to establish an identity or a stable self-image may also be affected if they do not have social relationships in which they can communicate their concerns and worries. These findings indicate the need for further research to discover more about adolescents' experience
living with the chronic illness of cancer and how this has affected the achievement of their developmental tasks.

Farrell and Hutter (1980) also studied the perceptions of adolescents about having cancer. The study was an attempt to go beyond simple description and to actually discover what the adolescents’ experiences were. Data were collected through extensive open-ended interviews and observations of three adolescents with cancer. Subjects studied spent a large amount of time in the outpatient setting and were observed there to be quite withdrawn, to relate to few individuals and to avoid contact with their peers. A limitation of the study was that the theoretical framework guiding the research in this study was not explicit. Another limitation was that the explanation of the findings was detailed and comprehensive but there was no indication that the data were analyzed according to any criteria. Results indicate that these adolescents were affected by the cancer treatments. The perception of some of their experiences were a change in their self-perception, dependency on parents, periodic isolation from peers, pain, physical limitations and uncertainty about their future. These findings are consistent with results from other research studies and in spite of the identified limitations they are still valuable.

A suggestion from the literature that cancer is different from other chronic illnesses in respect to the stigma and intensity of feelings associated with the illness was an underlying assumption of a study conducted by Michielutte and Diseker (1982). The purpose of
their study was to determine the perceptions of a group of seventh grade students (n=279) of cancer in comparison to heart disease, diabetes and mental illness. The Semantic Differential for Health was used to measure beliefs and attitudes toward cancer and other chronic diseases; and a series of questions was developed to determine the participants' general knowledge of cancer. Six semantic scales based on a widely validated procedure were developed by the researchers and were determined to have face validity. However, because the scales were developed within the context of this study, the researchers state further testing for validity and reliability is required. The questions to determine the students' knowledge of cancer were completed during a health class and clarification of the meaning of the questions was given by the teacher to decrease error due to the students' lack of comprehension or reading ability.

A limitation of this study is that only the students' knowledge of cancer was measured and not their knowledge of other chronic illnesses. Results indicated that cancer was perceived to be higher in severity than diabetes and mental illness, more prevalent than all of the other chronic illness, and lower in perceived benefits of treatment. The results from students' perceptions support the suggestions from the other literature that cancer is perceived differently, has a stigma and is a feared illness. Therefore, it is important to understand the perceptions adolescents with cancer have about their experience of living with their illness within their social
Further study can increase the understanding of how these adolescents experienced and perceived the reactions of others.

Summary

The review of the literature shows that there are developmental tasks associated with adolescence that need to be achieved to successfully progress through life span development. Various conceptualizations of chronic illness have been described in the literature depending upon the perspective of the author. There is an indication that adolescents with the chronic illness of cancer experience difficulties because of the nature of their chronic condition and its treatments. Some of their difficulties appear to be different from those experienced by adolescents with other chronic illnesses. It is possible that these differences may exist because of the nature of the treatments undergone by the adolescent with cancer. These treatments and the adolescents' perceptions of the treatments may adversely affect some social and functional aspects the lives of adolescents with cancer.

It is important to determine what the adolescents' perceptions are about experiencing this chronic illness and the necessary treatments and how this has impacted upon their lives and normal development as adolescents. Thomas' (1987) framework directs the researcher to understand how the chronic condition impacts upon the individual's development. Further research using valid and reliable measurement tools and rigorous qualitative methods is indicated to
discover more about how adolescents are living with the chronic illness of cancer. The phenomenologic method of qualitative research is therefore an appropriate and logical approach to use in this study. The use of the phenomenologic method determined the perceptions of the adolescents through an in-depth analysis of data from interviews. The findings of the researcher were reviewed with study participants to validate if the analysis accurately represented the actual perceptions and experiences of the participants. The next chapter will describe the methodological approach used in this study.
CHAPTER 3: METHODOLOGY

The phenomenological method of qualitative research was used to study the experience of adolescents living with the chronic illness of cancer. In this chapter, a description of how the researcher conducted this study will be presented. Sampling, data collection, and data analysis of the study will be discussed.

Sampling

The criteria for sample selection for phenomenological research guided the selection of the participants for this study. It was necessary for the group of adolescents to have experience with the topic under investigation and be able to communicate this experience (Knaack, 1984). The participants selected needed to be able and willing to speak about their experiences (Morse, 1986). The sample size was determined by the number of participants necessary to describe the phenomena being investigated. Also, the sample size in phenomenology is small because of the time and effort for comprehensive data collection and analysis (Morse, 1986).

Participants were selected according to the following criteria:

1. Participants were thirteen to eighteen years of age and had received or were receiving cancer treatments.

2. Participants spoke and understood English and were willing and able to speak of the experience of living with the chronic illness of cancer.
3. Participants were accessible to the researcher.

Selection Procedure

Potential study participants were recruited from the oncology clinic of a local pediatric facility. Potential participants and their parents were contacted in person or by telephone by the Clinical Nurse Specialist for Oncology. Letters of Information describing the study and nature of participation (Appendix D) were either given or mailed to potential participants by this Clinical Nurse Specialist.

Some of the adolescents completed the last page of the Letter of Information to indicate their interest in participating and to give a phone number where they could be contacted by the researcher. These pages were either returned to the Clinical Nurse Specialist who then gave them to the researcher, or were mailed directly back to the researcher. Other participants verbally indicated their interest in participating and gave the Clinical Nurse Specialist permission to give their phone numbers to the researcher.

Upon receiving the phone numbers of potential participants, the researcher telephoned the adolescents and provided additional information as necessary to the individual and/or the parents. After the researcher confirmed that the adolescent met the sample criteria, an appointment was set for the initial interview. The researcher also confirmed with the participant that parental permission was required and offered to answer any questions the parents may have had.
At the time of the first interview, the researcher explained the study and the method of recording interviews in further detail to the participant and his/her parent(s) and again offered to answer any questions. The participant was asked to read and sign a consent form (Appendix B) and the parent was also asked to read and sign a consent form (Appendix C). All participants were informed that participation was voluntary and medical and nursing care would not be prejudiced by their decision.

Description of the Respondents

Six adolescents indicated an interest in participating in the study. One adolescent withdrew from the study before the initial interview due to not feeling well enough physically to participate.

Five adolescents (two females and three males) participated in the study. The participants' ages were thirteen to seventeen and all were diagnosed with cancer during adolescence. The diagnoses of the adolescents included Ewing's sarcoma, leukemia and lymphoma. Four participants were receiving chemotherapy at the time of the interviews. The other participant had completed chemotherapy two months prior to interviewing and was receiving treatments for complications of prior treatments. Other treatments undergone by some of the participants included radiotherapy, surgery, and a bone marrow transplant.

The treatment protocols required regular treatments approximately every two weeks and ranged from one to six days of
treatment. All participants were hospitalized at some time for various reasons such as diagnosis, surgery, initial treatment, hydration, side effects and infections. At the time of the interviews all of the participants were outpatients for their treatments.

All participants lived at home with their parents and sibling(s). Two participants lived in rural areas outside of the Lower Mainland but travelled to Vancouver and stayed in rented accommodations during their treatments. These individuals were accompanied by their mothers to Vancouver. The other three participants lived in urban areas close to Vancouver. Thus, all five participants were accessible to the researcher.

All the participants were physically affected in some way by their treatments during the time of data collection. Physical effects included fatigue, nausea, low blood counts, colds and pain. Three adolescents were experiencing various degrees of alopecia. Only one of these three participants had chosen to wear a wig.

Three participants were attending school full time, one with the help of a tutor. Of the participants not in school full time one was attending classes part-time and completing full time requirements through correspondence. The other participant did not attend school at all and was uncertain about resuming school attendance. The decision whether or not to attend school was determined by the extent to which cancer affected the adolescents' physical abilities.
Ethics and Human Rights

The study involved personal contact and interaction between adolescent participants and the researcher. The participants were relating their personal experiences in the interviews and conditions to protect their rights needed to be addressed. Also, the participants were minors and it was especially necessary to ensure their safety. The following provisions were established to ensure ethical considerations were met:

1. Written approval was obtained from the University of British Columbia Behavioral Sciences Screening Committee.

2. Written approval was obtained from an In-Hospital Research Review Committee in the pediatric facility.

3. Participants and their parents were given written information (Appendix B, C, D) about the purpose of the study, the nature of the participation of the adolescent, the type of data to be collected and the manner in which the data would be handled.

4. Participants were advised that they could refuse to answer any questions, stop the interview at anytime, delete any information and/or withdraw from the study at anytime without penalty.

5. Participants signed an informed, written consent (Appendix B) before any interviews were conducted.

6. Parents of participants signed an informed, written consent (Appendix C) before any interviews were conducted.

7. Participants and parents were informed that tape recorded interviews and transcripts were confidential, and names would not
appear in any written material. Tapes and transcripts would be destroyed at a later date after the completion of the study.

Data Collection and Analysis

Data were collected in two in-depth interviews with each participant for an overall total of ten interviews. All but one interview, were conducted in the participants' homes or temporary accommodation. One of the second interviews with an out of town informant was conducted in a private room in the oncology clinic.

Parents were present for three interviews. These interviews were with rural participants and the parents were present due to lack of private space in their accommodations and no other place for the parents to be. The parents did not participate in any way during the interviews and their presence did not appear to be a distraction. The parents presence during the interview was agreed upon by the participants and the researcher. Participants maintained eye contact with the researcher and did not interact with the parent who was present. During the initial interviews with the urban adolescents, the parents were present in the house. They allowed the informant a measure of privacy with the researcher but were close at hand. Only one participant closed the doors to the room to have a completely private interview. The others stated they wanted the door left open or they asked to have the interview in an open area such as the kitchen.
The interviews lasted from forty-five minutes to one and a half hours. On the average the first interviews were longer than the second ones. One of the participants asked that the interview be stopped after forty-five minutes because he was feeling dizzy and could not continue. Second interviews with two of the participants were conducted before completing initial interviews with the others. During the second interviews, the parents were noticeably less visible and some of the parents were not home.

The interviews were completed within a two month period. Appointments for interviews were scheduled around the participants' treatment schedules to enable the participants to feel well enough to be interviewed. The Christmas holidays were a factor that extended the time for interviewing as none of the participants or the researcher were available for a three week period.

It was important to ensure that the participants were comfortable and at ease during the interviews in order to freely express themselves. Some of the participants had no previous experiences of being interviewed and were initially quiet and shy. The researcher wore casual clothes to the interviews in order to appear relaxed and less formal. At the beginning of the first interview, the researcher revealed some information about her knowledge and experience working with adolescents and cancer. The participants seemed to become more at ease when they realized that the researcher had experience and knowledge about their illness and age group. This was apparent when one of the participants removed a
wig in the beginning part of the interview after learning about the researcher's background.

The participants needed time to establish a sense of trust with the adult researcher. As the interviews progressed, the adolescents seemed to become more relaxed in their posturing, ease of speech, and interacting to be verbal with the researcher. The tape recorder did not appear to be a source of discomfort to the participants and some of them picked it up and spoke into it when they wanted to make a particular point.

In the initial interviews, the researcher used trigger questions (Appendix A) to outline the general direction of the interview and facilitate discussion. The researcher encouraged participants to express themselves and describe their experience of the phenomena in their own way. During the interviews the researcher validated her understanding and perceptions with the participants by asking questions or summarizing ideas.

Data analysis began during the process of interviewing the participants. This concurrent process of data collection and analysis is part of the nature of phenomenology (Lofland, 1971). Information, assumptions, and themes discovered during data analysis were validated with the participants during the subsequent interviews. For example, the participants used the term "friend" to cover a wide variety of people within their social world. Further questions were asked in the second interviews to enable the researcher to understand what the participants really meant when they used this term. It was
determined that the participants perceived different categories of people labelled "friends" that ranged from friends, to school mates to support people.

Field notes were written by the researcher after each interview to document observations pertinent to the interview. These notes described the participants, the interview setting, and the general tone of the interview. There were short conversations that took place after the tape recorder was turned off that were pertinent to data collection. These notes also served to describe these conversations. A demographic profile of the informants was completed from information gained during the course of the interviews and from specific questions at the end of the second interview which served to put the experience in context for the researcher.

The interviews were transcribed verbatim and then analyzed by the researcher. The four essential steps as outlined by Giorgi (1975, 1986) were used as a guideline for data analysis. The process of data collection and analysis was ongoing. Final analysis was done after this ongoing process was completed (Lofland, 1971). The process of data analysis will be described in the next section.

First, the transcripts were read to understand what the participants were saying. During the second reading, the researcher made notes and started to identify code categories. As the interviews were being conducted and the transcripts were being read, the researcher began to identify some similarities and differences in
the adolescents' descriptions. Then, the transcripts as a group were read again to determine what aspects needed to be validated with the participants in order to more fully understand their perceptions.

A second set of interview questions was drafted to guide the researcher during subsequent interviews with the participants. During these interviews, the researcher validated her understandings with the participants by asking these questions and clarifying her conceptualizations of the adolescents' experiences.

The second interviews were transcribed and analyzed in the same manner as the first interviews. The researcher reviewed all the transcripts again and again to determine if the code categories revealed the researcher's understanding of the participants' views of their illness experience. The researcher verified her understanding of these experiences with the participants. A synthesis of these meaning units from the data was completed as understood by the researcher.

This synthesis was discussed with a colleague to assist the researcher in organizing her thoughts in a coherent and logical manner. A summary of this verbal presentation was then written by the researcher and this summation became the initial analytic framework.

The transcripts were again read to determine if the data supported the overall framework. The framework was modified to present a more comprehensive and consistent statement about the adolescents' experience of living with the chronic illness of cancer.
The conceptualization of the adolescents' experience is grounded in the data collected during the interviews. The data and the researcher's understandings of the adolescents' experiences were validated with the participants.

Summary

The phenomenologic perspective was the research method used in this study. In this chapter, the process of using this method was outlined. A discussion of the method of selecting participants and ensuring their human rights was presented. A description of the informants was given. A discussion of how data collection and analysis were done concurrently was outlined. The results of the data analysis will be presented in the next section, chapter 4.
CHAPTER 4: PRESENTATION OF FINDINGS

Development of an Analytical Framework

Described in the preceding chapter, was the method used to understand adolescents' experiences of living with the chronic illness of cancer. Data collected during interviews with the adolescent participants were analyzed and impressions formed from the data were validated with the participants. In this chapter, the presentation of findings will provide a description of the adolescents' experiences as understood by the researcher.

The findings will be presented in a narrative format and illustrated with quotations from the participants' descriptions. Quotes from both male and female informants are presented within the text. However, in general, gender is not identified in the examples of dialogue in order to not reveal the identity of the subject. There are exceptions in the text to not using gender but the quotations used do not identify the teenager. In these specific cases, gender identification is necessary in order to better understand the adolescents' perceptions.

The experience of living with cancer was unique for each adolescent who participated in the study. However, all shared common experiences living with cancer. It became apparent that the similar responses had a consistent form. An analytical framework was developed from a compilation of the adolescents' perceptions of these experiences. This framework represents the researcher's
conceptualization of the consistent responses of the adolescents as three distinct elements.

The overall theme of the framework is "getting on with life". All of the adolescents expressed an all encompassing desire to deal with their cancer and its treatments and to get on with life. The most important thing in getting on with life was to be normal and to maintain the life they desired as adolescents.

In order to achieve this goal, all participants responded to their illness in a similar manner, characterized by three elements. The first element is experiencing the illness or "I'm the same/You're different". The participants defined their illness in terms of what it meant to them and how it affected them. This definition of cancer was based on the adolescents' views held by the adolescent participants, that they were unchanged by cancer. The definition acknowledges the view that others changed the way they interacted with the teenagers because of the others' views that cancer had changed the adolescents.

The second element is redefining their personal self or in their words "I deal with things differently". Within this category, the adolescents identified a personal philosophy that had developed in response to the diagnosis of cancer. The participants all described the need for a positive attitude. The priorities they set for their day to day lives were based upon this personal philosophy.

The last element of the adolescents' response to cancer was a redefinition of their social world, described as "I have this other
life". In order to get on with life, the participants tried to keep their world that was affected by cancer separate from what they defined as their normal, adolescent world. Sometimes the demarcation was not possible and the two worlds came together. Consequently, the adolescents experienced changes in the social and functional aspects of their lives. They also established supportive relationships in order to deal with cancer and achieve the goal of getting on with life. An outline of this conceptualization and the three elements of response to cancer is presented in Table 1.
1. Experiencing the Illness "I'm the Same/You're Different"
   A. Personal Perceptions
   B. Perceptions of Others

2. Philosophy "I Deal With Things Differently"
   A. Being Positive
   B. Setting Priorities

3. Redefinition of Social World "I Have This Other Life"
   A. Separation of Illness
   B. Changes
   C. Establishment of New Supportive Relationships

Getting On With Life

Adolescents were affected by the experience of having cancer and its treatments. One way in which they responded to the experience was to put cancer into perspective in their personal lives. It was very important for them to be normal adolescents and carry on as usual even though they had cancer. Their primary motive was to deal with the illness and then get on with their lives. One adolescent
explained, "instead of worrying about your illness, getting on with life". Another said, "I just decided to go on with life and forget about what I looked like and do the best I can do and people will forget". In order to accomplish this goal, the adolescents had to make sense of how cancer affected the functional and social aspects of their personal lives.

The adolescents' responses to their illness within the conceptualization of the three elements in the framework will be described in the remainder of this chapter. The first section will describe the way in which the participants experienced their illness. The researcher will illustrate how they responded to their illness in order to get on with life. The philosophy developed by the adolescents in response to having cancer will be explained in the second section. Also, the way in which this philosophy affected the participants' abilities to reach their overall goal of being normal as they get on with life will be described. The third and final element of response, redefining their social world, will be presented in the last section and will illustrate how the adolescents met their personal objectives of getting on with life as normal adolescents.

**Experiencing the Illness - "I'm the Same/You're Different"**

The adolescents' experiences of having cancer were unique but there were commonalities shared by all. Their responses to the illness were founded on views they held about themselves having cancer and also ones they perceived that other people held about them
having cancer. A discussion of these views will be presented in the following sections.

Personal Perceptions

Defining the Illness.

The illness of cancer was described by the adolescents in terms of a series of events. Each event appeared to be perceived initially as threatening the adolescents' identity. Some of these threats included the physical changes associated with the illness or treatments. While the adolescents used a variety of strategies to cope with or respond to what they perceived as threatening, the outcome was the ability to believe that "I am the same". They explained: "I'm me" and "I can cope very well" and "I wasn't handicapped from doing anything. I could work, lead a normal life, do normal things". Adolescents could be seen then as living through and coping with a series of illness related events.

All participants developed a perspective of how cancer and its treatments personally affected them physically, emotionally and socially. As they defined their illness, the adolescents established an overall perception of themselves as individuals who had cancer. However, in their descriptions it was noted that the teenagers maintained their individuality and did not personally identify themselves with cancer.

Cancer did not alter their personal identity and nor was it a label they used to describe themselves. One adolescent stated, "I
don't consider myself a patient or a cancer patient. I hate using that word too. I just call it the sickness because cancer is just such a nauseating word". The use of the term cancer was not seen positively as a term of reference for their illness or themselves.

The adolescents felt that they were the same as they were before the diagnosis regardless of having cancer. They believed that cancer and its treatments had not really affected them because they saw themselves as normal. One stated, "I'm just like normal without having cancer. Even after my treatments I still am." They did acknowledge that there might be a small difference in themselves that could be noticeable to others but they felt they had not really changed. A possible difference was not seen as significant for one adolescent who stated, "I'm in my normal state. If I was the same person a year ago today, I couldn't tell the difference without looking in a mirror". Again, if there was a difference, the adolescents perceived it to be small. This teen explained, "Out of a hundred if I thought I was different, it was probably 95, like five percent different but that's about it". Another adolescent attributed that any variations from normal were due to the effect of the treatments. This person did not change as a person and described how cancer had no real effect. "No, I'm not sick, I don't ever feel sick unless I'm getting chemo for the two days. The rest of the time I'm just perfect". The participants believed that they were normal even though they had cancer and they just wanted to get on with their lives.
The treatments did however have an effect on the adolescents' abilities to carry on their normal lives. They used different strategies to normalize the effects of the treatments. One teenager made a deliberate effort to be normal by participating in activities where there would be no apparent differences seen in the group. "I do team sports so I'm just one of the guys and I'm not noticed if I'm tired. It's not like an individual sport where you would stand out." By dealing with cancer and its treatments throughout the illness experience, the adolescents were able to conclude that they were still the same. However, there were threats to their ability to be the same. These threatening events and the adolescents' responses to them will be discussed in the next section.

**Threats to Being Normal: Events and Responses.**

The time of diagnosis was the beginning of the adolescents' personal formulation of what cancer was to them and what the treatments might be. Cancer was perceived as something that interfered with their ability to continue with their activities. One participant stated, "When I first heard about it, you know, I thought oh oh, I can't do anything". Cancer was seen as a name for the pain that was being experienced and the diagnostic period was a time of waiting and uncertainty. One teenager said, "I was diagnosed in June and all throughout July they were figuring out what they were going to do to me. And that's a month to sit to realize that this pain in your back is 'oh my god, it's cancer'". After diagnosis, the teenagers had a
name to give to their illness and had some ideas about what it might mean to them.

A further understanding of cancer was formulated by the participants when they learned about their treatments. They began to realize what the treatments were and how the treatments would affect them. One described it this way, "When I was first diagnosed... they told me about radiation, I can get through that. That’s a breeze... and then they told me six months of chemotherapy and it kind of blew it all out of proportion". There was a similar reaction to the impact of the diagnosis and treatment for another adolescent who stated, "When they told me I was sick, I didn’t know it. It came as a total shock to me because I felt fine. And they said that the treatment would probably make me feel more sick than the disease would". In the adolescents’ minds, the treatments for cancer were inseparable from the illness itself.

The ways in which the teenagers defined their illness were also determined in part by the degree to which the adolescents were personally affected by the treatments. The adolescents reacted differently to the effects of the treatments depending upon their individual perspectives. The definition of what was normal varied for each teenager but in some instances, the disease itself was perceived as a threat to normalcy. One of the participants discussed how cancer interfered with her view of what was normal, "I think girls have it harder because, I guess I just don’t feel feminine when you’re talking about a disease. I don’t feel attractive because it’s such an ugly
thing". She perceived her illness as something ugly that in itself, negatively affected her attractiveness and femininity. Other adolescents defined normalcy in different terms. For some, participation in sports was important to be normal. One participant explained, "Well right now I can't play football for six months and I really like football. And that kind of screws me up". The foregoing statements serve to illustrate how associated events could be seen by the adolescents as threatening. However, the participants dealt with the threats and subsequently decided that they were the same; they were normal.

While some of the side effects of the treatments were seen as more manageable by some of the participants than others, the effects had to be dealt with. The physical side effects from treatments caused the cancer to become a visible illness. This visibility had an effect on both how the adolescents saw themselves and how they perceived others viewed them. Alopecia was one visible side effect for all participants. The physical and social consequence of alopecia threatened their views of self. One participant said, "I was really upset about losing my hair. When my parents first told me, I just cried I was so upset. That's the worst - losing your hair. It's one of those teenager kinds of things. You want your hair".

Other participants identified that they were affected physically by their hair loss but it had less of an impact on them. One teenager stated, "chemotherapy does it to you, it makes you lose your hair, it is a noticeable difference. And my mom bought me a wig and I
refused to wear it... I can live through losing my hair. It's going to come back. That's what they tell me." The impact of alopecia was buffered by the realization that this side effect was temporary. These visible effects threatened the adolescents' normalcy and changed how others viewed them, but challenged them to re-examine themselves and reaffirm that they were still the same.

Sometimes this physical loss was not perceived to have an impact. One adolescent not personally affected by the alopecia said, "Even having no hair doesn't really embarrass me neither". The visible changes could be dealt with when they were perceived to not have a permanent or personal effect.

For all the teenagers, the establishment and maintenance of relationships with friends and schoolmates was important and was identified as part of what adolescence is all about. These visible aspects of the illness imposed limitations on the teenagers' social lives. One explained, "I don't like it... 'cause, I guess I don't like it because it takes up some time, you can't see your friends too much anymore, can't do any sports and I really like those. And some of the things you just can't do but you have to manage until it's gone". The adolescents were required to deal with these restrictions in order to manage the illness until it had ended. The illness and treatments could be seen as threatening their normal social world.

It was not easy for them to deal with cancer even when they were able to hide some of the physical side effects. They experienced difficulties when they had to provide reasons for wearing a wig. One
adolescent who wore a wig explained, "It's also harder wearing a wig too because you have to tell them it's not real, you know, when they start asking about it". The teenagers attempted to hide the physical effects of their treatments but they still had to manage the responses of others.

In the end, the illness and treatments were seen as a series of events that could potentially threaten the teenagers’ views of themselves as normal. However, with time and reflection, all of the teenagers concluded that they really had not changed and the illness and treatments, in effect, became a part of their normal lives. One accepted the treatments as a necessary part of life, "It's not that hard coping with it. Just going through, it's a natural process that you have to go through”.

The adolescents responded to the parts of their illness that were a threat to their identity as normal teenagers. There were factors that influenced their responses to these threats. A discussion of these factors follows.

**Issues Perceived to Threaten Normalcy.**

Various factors influenced how the adolescents were able to respond to threats from cancer and maintain their identity as normal adolescents. The factors will be discussed in the following order: the adolescents’ outlook about the outcome of the illness, living for today, gaining control, and looking toward the future.
The understanding the adolescents had of the outcome of the illness influenced their perceptions of cancer and the necessary treatments. All the prognoses were viewed positively by the adolescents and they did not consider a negative outcome even when given percentages for success and failure. "Well, I accepted it because the doctor said he could get rid of it. So there wasn't anything to think about". The participants had no doubts and it was a matter of fact that they defined their cancer as a treatable illness with a positive outcome. Their acceptance of the treatments was influenced by this positive outlook. One of the adolescents explained, "Like the first thing they told me was it was totally curable. I would go through chemotherapy and that kind of bothered me, but as long as I was going to be all right in the end...". The effects of treatments could be accepted and managed because they were seen as totally effective and there would be an end to the illness.

An understanding of this positive outcome of the illness influenced the way the teenagers managed their treatments. This was a significant factor in getting on with their lives. The adolescents accepted the illness and its treatments. They perceived that the treatments were "just a part of life". The treatments were viewed within the overall perspective of their life span and could be accepted as a temporary routine. This treatment regime was described as "it's almost gotten to be, the past two years, a normal routine. Going in to have my treatments is kind of part of life". The treatments were
managed because they were seen as having an end and thus, were just a part of their lives.

All participants put cancer into perspective in their own lives. They perceived that there was a positive end to the treatments and their cancer. They had a vision of what the future might be for them upon completion of their treatments. They saw a point where they could get on with their lives as they desired. One participant stated, "I kind of see the freedom of not having to think about the next day if I have to go in. Just getting on with my life. Not having to kind of fit around the things I want to do around having the treatments, and the weeks." The end of treatments meant the resumption of activities and their normal life. One participant described the end as a time to resume missed activities, "Like when I'm finished all my treatments, I have a mass plan, like I'm going to do all my sports, I'm going to catch up on everything...". They envisioned the end as the time when they would really be able to get on with life.

The ability to hope and dream of the end of treatments helped the adolescents deal with their illness. There was an end to the cancer part of their lives and then they could go on as they wanted. One adolescent explained this dream as, "It just gives you something to look forward to I guess. A goal, once you're there, you're there. I don't know, next thing you know, you're finished and I'll be doing all these things again". Cancer was managed more easily when a future without cancer was envisioned.
Envisioning the end was a way of dealing with the treatments from an overall perspective of the illness. The adolescents also dealt with their treatments as an event in the present. One way to live successfully through the treatments was to deal with them matter of factly. It was important to be normal during this part of their life when they were receiving treatments. One adolescent stated, "you just go on with life as normally as you were before you were sick and if anything comes up you just deal with it. Block it out. You know, understand it happened for a reason or something". By dealing with any problems arising from the cancer, they were able to live normally. The ability to deal with cancer was to block it out and not think about it was also successful for this teenager. "I just blocked it all out because I don't want to think about it". Even if they did not think about their cancer they were aware that it still had to be dealt with. Again this idea was stated as, "you have to deal with it. You can't throw it away because it will always come back".

The adolescents had no choice but to deal with cancer the best way that they could. Sometimes they were unable to manage their illness with their usual strategies. When this happened they had alternate plans. "Like I would just try and deal with it the best way that I could and ninety percent of the time it worked. And if it didn't, I would just come home and go to bed". Having an alternate plan that would certainly be successful allowed them to continue to have control over their illness.
It was important for the adolescents to control their illness and treatments. Control was achieved as they gained information and experience to be able to deal with their treatments. They perceived that information was useful in order to gain control because "once you sort of know what it is, it's no problem". Knowledge and control were achieved when specific strategies were taught to the adolescents by health care professionals. These strategies were used by the teenagers during their treatments. Techniques such as distraction and self-hypnosis were used by some so that "I can control the pain". Thinking about pleasant things was helpful for another adolescent who explained, "It actually helps to know I'm going out. I've always hated needles. They hurt and they sometimes get it in right away but then sometimes it takes two or three times. I make it worse because I'm so tense. But if I'm going out I relax and think about that and it's something to look forward to." Being in control for some of the other adolescents meant being able to control themselves rather than the treatments themselves. "I would just endure the pain and get it over with, yeah". Knowledge gained through experience also gave them control. One participant said, "So now I know what happens so I don't have to worry about it anymore". Another person explained, "I've gotten used to it. I've known what to expect and I know how things are going to be".

The adolescents placed cancer in perspective by looking toward their futures and where cancer fit into their overall lives. The future included careers, committed relationships with others, and the
possibility of having children. For some, cancer was seen as possibly having an effect on their lives in the future. However, cancer was seen as having less of an impact as time passed after treatments. One participant explained, "I'm most likely sterile and I'm going to have to explain to a future husband or a potential husband that I may not have kids... So that's always going to be there, something the farther I get away from, when, well in ten years it won't be as hard to say 'I've had cancer' You know, it was so long ago". There might be future effects from cancer but the illness was still perceived as having an end. Others saw the end of treatments as the end of cancer and it was not considered in their futures. This teenager explained, "And then, it will be finished. That's totally it". Cancer was not perceived to have a great effect upon their futures in life. The adolescents envisioned themselves having a normal future.

These descriptions illustrate the manner in which the adolescents assigned meaning to cancer. They saw themselves as still being the same. Cancer was viewed as an illness that could affect them physically and emotionally. It was also seen as having an end. The adolescents made sense of their illness and managed it in order to get on with their lives.

The adolescents' definitions of cancer were also influenced by people in their social environment, such as other adolescents and adults. The manner in which the adolescents were affected by these people will be described in the next section.
How Adolescents Perceived the Responses of Others

The adolescents had ideas about how others in their social world perceived them. The adolescents' views were based on the actual responses of others or the ideas the adolescents had about what these responses might be. The adolescents related their views of others' perceptions for different periods during the illness experience. At the beginning of the cancer experience, the responses that of others were significant to the adolescents. An accepting response by others influenced this participant's perception of having cancer in a positive manner. "When they first heard it, 'oh no!' and all that but after awhile they got used to it and they just treat me normal. The same as before".

There was a general desire on the part of the teenagers to be viewed and accepted by others in the same way that they perceived themselves, that is, that they were the same as they were before having cancer. The teenagers did not think that they were different because they had cancer and they wanted to be treated as normal teenagers like everyone else. One adolescent explained, "I don't want them to treat me any different than you". Similarly, another stated, "Well I think I just wanted to lead a normal life and I wanted to be normal. I just wanted to be treated normally". Being normal or achieving normalcy was a major theme that emerged. The findings related to this theme will be discussed in relation to the literature in chapter 5.
Being treated normally was important and was based on other people perceiving them as being the same and then accepting them as being the same. Others might notice that the adolescent had cancer but then they realized that the person was the same. This participant explained how others responded, "And you know people that you don't know, they give you a second look and maybe that's it. But after that they kind of just look at you for what you are and not what you have".

The importance of not being judged by others based upon looks, or for having cancer, was significant for these adolescents. One of the adolescents explained, "Yeah, basically the whole thing is trying to be accepted for what you are. And not what you have and not what you look like, just for what you are". The adolescents perceived that they were the same and were normal and that was how they wanted others to view them.

Individuals who had not yet revealed their illness to others had concerns about what others' responses would be. The responses of people were perceived as being potentially negative. The adolescents all identified difficulties when interacting with individuals. These differences were attributed to other persons' discomfort with cancer and different views of the illness. One stated, "I find it a bit of a worry sometimes about how they would treat me if they found out". Cancer was seen as something that could change the way that people perceived them. One participant explained, "So it's really hard to tell them what it really is and to accept me for what I am and not for what I have". There was a
possibility that they would be seen as different by other people because of having cancer.

The descriptions illustrate that the adolescents had different ideas about how people would perceive them. The participants provided for thinking other individuals had these perceptions. The teenagers recounted that they were continually challenging others' images of cancer, many of which they did not perceive as applying to them. The other person's experiences and knowledge of cancer were seen as significant factors in their responses to the adolescents who had cancer. One adolescent explained, "I guess it depends on what type of illness you have. But when most people think that you have cancer, they always think that you have no hair and you're bald".

The negative images of physical appearance associated with people with cancer were again addressed in the next account. The adolescent identified that there were differences between her personal perceptions and those of others, "Well everyone has had a sick grandmother or a sick uncle who has had cancer and when they're little they go to the hospital and they see this old man lying in a bed, or an old lady sick with a catheter in, and I always think that's how they see me. Even though I'm not like that though".

The teenagers concluded that other people perceived individuals with cancer as being sick and old. These ideas conflicted with the adolescents' who perceived that they were unchanged by cancer. They saw themselves as normal teenagers, not as someone with cancer.
Others' knowledge about cancer was thought to be due to previous personal experiences with someone sick with cancer or through media exposure. These sources of information contributed to others' perceptions about adolescents who had cancer. A participant explained, "Maybe they would think I'm different. They had seen pictures or a show or something on kids who may have had cancer". However, this limited knowledge of cancer was not the only factor influencing others' responses to the adolescents. Some adolescents perceived that others' perceptions were influenced by the fact that these people were inexperienced in relating to them in a social setting. The participants did not identify any differences between people they knew or strangers they encountered in their perceptions of others' reactions. One participant recounted, "Maybe they didn't just know how to react. I mean maybe they just didn't know what to say or how to react. Maybe they didn't really know, maybe they hadn't been exposed to a person like me before. Like socially. Like maybe they had just seen somebody like me like walk somewhere or pass by somewhere. Knowing me as a real person, they didn't know how to react". The person did not have any experience and knowledge of adolescents with cancer and they did not react in their usual manner to them.

The adolescents did not know how others would react to them but thought that others perceived them as different and would respond in an undesirable manner. They did not want to be treated any differently because of their cancer yet, it was possible that others
might do that. This adolescent described others' reactions, "I don't know, it makes people look at you differently. Like he has to be cared for or something like that, or he needs special attention or something like that. It's not what I want because I don't need it". The adolescents did not perceive that they were any different and did not need any special care. They wanted others to perceive them as normal and treat them the same.

Some of the feared negative responses of others actually occurred during the adolescents' illness experiences. The adolescents' perceptions that others would think they were different were actualized in real life. "People come up to you and say, you've changed, you've changed. I don't know how but you've changed".

The adolescents were concerned about other people's perceptions about their cancer treatments. Adolescents' worried about the responses of others to the visible signs of their illness. One adolescent explained, "I'm sure people might ask people about that. Like why has that guy lost his hair or something or what's wrong with this hair. Like some people thought I was a neo-Nazi skinhead for a while". The reactions of many others were not flattering and indicated a lack of knowledge and understanding. The adolescent was perceived to be different and was treated with rudeness and disrespect by some people. This negative behavior hurt the participants' feelings as explained by another teenager, "And a lot of people mistook me for a skinhead but I looked like Sluggo from that cartoon Nancy...I really lost a lot of my respect for older people who
I thought would understand because they would say you look disgusting. And that really hurt. I didn't shave my head. I lost my hair". The adolescents expected older people to know about cancer and understand them, rather than misattributing the meaning of their appearance. Another participant explained, "I think the adults are worse than the kids. They think 'did she shave her head to look cool' or something like that".

Even when the adolescents were not treated differently by others they worried about how others perceived them. The behaviors of others were accepted at face value but cancer was always present as a factor in their behavior. What was normal for anyone else might not be thought of as normal for the person with cancer. "Even though I have friends who are normal who say 'I'm not feeling well' and go home. No one thinks of it, at least I don't think anything of it. But I always think what if they think ... there's always that thing [cancer] lying there. It's sort of like a dead cat". Cancer was seen as something that was not pleasant nor talked about but had an intrusive presence and influenced the perceptions of others.

The adolescents defined cancer and its treatments in order to get on with their lives. The perceptions they had about cancer were a significant factor in how they defined their illness. Equally important to this definition were the adolescents' perceptions about the responses of others to cancer. The other elements of the response to the experience of living with cancer illness were influenced by this definition of the illness. The adolescents responded to cancer
and developed a philosophy and set priorities to get on with life. This element will be presented in the next section.

**Philosophy - I Deal With Things Differently**

**Being Positive**

The participants developed a personal philosophy or attitude during their experience of living with cancer. This philosophy developed as the adolescents were gaining an acceptance of their personal selves by confronting the reality of their illness and their own mortality.

The adolescents' philosophies were described within the context of their own illness experience. Even though each of their individual experiences was unique, there were many similarities in the adolescents' outlooks. All expressed the idea that it was important to be positive "When things get bad, you can't think the worst, you have to think the best and things like that". They chose to be positive even when they had bad experiences during their illness.

The adolescents believed that having this attitude would have a positive effect on the outcome of their illness. A positive attitude gave hope and resulted in a better outcome. One person stated, "But patients who keep a good outlook on life, you know always have hope, and seem to do a lot better". Another explained, "Well cancer is just a disease but if you act positive you know, you believe you don't have it, then when you pass a year you won't have it". Spiritual beliefs also helped giving some hope to maintain this attitude, "I was brought up
with religion too. I guess it was more reinforced too when I got sick. It was something to look to if everything looks bad or bleak or whatever. It helped me stay positive”.

For others it was the control over their cancer that they gained from a positive attitude that ensured a positive outcome. One said, “When you’re in charge the tumor can’t take over. It’s just like when you’re in a fight and you’re winning the other person can’t get you. And that’s what it’s like you know. If you keep on having a positive attitude you can’t lose”. They had the feeling that cancer could be beaten because of the control achieved by their outlook.

The level of happiness that was possible for the teenagers was influenced by their optimistic outlook. Being positive was personally satisfying for these adolescents. Looking at the good side of their illness rather than the bad was a conscious choice for the participants. One adolescent described this deliberate decision, “They gave me some kind of figure and you have to look at the good side instead of the bad side. I think you become very optimistic. Not that it shows all that much. I’m not saying optimistic, I guess you do try to see the good side of everything. Because if you look at the bad side you know then there really is nothing you can do. I think if I looked at the bad side every time I would be a very sad person”.

Happiness and the ability to do something about their illness were seen as related to their philosophy of being positive. One adolescent stated, “I take a better attitude in what I do. I’m not as much of a pessimist anymore. It’s not impossible. I have that type of
attitude. As opposed to before, like, I think I'm better natured. I'm a better person for it. I know". Another person explained, "I think I'm better for it. I've matured". They felt that optimism gained from their philosophy made them better persons.

All adolescents perceived that there would be a positive outcome to their illness because of their outlook. However, at one point, one of them did believe that a negative outcome and death was a possibility. The response to this threat to life was to not worry and to get on and live life as it was. This adolescent explained, "I guess I lived it up because what the hell, I'm going to die anyway so...". The negative outcome was acknowledged, but a negative outlook did not develop.

Other adolescents seriously examined the outcome of their illness and concluded that, for them, cancer was not fatal. This positive attitude enabled the adolescents to put their illness into perspective and to get on with their lives. One participant recounted, "I tried to keep it just like, I tried to keep it in perspective... I didn't, never at any point did I think I was going to die... so I just decided to go on with life and forget about what I looked like and do the best I can do and people will forget". Their ability to be positive and get on with life helped them to overcome the problems they were having in dealing with side effects or with other people's reactions to cancer.

Even though cancer was not perceived as having a fatal outcome, it was considered to be serious. The serious nature of
cancer was acknowledged by the participants and thus motivated them to get on with their lives. One explained this by saying, "No, I never thought about dying. I just know I'll get better. I've just matured. I know that there is a serious and a fun side to life and I have to get with life". Cancer was seen as significant but it was not fatal.

The positive attitudes that the adolescents developed were perceived to positively affect the outcome of cancer. Cancer was still viewed in a serious manner but it did not interfere in their ability to get on with life. The next part of this section will describe how they set priorities and got on with their lives.

**Setting Priorities**

The adolescents determined that getting on with life was important for them and they made decisions in their day to day lives in order to achieve this goal. One priority was to deal with the cancer by eliminating or ignoring it in order to get on with life, as was explained by one teenager, "To get rid of it. Get rid of it first and then go on living. I never gave up. I never give up". The adolescents' positive attitude again was seen as integral to the ability to overcome cancer.

The adolescents perceived that stresses encountered while getting on with life could negatively influence the outcome of their cancer. Activities that could lead to stress were not continued. One
person recounted, "I'm concentrating now on getting better before I start going out and putting more stress on myself".

It was not always necessary to eliminate the cancer completely before getting on with what was important in life. Cancer and its physical effects could be forgotten and life could be fun. One adolescent explained, "Enjoying life. Yeah, having fun. Kind of ignore the, try to ignore the other side, the pain and the illness. Try and shut that out. Instead of worrying about your illness, getting on with your life". The ability to mentally eliminate the physical effects of cancer to enjoy life was a priority.

To be able to live their lives as they wanted was important for the participants. Quality of life was significant for one person who said, "I think having a good quality of life is like my, I don't know, my number one priority". In this instance, quality of life meant "happiness, compassion and trying to do what you feel like doing".

The ability to achieve what was important in life in spite of having cancer was desirable. A participant explained, "Like when you get sick you realize you know how important things are and you just try to be the best that you can be. Also, to try and prove something to yourself and other people that if, just because you have an illness or something doesn't mean that you are disabled. And you have just as many capabilities as anybody else has. You just want to prove that to yourself". It was important for some people to demonstrate to themselves and others that cancer had not decreased their abilities or that they were different.
Participating in activities to show that cancer had not caused limitations was not important to one participant who said, "I don't do things to prove something. I just do it to get on with my life". For this adolescent, participation in activities was done for personal reasons and not to prove anything to anyone else.

The adolescents' abilities to live their lives the way that they wanted was affected by the reality of their illness experience. Limitations imposed by the effects of treatments made living in the present a priority. One teenager explained, "Just to live it one day at a time. Just to live it as it is...because a lot of things I used to do I can't do anymore". Getting on with life was a day to day experience.

The personal philosophies that evolved for these adolescents were generally focused on being positive. The adolescents' priorities were to carry on with their lives and enjoy them. This optimism about life was directly related to the adolescents' philosophies. This redefinition of personal self realized by these adolescents influenced the redefinition of their social world. This element of response will be presented in the next section.

**Redefinition of Social World - "I Have This Other Life"**

**Separation of Illness**

The adolescents perceived a distinct separation between two parts of their lives. One part of their lives was affected by cancer. The other part of their life was either not affected or one they did not want affected by cancer.
Social life was part the segment that they adolescents did not want affected by cancer. Keeping cancer separate from their social lives however was not always possible. One person stated, "It's two very different things and I don't like it when they sort of come together".

It was difficult for them to deal with the mixing of these parts of their lives. One adolescent explained, "It doesn't always work, to separate the hospital from home... I try my best to keep the two apart. I guess some of my hospital part leaks into my social life and vice-versa. I don't know how I deal with it". The adolescents' perceptions of themselves as the same as others was threatened when cancer invaded their social world. Cancer affected their personal identity because they might not fit in. The fact of having cancer and not being able to make plans affected their ability to participate in social activities. One adolescent said, "Yeah, I want to fit in and I want to be myself and I don't want people thinking well I don't want to like her because she has leukemia. I want to be myself and sometimes I can't be myself. Well I'm myself but I can't fit in with everybody else you see. Like most of the time I can't even make plans even a day ahead". There was a need to keep cancer separate so their identity and social lives were not compromised.

It was important for them to fit in and be normal. This was easier when cancer did not affect their social activities. "When I go out with my friends who are not connected with the hospital they give me you know a different life, not a different life, a different
lifestyle. They make me forget about the hospital. I never think about the hospital and I don't even think about my hair loss when I'm out with them. They make me forget about all that. I just go out with them. I honestly have a normal time with them. I'm a normal teenager". Getting on with life meant the ability to have a normal social life that was not affected by cancer.

Sometimes cancer invaded their social lives to the extent that it stopped them from participating in activities. One of the adolescents explained, "Yeah, sometimes, sometimes I just couldn't, I was completely out of breath or something. I just said well, I'm not feeling great today. I just said I can't do it so I won't". One way to deal with the effects of cancer was to accept these limitations and just quit.

Another way of dealing with the effect of cancer was to carry on rather than admit they were affected by their illness. One of the adolescents said, "I felt lousy. I really didn't feel like going to school but I kind of felt obligated. 'Cause I had exams and even though I knew that somehow I could get exempted from those exams, I didn't want to be treated any differently". The consequences of carrying on were suffered in order to be normal and not be treated differently. It was important to not let cancer get in the way in order to carry on with life as usual.

The adolescents experienced changes in their social world whether or not they were able to keep cancer separate. These changes will be described in the next part of the chapter.
Changes

Changes occurred in major areas of importance for the adolescents. The adolescents perceived that these changes in their friendships, activities, families and schools were caused by cancer.

Friendships

All but one of the adolescents perceived that they experienced changes in friendships. These changes were different for each adolescent but were attributed to the experience of cancer entering the social part of their lives. One individual who did not perceive any changes had successfully hidden the illness from friends. This person had only told one person about having cancer and this confidence had been maintained. However, this adolescent directly attributed the loss of one friend to having cancer. Social interactions were limited because of the illness and the participant was no longer able to “hang around” with the friend. This loss of friendship was viewed positively and cancer had “saved” this particular adolescent from engaging in deviant social behavior.

For other teenagers the changes also involved the actual loss of friends. These losses were directly attributed to having cancer. One adolescent explained, “I guess I’ve got really good friends now because I’ve sort of weeded them out with me, my illness. I really appreciate my friends, they’ve been with me the whole time ‘cause a lot of them just backed away”. There were people who remained friends and were not eliminated by their reactions to cancer.
The people who always stayed friends throughout the entire illness were considered to be special. "No, like, I had this one girl, she lives down the road, she's always been my best friend. She understands it like, she knows what I go through and all that and she's really good about it. I don't know, just losing your friends is really hard".

Even though there were people who remained, it was hard to accept the loss of friends because of cancer. The adolescents' desires and abilities to make new friends were influenced by these experiences. One person stated, "It's really hard to make really close friends now ... I think anyone who's my age or around my age who has an illness like cancer or epilepsy or anything like that will tell you the same thing". The type of illness and adolescence were factors that negatively affected an individual's ability to make close friends.

There were changes in the way that friendships were made by some of the participants. Some of them made a point of being open with the people in their lives. Adolescents who used this strategy were comfortable within their social world of friendships and activities. One adolescent explained, "when I'm getting friends, I tell them because like I don't want them hanging around me if they don't want to hang around with me because I have cancer so ... I tell them. Most of the time they accept it so that's pretty good". Cancer was not hidden and friendships were founded with an understanding and acceptance of the illness and the adolescent.
The special people who remained friends understood about cancer and how it affected the adolescents. One adolescent explained to friends that it was impossible to participate in an activity, "I told them I couldn't go out because I was sick. They understood, there was no argument". These individuals were able to maintain their friendships and social lives even though they could participate in limited activities. They were accepted by others and were able to get on with their lives in the best way that they could. One adolescent explained, "Some friends are more, like they accept it more and some people, they forget about it and pretend it doesn't happen. What I'm trying to say is there are friends that respond to what you have and there's others who know you have it but they just consider it, he's fine, he know's he's fine".

Some friendships remained intact but changes occurred in the amount of contact and social interaction that was possible. "I don't go out with my friends as much as I used to. I would love to. I really miss my friends. We go out sometimes but I can never do very much". The relationships between changes in friendships and activities will be discussed in the following section.

Activities
The changes in friendships are interconnected to the changes that occurred in the adolescents' activities. It is difficult to distinguish which occurred first, the changes in friendships or the changes in activities. It was necessary to keep up with activities to
be able to keep up with friends and maintain a social life during the illness. The continuation of a social life during the illness was important for the adolescents so that social activities would still be the same when they were feeling healthy. An adolescent explained, that, "I'm socially active. I want to be socially active now so like when, say if I wasn't socially active now and when I do feel better or when I do get better, I get socially active then, well, I'll be kind of like... They won't know who I am". It was essential to maintain a normal social life during the illness to ensure a normal social life at the end of cancer. The teenagers ensured that they would be able to get on with life as usual.

The adolescent whose friendships had not changed because the illness had been hidden, was able to maintain activities at a normal level throughout the illness experience. This adolescent stated, "My social life hasn't changed. I usually went out on Fridays right after my chemo. It didn't bother me at all." It was essential for this person to deal with the treatments and keep up with activities to continue hiding the cancer.

The others who did not hide their illness dealt with their social restrictions differently. Some friendships were maintained whether the participants did or did not participate in different activities. One adolescent who was not allowed to play contact sports for six months to two years explained, "The sports. I don't miss them 'cause I've got my friends."
Families.

The adolescents did not experience many changes within their families as a result of the cancer experience. Some of them indicated that their parents were more protective of them and worried more. One participant explained, "They're [parents] really protective over me. Even though I'm the eldest, they let my sister have more freedom because they are so worried about me". Another said, "You know, I can't blame her for feeling that way because she's my mom and that's her job... and now she's always there and she pampers me a little too much". However, others did not perceive that there were any changes. One participant stated, "My parents don't treat me any differently".

Both positive and negative changes in sibling relationships were identified by some of the teenagers. One person described a change for the better, "We're closer and everything... basically he's more of a really good friend rather than a brother". For another participant, cancer had a negative effect on sibling relationships, "I feel really bad because my sister and I were really close before I was sick... and we are just starting to be really good friends again".

For different reasons, the adolescents did not readily share their concerns about their illness with their parents. One teenager did not like the answers parents gave, "It's not that I don't appreciate my parents, it's just that they don't know, its not the type of response that I enjoy". Cancer did not affect communication for another teenager who stated "My parents don't treat me any differently. We don't talk about things. We never have." This individual placed
parental relationships and communication within the personal experiences of adolescence, "I never really talked to my parents. Only when they told me I was going to lose my hair. It's that teenage thing. You just don't talk to your parents much."

The teenagers did not think that having cancer seemed to affect the usual way in which they interacted within their families and there were few changes. Perhaps a reason that few changes occurred within the families was because the adolescents were more likely to be accepted and seen as normal by parents and siblings. One teenager talked about his parents, "My dad learned to accept it and he knew I was going to be fine".

An area outside the family where many changes occurred was in school. The adolescents' perceptions of these changes will be presented in the next section.

**School.**

The responses of schoolteachers were important to the teenagers. The teachers knew about the adolescent's cancer soon after the time of diagnosis or after the adolescent returned to school. The adolescents described their teachers as generally being understanding and maintaining confidentiality about their condition. This was very important to the teenagers because they did not want the teachers to treat them any differently than the other students. One of the participants recounted, "All my teachers know and all my teachers treat me the same as a student, but more as they ask how
you're feeling and you know." Adolescents appreciated that this concern of the teachers was not readily apparent to other students. The teachers responded positively to them as individuals who had cancer. "The teachers are really good about it... I mean he was really understanding". The changes seen in the teachers were viewed positively by the adolescents.

Cancer caused changes in the teenagers' abilities to achieve academically in school. Extra effort was required by the adolescents to keep up with their school work. One teenager needed a tutor and others used the help of the home bound teacher program. However, some were unable to do keep up no matter how hard they tried. One person stated, "Like in school right now, I was supposed to finish a novel a couple of weeks ago and I'm still reading it and it really hurts because you could see that all your other friends are way ahead of you." Another explained, "I had what is called a visiting teacher come. And I stayed up with my classes and everything... but then the treatments got stronger so I couldn't continue on".

One participant who had a tutor said, "I'm more ahead than some of the people at school. My french class, I know more from being away than half the guys do". Another said, "My grades have really picked up since. In first term grades I got the best report card I ever had". The extra effort put into school because of the cancer experience resulted in positive changes in some of the adolescents' academic achievements.
These changes in friendships, activities, families and school were described within the context of the adolescents' experiences. The social world of the participants were comprised of peers who participated in activities socially and at school. The adolescents' experienced changes in these situations because of having cancer. For most of the adolescents, there was not increased involvement or changes in relationships with parents or siblings.

The adolescents identified that there were friends within their social world who were viewed as supportive. However, all the participants also established at least one supportive relationship with a person outside of the scope of their friends and family. The next section will describe the establishment of these supportive relationships.

**Establishment of New Supportive Relationships**

The adolescents had some concerns about their illness and how it was affecting them. They established relationships with others with whom they could share these concerns and who would be supportive of them. Support was an important component to the teenagers' cancer experience. Their views are presented in this chapter and a discussion of these findings in relation to the literature will be presented in chapter 5.

The teenagers perceived that it was the personal qualities of these individuals that made them supportive. One adolescent described their supportive persons as the one who "stays with you
when you're sick and not feeling well. You can talk to them. I guess about what's happening. They're just with you. Your friends can't be with you all the time". Physical presence and accessibility are required for a person to be supportive. However, most important is the ability of the persons to communicate understanding and make themselves available during difficult times. This supportive person was outside of the usual social friendships and families of the adolescents. The people identified as supportive were older and included teachers, nurses, youth workers, and other parents.

In addition to these identified support people, the female participants also established supportive relationships with other children who had cancer. One girl explained why they could be supportive, "It's just easier to talk to them. They know what you've been through and stuff". However, there were risks involved in establishing these kinds of supportive relationships. One described it this way, "I try not to make too many friends actually. But it's hard not to when you have room mates and stuff. My very best friend in the hospital died".

Supportive people were seen as having the knowledge and experience that would enable them to understand the adolescent with cancer. The only person that one teenager had revealed the diagnosis of cancer to was seen as supportive because, "they've been in the same kind of situation and they've kind of experienced the same kind, the pain is the same... they kind of know where you're at. They understand a bit more". Similar experiences and knowledge enabled
this person to be supportive and understanding. The ability to understand was essential for a person to be able to help and provide support. Another explained, "if they didn't understand it would be really difficult".

The adolescents actively sought out these support people during the course of their illness for specific reasons. Thus, another quality that was identified as necessary for the support person was to be available when the adolescent needed them and asked for help. One teenager said, "All I can say is you know they're going to be there for you anytime." Another explained, "It just seems like they're there. And when ever you need them, they're there". When friends were not available or not suitable to help the teenager, the support person was there. This adolescent stated, "I guess I go to my support people sometimes more when I can't go out with my friends because they are never really too far from home."

The support person was able to do things for the adolescents at the home and in the hospital when cancer affected their physical abilities. Some of these things done for them included getting food, cleaning them up and adjusting the TV. A participant said, "I guess you do need them there, you need someone there or else you can't manage".

The supportive people also helped the adolescents when cancer affected them emotionally. One person described how a support person helped, "She kept me calm when things were really bad and she cheered me up when things were really bad". This supportive
individual could help the adolescents overcome some of the negative aspects of cancer.

The adolescents perceived only some of the health care professionals as being supportive. No relationships established with physicians were perceived by the participants as supportive. Supportive relationships went beyond meeting physical needs. As one adolescent said of the doctors, "They are supportive when I have a problem, you know, physically. Then they'll fix it or they should or they try but not mentally, not socially". The doctors were perceived as solving physical problems. The adolescents perceived that they needed more and established relationships with those who could meet all their needs.

The nurses were viewed as supportive because of "...their presence and because as I said they're objective". However, some of the adolescents thought that being supportive was part of the nurses' jobs and just accepted the support as a given. These adolescents did not view the nurses as someone who could be their friend and did not establish social relationships with them. One teenager explained, "The nurses at the oncology clinic are great. They are always there when you ask them for anything there is. No complaints. But you can't look at them at the same level as you do your friends because they are adults and your friends are adolescents". The nurses were seen by some adolescents as supportive in meeting their physical needs but were not seen by them in a broader context because of the age of
"older" nurses and "they were in a supportive role". They were seen as people who could provide physical support.

Some adolescents did establish supportive relationships with the nurses in the broader context. These adolescents viewed the nurses in emotionally and socially supportive roles in two ways. They were seen as nurses who were friends and who were nurses. This was described by one teenager as, "There's the friend part of the nurse and then there's the nurse nurse." These two separate parts to the nurses were necessary for the nurse relationship to be broadly supportive.

The support the nurses were able to give as a "friend" was seen as social and emotional. The adolescents perceived that this was when the nurse knew when "to laugh and have fun" and when "we talk about most everything together". The physical and emotional support given to them when the nurse was a "nurse" was equally important. This adolescent explained, "She was serious because I was really sick and this was a case of life and death and she was really a good nurse". All of the support given by the nurses was viewed as equally important to the participants.

Summary

In this chapter findings have been presented according to an analytic framework developed by the researcher.

The desire of the adolescents to get on with their lives became apparent through the adolescents' descriptions of their illness experiences. The participants defined what cancer meant to them
and their perceptions of others' responses to the illness. The way in which they defined their illness enabled them to get on with their lives. They also developed a philosophy of being positive and set priorities in their personal lives. Again this helped them to reach their goal to get on with life.

The teenagers also redefined their social worlds as they lived with the illness of cancer. Their social world consisted of a new dimension, the hospital, that was ideally kept separate from their personal worlds at home and at school. Some of these parts of the adolescents' lives changed because of having cancer. They had to deal with these changes in order to get on with life.

A discussion of these findings will be presented in Chapter 5. The discussion will include a re-examination of the literature to substantiate the ideas and conclusions presented in this next chapter.
CHAPTER 5: DISCUSSION OF FINDINGS

In this chapter the findings presented in chapter 4 are discussed in relation to the literature and other research findings. The chapter will be organized into sections discussing four major themes arising from the findings: adolescent development, chronic illness normalization, and social support.

Adolescent Development

Adolescence was identified in the literature review as a developmental stage of physical, emotional, cognitive and social maturation within life span development. A premise of developmental theory is that adolescents are required to achieve specific tasks during this developmental stage. It was an underlying assumption of Thomas' (1987) framework that chronic illnesses can interfere with development. A discussion of the literature and findings concerned with adolescent development and the effect of cancer on this development will be outlined in this section.

The adolescents were actively engaged in achieving the task of establishing an identity as a normal teenager. They could be seen as responding to the number of insults associated with cancer and concluding that they were the same even though they had this illness. Although the notion of being abnormal was considered as they tried to account for the perceptions of others about them, they decided that they were normal; and it was others who did not understand. The
participants perceived that the reason others saw them as being different was because of having cancer. However, this was not enough to affect the adolescents' identity. Previous research by Gavaghan and Roach (1986) identified adolescents with cancer having difficulty achieving an identity.

The results of the present study support the work of others by identifying that the adolescents used two sources of validation in order to establish their identity. The teenagers' conclusions that they were normal was based on their own perceptions about having cancer and those perceptions others held about them having cancer.

One finding of the current study was that cancer generally did not have a negative effect on the adolescents' self-image. Similarly, other research indicated the adolescents with chronic illnesses had normal self-images (Offer et al., 1984) and self-identity (Kellerman et al., 1980). In both of these studies the sample was not limited only to adolescents with physical illnesses; but included comparison groups of a large number of normal (non-patient) adolescents. Offer et al. (1984) stated that the tool used measured content areas and aspects of self that were important to the adolescents.

Only one of the female participants perceived that cancer had negatively affected her femininity and self-image as a female. While the other teenagers all spoke of cancer as threatening their images of self, they all spoke of arriving at the conclusion that they were still intact. The participants spoke of differences in relation to how they looked, how others treated them and how active they were able to be.
However, these differences were seen as peripheral and not affecting the core of their self. Differences in self-image related to gender were identified in the literature by Offer et al. (1984) who found males with cancer had a poorer self-image.

A positive influence on the participants' identity formation was that they felt they had control over the actual outcome of their illness; they saw it as resulting from their philosophy and positive attitudes. The adolescents believed that cancer had a positive end and they could affect this end by being positive. Zeltzer et al. (1980) also identified adolescents with cancer as having a positive outlook and that this positive attitude was the result of control gained from having a repertoire of coping behaviors.

Kellerman et al. (1980) and Zeltzer et al. (1980) also identifies the importance for adolescents to have control over their illness and treatments. Kellerman et al. (1980) in particular noted that adolescents had normal levels of anxiety and self-esteem, yet they felt that they had less control over their health than previously. The adolescents' ability to have control is an important part of dealing with the illness experience. This present study notes that control was important but it also adds to others' research by describing how adolescents achieved control. Specific measures to achieve control included gaining information about treatments and strategies to use during treatments; gaining experience about treatments; and learning to achieve personal control over themselves.
Tebbi and Koren (1983) identified that the adolescents had worries about coping with the effects of cancer on their physical abilities and appearance. This was not seen to be of concern for the participants in this present study, and physical changes were overall seen to be less important. It may be that the method of the present study enabled the researcher to not only identify concerns of the teenagers but also to locate these concerns within the broader social context of the adolescents' lives. However, the teenagers' worries appeared to become more important when the teenagers worried about what the reactions of others would be if they discovered that they had cancer.

Farrell and Hutter (1980), Moore et al. (1987), and Wasserman et al. (1987) documented the idea of the negative effect of treatments on adolescent development. However, they do not indicate the strategies used by the adolescents to deal with problems. The findings in this study indicate that the adolescents used different strategies to overcome the problems of negative effects of treatment. They chose different strategies depending upon how they perceived the situation and which strategy would result in a successful outcome for them.

The adolescents in the current study regarded their illness seriously and perceived that the treatment side effects were the worst part of cancer. Some perceived the hair loss from chemotherapy to be the worst part, while others felt that the worst was being left behind and not being able to participate in activities.
The worst treatment effects were somewhat different from those reported in the literature. Other research by Cohen and Klopovich (1986), Wasserman et al. (1987) and Zeltzer et al. (1980) indicated that adolescents with cancer perceived the treatments themselves to be worse than the disease. However, in this study, the illness of cancer and the treatments for cancer were not differentiated by the participants as separate entities. For example nausea, vomiting and infections (Wasserman et al., 1987), hair loss, weight loss and nausea (Cohen & Klopovich, 1986) and alopecia, "moon facies", amputation and skin changes (Zeltzer et al., 1980) were some of the side effects of treatment identified by adolescents in these other studies. All of these worries were also mentioned by the teenagers in this study but they minimized the side effects of cancer.

The participants' perceptions of cancer enabled them to deal with the treatment side effects in order to get on with their lives. They did not let the illness compromise their personal and social selves in any significant way. Zeltzer et al. (1980) identified that the adolescents perceived an overload on their coping abilities because of the number of stressors associated with living with cancer. Since the adolescents in the present study were also dealing with numbers of stressors, Zeltzer et al. (1980) might also have arrived at the same conclusions if they had spoken with the group. However, it is of significance to note that the teenagers themselves did not share this view. The teenagers all saw themselves as having satisfactory ways of dealing with their cancer. They even had
alternate plans if the usual successful ways of coping did not work. Cancer and its treatments posed a threat to the adolescents' development in areas such as their identity and self-image. However, the teenagers were able to deal with the effects of their illness by using various strategies in order to conclude that they were the same.

Another area of development that was threatened by cancer was the adolescents' abilities to establish friendships. In this study, the adolescents were able to accept support and concern from their families but they were also working to establish and maintain relationships outside of the family. This finding is consistent with the reports of Gode and Smith (1983), Mahon (1983), Miller (1974) and Zevon et al. (1987) which identified separation from the family and the establishment of peer relationships as developmental tasks in the stages of early and middle adolescence. The participants experienced extra attention and worry from their parents but this did not affect their relationships within and outside of the family. It would seem that although cancer and treatments were significant stresses, the teenagers were still working on developmental tasks of establishing a separate identity from their family by building friendships and a peer group.

The finding that parents changed and were more attentive was supported by the literature. However, there were differences seen in the research of Farrell and Hutter (1980) and Wasserman et al. (1987) who indicated that adolescents with cancer were more dependent upon their parents than they were prior to having this illness.
Differences may be noted in part due to whose perspectives were being sought in previous research and how they were measured. These differences may also be attributed to the fact that the participants of this study had a peer group which supported their ability to become independent from the family.

The social world of the adolescents extended beyond the family unit to include the people encountered in the community and at school. School was a major part of the social world of adolescents. Within this social environment cancer had some effect on the achievement of developmental tasks. In this study, the participants were concerned with their ability to keep up in school and achieve academically. Some of them were aware that they were falling behind and wanted to keep up. If they were still lagging in spite of their extra efforts they were forced to accept the situation for what it was.

Even though they were concerned, some adolescents were actually able to excel in school. The school related problems experienced by the teenagers in this study were different for this group than those found in other studies particularly those of Sawyer et al. (1986) and Wasserman et al. (1987). Different problems for the adolescents identified in this literature were worries about the reactions and treatment by their school peers, being ostracized or ridiculed by them, and having less social competence in school. The different concerns of the participants may be attributable to the positive regard and acceptance given by their teachers. Their support
in the classroom and as tutors helped the adolescents' school experiences to not be that difficult.

Another reason for these different school experiences may be explained by the finding that the adolescents were able to establish a peer group. They were able to have friends for several reasons. One reason was that the teenagers really did not see that they were any different from their friends other than the fact that they could not keep up sometimes. They did not perceive that they were different from their peers which differs from the study of Moore et al. (1987). The perceptions that they were the same seemed to enable the participants to socialize and engage in activities with friends which helped them to establish and/or maintain friendships. Friendships were very important for the adolescents even though cancer caused some difficulties in establishing and maintaining a peer group. The participants lost some friends because of their responses to them having cancer. They also experienced some difficulties establishing new friends. These difficulties were attributed to the fact that they had cancer and so others reacted negatively to this knowledge.

The literature on adolescent development supports the notion of how important the peer group was for these individuals. The problems experienced in school were related to having cancer but the existence of a peer group possibly buffered these negative effects from the illness and enabled them to get on with life.
Chronic Illness

The adolescents in this study developed a philosophy of being positive to deal with their cancer. A consequence of this philosophy was that the adolescents perceived that the outcome of their illness was positively influenced by their positive attitude. They believed that being positive and being in control of cancer ensured a successful outcome. Even when they were told that the chances of success were equal to the chances of failure, they looked to the positive or the good side. They believed that the outcome would be the same as what they believed. Thomas' (1987) framework directed an examination of factors with the potential of impeding development. In this study, outlook can be seen as a factor that fostered the adolescents' development.

Although conceptualizations of chronic illness differ among authors, these descriptions and the teenagers' accounts of chronic illness are compatible. Trajectory was identified in the literature as a consequence of a chronic illness and was described as having shape, duration and movement. In this study, cancer was defined by the participants within these terms. They perceived cancer to be a series of routine, predictable treatments that had a defined and positive end.

The adolescents' perceptions of their ability to influence their illness outcome is consistent with Lubkin's (1986) conceptualization of chronic illness. Lubkin proposed that the outcome of the illness along a trajectory could be affected by "shaping" by the individual and others to manage the illness. Thus it could be interpolated that a
positive outlook such as that held by the adolescents in this study, can "shape" the trajectory.

Through their experience of living with cancer, the participants defined their illness from two different perspectives: the personal and social. In their conceptualization of chronic illness, Dimond and Jones (1983) identified three perspectives that influence the way in which individuals who have a chronic illness and those in their environments respond to the illness. These perspectives are the clinical, personal and social definitions about the illness. Results indicate the perspectives taken by the adolescents add to the usefulness of Dimond and Jones' (1983) conceptualization of chronic illness for adolescents with cancer.

The teenagers' personal definitions were based on how they perceived themselves having cancer and how they perceived others in their social environment viewed them as adolescents with cancer. The perspectives they held as adolescents in viewing the world can be labelled as "egocentrism" which was identified in Elkind's (1967) theory of social cognition. The adolescents' perceptions presented in the element in the framework of "experiencing the illness" were consistent with Selman's (1977) stage of mutual perspective taking. Their perspectives included the perceptions they had of themselves, of others, and how others perceived them. The findings reinforce the idea of the importance of considering the developmental stage of the individual who has a chronic illness (Dimond and Jones, 1983; Gode and Smith, 1983; and Thomas, 1987).
The social perspective considered by the adolescents influenced the ways in which they responded to cancer. The adolescents' perceptions of the social consequences of having cancer are consistent with the term "handicap" in Thomas' (1987) framework described in chapter 2. The participants perceived that the responses of others were affected by the "impairment", cancer. Therefore, both cancer and the responses of others to the "impairment" could be seen as limiting the social role fulfillment of the teenagers. However, the teenagers maintained their sense of being normal and did not let cancer interfere with their getting on with life.

Because the teenagers perceived that others would think they were different due to their illness, they responded in various ways in order to deal with these negative perceptions. Some of them hid the visible aspects of their illness from others such as by non-disclosing or by limiting the noticeable differences by wearing wigs, modifying activities, and making excuses. Even the adolescents who were more open about having cancer still made an effort to minimize the physical effects of cancer.

The findings do not strongly support the idea of "disability" identified in Thomas' (1987) framework. "Disability" was described as the functional limitations experienced by the child because of the "impairment" or the child's psychological response to the "impairment". The participants perceived that cancer disrupted the activities in which they wanted to participate, both socially and at school. However, the functional limitations imposed by cancer were
overcome by their strategies. Therefore the social limitations or "handicap" of the illness were influenced by the responses of the adolescents themselves and others to the "impairment", cancer, rather than the "disability" of the illness. Differences noted in the findings raise questions about the usefulness of some aspects of Thomas' framework for some chronic illness such as cancer, if the illnesses are not characterized by major physical restrictions.

The findings indicate the participant's definition of cancer is different than the clinical definitions identified in the literature. Cancer has been defined as a chronic illness from the clinical perspective by authors such as Gavaghan and Roach (1986), Kellerman et al. (1980), Klopovich and Clancy (1985) Spinetta et al. (1982) and Zevon et al. (1987). The participants defined cancer from their personal and social perspectives and did not identify cancer as a chronic illness. The adolescents viewed cancer as an illness with a definite end and as something to be dealt with for a defined period of time. The idea of "shaping" supports the notion of considering the individual's perspectives about their illness. However, the considerations of these perceptions can be limited because only the end of treatments but not the end of cancer is expressed in a clinical definition of cancer. Thus the idea of cancer as a chronic illness, could be perpetuated by health care professionals but not the adolescents who have or have had the illness.

The discussion of the findings indicates the importance of considering the adolescents' perceptions. The next section will
discuss the perceptions of the teenagers in relation to the concept of normalization.

Normalization

Normalization is a concept relevant to the study results. The findings indicated that the adolescents perceived themselves as normal. They wanted to be normal and not to be treated any differently by others because they had cancer. Also, the teenagers viewed cancer as having an end and they perceived that they would have a normal future without any ongoing disability. They defined what was normal to them personally and were not trying to conform to some external standard. Their perceptions of normal were dependent upon their own identities as adolescents and these perceptions were described in view of their activities and friendships within their social worlds.

The literature indicates that normalization is a behavior used by individuals and families to overcome effects of an illness or disorder. Wiener (1975) in a study focusing on adults with rheumatoid arthritis identified that people with chronic illnesses try to live as normally as possible in spite of the effect of the symptoms or the illness itself. The person's ability to achieve normalcy depends upon various factors such as the individual's social arrangements and the intrusiveness of the symptoms and regimens of the illness.

Adolescents in studies by Moore et al. (1987) and Wasserman et al. (1987) perceived that they missed a part of growing up and were
not able to get on with their lives at the time of having cancer. An important finding in the study being presented here was that the adolescents were able to deal with their illness and get on with their lives. They felt like they were left behind at times and this was a concern. However, their overall perception was that they were the same and were normal adolescents. This allowed them to be able to keep up the best that they could with their peers and continue on with life as an adolescent.

Knafl and Deatrick (1986) examined the concept of normalization earlier identified by Birenbaum (1970, 1971), Darling (1979, 1982) Roskies (1972) and Voysey (1972). They categorized the findings of these theorists and identified normalization behaviors and criteria for defining and recognizing the concept. Normalization was viewed by all these authors within the context of the family of a person with a chronic illness. Their views were different from Strauss et al. (1984) in that they conceptualized normalization from an individual's perspective.

Although the findings of the present study indicated that the adolescents perceived themselves to be normal, they did employ strategies to ensure their normalcy. The behaviors they used were consistent with those identified in the literature by Knafl and Deatrick (1986) as normalizing by engaging in usual activities, appearing normal, avoiding embarrassing situations and controlling the amount of information given out about the illness. The participants attempted to participate in their usual activities with
their peers and at school. They were unable to keep up at times and modified the activities they participated in accordingly.

Wiener (1975) described tactics to be normal used by individuals with visible and non-visible symptoms. A normal appearance could be maintained by hiding visible symptoms or concealing non-visible symptoms and "passing" as normal. Some of the participants wore wigs to hide their baldness. Others never revealed their illness and kept up all their normal activities and "passed" as unchanged and normal. While such symptoms have the potential to impede development, both the adolescents' perspectives and philosophies, and the responses of others determined the significance of the threat.

Wiener (1975) also identified that a new level of normality could be attained by persons with chronic illnesses. The participants described new levels of normalcy for themselves during the period of their illness. The restrictions cancer imposed on their activities were seen as only temporary ones until the treatments were finished. They described another normality after their illness ended as a resumption of the previous normality before it was restricted by effects of their illness.

Cancer was perceived by the adolescents in this study to have an effect on this new normality in the future. However, as time passed the effects of cancer were perceived to lessen and might no longer have an effect. Some participants did not see cancer having any future effects because their definition of cancer made it an
illness that had an end. This finding can be supported by the literature that also indicated that adolescents were uncertain about their futures. Age may have been a factor that limited the amount of concern the participants had about their futures. In this study, only one of the informants had entered the stage of late adolescence. Thus, the future may not yet have become a concern to most of the participants.

Normalization has been identified as a behavior used by individuals to overcome the effects of an illness. Although the participants in this study perceived that they were normal they used strategies to ensure that others viewed them as normal. Normalization can be seen as having contributed to their overall goal to get on with life as a normal teenager. Another way in which the adolescents worked toward getting on with their lives was by establishing new supportive relationships. The topic of social support will be discussed in the next section.

Social Support

In the presentation of the findings, it was seen that the adolescents established new supportive relationships in order to get on with life. A discussion of social support will be presented to more fully understand these findings.

Social support is a multi-dimensional construct that has been identified in many studies in the literature (Norbeck & Tilden, 1988). The definition for social support varies according to the author but
all share commonalities (Norbeck & Tilden, 1988; Williams, 1988). Social support can be seen as emotional support, esteem support and mutual obligations between people (Cobb, 1976). Weiss (1974) identified six categories of relational provisions of social support as "attachment, social integration, opportunity for nurturance, reassurance of worth, a sense of reliable alliance and the obtaining of guidance". Social support has been identified as having an effect on health and acting directly or as a buffer against stress (Dimond & Jones, 1983; Norbeck & Tilden, 1988).

There is a cultural context to social support in that social support is shaped by cultural norms, beliefs and values (Norbeck & Tilden, 1988). In this study, adolescents can be seen as a distinct cultural group within the overall culture of society. The adolescent culture of the participants influenced what constituted support for them, who they perceived as providers of support and under what circumstances it should be offered.

Although the participants were able to deal with cancer and get on with their lives, they did have concerns. A major finding was that they established supportive relationships with individuals with whom they were able to share illness concerns, outside of the network of their friends and families. This finding is different from the experiences of adolescents described in the studies of Carr-Gregg and Hampson (1986) and Tebbi and Koren (1983). These teenagers perceived that they had no one with whom to share their concerns.
The establishment of these new supportive relationships by the participants is significant because it may be the reason they were able to deal with many of the problems of their illness. In this study the adolescents' repertoires of coping behaviors were not depleted when dealing with their illness. The definitions of social support indicate that support can be both psychological and tangible. Norbeck and Tilden (1988) summarized these definitions and described psychological support as "emotional support, trust, advice, information and support for self-worth" (p. 174). They described tangible support as "direct assistance and material items or money" (p. 174).

The lack of peer support is an important finding as models of support for cancer patients suggest that "support groups" are a good way of providing support (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Jacobs, Ross, Walker, & Stockdale, 1983). The work of Lynam (1987) raised questions about support groups' abilities to be universally supportive for parents of children with cancer. The present study raises questions about the appropriateness of a peer model to provide support for the adolescent age group.

The adolescents established relationships with various people whom they identified as support people. It is noteworthy that nurses were among these people who were identified by the participants as being supportive. The nurses were perceived to be able to provide support in two ways in their role as nurses. They could provide physical support and be helpful because of the "things that they did"
for the adolescents. The nurses' support can be seen as both psychological and tangible. This supportive role of the nurse was perceived by the adolescents as being part of their job.

Other nurses were seen as having a dual role as professionals in giving support. They were able to provide physical, emotional and social support by being nurses who were both friends and nurses. The perception that nurses proved care and support in a dual role as a friend and a nurse is substantiated by research. Trygstad (1986) found that oncology nurses perceived themselves having this dual role with patients and were effectual in providing care in this way. The findings reinforce the notion that this type of nursing care is acceptable and rewarding for both the providers and recipients of nursing care. However, nurses do not need to become friends to be supportive. They can be of benefit to patients by the nature of the support given in their professional role.

An important way in which the adolescents were able to get on with their lives was by establishing new supportive relationships. The social support provided within these relationships could be seen as having a positive effect on the adolescents state of well-being.

Summary

A discussion of the findings in relation to the literature in chapter 2 was presented in this chapter. The findings to be discussed were organized into four sections. First, the developmental stage of adolescence and its influence on the participants' experience of living
with cancer was described. This developmental stage affected the way that they perceived their illness, how it affected them, and how they dealt with it. A result of these effects was that in turn, cancer then affected their development as adolescents. Then, a discussion on chronic illness was presented, followed by sections on normalization and social support.

The findings have some implications for nursing practice, education, and research. These implications will be presented along with a summary of the study in Chapter six.
CHAPTER 6: IMPLICATIONS FOR NURSING AND SUMMARY OF THE STUDY

There were implications for nursing indicated in the discussion of findings in Chapter 5. These implications for nursing practice, education and research will be discussed in this chapter.

Implications for Nursing Practice

The findings suggest several implications for nursing practice. First, nurses need to gain an understanding about the adolescents for whom they are providing care. It is important to know how the adolescents view their illness and its treatments. Nurses need to determine what the adolescents see as important in order to plan interventions that are meaningful and effective in order to assist them to achieve what is important for them.

The adolescents in this study dealt in various ways with the threats from cancer in order to get on with their life. Nurses need to determine what helps adolescents cope with their illness. The findings indicated the importance of the philosophy of the teenagers and how it helped them deal with cancer. They also used various strategies such as normalizing in order to deal with their illness. Nurses need to understand if the adolescents they are caring for use any of these strategies. Nurses can help them continue to use them or teach them new strategies if they do not have ways of dealing with the threats of cancer or if their strategies do not work.
The discussion on social support indicated several implications for practice. The nurse needs to determine who are the people around the adolescent who helps them cope with their illness. These people include their families, friends and peers. Nurses need to encourage and assist the people identified by the adolescent as supportive to continue in this role. This may include helping those around the adolescent to treat them as normal and not as someone with cancer.

It is important for nurses to define the issues that are of concern for each particular adolescent. There may be teenagers who are at risk who require specific nursing interventions to help them deal with their illness. As noted previously, the philosophy of the adolescents in this study was that they perceived the prognosis of their cancer was positive and the treatments had a positive end. They always looked to the positive in dealing with their illness. However, adolescents who are deteriorating because of the progression of their cancer may be vulnerable and at risk if they have never even considered a negative outcome to their illness. These individuals may require support and understanding from nurses in order to discuss the possibility of a negative outcome to cancer and to deal with the consequence of this outcome.

Other adolescents who may be at risk and require nursing interventions are those who have no support. The adolescents in this study were able to establish a new supportive relationship in order to deal with some their illness concerns. Nurses can help the teenagers to discover a possible support person in their social network. Also,
the support person for the teenagers may be the nurses themselves as nurses were viewed as supportive by some of the participants in this study.

Nurses must be knowledgeable about the timing of their interventions to promote their success. Initially, nurses can give the teenagers some control over their illness by giving information and letting them know what to expect about their treatments. Strategies to help them deal with their treatments can be taught at the beginning and reinforced during the course of their treatments.

During follow-up after the completion of treatments, the nurses need to examine the perceptions they hold about cancer and those held by the adolescents. If the adolescents do not perceive that they have cancer anymore, there may be conflicts between the nurses and the adolescents during visits in the follow-up clinic. The nurses need to re-evaluate the messages they are communicating to these clients and determine if they are perpetuating the idea of illness rather than health to these adolescents.

The differing perspectives of patients and practitioners need to be addressed by health care professionals when caring for adolescents with cancer. The different definitions of cancer may result in the provision of ineffective and inappropriate nursing care. The findings of this study are supported by Kleinman's (1978) ideas of the importance of understanding the explanatory models within the popular and the professional domains in order to provide appropriate health care. Conflicts over desired treatments and care may arise
between adolescents and health care professionals. The adolescents' perceptions of cancer must be determined on an individual basis in order to provide meaningful and appropriate care.

**Implications for Nursing Research**

The findings indicate the need to understand more about chronicity. The study findings indicate that there are discrepancies between the adolescents' perceptions of cancer and those of health professionals. Further study on a group of adolescents who are attending follow-up clinics after their cancer treatments finish, may reveal if the adolescents' perceptions about cancer not being a chronic illness persist over time.

An issue of the conceptualizations of chronic illness is that there is no defined period of time specified for an illness in order for it to be thought of as chronic. Nurses need to question the label of chronicity that has been given to illnesses and determine if the individuals they are caring for share the same perceptions. This is especially relative to particular age groups as identified in Thomas (1987) conceptualization of chronic illness. She identified that the development of children can be affected by handicapping factors related to their chronic conditions. Further study is needed for nurses to understand if an illness is perceived by clients as having chronic treatments that occur for a period of time or is actually seen as a chronic illness. In this study, the findings are limited to a group
of adolescents with cancer. Research is necessary in order to determine how other groups of adolescents perceive their illnesses.

Findings indicated that some of the adolescents perceived nurses as supportive. They were able to provide physical, emotional and social support to these teenagers. How nurses define their roles in caring for adolescents with cancer requires further research. It is important to know how nurses perceive that they provide support to teenage clients. Some adolescents in this study perceived the nurses to be in a dual role as friends and as nurses. Further study is needed in order to determine the mesh between these two ideas of how nursing care is provided for adolescents.

Normalization was identified as a relevant concept in the discussion of findings. The adolescents perceived that they were normal but they still used strategies in order to maintain normalcy. Further study is indicated to understand how adolescents with other chronic illness perceive normalcy. Also, research could indicate which of the strategies to ensure normalcy were most effective and why. Results of this research could help nurses to teach adolescents with cancer ways they could implement in order to maintain their normalcy in order to successfully get on with their lives.

Implications for Nursing Education

In order for nurses to provide optimal care for adolescents with cancer they need to understand adolescent development stages. Further, teenagers perceive the world from their perspectives as
adolescents and nurses need to have knowledge about these perspectives. Therefore, course content should include associated clinical experiences in order for nurses to gain the necessary skills in order to communicate with adolescents. Interpersonal skills need to be learned in practical experiences by nurses to enable them to interact skillfully and meaningfully with the adolescents.

Nurses were seen by some of the participants as support persons who could help them deal with illness concerns. Skill in establishing therapeutic relationships and being able to communicate effectively in such relationships is a requirement for nurses. Nurses must gain knowledge in their education about therapeutic use of self when caring for adolescents within these professional supportive relationships.

Nursing education needs to address the different types of interactions that the nurses have with adolescent clients in the inpatient and outpatient settings. The nature of the differences between these two settings may have an impact on the type of relationship that nurses are able to establish with a client. The amount of time that an adolescent spends in a clinic may be limited and nurses need to learn how to provide establish relationships with the adolescents and be able to provide support on a short term basis. The greater amount of time that nurses have to interact with an adolescent who is admitted as an inpatient may enable them to more easily establish therapeutic relationships. However, nurses need to learn what their roles are in both of these settings in order to provide
the most suitable type of support that the setting will allow. The nurses are perceived as having an important role by the adolescents and must learn the various types of support that they can provide for this group of clients within the parameters of their professional roles as nurses.

Summary of the Study

A phenomenologic approach was used to understand the experience of adolescents with cancer living with a chronic illness. The purpose of the study was understand how adolescents perceive their experience of living with the cancer in order for nurses to provide care that is effective.

Literature on adolescent development, chronic illness, the effects of cancer on adolescent development, and the perceptions of adolescents about cancer was reviewed to provide relevant background to this study.

Five adolescents, three male and two female, were interviewed extensively to understand their perceptions. The audio-taped interviews were transcribed verbatim and analyzed. The analysis indicated that the adolescents responded to the illness of cancer in order to get on with life. The three elements of the adolescents' response were identified as experiencing the illness or "I'm the same/You're different; philosophy or "I deal with things differently" and redefinition of social world or "I have this other life".
The discussion of the findings addressed the effect of cancer on adolescent development and focused on the concepts of chronic illness, normalization and social support.

Implications for nursing practice, research and education were outlined. Nurses in practice need to understand what is important for the adolescents and what helps them cope. Implications for nursing research emphasized the need for further study of social support and normalization in adolescents with chronic illnesses. The role of nurses as supportive individuals for adolescents with cancer also needs further examination. The education of nurses should include knowledge and experiences which will assist them to develop interpersonal skills in working with adolescents in order to provide care to the person as an individual and as a person with an illness.

The results of this study can be used by nurses in their development of knowledge about adolescents with cancer. The directions from studies such as this can help nurses build a body of knowledge about a specific group of clients. In this way, individualized and appropriate nursing care can be provided.

Summary

A summary of the research was outlined in this chapter. Also the implications for nursing practice, research and education that were indicated from the findings of this study were presented.
References


Peterson, & C. Perry (Eds.), Promoting Adolescent Health: A

Havighurst, R. (1972). Developmental Tasks and Education (3rd ed.).
New York: David McKay.

Jacobs, C., Ross, R., Walker, I., Stockdale, F. (1983). Behavior of
cancer patients: A randomized study of the effects of education
and peer support groups. American Journal of Clinical Oncology
(CCT). 6, 347-350.

Psychological effects of illness in adolescence. I. Anxiety, self-
esteem and perception of control. Journal of Pediatrics, 97, 126-
131.

Kleinman, A. (1978). Concepts and a model for the comparison of
medical systems as cultural systems. Social Science and
Medicine, 12, 85-93.

Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness and
care. Annals of Internal Medicine, 88, 251-258.


Nursing Research, 6, 107-114.

Knaf, K., & Deatrick, J. (1986). How families manage chronic
conditions: An analysis of the concept of normalization. Research
in Nursing and Health, 9, 215-222.


Appendixes
Appendix A

Interview Guide with Trigger Questions

The purpose of the interview guide is to outline the general direction for the interview and open up discussion. The questions are intended only to promote communication by the participant. The specific direction taken to describe the experience of the phenomena is left up to the participant. The interviewer may validate her understanding and perceptions of the participant's explanations. This validation with the participant may be the clarification of information by summarizing ideas or by giving a label to information. For example, the interviewer might say "Am I correct in my understanding, that you were irritated, or sad etc...?"

Trigger questions:

1. Can you tell me about your experience of having been diagnosed with cancer and receiving treatments for this chronic illness? (The intent of this general question is to enable the adolescents to begin to speak of their personal experience of having cancer and undergoing treatments). In speaking with the participant, the interviewer would be endeavoring to gain an understanding of the positive and negative experiences and how the adolescent has been affected by these experiences.
2. Have these experiences of living with cancer had any effect on your abilities to function in your day to day activities? Again, this question is general and is intended to determine what functional aspects of the adolescents' lifestyle have been affected.

3. If there have been any changes in your ability to function in your day to day life, have these changes affected your relationships with others in any way? Do you have any ideas why or why not? These questions will seek to determine if the adolescent perceives that changes in social relationships are due to the illness and the restrictions imposed by it or the social difficulties of others interacting with them.
Appendix B

Consent Form

I would like to participate in the study titled: "Adolescents with Cancer: Their Experience Living With A Chronic Illness". This study is being conducted by Mona Rechner, RN, BSN for her Masters thesis. She is a student in the Masters of Science in Nursing program at the University of British Columbia. The supervisor for this thesis is Professor Judith Lynam from the University of British Columbia.

The purpose of the study will be to determine the perceptions of adolescents with cancer about their illness, its treatments and how living with cancer affects the functional and social aspects of their lives.

I understand that I will participate in audiotaped interviews. I consent to be interviewed by Mona Rechner up to three times. I understand that each interview will last approximately one hour. The interviews will take place at a mutually convenient time and location.

My participation in this study is voluntary and I may refuse to answer any questions or withdraw at any time. My refusal will have no effect on my nursing or medical care and I will continue to receive the best possible care whether I participate or not.

I understand that during the interview I will be asked to describe my experiences with the diagnosis of cancer and the
treatments for this chronic illness. I will be asked to talk about how living with cancer has impacted on my day to day life.

I know that the information from this study will be strictly confidential and I will not be identified by name in any publication or descriptions arising from this work. All information that I share will be kept confidential. The only people with access to the taped interviews will be Mona Rechner and the members of the Thesis Committee: Judith Lynam and Marilyn Dewis. Names and other identifying characteristics will be deleted from the audiotapes and will not appear on typed transcripts of the interviews. Reports written from the study data will not identify me in any way.

I understand that there are no risks involved in participating in this study and the benefits will only be the satisfaction that may result from having "told my story". The research is being conducted so that other adolescents with cancer may benefit from my participation in this study. Recommendations for the care of other adolescents with cancer will be made from study results.

By signing this form I acknowledge that this study has been explained to me and my questions have been answered to my satisfaction. I have also received a copy of this consent form. I am aware my parents must also give consent for my participation.

Signed_________________________ Date_________________________

Witness_________________________ Date_________________________
Appendix C

Parental Consent Form

I consent/ I do not consent to my child's participation in the study titled: "Adolescents with Cancer: Their Experience Living with A Chronic Illness". This study is being conducted by Mona Rechner, RN, BSN for her Masters thesis. She is a student in the Masters of Science in Nursing program at the University of British Columbia. The supervisor for this thesis is Professor Judith Lynam from the University of British Columbia.

The purpose of the study will be to determine the perceptions of adolescents with cancer about their illness, its treatments and how living with cancer affects the functional and social aspects of their lives.

I understand that my child will participate in audiotaped interviews. I consent/ I do not consent to my child being interviewed by Mona Rechner up to three times. I understand each interview will last approximately one hour. I understand my child's participation in this study is voluntary and he/she may refuse to answer any questions or withdraw at any time. This refusal to participate will have no effect on the nursing or medical care. Also, my child will continue to receive the best possible care whether I consent or / I do not consent to allow my child to participate in this study.

I understand that during the interview my child will be asked to describe his/her experiences with the diagnosis of cancer and the
treatments for this chronic illness. My child will be asked to talk about how living with cancer has impacted on his/her day to day life.

All information that my child shares will be kept confidential. My child will not be identified by name in any publication or descriptions arising from this work. The only people with access to the taped interviews will be Mona Rechner and the members of the Thesis Committee: Judith Lynam and Marilyn Dewis. Names and other identifying characteristics will be deleted from the audiotapes and will not appear on typed transcripts of the interviews. Reports written from the study data will not identify my child in any way.

I am told there are no risks involved in participating in this study and the benefits will only be the satisfaction that may result from my child having "told his/her story". Participation in this study may benefit other adolescents with cancer and recommendations for the care of other adolescents will be made from the study findings.

By signing this form I acknowledge that this study has been explained to me and my questions have been answered to my satisfaction. I have also received a copy of this consent form.

I am aware my son/daughter must also give his/her consent to participate.

Signed_____________________ Date____________________
(Parent(s)/Guardian(s))
Witness____________________ Date__________________
APPENDIX D

LETTER OF INFORMATION

November 1988

My name is Mona Rechner, I am a Registered Nurse and a student in the Masters in Science of Nursing program at the University of British Columbia. For the past several years I have been working with adolescents and young adults with chronic illnesses, especially cancer. Little is known about adolescents' experiences living with the chronic illness of cancer. At present I am conducting a study for my Masters Thesis titled: "Adolescents with Cancer: Their Experience Living With a Chronic Illness". I am looking for volunteers to participate in this study and have asked the Nurse and the Oncologist from the Clinic to give letters such as this one to people who might be interested.

Children's Hospital has agreed to distribute the letters to adolescents attending the Oncology Clinic. However, your participation in the study is voluntary and you may choose not to participate if you wish. Your consent and the consent of your parent(s)/guardian(s) will also be required in order to participate in the study. **If you choose to participate or if you withdraw from the study this will not affect your care at the clinic. You will be still offered the best treatment available.**
Your participation in this study involves being interviewed by myself. Should you agree I would like to interview you a maximum of three times at a location that is convenient for you. Each interview would last approximately one hour. The total time commitment as a participant in this study would be three hours.

During the interviews, I will ask you to talk about what it has been like for you to have been diagnosed with cancer and receive treatments for this chronic illness. I will ask you how living with cancer has affected your day to day life. Typical questions that could be included in the first interview could include: Has your experience living with cancer had any influence on your abilities to function in your day to day activities? Has living with cancer influenced your relationships with others in any way? If there have been changes in your social relationships, are some of these changes due to the manner in which others respond to you?

With your permission the interviews will be tape recorded. All information that you share will be kept confidential. The only people with access to the taped interviews will be myself and the members of my Thesis Committee: Judith Lynam and Marilyn Dewis. These individuals are also registered nurses and are Assistant Professors in the School of Nursing at the University of British Columbia. Names and other identifying characteristics will be deleted from the
I am interested in receiving a follow up telephone call in order to find out more about the study titled: Adolescents with Cancer: Their Experience Living with a Chronic Illness.

My name is: ______________________

I may be contacted at the following number: ___________________

The best time to call me is: ____________________