LEUKEMIA AND BONE MARROW TRANSPLANTATION: PERSONAL
MEANINGS AND PERCEPTIONS OF THE ILLNESS EXPERIENCE

by

DEBRA C. RICHARDS

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Department of Social Work

The University of British Columbia
Vancouver, Canada

Date August 8, 1993
Abstract

A non-probability, purposive sample was selected from the bone marrow transplant (BMT) directory of a North American transplant center to describe the personal meanings and perceptions of the illness experience of individuals who had been diagnosed with leukemia, and undergone BMT, and to explore and describe how the individuals' explanatory model of health and illness differs from the professional biomedical model of health care.

A phenomenological approach guided the data collection process. Personal interviews with the four participants were conducted with the interview format and questions being based on Kleinman, Eisenberg and Good's (1978) model for eliciting a person's explanatory model of health and illness.

The data, comprised of verbatim transcripts of the audio-recorded interviews, and field notes of the researcher, were analyzed by employing the steps of phenomenological analysis as outlined by Patton (1991), and Giorgi (1985), which resulted in the identification of recurrent themes.

Findings revealed that individuals perceive their illness in ways that differ from professionals. The participants perceived leukemia as a chronic illness rather than an acute disease. BMT, perceived as a life-saving - death-postponing treatment, possessed characteristics which led to personal and moral dilemmas. Participants viewed the cause of disease to
be external to themselves, and beyond their control. The chronic implications of the illness were controlled for, and coped with by adopting altered definitions of normalcy and going through a process of re-learning. The study found that living with a life-threatening illness, although "successfully treated," took the meaning of uncertainty. Being faced with, and learning to live with a life-threatening illness was perceived as an opportunity for enrichment of life.

The findings indicate the biomedical approach to health care is narrow in focus, and fails to consider the personal meanings and perceptions the illness experience hold for individuals who have been diagnosed with leukemia, and treated with BMT. For effective health care to be provided, and to reduce the differences and discrepancies between individuals and health care professionals, health care professionals must consider and incorporate the individual's explanatory model of health and illness into the health care plan.
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CHAPTER ONE: INTRODUCTION

Background to the Problem

Health care is a social process in which each party - the professional and the patient, brings a set of beliefs, expectations, and practices to the encounter (Waxler-Morrison, 1990). Arising from this premise are various explanatory models of "health" and "illness" with each model having corresponding value positions and underlying premises. The context in which health and illness is viewed determines one's perspective towards health and illness and forms a framework for the provision of health care.

Within the domain of Western medicine, the biomedical model of health care is the prevailing model of care towards health and illness. The biomedical model, originally formulated as a research model, is a deductive, scientific model which places emphasis on the study and treatment of disease. It is regarded as a curative model with health being the absence of disease, and disease being seen as a disarrangement of the body. All "problems" are seen as being extraneous to the person. Causes of disease are entities such as viruses, genetic disorders and malfunctioning of physiological processes. With the body being viewed as a machine in good shape, or in need of repair, externally instigated treatments are provided with an emphasis being placed on eliminating symptoms. The ultimate goal is eradication of the disease. Within the model, the patient is
viewed as passive and cooperative. The mind and body are considered separate entities with the mind being a secondary factor in organic illness.

Due to the fact that many patients are not health professionals, the explanatory models of health and illness of these two sectors may be incongruent. Two essential value premises which underlay the practice of social work are, belief in the uniqueness and inherent dignity of individuals and, belief in client self-determination (Compton & Gallaway, 1984). In adhering to these values, the medical social worker can begin to understand that a client's perception of illness may differ from their own, and that it can not be assumed that social workers or other health care professionals will understand the client's illness experience. Furthermore, one cannot presume that a lay person's view of health and illness will be congruent with the professional healthcare worker's view of health and illness. Health professionals bring to the clinical encounter their biomedical culture as well as beliefs and values derived from their ethnic and socio-cultural background. Patients bring their interpretation of the biomedical model, and a set of beliefs and values about illness (Waxler-Morrison, 1990). While the professional approach can be characterized as scientific and rational, with care directed toward the elimination of disease, the lay person's interpretation of sickness may be perceived in terms of concrete symptoms and causes, past experience or socially
accepted ideas (Levanthal, 1982). These varying perceptions, in turn, influence the way people cope with illness (Field, 1973).

Although socio-cultural factors may be of some relevance in professional health care practice, the predominant custom is to structure the client's behavior into preconceived entities - disease states. Little consideration is given to how clients actually perceive and experience illness. This lack of consideration to the meaning of illness may result in ineffective care with disregard for the client's inherent uniqueness and dignity.

Bone marrow transplantation (BMT) is a complex medical procedure used in the treatment of life-threatening hematological and solid tumour malignancies, other haematopoietic disorders, and immunological disorders (Gale, 1986). BMT is advocated as a therapeutic option that results in more effective disease treatment than conventional cytotoxic regimens for selected patients with leukemia (Appelbaum et al., 1985; Champlin et al., 1984; Phillips, 1985; Sullivan et al., 1984). Introduced as an experimental treatment in the seventies, it has now become a standard treatment for leukemia. The recipient's disease diagnosis and many other factors contribute to the use of varied chemotherapy and radiation therapy protocols in BMT conditioning regimens (Wolcott & Stuber, 1991). BMT is followed by a several week recovery phase in hospital, a
subacute phase of several months of more gradual medical recovery, and an extended phase of adjustment and rehabilitation (Wolcott & Stuber, 1991). Although the mortality rate is relatively high at 15-20%, achievements have been gained in the management of treatment-induced complications. As a result, more BMT's are being performed each year and hence, more people are surviving the disease. The majority of the literature surrounding leukemia and BMT focuses on the medical management of the process with little consideration being given to the illness experience. Consequently, the provision of patient care, with the focus directed towards improving the treatment related aspects of the disease, and the goal to be eradication of the disease, follows the biomedical model of health care. Correspondingly, minimal consideration is given to the patient's explanatory model of health and illness. The provision of care therefore, is narrow in focus, and not tailored according to the patient's unique needs, values, and perceptions of the illness experience.

Conceptual Framework Guiding the Study
Kleinman's cultural system model addresses the discrepancy between lay and professional interpretations of disease and illness (Kleinman, 1978). With the model recognizing that an individual's experience with sickness is structured within a social and cultural context, health, illness, and health care
related aspects of societies are conceptualized as cultural systems. That is, symbolic systems are built out of meanings, values, behavioral norms and the like (Kleinman, 1978, p.86). Due to one's perception of reality being affected by their unique beliefs, roles, expectations and relationships, different groups in society may have incongruent viewpoints on the same phenomenon. Therefore, patients and health care professionals may perceive the same sickness in different ways.

Kleinman (1978), describes the health care system model as being comprised of a professional sector (medical practitioners, professional indigenous healing traditions), a popular sector (individual, family, social network, community activities), and a folk sector (non professional healing specialists). Kleinman describes the sectors as distinct, interacting domains. Kleinman utilizes the concept of explanatory models to describe the process of construction of clinical reality for sickness episodes with each sector of the health care system developing a particular explanatory model of illness which includes explanations of cause, onset, course of sickness, and treatment goals. Each sector can be distinguished from another as each has a different way of interpreting, experiencing, and reacting to sickness based on different explanatory systems, social roles, interactional settings and institutions (Kleinman, Eisenberg & Good, 1978).

How individuals subjectively construct distinct forms of
social reality and make sense of ill health is based on explanations of sickness specific to the social positions they occupy and the systems of meaning they employ (Kleinman, Eisenberg & Good, 1978). Therefore, the domain of health care that an individual occupies in society plays a role in her/his perception of illness and disease. The professional sector is most often concerned with the management of disease, whereas the popular sector regards the experience of illness and the impact of illness on the client's life as the dominant focus. Coupled with this discrepancy in focus of concern is the resulting consequence of disparate therapeutic goals, treatments and evaluation of therapeutic outcomes between these two sectors.

In Kleinman's model, sickness is not conceived of as an isolated psychologic or biologic event, but rather a complex experience shaped by the body, mind, and socio-cultural milieu (Kleinman, Eisenberg & Good, 1978). Kleinman discusses healing as a process whereby the individual is provided with effective control of the disease, as well as personal and social meaning for the illness experience. Kleinman suggests that discrepancies between the explanatory models of the professional and popular sector inhibit healing in this sense. In order to promote healing, and provide a quality of health care which promotes respect for, and appreciation of the uniqueness of all individuals, it is essential that health care professionals acknowledge the existence of different
explanatory models and endeavour to understand them. With Kleinman's cultural system as the conceptual model guiding this study, direction is provided to extract the participants' personal meanings, and perceptions of their illness experience with leukemia and bone marrow transplantation.

Figure 1. Kleinman's conceptualization of the health care system: internal structure (Kleinman, 1978, p.86).
Health care professionals caring for clients often assume they understand the illness experience. Or perhaps, may assume their explanatory model of health and illness is congruent with the clients'.

With the practice of Western medicine being based on the biomedical model of health care, there is little "room" for consideration of the clients' concerns, and their perspective on their illness and the personal meaning they attribute to it. This lack of consideration and understanding may foster the development and delivery of ineffective, narrowly focused health care. "The biomedical system replaces allegedly soft, therefore devalued psychosocial concern with meanings, for the scientifically hard, therefore overvalued, technical quest for control of the symptoms. This pernicious value transformation is a serious failing of modern medicine: it disables the healer and disempowers the chronically ill" (Kleinman A., 1988, p.9). It also, "inhibits the view of the patient as a total person in a total environment by overlooking the personal and environmental dimensions in health and illness" (Germain, 1984, p. 34.)

To narrow the gap in understanding between health care professionals and the clients of the health care system, efforts must be made to approach treatment and care with a more "client centered" approach.

Health care professionals must therefore make a
conscious effort to determine the extent of which their own viewpoints differ from those of their clients. The issue is not that the viewpoints differ, but that these differences and discrepancies can lead to misunderstandings which may negatively effect the results of treatment and perhaps the client's quality of life with an illness. Kleinman (1978), proposes in situations where only "disease" is treated, care will be less satisfactory to the client and less clinically effective than in situations where both "disease" and "illness" are treated together. As a beginning endpoint to this problem, Waxler-Morrison (1990), suggests "healthcare professionals need to explore with patients their beliefs about illness, expectations of treatment and how illness is managed in daily life" (p.258).

To explore and determine the participants' personal meanings and perceptions about illness, and the differences and discrepancies between the professional biomedical model of health care and the popular sector's explanatory model of health and illness, the researcher focused on the professional and popular sectors. Although Kleinman's model also includes the folk sector, the researcher's experience in a hospital setting illustrated that there is little apparent influence of the folk sector on one's illness experience and therefore was not included within the scope of this study.
Purposes of the Study

As a result of the paucity of literature depicting how persons who have been diagnosed with leukemia, and treated with bone marrow transplantation perceive their illness experience and the meaning they attach to it, the researcher developed the following purposes of the study.

1) To determine how clients perceive their illness experience,

2) To determine the personal meaning the clients attribute to their illness,

3) To determine how the clients' explanatory model of health and illness differs from the professional biomedical model of health care,

4) To describe and succinctly communicate the findings.

Definition of Terms

Terms contained within the study were defined as follows:

ADULT - an individual 19 years of age or older.

BIOMEDICAL MODEL - a curative model with health being the absence of disease, and disease being seen as disarrangement of the body. A deductive and scientifically based model.

BONE MARROW TRANSPLANTATION - the replacement of a non-functioning, or diseased bone marrow with healthy bone marrow.

DISEASE - alteration in biological structure or functioning.

EXPLANATORY MODEL - explanations of sickness which influence expectations, perceptions of symptoms, the way labels are attached to symptoms, and behavior during care (Kleinman, Eisenberg & Good, 1978).
HEALTH - a multidimensional process involving the whole person in the context of her/his environment (Ahmed, Kolker, & Coelho, 1979).

ILLNESS - refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability (Kleinman, A. 1988). The subjective state of being unwell, or experiencing distress or pain (Germain, 1984).

ILLNESS EXPERIENCE - forms of distress caused by pathophysiological processes (Kleinman, A. 1988).

PERCEPTION - the way in which one observes, feels, understands, or senses.

PERSONAL MEANING - the individual constructs formulated by one's perceptions.

Assumptions and Limitations

The study was based on the following assumptions:

1) Leukemia and bone marrow transplantation have meaning for the participant and this meaning has an effect on the person's illness experience,

2) Common units of meaning, or perceptions, will exist amongst the participant's regarding the illness and the illness experience and can be identified as common themes,

3) The researcher would be able to understand the participants' points of view even though they may differ from her own perspective or explanatory model
of health and illness,

4) The participants' explanatory models will differ from the professional explanatory model of health care,

5) The participants can communicate subjective meaning to others and describe their perceptions based on their own experience,

6) Phenomenological research methods could elicit an understanding of the meanings and perceptions of the illness experience.

The following limitations of the study were recognized at the onset:

1) All participants were recruited from one treatment center. As illness is socio-culturally constructed, any particularities of this setting may influence the participant's perception of the illness experience.

2) Participants may be unable to articulate what they mean. Attempts to reduce the effects of this limitation were exercised by clarifying and validating the participants' accounts during data collection.

3) Due to the personal nature of the research topic the possibility existed that participants may be reluctant to share extensive personal data. Efforts to control for this limitation were exercised with the researcher establishing a rapport with the
participants which conveyed trust, comfortableness, understanding and respect.

4) The quality of the data, and the amount of data collected was limited by the time and resources available to the researcher.

Relevance of Study to Social Work Practice

Germain (1973) defines social work as, "a helping profession concerned with the relationships between human beings and their interpersonal and organizational environments, with helping to modify or to enhance the quality of transactions between people and their environments, and with seeking to promote environments that support human well-being" (p.326).

From this definition one can discern the purposes of social work practice as, assisting individuals and groups to identify, resolve, or minimize problems arising out of disequilibrium between themselves and the environment, to identify potential areas of disequilibrium between individuals, or groups and the environment, to prevent the occurrence of disequilibrium, and to seek out, identify, and strengthen the maximum potential in individuals, groups and communities (Compton & Gallaway, 1984). The above definition of "social work" and the corresponding purposes direct the medical social worker to seek out and understand the client's explanatory model of health and illness. Elicitation of the
client's explanatory model will allow for the explanatory model of the client, and that of the professional sector to be openly compared and discussed, enabling identification of discrepancies, clarification of value conflicts, and planning and implementation of appropriate interventions (Germain, 1984). Therefore, attainment and understanding of the client's explanatory model allows the social worker the opportunity to make an important contribution to the delivery of health care by incorporating "illness" into patient care, and expanding treatment beyond the physical aspects of disease. Collaboration of the medical perspective which focuses on disease entities and elimination of disease states, with the psychosocial perspective of the importance of the illness experience, will result in a broader understanding of the client's needs and the environmental context of care, resulting in a state of optimum equilibrium between the client and her/his environment allowing for the client's full potential to be realized. In addition, an understanding of the client's perspective of illness establishes the basis for caring relationships with clients (Marck, 1990). Therefore, understanding the meaning of leukemia and bone marrow transplantation fosters the social worker's understanding of the client, places the client's responses to illness in context, enhances communication, enables a therapeutic relationship to develop, and provides a basis for planning effective social work interventions.
Two value premises which underlay social work practice are, respect for the dignity and uniqueness of individuals and respect for an individual's right to exercise self determination. Elicitation, understanding and incorporation of the client's explanatory model into the health care plan, coupled with the awareness that discrepancies and differences may exist between the lay and professional explanatory models of health and illness encourages medical social workers and other health care professionals to uphold these value premises.

Summary

The background to the problem, problem statement, and the purposes of the study were outlined in this chapter. A discussion of the conceptual model guiding this study was offered and definitions of terms utilized in the study, and the assumptions and limitations of the study were recognized. The relevance of the study to social work practice was also discussed. A review of the literature related to the topic will be presented in Chapter 2. Chapter 3 presents the methodology implemented in the study. Participants' accounts are presented and described in Chapter 4. In Chapter 5 these accounts are discussed in relation to existing literature. In Chapter 6 conclusions are stated, recommendations for social work practice in health care and research are provided and the researcher's personal comments offered.
CHAPTER 2: REVIEW OF THE LITERATURE

This chapter presents the initial review of the literature. The conceptualization of the research purpose directed the literature review in two directions.

Firstly, the investigator searched for literature which illustrated differences and discrepancies between the explanatory models held by the professional sector and that held by the popular sector. Secondly, the investigator was directed towards literature concerned with the psychosocial adjustment of the adult to illness and treatment. The purpose of searching such literature was to illustrate that illness and the meanings and perceptions attributed to the illness experience, extend beyond the hospitalization period. Review of such literature allows one to see that the medical encounter is but one step in a more inclusive sequence (Kleinman, Eisenberg & Good, 1987, p.251). That is, illness and illness problems extend beyond the disease itself with leukemia and bone marrow transplantation being much more than a disease and a medical treatment marked by hospitalization.

Differences and Discrepancies

For physicians, illness problems are often disregarded as they look upon the disease as the disorder (Kleinman, Eisenberg & Good, 1978, pg.252). When assessing patients' status and outcome physicians are wont to emphasize physical criteria measured with ever increasing sophistication and sensitivity (Wolf, F., 1982, pg.851). Conversely, for
patients, the illness problems and the difficulties in living resulting from sickness are usually viewed as constituting the entire disorder (Zola, I. 1972). Patients evaluate their status or outcome on the basis of how they feel, or function in their interpersonal relationships and professional or work related activities. This discrepancy between what the physician and what the patient see as constituting the "disorder" or "problem" is fostered by the medical educational system. Wolf (1982) surveyed the interests of seventy three first year medical students in the social and cultural aspects of medicine. Utilizing a five point Likert type scale and a questionnaire, subjects were asked to rate how interested they would be in learning about the role of the following in health and illness: society (i.e. historical trends, cross national similarities and differences); community (i.e. urban-rural similarities and differences); family; individual status (age, sex, socioeconomic status, race/ethnic similarities and differences). Although 50% of the respondents indicated they were either "very" or "extremely" interested in learning the role of family in health and illness, less than half of the respondents showed a strong interest in each of the other topics and one in five subjects indicated little or no interest at all in these topics. The study indicates medical students and hence, following generations of physicians, will continue to be inclined to view patients more as receptacles of disease, with less understanding of the problems of
patients as human beings. This in turn results in a widening of the gap of understanding between patients and health care professionals.

Personal accounts of illness provide insight into how clients perceive their experience and how their interpretation of illness may be based on an entirely different model from that of the professional's scientific one. This is illustrated by the following vignette:

The patient was a 60 year old white Protestant grandmother recovering from pulmonary edema secondary to atherosclerotic cardiovascular disease and chronic congestive heart failure. Her behavior in the recovery phase of the illness was described as bizarre by the staff and nurses. Although her cardiac status greatly improved and she became virtually asymptomatic, she induced vomiting and urinated frequently into her bed. She became angry when told to stop. Psychiatric consultation was requested. Review of her medical record showed nothing as to the personal significance of the patient's behavior. When asked to explain why she was engaging in it and what meaning it had for her, the patient's response was most revealing. Describing herself as the wife and daughter of plumbers, the patient noted that she was informed by the medical team that she had "water on the lungs." Her concept of the anatomy of the human body had the chest hooked up to two pipes leading to the mouth and the urethra. The patient explained that she had been trying to remove as much water from her chest as possible through self-induced vomiting and frequent urination. She analogized the latter to the work of the "water pills" she was taking, which she had been told were getting rid of the water on her chest. She concluded: "I can't understand why people are angry at me." After appropriate explanations, along with diagrams, she acknowledged that the "plumbing" of the body is remarkable and quite different from what she had believed. Her unusual behavior ended at that time (Kleinman, Eisenberg & Good, 1978, pg.254).

Such accounts of the patient's explanatory model and perception of the illness experience demonstrate the incongruencies with the professional medical model. It also illustrates the value of acknowledging, understanding and
incorporating patients' explanatory models and beliefs into the health care plan to eliminate misunderstandings and problems in clinical management.

Personal accounts of illness also reveal that professionals and lay people may not interpret the same sickness in the same way. *Anatomy of An Illness As Perceived by the Patient*, by Norman Cousins (1979), illustrates that sickness is interpreted differently by lay persons and professionals. Cousins, diagnosed with ankylosing spondilitis, describes how the professionals in diagnosing a scientific basis for his symptoms were more "concerned with the clinical capability of the hospital than of concern for the well-being of the patient" (Cousins 1979, pg. 28) This, coupled with Cousins fast growing conviction that a hospital is no place for a person who is seriously ill, led him to embark upon his own journey of searching his own past experiences and beliefs in order to determine what he believed to be the underlying causes of his symptoms and to "make sense" of his symptoms. Rather than accepting the professional viewpoint that he had a one in five hundred chance of full recovery, Cousins adopted his own cure for his illness. This "cure" took the form of laughter therapy and Cousins recovered.

**Psychosocial Adjustment to Illness**

With biomedicine's primary interest in the recognition and treatment of disease, the illness experience is banished
as a legitimate object of clinical concern.

In relation to leukemia and bone marrow transplantation this professional/biomedical concern for disease is reflected in the literature. Although leukemia and bone marrow transplantation frequently appear in the literature, the emphasis is primarily directed toward the medical management of the process. Much attention is focused on the individual undergoing bone marrow transplant during the inpatient experience, particularly the prevention and treatment of bone marrow transplant related complications. What has not received enough consideration is the meaning of illness and the impact of the illness experience on the more global aspects of an individual's life in terms of everyday functioning following discharge from the inpatient setting. Mages and Mendelsohn (1979) note that people with cancer are confronted with a continuing series of stressors rather than with a single, time limited crisis.

Descriptions of BMT in the literature, written from the perspective of professionals or researchers, depict BMT as a stressful, intense, anxiety provoking, isolating and uncertain time (Brown & Kelly, 1976; Patenaude, Levinger & Baker, 1986; Patenaude, Szymanski & Rappeport, 1979). Such descriptions establish the profound impact of bone marrow transplant, however they do not fully capture the meaning of bone marrow transplantation to those who are living the experience. What the literature does indicate however, is that leukemia and
bone marrow transplant extend far beyond the diagnosis and treatment stage. Eradication of the disease implies recovery in the professional/scientific sense, however the quality of life of the survivors indicate the diagnosis and treatment phase is but one small part of the illness experience (Andrykowski, Henslee, & Farrall, 1989; Hengeveld, Houtman & Swan, 1988; Wolcott, Wellisch Fawzy & Landsverk, 1986).

Wolcott, et al., (1986), documented the health status and psychosocial adjustment of bone marrow transplant recipients survivors. In this investigation, 17 adults who received a bone marrow transplant for leukemia or other disease processes such as aplastic anemia, were surveyed on such variables as self reported health status, mood state, and self esteem. The participants ranged between 19 and 91 months post bone marrow transplant with a mean of 42 months. The findings of this study suggest that the participants' current level of social role functioning was similar to that of the general population however, higher levels of anxiety, depression, anger and total mood disturbance were found in male and female bone marrow transplant recipients. Self esteem was also found to be slightly lower than sex matched donors and moderately lower than kidney transplant recipients. Wolcott et al., (1986) conclude that approximately 15% to 25% of long term bone marrow transplant survivors may have significant psychological distress and poor adaptation.

Andrykowski and colleagues (1988) compared Profile of
Mood State scores of recently diagnosed lung cancer patients and survivors of testicular cancer to those of bone marrow transplant recipients. The results suggested that the bone marrow transplant recipients had greater mood disturbance than either of the other two groups. Andrykowski and colleagues (1989) suggested that emotional readjustment for bone marrow transplant recipients may pose a greater challenge than is currently recognized. As Burge et al., (1975) noted in an article on the treatment of acute myeloid leukemia, "the present preoccupation with intensive therapy appears to blind physicians to the poor quality of life which their patients lead. The aim of treatment is too often to induce a hematological remission (an irrelevance to the patient) rather than to improve the quality of life" (p.19 in Eisenberg, L., 1977).

Haberman (1988) conducted a study which examined the personal meaning attributed to illness and treatment by adults undergoing bone marrow transplantation. Utilizing a sample of 23 adult persons with leukemia, the study found that prolonged uncertainty was the hallmark of living with leukemia. Furthermore, individuals preparing for a bone marrow transplant were found to have a paradoxical self image as they considered themselves to be healthy, yet living with a fatal illness (Haberman, 1988). Although this investigation focused on the pre-bone marrow transplant, and bone marrow transplant phase of the experience, the findings also have significance
for the consideration of patients in the post hospitalization adjustment period. Bone marrow transplant recipients who have returned home continue to face the possibility of relapse or life-threatening complications.

The transition from sickness to wellness is frequently referred to in relation to the cancer experience (Feldman, 1974; Quint, 1963; Sanders et al., 1977; Scott et al., 1983). In the study by Quint (1963), a participant stated the real impact of cancer does not hit until the patient returns home from the hospital. Closely tied to the transition from sickness to wellness is the concept of meaning. Individuals who have experienced cancer acknowledge that life is never the same again (Quint, 1963; Scott et al., 1983). Feldman (1974) discusses chronic illness in terms of a transition from sickness to "different." "The stricken one must accept that life is irrevocably different, and because of that difference a new meaning and way of life must be found" (p. 289)

It is widely acknowledged that all patients diagnosed with cancer face a significant challenge in learning to cope with the outcomes of illness and treatment (Brown & Kelly, 1984; Krouse & Krouse, 1982; Miller, Denner & Richardson, 1976; Quint, 1963; Sanders & Kardinal, 1977; Scott, Goode, & Arlin, 1983; Tiedt, 1975). It is the implications of illness, such as the impact on everyday functioning that influence the quality of life and the meaning the illness holds for the person. Persons recovering from serious illness are
confronted with major changes in their lives — physiologically, socially and emotionally (Smith, 1979). Physically, the patient must adjust to side effects of the disease and treatment; socially, the patient must adapt to an altered life-style; and emotionally, the patient must learn to cope with the ever present knowledge that the disease may recur. The concerns they perceive during and after hospitalization affect the way they cope with these changes and recuperate. How illness is experienced and the specific meaning that illness and treatment has for an individual influences how that individual will cope (Brown et al., 1984; Sanders et al., 1977). Therefore, in order to facilitate and foster the patient's recovery in a meaningful sense for them, the health care professional must understand the patient's own knowledge and values concerning leukemia and bone marrow transplant and incorporate these into the health care plan.

Psychosocial responses to cancer are influenced by factors that create the perceived reality of cancer for the individual. The reality of the cancer experience is complex, uncertain and results in psychosocial responses that are dynamic, nonlinear, nonhierarchial and that vary in severity (Clark, J. 1991 p. 347). Generally, clinical case studies of individuals and groups experiencing cancer are used to identify the unique psychosocial responses to cancer, to describe the types of coping patterns among persons with cancer, and to guide health care professionals in assisting
the person with cancer to adapt to the diagnosis, the demands of treatment and the demands of living with a cancer diagnosis. However, this approach with its generalizations is narrow in scope. Clark (1991) recognizing the inherent uniqueness of individuals, coupled with their unique explanatory models of health and illness states, "just as significant variability exists in physiologic responses to cancer of different sites as well as within the same site, the variability of psychosocial responses is multiplied by the fact that each individual brings his or her values, beliefs, attitudes, personality, resources, and coping patterns to the cancer experience (Clark, J., 1991, p.347).

By studying the illness experience from the patient's viewpoint a more valid basis can be formed to set priorities for in-hospital care and plan effective teaching and rehabilitation programs. In this way, patient's will receive a more individualized approach to care with their concerns being addressed in a manner which conveys respect for and acknowledgement of their personal explanatory models of health and illness. This in turn may allow for the provision of assistance in coping with the changes that occur following bone marrow transplantation and recognition that the illness experience does not end with discharge from hospital nor with remission from the disease. As Eisenberg (1977) states, "It is essential to reintegrate "scientific" and "social" concepts of disease and illness as a basis for a functional system of
The review of the literature reveals that provision of care for persons with leukemia and other life-threatening illnesses is narrow in scope. Adherence to the biomedical model of health care, with little consideration, if any, being given to the popular sector's explanatory model of health and illness results in the illness experience and implications of illness being ignored. The literature clearly reveals that the illness experience does not end with hospitalization nor with remission from the disease. The literature illustrates that the illness experience extends into many facets of a person's life resulting in a life which is irrevocably different than it was pre-diagnosis. Although literature was found which focused on psychosocial adjustment and quality of life issues for persons with a life-threatening illness, a scant amount of literature addresses the personal meaning and perceptions the illness experience holds for these persons.

This study is designed to yield a description of the personal meanings and perceptions of the illness experience for persons who have undergone bone marrow transplantation. A qualitative research approach with an open-ended interview format based on Kleinman, Eisenberg & Good's (1978) framework for eliciting the client's explanatory model is utilized to capture the participants' meanings and perceptions and allow them to be expressed in their own words. The study is guided
by a phenomenological approach. The methodology of the study will be presented and discussed in Chapter 3.
A qualitative, phenomenological approach was the method by which this study was conducted. Kleinman (1977) argues that clients' subjective experiences of illness can be investigated by using the phenomenological approach. Phenomenology is considered both a research method and a philosophy (Oiler, 1986). This chapter briefly outlines the beliefs and values which underlay the philosophy of phenomenology and describes how this philosophy was most suited to the research question and research design.

The Phenomenological Perspective

Phenomenological inquiry and logical positivism are two fundamentally different and competing inquiry paradigms. The latter is often referred to as the traditional scientific approach and is based on the positivist-empiricist philosophy. While the purpose of both methods is to acquire and accumulate knowledge, the approach to and philosophy underlying these purposes differ. Within the positivist-empiricist philosophy, human behavior as the object of analysis, is assumed to be embedded in a physical system of cause-and-effect relationships and there is little regard for the subjective states of individuals. The methods of positivism require a detached, objective observer. To operate from this position the researcher must necessarily assume that there is a clear separation between the observer and the observed. Logical positivism aims to test deductive hypotheses derived from
theoretical premises (Patton, 1990). The rules and procedures of the quantitative-experimental paradigm are aimed at producing internally valid, reliable, replicable and generalizable findings (Patton, 1991, p.193). In comparison, while logical positivism utilizes quantitative and experimental methods to test hypothetical-deductive generalizations and is based on the assumptions and research methods of the natural sciences with the emphasis of acquiring objective knowledge, phenomenological inquiry utilizes qualitative and naturalistic approaches to inductively and holistically understand human experience in context-specific settings. The phenomenologist examines how the world is experienced with the important reality being what people imagine it to be (Bogden & Taylor, 1975). In this sense inquiry is a never ending process as there are multiple interpretations based on different individuals and contexts. The phenomenological perspective assumes that reality is individually constructed, dynamic, and must be considered in relation to the context in which the phenomenon of interest occurs (Lewis & Haberman, 1990). As a philosophy, approach, and type of qualitative research method, phenomenology recognizes the importance of understanding experience based on the individual's inner or subjective understanding of events, behaviors and surroundings (Oiler, 1986; Rist, 1979). When phenomenology is applied in research the lived experience of individuals is considered the basic unit of research and
knowledge is constructed from participants' descriptions of their experience (Oiler, 1986).

To elicit the participants' perceptions and meanings of their illness experience the investigator adopted a qualitative stance and phenomenology was selected as the method to address the research question. The phenomenological approach is congruent with the purposes of this study as it allows the investigator to obtain the participants' perspectives as the aim of phenomenology is to describe experience as it is lived by people (Oiler, 1986).

Characteristics of the study which reflect phenomenology are as follows. Firstly, the researcher's assumptions, ideas, and thoughts about personal meanings and perceptions of the illness experience were controlled for by bracketing (Swanson-Kaufman & Schonwald, 1988). Secondly, the open-ended interview questions allowed participants to describe their experience in their own words. In addition, entire transcripts were accepted as data which allowed the variables of interest to emerge (Omery, 1983). Lastly, to assure the description of the experience remained true to the data the natural language of the participants was used in the presentation of the findings (Oiler, 1986).

**Validity and Reliability**

Traditionally, the definitions of validity and reliability refer to, the ability of the research instrument to measure what it is purported to measure and the consistency
of the instrument in the measurement of a particular concept respectively (Manson-Wilms, 1992). Review of the literature suggests these standard definitions are only relevant to the quantitative approach to research. To satisfy the requirements of validity and reliability within qualitative research, various authors have re-defined the standard meanings of the concepts to better suit qualitative methods (Guba, 1981; Leninger, 1985; Agar, 1986; Sandelowski, 1986; Atkinson & Heath, 1991; Sykes, 1991). Coupled with these distinct definitions of validity and reliability within qualitative research are different criteria to measure the validity and reliability of qualitative research. Guba (1985) suggests that the criterion of truth value and applicability replace the terms internal and external validity and the criterion of consistency and neutrality replace reliability. Truth value is maintained when the researcher has established confidence in the truth of the findings for the subjects or informants and the context in which the study was undertaken. That is, the accuracy of the descriptions or interpretations enables people outside of the study who also share the experience to recognize it immediately. Guba refers to the concept of fittingness as the criterion against which to assess applicability of qualitative findings. Fittingness is maintained when the findings fit the data from which they are derived, fit contexts outside the study situation and fit the experience of others. Credibility of a qualitative study is
upheld when the descriptions or interpretations of human experience are so accurate that people who also share that experience would recognize it immediately. Guba defines consistency in terms of dependability. Dependability implies trackable variability. That is, variability can be ascribed to identified resources. Neutrality is equated with freedom from bias and is the degree to which the findings are solely a function of the informants and conditions of the research and not other biases, motivations or perspectives.

Various strategies were implemented during the research process to meet these criteria. Firstly, the criterion of truth value and fittingness was upheld by the researcher presenting her analysis of the participants' accounts to three former BMT recipients. These recipients expressed they could identify with the findings and could recognize them as meanings and perceptions inherent within the illness experience. Secondly, the criteria of credibility was maintained by feedback on the findings from the participants themselves. The participants recognized the findings to be true and indicative of the perceptions and personal meanings surrounding their illness experience. Thirdly, the criteria of neutrality was addressed by the researcher examining her own explanatory model of health and illness and recognizing any discrepancies between the two sectors. This allowed for any judgements to be suspended and served to eliminate any biases.
Ethical Considerations

Approval for this study was granted from the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects, the Hospital Research Committee, the Hospital Department of Social Work and the Director of the Leukemia/Bone Marrow Transplant Program of British Columbia.

Prior to recruitment each potential participant received an introductory letter describing the purpose of the study and explaining the involvement requested (Appendix A). Written consent was obtained from each individual who agreed to participate and a copy of the signed consent form given to them (Appendix B). Protection of the rights of the participants was also exercised. Confidentiality in relation to participation and all sources of data collected was assured and respected at all times. To ensure confidentiality each participant was assigned a code name. The list of participant names, code names and consent forms were kept separate from the audiotapes and transcripts and were only accessible to the investigator and research advisor. Participants were assured that the audiotapes would be erased after completion of the research report and that any information that may identify the participant, or the name of the hospital, would be omitted from the transcripts. The freedom to withdraw from the study at any time, the right to choose to not answer any question during the interview and the right to stop the interview at
any time without jeopardizing their health care was emphasized to the participants at the beginning of each interview. Prior to each interview the participants were reminded that they had the right to stop the tape recorder. The researcher was sensitive to the possibility that the sharing of one's experience could prove to be extremely distressing for the participant's. The researcher acknowledged this with each participant prior to the onset of the interview and offered her support should the participant wish to discontinue the interview or discuss her/his feelings after the interview.

**Selection of Participants**

A non-probability, purposive sampling design was utilized in this study. This method of sample selection is congruent with the phenomenological approach as phenomenology directs one to collect data from those who have lived the experience (Omer, 1983). Purposive sampling directs the researcher to acquire participants for a specific purpose (Wood & Catanzaro, 1988). With this sampling design the researcher was able to gain access to subjective meaning by searching for individuals who were competent to answer the questions of the study - that is, the persons who have actually undergone bone marrow transplantation for the treatment of leukemia.

**Selection Criteria**

Appropriateness and competency of the potential
participants was established utilizing the following criteria:

1) at least 19 years of age,
2) have received a bone marrow transplant for the treatment of a form of leukemia,
3) are presumed to be disease free or in remission,
4) are not hospitalized at the time of the study,
5) have been discharged from hospital for at least four weeks,
6) are able to read, understand, and speak English.

The criterion of disease free status or remission status was established as the researcher wished to focus on those individuals who were attempting to resume their life after being faced with a life threatening disease.

The criterion of at least four weeks post discharge from the hospital was established to allow participants the opportunity to begin adjusting to life after discharge.

Sample Recruitment

Participants were accessed through the Bone Marrow Transplant Program of a large tertiary care hospital in Canada. Potential participants who met the established criteria were identified by the investigator. A list of potential participants was given to a nurse of the outpatient clinic. Potential participants were approached by a nurse in the outpatient department at the time of their clinic appointment. The nurse advised them of the study and provided them with the Information Letter (Appendix A) of the study. Potential participants were advised to contact the researcher
should they wish to participate. Upon contact with the researcher further details of the study were explained, questions regarding the study answered and an interview time and place scheduled. Consent forms were signed prior to the first interview. A copy of the signed consent was given to the participant (Appendix B).

A total of eight participants were recruited for the study however, only four first interviews were conducted.

Two individuals who were approached to participate declined. One individual felt talking about his illness would be "too heavy," while another individual thought he had talked about his illness too much already. One recruited participant was excluded due to re-admission to hospital. One recruited participant unexpectedly died prior to the first interview.

**Characteristics of the Participants**

One woman and three men were interviewed. All participants were between the ages of 29 and 42. One of the participants resided outside the province of the transplant center. Of the three participants who resided in the province, one resided outside of the city, one participant resided outside the immediate vicinity, while one participant lived in the city in which the transplant took place. Three of the participants were married, one divorced. The partners of the three married participants were with them during the course of the treatment. All participants had children. None of the participants had post secondary education and all
had completed grade twelve education. While all participants had been actively employed prior to their illness, all participants were not working at the time of the interview. Two of the participants were on sick leave from their previous places of employment and two participants were unemployed and not seeking work at the time of the interviews.

The underlying diseases were acute myelogenous leukemia, chronic myelogenous leukemia, and myelodysplastic syndrome. All of the participants had allogeneic transplants with two of the participants having unrelated bone marrow donors. In addition to the bone marrow transplant, the treatment also included chemotherapy or radiation as part of the conditioning regime prior to bone marrow transplantation for all four of the participants. One participant had been diagnosed with leukemia for thirteen months prior to transplantation, one participant had the disease for seven months, while two participants had a time of three months between diagnosis and transplantation. Two of the participants had re-admissions to hospital post transplant.

Data Collection

Data for the study was compiled with information gathered from two stages of interviews. All four participants took part in the first stage of interviews. The first interviews focused on the participants sharing information which described their illness experience and the meaning they attached to their illness. In addition, the first interviews
allowed for a further development of rapport between the researcher and the participants. With all participants this took the form of "socializing" with the participant and any family members who were present prior to the onset of the interview. The average time for the first interview with each participant was approximately one hour and thirty minutes. However, the actual time the researcher spent with each participant for the first interview was much longer due to the time spent socializing prior to and after the interview. Following analysis of the data obtained from these first interviews, second interviews were conducted with three of the four participants to clarify, and further develop and validate the descriptions assuring that all prominent aspects of the participants' experiences were included. The second interview also allowed the researcher the opportunity to ensure that the participants identified the descriptions as being true. The second interviews were conducted over the telephone due to re-location of the researcher outside of the city of the bone marrow transplant center. One participant could not be reached for a second interview. In total, seven interviews were conducted totalling approximately ten hours. Four of the interviews were conducted in-person and were audio tape recorded resulting in approximately six hours of taped interviews which were then transcribed verbatim by the researcher. Field notes were also collected following each interview to note non verbal behaviors, the emotional climate
of the interview, distractions and disruptions. Field notes were recorded for the following three telephone interviews.

At the time of the first interviews one participant was approximately one year post transplant, two participants were approximately six months post transplant and one participant was seven weeks post transplant. The time between the first and second interviews varied from seven weeks to three months.

Oiler (1986) states, "the selection of data collection procedures is guided by the intent to preserve the natural spontaneity of subjects lived experiences and an effort is made to approach the question holistically by going to people in their circumstances, where they are involved with the world" (p.80). Although it was preferable to have the interviews occur in the participant's place of residence, the researcher respected the privacy of the participants by giving them the option to have the interviews within their place of residence or at an office within the hospital. Three of the participants chose to be interviewed within their home while one participant chose to be interviewed at the hospital. An interview guide approach, utilizing Kleinman, Eisenberg & Good's (1978) framework for eliciting a persons explanatory model of health was utilized to gain access to the participants' meanings and perceptions of their illness experience (Appendix C).

The researcher found the data collection and interviewing process to be a learning experience within itself. Conducting
the initial interviews within the participants' surroundings provided the researcher with the opportunity to see what life was like for the participants outside of the hospital setting. It also provided an occasion in which the researcher, rather than the participant, was the one in unfamiliar territory. This helped the researcher in recognizing how difficult it must be for patients and families to adapt to the hospital surroundings and the accompanying routines such that they feel welcome, comfortable and part of the team.

Playing the role of interviewer was perhaps the most difficult part of this project as the researcher found it difficult to switch from being the social worker, "support person" and "friend" to playing the role of "researcher." The researcher found her role and interviewing style as a researcher to be incongruous with her role and interviewing style as a social worker within the hospital setting.

Within her practice as a social worker, the researcher's role is one which focuses around provision of support and empathy. The role of researcher however, seemed to disallow for this as it felt too "scientific" like. These incongruencies were somewhat minimized by socializing with the participants and their families prior to and after the interviews.

Discrepancies between the interview style as a researcher and as a social worker were also apparent. The researcher's interviewing style, when performing the role of social worker,
is one which includes a great deal of personal touch such as hand-holding and hugging. The researcher felt however, that as a "researcher" she couldn't utilize any form of personal touch as it seemed inappropriate for the current situation. The researcher also sensed that the participants were aware of this as the researcher and the participants' usual styles of relating did not resume until completion of the interviews.

Data Analysis

The purpose of this study was to effectively convey and describe the personal meanings and perceptions of the participant's illness experience. To achieve this goal, the researcher analyzed the data by employing the steps of phenomenological analysis as outlined by Patton (1990). These steps were enhanced with a basic method of data analysis as described by Giorgi (1985). The following paragraphs highlight the steps utilized to analyze the data.

Data analysis began with the researcher reflecting upon personal biases, preconceptions, assumptions, and viewpoints regarding the phenomenon under investigation (Patton, 1990). In order to see the experience for itself the researcher attempted to suspend her judgements, enabling her to investigate the phenomena from a fresh and open viewpoint (Patton, 1990). Being aware of her own professional perspective and the differences in viewpoint between herself and the participant allowed for a clearer understanding of the participant's viewpoint (Giorgi, 1975). This was a continual
process throughout the study.

Utilization of an open ended interview format enabled the participants to identify the relevant aspects of their experience and describe their experience in their own words. This approach assisted in obtaining unbiased descriptions of the experience of leukemia and bone marrow transplantation. The first interview was reviewed by a member of the thesis committee and suggestions for improving the interview process were incorporated into subsequent interviews.

Data analysis was completed concurrently with, and subsequent to the interviews. To establish a context for interpreting and making sense of the interview, the researcher noted observations pertaining to the interview itself. Immediately following the interview the researcher noted where the interview occurred, who was present, how the participant responded to the interview and the researcher's perception of her role in the interview. Following each interview the tape was listened to by the researcher to obtain an initial sense of the participant's perspective and to become familiar with the content of the interview. The tapes were then transcribed by the researcher verbatim. Transcripts were read while listening to the audiotape to ensure the transcripts were correct and to get a sense of the whole. This also provided the researcher with the opportunity to recall the situation surrounding the interview stimulating any impressions the researcher had at the time of the interview.
Transcripts were then read again, slowly, to allow identification of transitions and meaning units in the experience (Giorgi, 1985). A meaning unit was considered a section of the transcript which contained a singular idea. The units were regarded as discriminate, together making up the whole meaning of the experience. Holding the phenomenon up for serious inspection, or bracketing, assisted in uncovering, defining, and analyzing the data (Patton, 1990).

With the completion of bracketing, the data were grouped into meaningful clusters whereby irrelevant, repetitive, or overlapping data were eliminated (Patton, 1990). Invariant themes within the data were identified and the meaning of the remaining units were clarified and elaborated upon by relating them to each other and the whole.

As transcripts were read and themes noted from succeeding interviews, previously identified meaning units were transformed to reflect more general themes arising from the data (Kerzner, 1992). Patterns and relationships amongst the themes were noted.

The final step of the data analysis was the development of a structural synthesis with the true meanings of the experience being described and communicated.

Summary

Phenomenological theory guided this qualitative study. Participant selection was determined according to the individual's ability, competency, and willingness to describe
the meanings and perceptions of her/his illness experience. Four participants were interviewed with a total of seven interviews occurring over a three month period. Transcribed audiotapes and field notes from the interviews formed the data for the study. Analysis of the data was completed utilizing steps as outlined by Patton (1990), and Giorgi (1985). Completion of data analysis resulted in the description of the participants' accounts. The participants' accounts, organized into common perceptual themes, are presented in Chapter Four.
CHAPTER 4: THE PARTICIPANTS' ACCOUNTS

Section One of this chapter presents the participants' accounts and the common themes of the personal perceptions of their illness experience with leukemia and bone marrow transplantation. Section Two presents accounts which indicate differences and discrepancies between the explanatory models of the professional and popular sector. Recognizing the uniqueness of each participant, coupled with their distinctive circumstances, it is acknowledged that each participant offers a unique perspective and experience. This uniqueness is reflected in the variations in the themes and is portrayed through excerpts of the interviews. Although no two participants relate the same story, seven common themes emerge repeatedly within the participants' accounts. The seven themes that emerged, surround the attempts made by the participants to make sense of, causality; BMT; chronicity of the illness; possibility of disease recurrence; communication with health professionals; support; and life. These themes were grouped by the researcher according to etiology of the disease, BMT and care-related issues, implications of the illness, and positive aspects of the illness experience. Grouping of the themes was implemented to facilitate the presentation of the descriptions and explanations of the participants' accounts. Each theme, and the corresponding meanings constructed from the participants' perceptions are
Search for Answers

The participants' quest to find answers as to what caused the disease led them to external sources. It was clear from all of the accounts that the cause was not internally based:

Hmm, that's something that's run through my mind a lot of times - umm, I personally think it is chemically related one way or another. I think it was either somethin' I inhaled or ate or absorbed one way or another. Whether it was food or from the environment or whatever I have no idea."

I used to work in a fish farm, I was always handling dead fish off the bottom of pens, we were constantly mixing up medicated feed for them so you're dealing with chemicals there and everything and they say try not to get it on your bare skin, well it's pretty hard when you're digging in into the feed barrels to make sure it is all mixed proper."

Umm, I don't know, I don't know, I was thinking maybe, I don't know, my friends all say to me I am very healthy, I care for myself, I don't eat the wrong food, I don't eat things from the can, I eat very, very careful but I still get sick. My grandfathers's brother, he had the same type of cancer as me in China but he was 83 years old when he got the leukemia. Then I think in 1980 I went to China and maybe it was when they had the radiation over there."
One participant adopted the germ theory of causation perceiving that prior bouts of disease were to blame for the disease:

I think uh, I don't think the doctors know 100% but I got my theories and stuff and I think it was the fact that I kept getting mononucleosis and the Epstein Barr syndrome and they, I had been told that uh, uh, that it attacked my immune system and it became a virus and it attacked and got my white blood cells to go way up and that's probably a good educated guess, that's probably what happened like I said in a three year period I had about three or four bouts of it.

Questioning Why

Along with searching for explanations as to what caused the disease, the participants actively considered "why" they had succumbed to such a horrid disease.

I, uh, just basically, uh, yeah, okay I've got it and there's not much you can do about it you know. Umm (pause) I didn't ask "why me" until after the transplant, and then I asked that question, like why did this happen to me.

To me it means I am uh, and to survive it, it means I am a special person and somewhere along the way you know, I did something right. Sometimes when you get ill you say to yourself what did I do wrong you know. Umm, I was just questioning, you know why did it happen to me you know, the famous question, why me you know, and you know you can't figure it out, you were never a bad person or anything like that and uh, you know.

One participant, rather than taking an individualistic stance and focusing on himself, took a global approach and questioned why the disease strikes anyone.

Uh, yeah I have bouts of anger, mmm, mmm, yup....not in
the sense why did it happen to me particularly just why does it happen at all...would be more a question of asking. I would think...I wasn't really thinking singular you know, why does it happen to people as opposed to why did it happen to me.

Seriousness of the Disease

Most participants conveyed the seriousness of their disease with the acknowledgement that it is life threatening.

I'd say it's very serious (laugh) because if you don't get, learn to get it under control it can go from chronic to acute and then you can get very sick and it can kill ya.

It's a matter of life and death.

The doctors say it is very serious, yup it is a very serious problem.

Coping with the Life Threatening Nature of the Disease

From the participants' accounts it was clear they were not expecting a complete cure, nor imminent death at that time. In acknowledging the life threatening nature of the disease, one participant portrayed a view of the future which included a sense of preparedness for death. He articulated the belief that a "fighting" strategy or attitude had the potential to postpone death.

I can physically adjust to all of these things relatively easy - mentally, not so easy because I don't want to (pause). And if I wanted to, um, um, I would've let go, I woulda quit fighting and I woulda never made it thru ICU.
Along with a "fighting attitude," the participant also views letting go of fear as a means to survival or postponement of death.

You have to...you have to let go of the fears because if you don't uh, if the disease won't kill you the fear will. So you just gotta let go.

......................................................

Control was seen by another participant as a means to deal with the seriousness of the disease.

I feel we've kept it under control and that's one of the things that's helped me all along is its been under control.

......................................................

BONE MARROW TRANSPLANT and CARE-RELATED ISSUES

Perceptions of Bone Marrow Transplantation

All participants held the common perception that bone marrow transplantation was a means to maintaining life, or postponing death. Therefore, the decision to proceed with treatment was ultimately based on the belief, or hope, that a BMT could extend their life.

I thought it might uh, um, keep me alive so much longer you know.

......................................................

I hope umm, umm, it makes me live longer.

......................................................

It's the only thing that probably would have saved me eventually, you know.

......................................................

Hopefully the transplant is secured and that'll be that
and I'll be able to have a healthy life again.

Life Threatening - Life Saving Treatment

One participant expressed a two-sided view of the transplant, acknowledging the capability of BMT to save her life and at the same time posing as a risk to her life.

Yes, I want to see (stated child's name) get an education, be a Grandma, that is what Doctor (stated Doctor's name) explained to me - he said if I want to see grandchildren I should have the transplant but you know, it is a big gamble, sometimes the transplant can kill you faster.

Trust in BMT Capabilities

The participants' decisions to proceed with bone marrow transplantation appear to have been made with little doubt or speculation as to whether it was the most appropriate method of treatment as the majority of the participants did not seek alternative therapies or methods of treatment. A sense of "trust" towards the BMT was evident.

No, only the chemotherapy and BMT. I listened to whatever the doctors said, I did whatever the doctors asked me.

No, no, there was nurses giving me names of herbal stuff that you could try and they say that it worked on other types of cancers and maybe it'd work on this, but I really don't believe in that type of stuff so I just never bothered with anything.

One participant did experiment with some homeopathic medicines upon diagnosis, however, post BMT he has, upon recommendation
of the physician, discontinued their use.

I got on some homeopathic medicine right away and I am not on it right now and I would really like to go back to it but the doctors say maybe I shouldn't because of the chemical imbalances that occur in your body after a transplant so I am a little scared to go back to it but I would like to.

Although no hesitancy was expressed by the participants to go through with the BMT, one participant expressed that if he knew at the time of diagnosis what he knew now about the difficulty of going through a transplant, the decision to have a transplant would have been much more difficult to make.

After that three hour talk with the doctor I said go ahead, set the appointments up, let's get started with it. Knowing what I know now, I would have said well I'll get back to you in a few days and had to go off by myself and seriously think about it.

CARE-RELATED ISSUES

Communication With the Professional Sector

The participants' accounts of their illness experience included their attitudes toward medical professionals. Although the professional nurse was mentioned by one participant, the accounts focused primarily on the participants' thoughts and feelings towards physicians. The descriptions were expressed as concerns in the medical management of the disease. It was clear from the accounts that concerns arising from the medical management of the disease held the potential for notable implications upon the participants' experience of living with an illness. Lack of
information or withholding of information, and inattentiveness or lack of concern for the physical and psychosocial implications of the illness were described.

The power of the physicians may have been recognized by the participants as the physicians controlled the amount of information the participants received. When the participants had difficulty acquiring information they experienced considerable distress.

And when it comes to patient-doctor relationships...the most annoying thing for me is to squeeze information out of the doctor...I find it extremely annoying. If my daughter, at age fourteen, can be that honest and ask me straight out somethin, why can't they tell straight out. That annoys me a lot.

They have a habit sometimes of just leaving you hanging, you've got to learn to actually ask them what they are talking about and you know, make sure they explain it to you and everything like that because they do have a habit of sometimes they'll just, well, okay we'll see you later so you are just kind of left hanging and in limbo with what is actually going on.

Something that we really didn't get told, or we could have missed, but I think we weren't informed was the fact that this could be an ongoing thing for the rest of my life, something is going to come out of it so far its just graft versus host of the gut and VOD and some liver damage, but I didn't realize that I am sort of going to be in and out of hospital over the next year and the possibility of anywhere from 2 to 8 times, more perhaps, so we weren't prepared from that, therefore we haven't prepared out children for that and that it can be forever, I can be bouncing back and forth for the rest of my life.

Yeah, you know, the doctors tell you, oh you are going to have vomiting and nausea, but they don't tell you you are going to puke so much your toe nails are going to come up
and you know, and well we'll control it with drugs, well the drugs don't help all of the time they only help some of the time.

One participant associated the lack of information sharing with dishonesty on the part of the physicians.

I think there could've been a little more honesty along the way - from time to time - because uh, some of the questions I asked uh, got smoothed over very quick and I wasn't exactly pleased with the answer.

Lack of attentiveness, or lack of concern, for the physical and psychosocial implications of the illness were described by two participants.

And we found too that if you are vomiting and the doctors come in to talk to you and as soon as they find out you are vomiting it's all, okay we'll come back and see you, they don't want to deal with it, they you know, let the nurses deal with it and they don't seem to want to deal with it, they want to live in this world where it's you know, you have fifty-fifty chances of this and this and this and this, you will vomit but we can control it with drugs, they don't want to face that heh, sometimes these drugs aren't working.

For somebody that's trying to deal with the sickness and the financial uh, things and everything, heavy duty, a big problem, a real big problem and then uh, (chuckle) the doc says, well don't worry about that, think only about your health that instantly makes you angry.

From one participant's account, a physicians attempt at empathy culminated in what the participant perceived as lack of understanding on behalf of the physician.

They said, well I understand how you feel. Wrong - you don't understand how I feel. I don't care how many degrees you got as a doctor or whatever else...you don't understand at all how I feel, not even close.
One participant described a strategy of searching out alternative sources of information as a means to help eliminate the problem of lack of information provided by the physicians.

Basically just if after the doctors have had their talk with you like when they, like their three hour chat you know explaining the chances that they, you know, that they have to go through you know, for the risks and everything like that, if at some point in time there was time for a couple of nurses to come down and have a chat with you to fill you in a little bit more.

Another participant chose to deal with the lack of understanding provided by the physicians by choosing to ignore it.

So I just let it fly by and say nothing you know.

While none of participants questioned the medical competence, skill, or knowledge of the physicians, it was clear from their accounts that they felt the physicians lacked essential skills in the areas of communication, and illustration of empathy and understanding towards the implications of the disease. The fact that the participants' thoughts and feelings towards the physicians arose during the interviews on the participants' own initiative is a strong indicator of the impact health care professionals, such as physicians, have on their illness experience. From the accounts it also appears that a significant portion of the evaluation of physicians is placed upon the physicians ability to communicate and to provide
empathy and understanding.

**Significance of Family Support**

The participants conveyed a genuine appreciation for the support and encouragement family members provided them. The accounts suggest this provision of support clearly eased the stress of the experience. The significance of this support was conveyed through comparison of themselves to those whom they perceived did not have sufficient family support.

I don't know how someone does it on their own. I really don't. I think it would, I think I would find it a real hard thing to do.

Well, I had my wife and family here with me you know, they've gone through it all with me and that and helped me you know. I am lucky when you think of those people who come from Saskatchewan and wherever and they don't have nobody.

Support from family members was described as crucial to the coping process.

I think the thing that saved me was that I had two parents who really deserve medals to do all this, my father is incredible and my mother is incredible and really those two people are the ones, uh, even besides my wife umm, who kept me going.

If the leukemia didn't kill me, then the anxiety would've if I didn't have (partner's name) there with me. She, you know, knew how to keep my head straight.

One participant described open honest communication amongst himself and family members to be supportive and serve as a means of positive, successful coping for both himself and his
And I think the secret to that is uh, we don't cover for each other you know, like I mentioned the other couple were trying to protect each other you know, and that type of thing uh, no that doesn't work. Tell the truth - kids too uh, I promised the kids before I left - I won't hide nothin' from them, no matter what happens I said if they told me I was gonna die then 'll tell you and I would too. I wouldn't hide it from them. That uh, saving a person's feelings - that's a bunch of bull, never works, or at least I don't think it does, it never worked for me.

Family members were seen to be supportive when their encouragement was congruent with the participants' capabilities.

On track, oh yeah, she's been great that way, like she has been encouraging but she has never pushed, you know, she thinks let him do it on his own, you know, my sister was saying to her you know, push him a little bit, and she finally, she, (partner's name), as I said is very quiet and stuff and she finally said will you just let him do it on his time, you know he knows what is right for him, not you, you know.

One participant indicated the significance of family support by acknowledging the difficulty of coping when support people were absent. The participant also recognized the stress on his partner in being a caregiver and support person.

One thing I found hard, even as being as close to Vancouver as we do, you know living in (Town name) and everything like that it is hard for people to come over and visit and that which I found really hard cause there's times which you go through and nobody will be around and one couple that I've been friends with for years that live in Vancouver and they get in once in a while and umm, my parents come over, they try to come over about once a week but still you know, you go through days where there is absolutely no one, and you find that kind of hard and (pause) especially when (partner's name)
has been in there every day and she needs a break to get out.

IMPLICATIONS OF THE ILLNESS

Chronicity of the Illness

From the participants' accounts it is readily apparent that the illness experience goes beyond the disease itself. The participants discussed chronicity in terms of how long it would be before they would "return to normal." Although the time dimension differed for the participants in terms of how long their illness would last, or if the impact of the illness would ever go away at all, it was clear all the participants view their illness as a chronic state rather than an acute disease.

The chronicity of the illness was described by one participant as the most fearful aspect of the illness.

Umm...the fact that it doesn't end. It's sorta like a, a itch that won't go away cause no matter what I do I am still going to have to go and see doctors on some regular basis you know, so it's not something that I can fix or break and forget about it.

Chronicity was also viewed in terms of the resulting, and continual, physical complications of the disease.

That's something, graft versus host, is something that I am going to have to learn to live with for the rest of my life.

Two participants communicated they felt their illness would last forever. One of these participants described chronicity as the most negative aspect of his illness.
The fact that it just doesn't go away, it just keeps following you around - that's negative cause you gotta deal with it everyday, and you get tired - like some day you would just like to take a day off, and you can't and I guess I never will be able to and that takes awhile for it to sink in - to realize that you are never going to get a day off from it - ever. And when that realization hits home...wow.

I don't think this illness ever stops, you know.

Variability in the extent of chronicity is illustrated by the following excerpt. This participant, while he views the illness as chronic, measures the chronic nature of his illness by his ability to return to work. Re-entry into the work force also signifies a return to normalcy and, rather than viewing the chronicity as a life long venture, the participant has attached a one year period to this chronic state.

I've pretty well laid out, well I've already told them that I'll be off work for a year and I figure if I can get back before them, if everything goes well so be it.

One participant, when asked how long he felt the illness would last, noted the chronicity of his illness and how he felt this aspect of the illness was positive.

Uh, probably forever. I'll probably have a little part of it in me forever, you know, and that's good because hey, that is reality, you know, don't ever forget that you had it, you know cause if you forget that you are forgetting a lot of the things that you uh, you learnt while you got it you know, you know that is not to say I am going to let it cripple me for the rest of my life cause it's not you know.

Coping with the implications of the illness was also seen to
possess the element of chronicity.

Like lets face it, I will always be coping the rest of my life with this, you know, in different ways and stuff.

From the above excerpts it is apparent that the element of chronicity took on many different forms.

Coping with Chronicity: Adopting an Altered Definition of Normalcy

Loss of normalcy was described by the majority of the participants. Two of the participants felt their life would never return to the state of normalcy it was prior to the diagnosis and treatment, while one participant expressed hope that things would once again return to the normal he knew prior to his illness.

Another thing I also know is I don't think things will ever get back to normal, and maybe it shouldn't you know, yet I hope people treat me like I am normal, now some people who have a transplant maybe their normal becomes normal again you know, but I know in my case I don't think it will never be normal, not what it used to be, it will be different all my life so you know you live with it, you learn how to accept it and make it positive.

Well where you turn - where you get back to normal like you were before - before you were diagnosed in the first place - no I don't believe it. I don't think that'll ever happen. In my own mind and in my own heart I know it won't happen.

Some participants expressed they have adapted their lifestyle and personal expectations to better fit their newly achieved sense of normalcy. Parenting, employment abilities, physical capabilities and hobbies were specified as aspects of the
participants' lives which succumbed to an altered state of normalcy.

Yeah, like uh, umm, like I was a very strong person, I supported my daughter, I did everything on my own right, but since I got sick I can only lie down, get treatment, I can not do nothing, and I feel like I lost things to do.

Umm, yup, I think umm, it's obvious to me I am going to have to change uh, work and stuff, I did a very physical job and stuff and umm, probably shouldn't be doing that anymore.

Well, I'm using carpentry as an example but there is actually so many things uh, besides that in my life but I just use that as an example. Uh...if I have to do them on a smaller scale I'll just do them on a smaller scale - I'm not particularly satisfied with that but that's just the way it's gonna havta be. And that's why I think that uh, so called back to normal - no - it'll never happen.

An indication that life at the present time was not normal was illustrated by one participant expressing anticipation and hope for an eventual return to normalcy.

Well, having the transplant, I am hoping, having gone through the TBI and chemo and all that stuff, I am hoping that has killed it off and now that I've had the transplant I am hoping that everything will get back to normal again.

Bodily responses were also noted by some participants to have been altered by the treatment process. The participants' accounts of how they feel the treatment has changed the way their body works indicates how their bodily responses have also attained a new definition of normal.

Umm, yeah. That together with uh, you know, the number
of drugs I'm takin' and everything - yeah, it works
different, feels different. Sometimes it feels
unfamiliar you know, or gives me a response that I didn't
expect cause my old self would've reacted this way and
the new self I'm unsure how it's gonna react.

I notice I get, I notice the cold a lot quicker right
now, I know my immune system is down, that is about all.
And depending on how much walking I do, I do get tired
and just want to lay down in the afternoons and have a
nap.

One participant described his alteration of normalcy regarding
his body as being the most negative aspect of his illness.

Well, umm I mean that's one of those things to me, I look
at myself in the mirror now and I go, oh no, and that has
been quite a change and a very negative change.

One participant indicated she felt the treatment had altered
her bodily responses to a minimal degree.

Umm, not very much, not very much, but I know I am easy
to get nervous.

Process of Re-Learning

Along with altered definitions of normalcy came a process
of re-learning as described by the participants. A great deal
of re-learning was focused upon physical capabilities and
bodily responses.

And right now things are going so slow, you know it is
like learning how to walk all over again, you know like
little things that you do everyday are now like big
things to me, things you take for granted like simple
things like changing a light bulb, you know, well up
until a couple of months ago it was impossible for me to
do, I can do it now.
Yup, yup, a lot of re-learning and stuff like my writing is terrible, I just write for the sake of writing everyday just to get my writing back you know, cause my fingers, the dexterity in my fingers went crazy on me and stuff.

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Yeah, it's just like learning how to walk. As a matter of fact when I got out of ICU I had to learn that too - didn't know how to walk - totally forgot and had to mentally concentrate, look down at my feet like I was learning how to dance, yeah, darn hard work all over again.

Uncertainty and Fear Associated With Relapse

The majority of participants expressed dealing with the possibility of relapse as being the most fearful aspect of the illness.

Uh, it's like everybody else who gets ill with this, is it coming back.

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Fear of relapse, coupled with loss of BMT as a treatment option was expressed by one participant.

Probably that it will come back I guess, and knowing that if it does come back that I couldn't go through it again, I couldn't go through another transplant.

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One participant associated relapse with imminent death.

If it comes back. I know I would die so fast.

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Strategies for Coping With Possibility of Relapse

In the accounts, hope, denial, and resolve were described as methods to cope with the prospect of relapse.

If it happens, it happens and there again you gotta you know, I shouldn't say you gotta take it with a grain of
salt, you wouldn't take that with a grain of salt it would be a terrible thing.

Well, it's like, it's like before you got sick you know, like I said I had a dream about you know, having cancer and stuff and umm yes you learn to put it away, in the back, the back closet there of your mind and stuff and keep hoping that it doesn't come back, hope that this is the only time you've gotta fight, you know.

It's something I'll have to learn to deal with and everything and know that it is always a possibility of it showing up again and deal with it when it, when and if does I guess.

When the time comes I can not ask nothing, cannot do nothing.

POSITIVE ASPECTS OF THE ILLNESS EXPERIENCE

Enrichment of Life

Although the implications of the illness experience were regarded by the participants as generally negative, some participants did identify aspects of their life that had been enriched by having to consider its ending. Enrichment of life was described in terms of the positive implications of the illness experience. The participants noted the positive implications as being greater self awareness, increased appreciation for others and for life, and recognition of previously misplaced priorities. These positive implications appear to stem from an overall change in perspective towards oneself, others and life. Participants describe viewing life,
others and themselves differently.

Yeah, uh, you think things and you feel things that you otherwise would never ever dreamed of thinking or doing in my whole life because you develop a different way of looking at things...you look at people and the world a lot differently or at least I do...I see things I've never seen before.

You know the whole thing really makes you learn a lot about yourself, and you really got to look inwards towards yourself, you know it makes you a better person.

I try to be better to myself now. Umm, I take it easy at home, whenever I feel like getting up, I get up, I don't push myself. I try to listen to my body more because, umm, now I know how important it is.

One participant noted the most positive aspect of the illness experience as allowing him the opportunity for self introspection and self growth. The participant also expressed that failure to utilize the illness experience as an opportunity for self introspection and self growth is an indicant of inability to accept the illness.

You learn a lot about yourself and I think anybody that gets sick the way I did and they say well I haven't learned anything about myself they, they are not thinking or they are not able to accept what has happened. That is the whole, that is the really, I think the biggest positive towards being sick is that I have really been able to look inward and learn a lot from it.

For two participants, a further developed appreciation of others and of life, formed a portion of what they saw as being positive features of their illness experience.
Umm, mostly in the sense of appreciation you know. I appreciate what other people say and uh, do a lot more than I used to and uh, I appreciate things like uh, oh, outdoors, trees, flowers, birds, everything more than I used to and I thought I used to appreciate those things a lot...being a farm boy.

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Uh, um, yeah, um, I am a lot more calmer now and everything, more relaxed, I enjoy life and everything more now, you know, you gotta live your life while you can, you know.

Recognition of Previously Misplaced Priorities

Along with the above changes in perspective and attitude came a recognition of previously misplaced priorities.

I realize I don't care about the money, it's not, it's not important. What is important is your family and yourself. Like you know, I don't sweat the small stuff anymore, and everything like that you know.

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I was too busy...I was so caught up in my own world I didn't have time to, or I didn't think I had time I think that's the key word right there - I didn't think I had time. I did but I just didn't think I had time. I don't have any more time now than I did before - I just utilize it different.

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Moving On

From the participants' accounts it is apparent they are attempting to focus their attention upon issues and activities associated with living in the everyday world. From the accounts it seems there is a natural limit to the benefit of focusing on the fact that one has a life threatening illness. While it was clear from the interviews the participants had chosen to go on living, it was equally evident that none of
them would ever forget their experience or deny its occurrence.

    Yeah, you know something, there are certain aspects of it I want to put to bed and say okay, this has happened, don't worry about it and stuff and don't dwell on it you know, but there is the old saying forgive and forget, umm, I think you can umm, you can always forgive but never forget cause if you forget you, you haven't learnt a lot so, umm, you know by not forgetting I've retained a lot of that stuff that happened and stuff.

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    What is important is now, you know. I have been to hell and back and everything so I don't you know, want to keep thinking about, or talking about it you know. I just want to live my life.

One participant found speaking of his illness all of the time contributed to anxiety and deterred him from letting go of fears which he saw as crucial to coping.

    Uh, I don't like to talk about uh, my illness too much, not because it embarrasses me or anything like that, it's uh, I have it, I accept it, I don't feel like talking about it all day...I want to go on with something else you know.

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Section Two

Perceptions Which Indicate Differences and Discrepancies Between the Explanatory Models of the Professional and Popular Sector

The participants' descriptions of their perceptions of illness and care illustrated that differences and discrepancies exist between the professional biomedical model of health care and the explanatory model of health and
illness held by the popular sector.

One participant indicated that the biomedical model's concern with the physical aspect of the disease is narrow in scope and fails to consider mental well-being as an important factor in the illness experience:

I wish they would run more studies like this and you know listen to what people have to say and they are so concerned with helping people with the physical aspect that they forget about the mind, the mind is just as important.

Another participant relayed that a physical oriented approach to treatment and the mere administration of physical remedies is an inadequate approach to treatment and cure:

...I feel it's very necessary to attach the personal side of things to medicine period or the whole concept of healing and helping people and so on and so forth, because uh, if it's left out then (pause) perhaps people's suffering and so on is reduced but they're not cured.

This participant also perceived mental preparation to be as important as the chemotherapy and various drugs in the treatment of the disease:

If you're not mentally prepared for something it doesn't work very well and (pause) I've been here long enough that a couple of 'em never made it, and they come after me and they're already gone (chuckle) and I am still here.

The biomedical model considers the mind and body as being separate entities and the mind is considered a secondary factor in organic illness. One participant relayed a
disparate viewpoint expressing his belief that the mind and body are inter-dependent systems and therefore can not be considered separate entities in the treatment of disease:

...if my thinking starts to go negative then all the pills in the world won't make a damn bit of difference...it's all, all the healing that's gotta take place above the shoulders or else everything below the shoulders won't respond.

One participant noted that the implications of the illness are not limited to the physical problems of the disease but rather expand to include and impact upon various aspects of one's life. This runs contrary to the biomedical model as the biomedical model only considers the physical dimensions of disease.

Uh, that it encompasses every aspect of my life. It touches everything in my life and it excludes nothing. I thought about that a lot and no matter what I think of, it affects it. I, umm, umm...and that's everything from marriage to job to...just everything...physical fitness, the way you think...uh...uh...everything...just everything you can think of it has affected one way or another and very few for the better I must say.

...for somebody that's trying to deal with the sickness and the financial uh, things and everything, heavy duty, a big problem, a real big problem and then uh, (chuckle) the doc says, well don't worry about that, think only about your health, that instantly makes you angry.

The biomedical model measures success with eradication of the disease. Successful eradication of the disease, completion of treatment and a return to health therefore signal the
conclusion of the illness experience. One participant relayed that this theoretical standpoint or belief was not congruent with his illness experience:

...I think uh, your recovery is uh, uh, painted into a much nicer picture than it is in reality you know, uh, cause the emphasis is on um, you returning back to normal and leading a normal life is quite heavily emphasized and uh, that's something I don't really believe should be done because uh, it isn't quite true. For some people maybe, but for the majority I 'd say not.

Summary

The participants' accounts of their perceptions of leukemia and bone marrow transplantation, describe the illness and the illness experience as much more than a disease marked by hospitalization.

To assist themselves in making sense of the illness all participants searched for the cause(s) of the disease. Searching for answers led them to external sources which allowed the participants freedom from guilt and self blame. The seriousness of the disease was conveyed by the acknowledgment that it is life-threatening. Coupled with this acknowledgment the participants questioned "why" they had succumbed to such a horrid disease.

All participants made the decision to undergo bone marrow transplantation immediately upon it being offered to them. The quick decision making process was fostered by the participants viewing BMT as a means to maintain their life or postpone their death. The complexity inherent within the
treatment was revealed by one participant expressing the dual nature of BMT - that is, it can be a life-saving or a life-threatening procedure.

The participants perceived communication with the professional sector to be very distressing and unhelpful in coping with the illness experience. These descriptions focused around communication with physicians. The participants noted the difficulty and distress they experienced surrounding the issues of information sharing. Lack of concern on behalf of the physician for the psychosocial implications of the illness was also expressed indicating incongruencies between the participants' and the professionals' understanding and meaning of the illness and the illness experience.

Descriptions of support focused on provision of support from family members. This support was seen to be crucial to the coping process. The account of one participant indicated the importance of support being congruent with one's needs and capabilities.

The implications of the illness were described as affecting every facet of one's life. The accounts clearly indicated that the participants perceive leukemia to be a chronic illness rather than an acute disease. Chronicity of the illness was viewed as the most fearful and negative implication of the illness. Although variability in the
extent of the chronicity was expressed, coupled with differences in anticipated length of the chronicity, all participants expressed that they adopted altered definitions of normalcy, and went through a process of re-learning in order to cope with the chronic nature of the illness.

Fear of relapse, and living with uncertainty, was also described as a negative implication of the illness that weighed heavily upon the participants' minds. Hope, denial, and resolve were the strategies mentioned to cope with the uncertainty surrounding the possibility of disease recurrence.

Although the majority of the accounts depict leukemia and BMT to be a negative, stressful experience, all participants expressed that parts of their lives had been enriched by having to consider its ending. Positive implications of the illness experience were noted as being greater self awareness, increased appreciation for others and for life, and recognition of previously misplaced priorities. Turning a negative life event into an opportunity for enhancement of oneself and one's life encouraged the participants to "get on with living" rather than focusing on their illness.

Differences and discrepancies between the participants' explanatory model of health and illness, and the biomedical model of health care held by the professional sector was highlighted in the participants' descriptions of their perception that the concern with the physical aspects of
disease and the corresponding implementation of treatment directed only towards one's physical being was narrow in focus. The perception that the mind and body cannot be considered separate entities which function independent of one another was also expressed. Differences and discrepancies between the explanatory models were also illustrated by the participants' perception that the implications of disease are not only physical in nature and that there is no conclusion to the illness experience.

In Chapter 5 the meanings of the illness experience, which were constructed from the participants' perceptions, are discussed. The meanings are related to other theoretical perspectives and the findings of other authors and researchers.
CHAPTER 5: DISCUSSION OF THE FINDINGS

In this chapter, the findings of the study and the corresponding meanings are discussed. The findings and meanings will be discussed and related to the theoretical perspectives and findings of other authors and researchers. The discussion will illustrate the value of examining the meaning of illness from the perspective of the individual and support the notion that gaining meaning through phenomenological approaches to research is necessary to fully understand how the individual responds to illness and suffering (Benner, 1985; O'Connor et al., 1990). The framework for discussion will follow the themes as they were presented in Chapter 4. A discussion of how the findings indicate there are differences and discrepancies between the professional biomedical model of health care and the explanatory model of health and illness held by the popular sector will be presented.

ETIOLOGY

The Meaning of Causality

In this study the participants' quest of causal attribution led them to external sources. The majority of the participants cited environmental and/or chemical factors as the cause of the disease. One participant chose to subscribe to the germ model of causation which follows the medical model
of infectious disease with his disease being caused by viruses. No indication of an internally based locus of control was revealed in any of the accounts as no evidence of self blame or self responsibility for the onset of disease was mentioned, or even alluded to, by any of the participants. These findings are congruent with a study by Pill and Stott (1982) as greater than 80% of the respondents reported causation of illness to be external to themselves and more or less out of their control.

A person's belief surrounding etiology of illness is an important factor to consider when trying to understand a person's responses to illness and her/his illness behaviors as according to Kelly (1973), people make causal attributions in an effort to understand or make sense of events and experiences and also to exercise some control in relation to what happens in their world. In addition, "a person's readiness to accept responsibility for health, defined as accepting that one may be accountable for falling ill and for maintaining one's health, can be seen as depending partly on his/her view about the etiology of illness" (Pill and Stott, 1982, p. 43). Generally speaking, there are two major concepts regarding illness causation. Both concepts focus on responsibility for illness. Firstly, is the concept and belief that illness is a result of personal choices and the individual is held responsible. Secondly, is the concept or belief that an individual is considered fated and disease is
attributed to chance or coincidence. With the cause of disease being seen as external to the individual, no blame or responsibility can be attached to the individual. In terms of meaning therefore, one can suppose that the participants in this study consider themselves fated. This philosophy, according to Pill and Stott (1983) allows for freedom from self blame, and discourages feelings of responsibility for illness and subsequent guilt.

Beliefs about etiology of disease can be extrapolated to include one's sense of personal control. An exploratory, descriptive study by Lewis (1982) investigated the relationship between experienced personal control and psychological well-being in individuals with cancer. The findings of the study indicated that cancer patients varied in the degree to which they believed their own behavior could affect their situation. Feelings of less anxiety, a greater sense of self-esteem and a greater sense of purpose in life were associated with a heightened sense of personal control relative to those who perceived their situation to be a result of forces beyond their control. Therefore, from a therapeutic standpoint one could view the participants' philosophy that the cause of disease was beyond their control as being positive as it allowed them freedom from self blame and feelings of guilt surrounding their diagnosis. However, one must be cognizant of the long term implications of this philosophy as individuals base their behavior, (i.e. following
treatment programs, making life-style changes etc.), related to an illness on their beliefs about what caused the illness. The finding of this study that the participants perceived the cause of disease to be external to themselves and therefore considered themselves fated, was an expected finding. The majority of patients the researcher has encountered throughout her professional experience with leukemia and BMT have subscribed to similar beliefs and philosophy's. What varies however, is the emotional turmoil an individual experiences during the process of searching for and coming to terms with what they believe caused the disease. Thus, it is imperative that health care professionals gather information regarding beliefs surrounding etiology of disease from patients as part of their on-going assessment such that the patients' beliefs and meanings can be incorporated into the health care plan.

Coupled with the distress associated with causal attribution is the existential question, "why me?" In this study, all participants relayed accounts of pondering "why" they had succumbed to such a horrid disease. This is congruent with Mumma and McCorkle (1983), who suggest that when individuals are confronted with a diagnosis of a serious disease they try to understand why it happened to them. This phenomena was also found to be an experience of cancer patients in a study conducted by Johnson (1980). Johnson reported patients experienced a specific period of time in which "why me?" dominated their thinking. The time period
this question was posed in relation to the trajectory of the illness experience was not specified. In this study, the majority of participants reported questioning "why" upon diagnosis. One participant pondered this question after having gone through the transplant. With the variations in the time during which this questioning occurred, it is feasible to assume that the existential predicament of finding meaning as to why one succumbed to such a disease may be a continual or recurring process. This assumption was not only fostered by the findings of this study, but also by the researcher witnessing many of her patients experiencing this existential predicament. In her professional experience the researcher has found that this existential predicament is not limited to the disease itself. Rather, this existential predicament extends into all facets of the illness experience, culminating in persons asking "why now," "why didn't I respond to treatment," "why am I having a more difficult time than the person down the hall" etc. Weisman and Worden (1976) suggest, and the researcher agrees, that emotional distress is associated with such doubt and questioning. As a factor therefore, which plays a role in shaping the meaning of the illness and the illness experience and which has the potential to cause extreme distress and anxiety, health care professionals must attribute significance to these "existential plights" and assist patients in "making sense" of their diagnosis.
The Meaning of Bone Marrow Transplant

In this study, the bone marrow transplant carried the meaning of hope for maintaining life or postponing death. This finding is congruent with the viewpoint of Andrykowski, Henslee & Farrall (1989), who state, "first and foremost, patients recognize and value bone marrow transplant as a life extending therapy (p.80).

The participants' strong belief that bone marrow transplant symbolized an opportunity to continue life was expressed in what seemed an immediate decision to undergo transplantation upon it being offered to them as a therapeutic option. The participants' quick decision making was an unexpected finding of the study and runs contrary to Haberman (1988) who suggests, "the decision to undergo BMT may be fraught with uncertainty and ambiguity" (p.57). However, the participants' accounts, when taken as a whole, portray the BMT process to be somewhat other than what they expected. In short, the process was much more difficult and stressful than anticipated. This finding was supported by the study by Andrykowski, M., Henslee, P., and Farrall, M. (1991), of twenty three BMT patients ranging from 3 and 52 months post transplant as it was found that 34.8% of respondents reported that their course of transplantation and its sequelae were worse than expected. In this study, one participant's account
clearly supported this by stating in retrospect, that if he knew then what he knew now about the transplant he would require a great deal more time to make the decision about whether or not to proceed with transplant. Therefore, one can conclude that at the time of decision making, the participants, having vague or unclear notions of what to expect of themselves and the BMT protocol, allowed their hopes of maintaining life override other concerns and/or thoughts of treatment impact and implications. This may have resulted in minimizing any feelings of uncertainty and ambiguity. Once a transplant is recommended, many patients will make an immediate decision to proceed. This may reflect adequate adjustment and preparation on the part of the applicant prior to the time of the recommendation. Alternatively, a rapid decision may function defensively to minimize the patient's reflection of an emotionally charged predicament (Soos, 1991). Although few data exist concerning the patient's decision to undergo transplant, candidates commonly report that they made their decision almost instantaneously, well before detailed discussion of the procedure itself (Wolcott et al, 1987). From her professional experience, the researcher proposes that while the decision making process is indeed influenced by the belief that BMT offers the hope for maintaining life as depicted in this study, other factors also play a role in this decision making process. The factors the researcher offers are an individual's sense of self esteem, her/his perceived
capability to survive the transplant, the individual's past experience with disease and health care institutions, and the viewpoints or biases of family members and significant others.

Evidence of trust toward the life maintaining capabilities of BMT was expressed by the participants. All participants chose BMT as the sole method of treatment, and none chose to pursue alternative therapies or utilize alternative remedies as an adjunct to BMT.

The participants spoke minimally of the transplant itself relative to the entire process of treatment and the illness experience. Although the powers of the transplant are recognized, the transplant seems to have been somewhat of an insignificant event when compared to the illness experience in its entirety. Also, the actual transplant may pale in comparison to the strenuous conditioning regime, culminating in what seems an anticlimactic event (Jenkins P., Linington A., Whittaker, J. 1991).

Although all participants looked upon bone marrow transplant as a means to maintaining their life, variations in the themes of meaning of bone marrow transplant and indication for the complexity of the meanings constructed were also illustrated by the participants' accounts. A dual viewpoint of the transplant was expressed by one participant. Although she saw the hope in BMT of maintaining her life, and expressed no difficulty in deciding to undergo a BMT, she also recognized BMT as a risky venture which could lead her to
The realization that treatment complications or treatment failure could result in death, further complicates the life and death issues that are inherent within a treatment which possesses a life-saving dimension and a dimension of risk which could end in death. Another participant communicated that bone marrow transplant posed a moral dilemma for himself. The participant's existential concerns culminated in him questioning if the acceptance of a bone marrow transplant was morally correct. From a "biblical" viewpoint the participant wondered if the bone marrow transplant, and hence medical technology, were playing the role of "God". The impact of this concern for the participant was so great he questioned whether or not he would ever be able to come to terms with it and say, "yeah it's okay to have somebody else's blood and somebody else's bone marrow." Although this dilemma and its corresponding concerns have been reported by other researchers (Christopherson, 1987; Soos, 1991), it was an unexpected finding of this study. The researcher had never encountered an individual who perceived BMT as being a moral dilemma. In addition, although the researcher and the participant had a close relationship, she was unaware of his biblical viewpoints and the impact they had on his illness experience.

The variations in meaning of BMT illustrates the importance of understanding each patient's unique perspective surrounding the treatment and the personal implications that
accepting such treatment holds. Therefore, gaining an understanding of what BMT means to an individual can encourage a better understanding of the individual, foster a clearer understanding of the individual's responses to illness and provide a basis for more effective, patient centered interventions.

The Meaning of Communication with the Professional Sector

In this study, the participants' descriptions of communication with the professional sector was focused solely on communication with physicians. Other health care professionals such as nurses, physiotherapists, dieticians, or social workers were not mentioned by the participants.

The communication with physicians meant loss of personal control as expressed by the participants. This finding is congruent with Gray & Doan, (1990) who note that persons with cancer are likely to encounter a loss of personal control as a result of their illness experience. In this study, a significant loss of personal empowerment and control was associated with the participants' relationships with their physicians. With the power of the physicians being recognized due to their inherent knowledge of the disease and treatment modalities, the participants' lack of empowerment and loss of personal control focused around communication and sharing of information. The participants' accounts revealed that communication between themselves and their physicians was
limited and short of being helpful. Lack of honesty, withholding of information, sharing of limited information and sharing of information with a narrow focus were expressed by the participants. McIntosh (1974) offers an explanation for this phenomenon. McIntosh states, "Doctors may have a general inclination not to convey information to patients as the doctors authority is in part based upon the esoteric nature of her/his knowledge. Therefore, because increased knowledge and perception of her/his work may lay it open to evaluation and criticism, and because increased information allows a patient to assess more adequately what is being done to her/him, doctors may, in general, have predisposition to restrict the information available to patients (p.168). Gray and Doan (1990) state, "information is a potential source of control and information about illness and treatment is necessary if patients are to help define their situation, reflect on it, and act in their own best interest" (p.37).

In this study, the participants clearly expressed a desire for information. This is congruent with the study by Casselith and Zupkis (1980) in which 98% of the cancer patients surveyed indicated a desire to know about all possible side effects of treatment.

The participants' descriptions of their perceptions of the physicians in terms of poor communication and inadequate information sharing emerged spontaneously during the interviews. This perhaps lends credence to the importance of
the need for information sharing and positive communication patterns between the professional sector and the patient population. In addition, it supports the notion that health care communications are seen as important aspects of the cancer experience and play a role in the meaning of the illness experience. This perspective is congruent with Thorne (1988) who suggests that the fear and uncertainty associated with cancer produces intense demands for information and assurance, and therefore, the cancer patient expects special communication with the health care professional.

The participants' descriptions of information seeking reveal the process to have been one of extreme distress. A study by Thorne (1988), suggests that cancer patients perceive communications with health care professionals to be important in enhancing or detracting from the quality of their lives. In this study, the descriptions of the communications with physicians could be classified as unhelpful and be seen as detracting from the participants' quality of life as it led to distress for the participants rather than being found to ease the experience. These findings are supported by the study by Thorne (1988) as 61.3% of the respondents reported communication with physicians to be unhelpful. The communication instances patients related included withholding of information. Studies by Messerli et al, (1980), and Strull et al, (1984), reveal that many patients experience difficulty in obtaining the information they need from health
professionals and in achieving meaningful participation in treatment decisions. A study of surgeons' attitudes towards breast cancer patients by Messerli et al (1980) revealed that only 60% reported usually/sometimes consulting a patient regarding treatment decisions. A mere 10% saw consultation with the patient as a key aspect of their therapeutic role.

One can surmise that lack of positive, helpful communication is the result of patients' unrealistic expectations of the health care professional's ability to alleviate distress. The impact of the disease and treatment may in turn exacerbate these unrealistic expectations.

The participants' accounts revealed a feeling of lack of concern and understanding for the psychosocial implications of the illness on behalf of the physicians. This feeling was perhaps perpetuated by the physicians' lack of communication regarding issues other than the physical aspects of the disease as described by the participants. This is congruent with Kleinman, Eisenberg & Good's (1978) viewpoint that, "for physicians, illness problems are often disregarded as they look upon the disease as the disorder" (p.252). Correspondingly, Thorne (1988) found that in only 37.3% of instances did patients perceive that health care professionals expressed concern for the patient, and 92.5% of the unhelpful instances were associated with a communication style characterized by lack of concern. Thorne (1988) offers an explanation for the difficulties experienced surrounding
communication in cancer care. She suggests patients and practitioners may not interpret the meaning of "communications" in the same way. For example, cancer patients often misinterpret the intentions of health care professionals in such basic communications as information giving and the expression of caring. Thus without understanding the nature of communication dynamics in cancer, merely increasing the quantity of communication is unlikely to rectify the problem (Thorne, 1988). In this study, perhaps the physicians whom the participants encountered view their role as one which adheres to the medical model of health care whereby physicians merely treat the medical or physical aspects of disease. The researcher's experience supports this and suggests that reliance is often placed on other health care professionals such as social workers and nurses to communicate information regarding the psychosocial aspects of illness. In addition, these other health care professionals are often seen by the physicians as more skilled and appropriate for the conveying of empathy and understanding.

The researcher was somewhat intrigued that physicians were the only health care professionals mentioned by the participants. The researcher proposes, on the basis of her experience, that the interviews allowed the participants a safe opportunity to express their personal viewpoints and feelings towards their physicians. The interviews may have also provided an opportunity and an outlet for the expression
of anger. Within her experience the researcher has witnessed patients not conveying their negative feelings and concerns regarding the manner in which the physician conducts and directs their care. The researcher's experience dictates this "silence" is due largely to patients' fear that their care may be jeopardized. In addition, the participants' focus on physicians and exclusion of the role of other health care professionals in their care and treatment points to the significance and power of the role of the physician in directing patient care.

The Meaning of Support

In this study it was found that the presence of social support eased the stress of living with a life threatening illness. This finding is supported by various researchers. Maxwell (1982) states, "social support may act as a buffer to mediate the negative effects of illness" (p.275). Cassel, J. (1976), Cobb, S. (1976), and Dean, A. (1977) suggest that the presence of supportive relationships benefit persons faced with stressful life circumstances, such as serious illness, by protecting them from potential declines in their physical and emotional well-being. Lichter (1987), mentions social support as an important factor in helping the patient adjust to her/his problems and to cope with the stresses imposed by the illness. Caplan (1974) describes social support systems as consisting of "people who can be relied upon to promote mastery, offer guidance, and provide feedback and validation
about the individual's stressful experiences and coping choices" (p. 321 in Revenson et al, 1983). Other definitions emphasize the message received from others that one is valued, loved, and part of a meaningful network (Cassel and Cobb, 1976).

Understanding the meaning that support held for the participants can be achieved by examining the functions that it served. The participants focused on the support provided to them by spouses and family members and did not mention the presence of, or effects of external support systems. The significance of family support on the coping process was conveyed by the participants by comparison of themselves to others whom they deemed lacked a sufficient amount of support.

Dean and Lin (1977) distinguish two types of support; expressive support which is affect-laden, and instrumental support which is related to provision of goods and services. The support, as described by the participants, could be characterized as expressive support, and the meaning the support held, and the functions it served, could be portrayed by utilizing Weiss's (1969) categories of support functions. Weiss (1969), identified five categories of support functions: intimacy which counteracts the sense of emotional isolation or loneliness; social integration which involves the sharing of mutual concerns; opportunity for nurturant behavior which provides a sense of purpose; reassurance of worth which increases self esteem; and assistance in assuring the
availability of resources such that vulnerability and anxiety are decreased.

Although all participants described support as being beneficial, the function of the support varied. Therefore, the meaning of support differed for each participant. Support was expressed by the participants in terms of provision of intimacy, social integration, and opportunity for nurturant behavior. Two participants noted the mere presence of their spouse as being incredibly supportive. This could be likened to the function of intimacy as defined by Weiss as it prevented feelings of emotional isolation and loneliness. Another participant conveyed open, honest communication with family members as a means of support. Congruent with Weiss's category of social integration, the sharing of mutual concerns implied support. Two of the participants expressed that the significance of support was so great it "kept them going" and "saved them" from death. The function of support for these individuals could therefore be interpreted as meaning "the will to carry on". Providing a sense of purpose, this support took on the form of opportunity for nurturant behavior as described by Weiss. An epidemiological study by Beckman and Syme (1979) supports this finding as it was revealed that people who lacked social and community ties were more likely to die during a seven year period than those with more extensive contacts. Variations in the type of support perceived to be beneficial, and in the meaning of support to
the participants, can be explained by the fact that all participants were at different points within the rehabilitation/discharge stage of the illness experience. Although all participants were post transplant and had been discharged from hospital for at least four weeks at the time of the interviews, and were in the final stage of the illness trajectory, their illness trajectories differed due to variations in times since diagnosis, time since transplant and time since discharge. This indicates the importance of regarding the provision of support as a dynamic, rather than static variable. Under various kinds of stresses and strains, as the illness progresses, support needs and supplies will change (Maxwell, 1982). With support being seen as a dynamic concept, one must be cognizant of the presence of and stages of the illness experience which comprise the illness trajectory. Germain (1984, p.38) illustrates stages of the illness experience as developed by Coe (1978). The stages Coe depicts are: Stage I: symptom experience (something is wrong); Stage II: assumption of the sick role (relinquishing of normal roles); Stage III: medical care contact (seeking professional help); Stage IV: dependent - patient role (accepting professional treatment); and Stage IV: recovery and rehabilitation (relinquishing of sick role or entry into chronic sick role). The researcher extrapolated upon stages III, IV, and V to equate them with the point of diagnosis, BMT and period of hospitalization, and point of discharge
respectively. Point of discharge, rather than point of completion of the actual BMT was equated with the recovery and rehabilitation stage as active medical treatment post transplant is often required for transplant related complications. While all participants had been discharged from hospital, and were therefore in the recovery/rehabilitation/discharge stage of the illness experience, the illness trajectory for each participant varied in terms of time between each stage and amount of time spent within each stage. The researcher proposes that the amount of time spent within, and between each stage, impacts upon the opportunity for resolution of the psychosocial tasks which are presented at each stage and therefore effect one's support requirements. It is important to note that while the trajectory for the treatment of leukemia follows a linear path, the trajectory of the illness experience is a dynamic, non-linear process.
**Figure 2.**

Representation of each participant's unique illness trajectory illustrating differences in time between, and within the stages of the illness experience.

Time is expressed in number of weeks.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Symptom experience</td>
</tr>
<tr>
<td>II</td>
<td>Assumption of sick role/relinquishing of normal roles</td>
</tr>
<tr>
<td>III</td>
<td>Medical care contact/diagnosis</td>
</tr>
<tr>
<td>IV</td>
<td>Dependent patient-role/BMT and hospitalization</td>
</tr>
<tr>
<td>V</td>
<td>Recovery and rehabilitation/discharge</td>
</tr>
</tbody>
</table>

**Participant One:**

Stage I-----Stage II-----Stage III-----Stage IV-----Stage V
[--------------12wks----------------][20wks][---18wks--][7wks--]

**Participant Two:**

Stage I-----Stage II-----Stage III-----Stage IV-----Stage V
[--------------20wks----------------][12wks][---7wks---][46wks--]

**Participant Three:**

Stage I-----Stage II-----Stage III-----Stage IV-----Stage V
[--------------8wks----------------][28wks][---4wks---][4wks--]

**Participant Four:**

Stage I-----Stage II-----Stage III-----Stage IV-----Stage V
[--------------58wks----------------][52wks][---12wks--][13wks--]
In addition to utilizing the illness trajectory, variations in the meaning of support and how it is perceived as beneficial, can be understood by recognizing the uniqueness of all individuals in terms of personality factors, past history with stressful experiences and interactional skills. Social network theory holds that people are in some way linked or joined by ties of affect, trust, right and obligation, and that these social ties exert an influence on the behavior and cognition of the participants (Coombs, 1973).

Cohen (1983) suggests support can only function as an effective buffer in coping with illness if there is a match between the interpersonal relationships and the type of support that is needed. Attempts to provide social support may sometimes be counter-productive (Silver and Wortman, 1980; DiMatteo, and Hays, 1981). Some attempts at support may threaten the patient's freedom to make his own decisions, or interfere with the development of coping mechanisms (Maxwell, 1982). Evidence for this premise was found in this study with one of the participants describing the importance of fit between what a family member saw as supportive and helpful in the provision of encouragement, and what his physical capabilities were. Fruend and Siegal (1986) offer an explanation for this by suggesting that family members "as part of their need to view the patient as cured, encourage the patient prematurely to take up activities (p.250). The researcher supports this explanation as she has observed
family members attempting to hasten one's recovery in an attempt to bring their own experience with the illness to a conclusion. The researcher offers, through her experience, that the family members' need to conclude the illness experience prematurely is fostered by feelings of helplessness, fear and loss of control.

The findings of this study indicate people may have different sensitivities to social support at different stages. Later in illness, social support may become more easily perceived than when one is functioning at near-normal levels. Maxwell (1982) suggests that initially more affective-expressive (affect-laden) support may be needed, whereas later on as the individual becomes more debilitated, instrumental (related to goods and services) support will be important.

The findings of the study concerning the meaning of support suggest that the focus of support must be according to individual needs and concerns. The findings also illustrate that health care professionals must be cognizant of where an individual is at in the illness trajectory as support is a dynamic, rather than static concept. Finally, research is required to explore, determine and examine what the support needs are at various points of the illness experience.
The findings of this study suggest that leukemia is a chronic illness rather than an acute disease. The participants' accounts reveal the implications of their illness are far reaching and the process of surviving a life threatening illness will continue throughout their lives. The participants' view that the experience of having leukemia is a permanent one, without a conclusion, is supported in the literature. Mages and Mendelsohn (1979) note that people with cancer are confronted with a continuing series of stressors rather than with a single, time limited crisis.

Chronicity of illness is often discussed in terms of survivorship. Gambosi, J.R., & Ulreich, S., (1990) discuss that cancer survival is an ongoing process that begins the day of diagnosis.

The participants, having acknowledged the chronicity of their illness, also recognized that life would never again be "normal" as they knew it to be prior to diagnosis. The participants adopted altered definitions of normalcy such that new meaning in their life could be found. Altered definitions of normalcy are widely discussed in the literature supporting the findings of this study. Belec (1992) in a study of post bone marrow transplant patients found that respondents doubted
that their lives ever would be the "normal" that they knew before the transplant as their experiences had changed them. Kelly (1978) theorizes that life with cancer can never be normal again. Major life style adjustments, and an altered definition of normalcy were found by Johnson (1980) in his descriptive study of chemotherapy patients. Life adjustments in his subjects were discussed "as if previous identities no longer mattered" (p.33). Adopting an altered definition of normalcy could be viewed as a method for the participants to cope with the chronic nature of their illness. Lewis (1982) conducted an exploratory descriptive study into the relationship between experienced personal control and the psychological well-being of individuals with cancer. She found that cancer patients varied in the degree to which they believed that their own behavior could affect their situation. She also observed that those who did experience a sense of personal control tended to feel less anxiety, a greater sense of self esteem, and a greater sense of purpose in life than those who perceived their situations to be a result of forces beyond their control. Therefore, the participants' adoption of an altered definition of normalcy as a mechanism utilized to cope with the chronicity of the illness, may be a measure of experienced personal control. This sense of personal control is apparent in the degree of normalcy the participants have been able to achieve in their lives, albeit different from the pre-morbid state. The participants' beliefs are
substantiated in the literature. Feldman (1974), notes, the intrusion of a significant illness, especially of a chronic and disabling nature, is a major life crisis posing a formidable challenge to what was previously a workable adaptation to life, and with little possibility of a complete return to the pre-morbid state the crisis is ongoing. The stricken one must accept that life is irrevocably different and because of that difference a new meaning and way of life must be found (p.287). Dow (1990) states, "getting well does not mean getting back to normal, because lives can be radically changed by cancer" (p. 512). Therefore, return to normalcy does not mean a return to the same place, but re-entry into a different place after treatment. The participants noted various aspects of their life they had adjusted to better fit their newly achieved sense of normalcy with parenting, employment abilities, and physical capabilities being a few of the areas of life in which they had to "re-enter" from a new vantage point.

In terms of personal control it is interesting to note that the findings of this study illustrated that while the participants felt the cause of disease to be external to themselves, and therefore possessing an external locus of control, the participants expressed an internal locus of control in terms of coping with the illness experience. This internal locus of control was symbolized in the participants' endeavors to achieve, adapt to and accept an altered
definition of normalcy. Various explanations could be offered to assist one in understanding this shift in thinking.

Firstly, according to Young (1991), reality-oriented adaptation and mastery require that we alter the threats we can alter and accept the things we can not control (p.77). The participants were able to adhere to this philosophy by making a clear distinction between the disease and the illness experience. While attributing disease causation to external sources and therefore considering themselves fated, the participants accepted the diagnosis as an event which they could not control. Considering the illness experience as being distinct or separate from the diagnosis enabled the participants to exercise self responsibility and control as it was seen as an event which they could alter and have some personal effect over.

Secondly, according to Mumma & McCorkle (1983), different diseases carry with them varying degrees of implied responsibility. For example, certain diseases such as heart attacks have associated risk factors and presumably avoiding these risk factors will have some effect on a person's chance of developing such disease. To date, medical research has been unable to determine causes or risk factors associated with the onset of leukemia. This lack of knowledge permits an escape from any feelings of self responsibility for onset of disease and therefore, encourages persons diagnosed with leukemia to attribute disease causation to external sources.
This perhaps is much preferred over taking self responsibility for disease and threatening one's concept of themselves and who they are.

Thirdly, according to Wilber (1988) there are four levels of disease: physical, emotional, mental and spiritual. Perhaps the participants perceived the disease to be purely physical. Evidence to support this was their quick decision making process to undergo BMT - a physical treatment. The illness experience however, being distinct and separate from the disease, may have been viewed by the participants as being on an emotional, mental or spiritual level. Such beliefs, emanating from an internal locus of control, would therefore allow the participants to base their illness behavior on beliefs and attitudes other than those which were operating from an external locus of control when searching for answers as to causal attribution of disease.

Fourthly, Pill & Stott (1982) note there is a fundamental distinction between self as source of health and other as bringer of disease. In keeping with this premise, one could surmise that while the participants perceived they had no control over disease causation they did perceive themselves to have personal control and self responsibility in behaviors which they believed would promote wellness within the realm of their illness experience. Although the participants may have subscribed to all four of the above explanations in varying degrees of intensity and
conviction, the researcher proposes that the primary operating factor in the participants' shift in thinking was the distinction between themselves as source of health and bringer of disease. The researcher offers this proposal based on her perception that all the participants exhibited a great sense of self esteem, confidence and integrity throughout the illness experience. The participants clearly believed in themselves and their capability to survive the disease, therefore enabling them to view themselves as a source of health.

Although all participants relayed the viewpoint that the illness possessed the element of chronicity, the time period for which this "chronicity" or loss of normalcy would last, varied. While two participants saw the illness as lasting their lifetime, and expressed no hope for a return to normal as they once knew it, one participant imposed a one year time period to his chronic state. It is important to note the two participants who shared the feeling that their illness would last a lifetime were a greater number of months post transplant than the participant who felt a return to normalcy would be achieved within one year. Perhaps this participant had insufficient time to allow for an appraisal and assessment of the long term implications of his illness. Feldman (1973), in discussing coping with chronic illness notes that a general denial of the frightening implications for the future seem to be the first response. With the passage of time this denial
is relinquished and mourning the loss of the pre-morbid self and one's potential is experienced. Upon completion of these tasks, reality can be approached. Dow (1990), notes that the meaning and impact of chronic effects may not emerge until well after the treatment episode.

Coupled with the chronic nature of the illness and an altered definition of normalcy, came a period of re-learning as described by the participants. This element of re-learning can be likened to the process of rehabilitation by which "individuals, within their environments, are assisted to achieve optimal functioning within the limits imposed by cancer" (Wells, 1990 p. 504). The findings of this study which indicate a need for re-learning and rehabilitation as described by the participants, further supports the premise that leukemia is a chronic illness rather than an acute disease. Furthermore, it illustrates that the biomedical model of healthcare, with its limited focus on the physical aspects of disease and disease entities, is insufficient and does not allow for provision of care which is congruent with the patients needs.

The Meaning of the Possibility of Disease Recurrence

In this study, living with a life threatening illness, although in remission at the present time, carried a meaning of uncertainty for the participants. This element of uncertainty was manifest in the possibility of relapse or
recurrence of the disease as described by the participants. Gray and Doan (1990) note, "the possibility of disease recurrence often extends survivor uncertainty and helplessness indefinitely following completion of successful treatment" (p.34). In this study, the factor of uncertainty associated with possibility of relapse weighed heavily upon the participants, and expanded into meanings of powerlessness and hopelessness. Powerlessness was described by one participant who felt, should the disease relapse, he would be unable to overcome the disease a second time as he felt he would be incapable of having to go through a second BMT. Hopelessness was expressed by another participant in terms of relapse meaning imminent death.

In this study, recurrence of the disease was noted by the majority of participants to be the most fearful aspect of the illness. Several studies support this finding and identify fear of recurrence as a major theme in the process of surviving a life threatening illness (Welch-McCaffrey, D., Hoffman S. et al 1989; Carpenter, P., Morrow, G., Schmale, A., 1989). Northouse (1981) found that women with breast cancer had heightened fears about cancer recurrence at the end of treatment even though there was no medical evidence of disease. However, a study conducted by two teams of researchers - one at the Fred Hutchinson Cancer Research Center, and a second one at the City of Hope Medical Center (1993), on 125 long term BMT survivors, found only 14% of
respondents cited the fear of relapse as being one of the long term psychological stresses of transplant. While most survivors interviewed said they worry occasionally about relapse, they also said it is less of a problem as time goes by (p.2). It is important to note the respondents ranged from 6 to 18 1/2 years post transplant. While the discrepancies in findings between this study, and the above study could be explained by the element of time, one could also utilize Mullan's (1985) concept of "enduring seasons of survival." Dow (1990), discusses Mullan's (1985) concept of "enduring seasons of survival" to assist one in gaining a perspective on surviving cancer. The three seasons identified by Mullan are: diagnosis of disease where the season is defined and dominated by cancer treatment; extended survival where patients enter a phase of watchful waiting that is eclipsed by fear of disease recurrence; and permanent survival where the likelihood of recurrence is so small that the disease is considered to be permanently arrested (Dow, 1990, p. 512). With the participants of this study no longer receiving active cancer treatment, yet not long enough post transplant to be likened to the season of permanent survival, one could place them in the middle season of extended survival. Correspondingly, the respondents of the study conducted by the above mentioned research centers would most appropriately fit into the final season of permanent survival.

For the participants of this study, coping with the
possibility of relapse meant adherence to the concept of hope, exercising of denial, and surrendering to the resolution of helplessness. Ersek (1990), describes how adults undergoing BMT maintain hope. In her description she identifies three core concepts; "dealing with it," "keeping it in its place," and the "dialectic of maintaining hope." "Dealing with it" refers to the recipients' efforts to confront and experience the negative possibilities posed by their situation, "keeping it in its place" connotes that the recipients controlled what, when, and how they approached the negative possibilities, and the "dialectic of maintaining hope", represents the dynamic, interactive and interdependent relationship between the concepts of dealing with it and keeping it in place. This last concept allows for the sustainment of hope while facing a life-threatening illness. The participants of this study exercised all of Ersek's concepts at various points of their illness experience.

Uncertainty seems the hardest experience of all for the psyche to bear (Stedeford, 1984). Once a person knows what is likely to happen he can adapt or plan accordingly, but if he does not know what action is appropriate he can do nothing, and remains helplessly paralysed or distressed and agitated. The anxiety of dealing with the unknown can be far more upsetting than the distress of dealing with a known, albeit painful truth (Lichter and Davidson, 1981).

The finding of this study that the possibility of disease
recurrence weighs heavily upon the minds of those facing a life threatening illness even though the treatment has been considered a "success," further amplifies the need for attention to be paid to the meanings and perceptions that one attributes to their illness. With the awareness that possibility of relapse connotes uncertainty, measures can be taken to assist the patient in balancing hope and fear such that feelings of uncertainty do not serve to overwhelm the patient. In addition, aspects of the illness upon which the patient can exert control can be emphasized as, uncertainty as a stressor is based on the belief that understanding, predicting, and controlling events is desirable (Brown & Powell-Cope, 1991; Mishel, 1990).

POSITIVE ASPECTS OF THE ILLNESS EXPERIENCE

Illness Meaning Opportunity for Enrichment of Life

In this study, the participants noted positive implications of their illness in terms of greater self awareness, increased appreciation for others and for life, and recognition of previously misplaced priorities. These changes in one's outlook on life, after having experienced a life threatening disease, have been previously reported by BMT survivors. A study conducted by Haberman (1990) on the quality of life of BMT survivors reports that all 12 participants felt the experience in some way improved their
life. The majority of participants in the study by Haberman also said the BMT experience helped them get their priorities straight, and prompted them to live each day to the fullest, rather than put things off for the future. Belec (1992), in studying the quality of life and perceptions of long term survivors of BMT found the impact of BMT had been positive. For approximately 90% of the subjects, the transplant experience led to a reassessment of their priorities and values. Subjects expressed that they were leading fuller, more meaningful lives and had developed a greater appreciation for life. Others expressed that they had become better people - less selfish, more understanding and accepting of others, and more patient. Participants in this study articulated corresponding shifts in self and life outlook. All of the subjects in the above mentioned studies were at least one year post transplant. Whereas, the participants in this study were one and one half to approximately 12 months post transplant one can conclude that a shift in life outlook, and change in perception of self and others, along with recognition of previously misplaced priorities occurs upon completion of the transplant phase with the BMT serving as a climax or crisis point.

The majority of the participant's in this study revealed a heightened valuing of life with the awareness of mortality. Several theorists report awareness of this potential for enrichment in life threatening illness (MacDonald, 1979;
Ehlke, 1978; Rosenbaum, 1975). Cancer tends to generate a search for meaning among those touched by the illness which involves a restructuring and revaluing of attitudes towards self, life, and others (O'Connor et al., 1990; Spiegel & Yalom, 1978). Rapoport (1965), and Parad and Caplan (1964) also note that a crisis presents an opportunity for personal growth. Hamburg (1974), who studied the parents of children with leukemia, noted that persons recovering from crisis reported resolution that included positive changes. Shanfield (1980) described the experiences of 20 individuals with diverse cancer diagnoses. Survivors endeavoured to find meaning in their suffering and in doing so, found that their priorities in life became more focused and they developed an enhanced appreciation for life.

Some of the participants in this study adopted an opportunistic view of their illness and reported a process of self growth and introspection, coupled with a desire to get on with living. Loescher et al (1990), in a study of 17 long term survivors of cancer, report the survivors as growing from the difficult cancer experience and as having a desire to move forward and "get on with living." The finding of this study that participants believed there is a time to stop focusing on the illness and to begin focusing on life, points to the importance of health care professionals in recognizing when frank and open communication about the disease is no longer helpful or necessary. Correspondingly, it may assist health
care professionals in understanding patients whom they label as "non-communicative."

The theory of mastery can be utilized to explain how a life threatening illness can be viewed as an opportunity for self growth and enhancement of life. "The goal of the theory of mastery is to explain how individuals who experience illness or other stressful health conditions and enter into a state of stress may emerge, not demoralized and vulnerable, but healthy and possibly stronger. In the theory of mastery, illness is viewed as a special case of stress" (Younger, J., 1991, p. 77). Mastery is, "a human response to difficult or stressful circumstances in which competency, control, and dominion are gained over the experience of stress" (Younger J., 1991, p. 81). Mastery implies having developed new capabilities, having changed the environment, and/or reorganized the self so that there is meaning and purpose in living that transcends the difficulty of the experience (Taylor, 1983).

One could also employ Mishel's (1990) reconceptualization of uncertainty in illness wherein chaos theory is incorporated to explain how opportunity is derived from uncertainty. Accordingly, when uncertainty disrupts the meaning of everyday events, the individual, compelled by a need to structure meaning, gradually reframes their evaluation of uncertainty as a negative occurrence into one that recognizes opportunity (Kerzner, 1992). Therefore, "catastrophic illness is seen as
an event which has the potential to stimulate the individual toward a new, higher order, more complex orientation toward life" (Mishel, 1990, p.260).

Fostering an opportunistic view of illness, if congruent with the individual's explanatory model, can be supported by health care professionals. Support groups could be developed which focus on turning the illness experience into an opportunity for self growth, and educational programs could be implemented to provide knowledge and counselling around the process of re-framing.

How the Findings Indicate Differences and Discrepancies Between the Professional Biomedical Model of Healthcare and the Popular Explanatory Model of Health and Illness

The participants' accounts, in their entirety, suggest that their experience with leukemia and BMT was something other than an acute physical disease marked by hospitalization and treatment. With the participants perceiving leukemia as a chronic illness with everlasting implications, one can begin to see the discrepancies and differences between the professional biomedical model of healthcare and the explanatory model of health and illness held by the popular sector. Perhaps if one were to view leukemia as an acute disease, the biomedical model may be an appropriate and productive approach to care. However, acute diseases are
characterized by complete recovery, total resumption of prior activities and absence of psychosocial implications. The participants' accounts clearly run contrary to this.

Within the biomedical model, the mind and body are considered separate entities with the mind being a secondary factor in organic illness. Viewing leukemia as a disease entity separate from the whole of the person disallows the person to possess a sense of control over the disease itself, the treatment plan and the corresponding illness experience. This lack of control fosters vulnerability within the person forcing her/him to take on a passive role towards the disease and the illness experience, and disregards any degree of personal healing power one may possess. While the participants in this study did concur with the biomedical model in terms of disease causation being external to themselves and therefore out of their personal control, the participants expressed a form of personal healing power. Adopting an internal locus of control regarding the illness experience symbolized this personal healing power and was expressed in the participants' endeavour's to achieve, and adapt to altered definitions of normalcy as a way of coping with the illness.

The biomedical model views health as being the absence of disease, and disease as being disarrangement of the body. Successful treatment is therefore equated with eradication of the disease. All of the participants in this study were in
remission from disease at the time of the interviews. According to the biomedical model, the treatment would therefore be considered a success, the participants would be deemed healthy and the illness experience completed. While hope was expressed by the participants that the BMT was successful, the uncertainty and fear associated with the possibility of relapse lends a time limit to this success. Within the accounts no participant conveyed the belief that since they were in remission they had resumed the level of health they had prior to diagnosis. Contrary to the biomedical model, the completion of treatment did not signal to the participants the completion of the illness experience. The participants' accounts reveal that they believe their illness experience does not have an endpoint and will therefore continue throughout their lives. This belief was acknowledged by the participants recognizing the chronic implications of disease.

The biomedical model is concerned with disease entities and physical states and fails to regard the psychosocial implications inherent within disease and the corresponding impact upon one's life. The participants' accounts clearly indicate that the implications of leukemia and BMT were not limited to their physical being. The participants expressed this belief in their description of how their lives had been altered and were now "different" due to changes in lifestyle, personal expectations, relationships, roles and priorities.
The biomedical model is individualistic in nature and treatment is focused on the patient only. This may in turn result in isolation of the patient from their support system. The participants' descriptions of their illness experience indicate that such an individualistic focus is inadequate. This belief was expressed in the importance the participants placed upon the significance of the support role played by family members in helping them survive and cope with the disease and corresponding psychosocial implications.

Finally, within the biomedical model the patient is viewed as dependent and passive. The participants' accounts suggest they weren't comfortable playing a passive role in their treatment. This was expressed in the participants' descriptions of the difficulty and distress they experienced in attempting to acquire information from health care professionals such that they could fully define their situation, reflect on it and act in their own best interests.

Summary

This chapter presented a discussion of the findings of the study as they relate to other theoretical perspectives and findings of other authors and researchers. A summary of the research project, conclusions, recommendations for social work practice, and recommendations for social work research which arise from the discussion of the findings will be presented in Chapter 6. Personal comments of the researcher will also be presented.
CHAPTER 6: CONCLUSIONS and RECOMMENDATIONS

Conclusions

A conclusion of this study is that persons faced with leukemia perceive the cause of the disease to be beyond their control. With external factors of causation being cited, coupled with the perception that cause of disease is external to oneself, and the subscription to the philosophy that one is fated, means freedom from guilt and self responsibility for onset of disease.

This study concluded that BMT has various meanings. While the common perception of BMT as a life-saving or death-postponing treatment was expressed, the study also illustrated the complexity of the meanings inherent within a treatment which has life-saving and life-threatening capabilities. The various meanings of BMT extended to include existential concerns and the personal dilemma as to the whether or not the acceptance of a BMT is "morally correct." The acceptance of a BMT also connoted "risk-taking" with the acknowledgement that BMT could hasten one's death.

The findings of the study indicate that differences and discrepancies exist between the professional biomedical model of health care and the popular sector's explanatory model of health and illness. These differences and discrepancies were highlighted in the disparate viewpoints on the focus of treatment, what treatment should encompass, the disease
implications and the chronic nature of the illness experience. Further evidence to indicate that differences and discrepancies between the professional biomedical model of health care and the popular explanatory model of health and illness exist was illustrated in the participants' descriptions of communication with the professional sector. The descriptions focused around communication with the physicians. The participants perceived a lack of concern and understanding for the psychosocial implications of illness on behalf of the physicians. These differences and discrepancies took the meaning of dis-empowerment and loss of personal control. The findings conclude therefore, that the biomedical model is an inadequate approach to health care.

In this study, support from family members was perceived to facilitate the coping process and ease the stress of living with a life-threatening illness. The meanings of support varied from provision of intimacy, opportunity for social integration and provision of nurturant behavior. The study also illustrated that for support to hold positive meaning for the individual the provision of support must be congruent with the individual's needs.

The study concluded that leukemia is perceived as a chronic illness rather than an acute disease by those who are suffering the illness. Acceptance of, and coping with chronicity meant adopting an altered definition of normalcy and going through a process of re-learning. The chronic
nature of the disease means that life is irrevocably different and that new meaning in life must be found.

The study found that living with a life-threatening illness, although "successfully treated", took the meaning of uncertainty. This element of uncertainty expanded into meanings of powerlessness, hopelessness and fear. It was perceived that adherence to the concept of hope, exercising of denial, and surrendering to helplessness assisted one in making sense of the uncertainty and coping with it.

A final conclusion of the study was that the participants perceived their situation of living with a life-threatening illness to be one of opportunity for personal growth and enrichment of their lives. This was the only aspect of the illness experience that took on positive meaning for the participants.

**Recommendations for Social Work Practice**

The findings of this study suggest that for social work in health care to be effective one must explore and incorporate the client's explanatory model of health and illness into all therapeutic interventions. Correspondingly, social worker's must make a conscious effort to explore their own explanatory model of health and illness. This personal exploration will allow for not only an understanding of one's own viewpoints concerning health and illness, but also allow for differences and discrepancies between one's model and that
of the client to become apparent, minimizing any misunderstandings which may negatively affect the client's illness experience.

The study revealed that the biomedical approach to the provision of health care is narrow in focus and fails to consider the values, ideas and perceptions of the patient. What results is not only an inadequate provision of care, but also a provision of care which fails to foster the inherent dignity and uniqueness of all individuals. Furthermore, adherence to the biomedical model, with lack of consideration for the patient's explanatory model of health and illness falls short of conveying respect for the patient.

As an integral member of the health care team, social workers can implement steps within their practice to expand the provision of care beyond treatment of the disease. Social workers can begin by playing the role of educator, providing other health care professionals with knowledge pertaining to the importance of eliciting and understanding patients' explanatory models of health and illness. Such an understanding will illustrate the importance of incorporating patients' beliefs, values and perceptions into the health care plan. In addition, an enhanced understanding of the patient will provide the health care team with a basis upon which more patient centered care can be provided. Furthermore, eliciting and understanding the meaning leukemia and bone marrow transplantation hold for the patient, places the patient's
responses to illness in context. This in turn, presents the opportunity for the health care worker to better understand patient behaviors and responses to treatment. Social workers can extend their educational role to health care team members to include teaching in the area of chronic aspects of leukemia and the psychosocial implications of living with a life-threatening illness. Imparting of this knowledge would permit collaboration of the biomedical perspective with the psychosocial perspective of the importance and significance of the illness experience.

With the study establishing that the illness experience is not limited to the hospitalization period, but rather begins with diagnosis and extends well into the post-discharge phase, social workers can initiate the development of support groups, educational programs and rehabilitation programs geared towards the patients' needs and concerns that arise during the various phases of the illness experience. When developing and implementing such groups and programs, one must be cognizant of the notion that support is a dynamic rather than static concept. In keeping with this premise one needs to be aware that support needs may change during the various phases of the illness trajectory. One must also take into account that the function of support differs for individuals according to their past experiences, their personality, and their perspectives on health and illness. Therefore, support must be tailored according to individual needs and concerns.
Programs and groups aimed at Stage III (medical care contact/diagnosis) of the illness trajectory could focus on beliefs about etiology of illness. With beliefs of disease causation influencing one's behavior towards illness and treatment, and impacting upon one's sense of personal control, such exploration and discussion may assist the patient in making sense of her/his disease and provide the opportunity for the health care team and the patient to develop a care plan which is congruent with the patient's beliefs, values and needs. In addition, the researcher proposes it would be beneficial for the social worker to meet with the patient and family at Stage III of the illness trajectory. The researcher suggests that social workers be included in the initial meeting of the physician and patient in which the disease and medical treatment is explained and discussed. This would provide the opportunity for the social worker to assess the patient and his/her family's understanding of BMT and its corresponding implications. In addition it would allow for the inclusion of the psychosocial aspects of illness.

The findings of the study suggest that it may be beneficial to the patient, and help ease the stress of the hospitalization phase, if therapeutic interventions were directed towards enhancing communication between the patient and the health care professional. In this sense, social workers can play the role of advocate for the patient, ensuring that steps are taken to address communication issues
and concerns and reinforce to the health care team the importance and significance of positive communication in easing the stress of the illness experience. This advocacy role could be initiated at Stage III (medical care contact/diagnosis) of the illness trajectory and continue throughout the illness experience.

Rehabilitation, or post discharge support groups could be established to assist the patient in making the adjustment from hospital to home and the adjustment of living life with a life-threatening illness. Support and education surrounding the chronic implications of the illness could be provided to enable the patient to find new meaning in life and find new ways to achieve personal fulfilment and satisfaction. Rehabilitation programs could begin during the latter part of Stage IV (Dependent patient role/hospitalization) of the illness trajectory. The researcher proposes this would assist patients in better preparing themselves for discharge from hospital such that the adjustment to living life with a life threatening illness may be eased somewhat. Post discharge support groups aimed at Stage V (Recovery and rehabilitation/discharge) of the illness trajectory would provide the opportunity for the continuation of emotional support and follow-up.

Finally, the findings of this study suggest that it is a mistake for health care professionals to make the assumption that all implications of the disease and the illness
experience are negative. The incorporation of the theory of mastery into one's practice and the utilization of the therapeutic technique of re-framing can assist and encourage the adoption of an opportunistic view of illness.

Recommendations for Social Work Research

Conducting this study pointed to the need for further research regarding the personal meanings and perceptions of the illness experience. The researcher encourages health care social workers to participate in, or conduct such studies, as very few studies were found which were performed by social work professionals. While studies such as this one could be replicated to provide a more in-depth understanding of the personal meanings and perceptions of the illness experience and provide a further illustration of how the professional and popular explanatory models of health and illness differ, the findings of the study suggest further research needs to be conducted concerning specific facets of the illness experience.

While this study was targeted towards persons who were in the post-discharge phase of the illness experience, future studies could be targeted towards the pre-BMT period and the hospitalization period. Gaining an understanding of the personal meanings and perceptions prior to BMT and during the hospitalization phase may allow for health care professionals to better prepare understand persons' responses to illness and
their illness behaviors.

Utilizing the philosophy underlying the theory of mastery as a framework, an exploratory, descriptive research study investigating the relationship between an external locus of control regarding disease causation and feelings of an internal locus of control regarding the illness experience and illness behavior could be investigated. This may assist one in grasping an understanding of the process of how an individual re-frames a negative life event in which they feel little personal control into a positive life experience in which feelings of personal control allow for a greater sense of well-being. Longitudinal studies tracking one's feelings of personal control throughout the phases of the illness trajectory could also be of use in achieving a greater understanding of this process.

While all participants in this study made the decision to proceed with BMT immediately upon it being offered to them as a therapeutic option, it was beyond the scope of this study to investigate this decision making process. The findings of this study suggest that the BMT process was somewhat other than what the participants expected and the discrepancies in the perceived and actual event caused a great deal of stress and anxiety for the participants. As a factor therefore, in shaping the illness experience, a greater understanding of the decision making process needs to be acquired. Acquisition of such knowledge will foster a greater understanding of how the
individual perceives BMT and provide a clearer understanding of the individual's responses to illness.

With the findings of this study suggesting the process of communication with health care professionals to be one of extreme distress and unhelpful in easing the illness experience, coupled with the findings of other researchers that communication with health care professionals plays a role in enhancing or detracting from the quality of a patient's life, further research regarding the nature of communication dynamics between the health care professional and the patient population needs to be done.

In this study it was found that the meaning of support differed for each participant. Recognizing that support is a dynamic rather than static concept and acknowledging that support needs may change during the various phases of the illness trajectory points to the need for research to explore, determine and examine what these support needs are.

This study found that acceptance of an altered definition of normalcy and the process of re-learning played an integral role in coping with the chronic nature of the illness. Future studies could be directed towards how an individual integrates the illness experience and provides it with meaning such that life with a chronic illness, although different from the pre-morbid state, can continue to be worthwhile and satisfying. Such studies would provide the health care professional with greater knowledge and understanding surrounding the process of
adjustment to and coping with chronic illness.

In this study, the factor of uncertainty associated with the possibility of relapse posed as a great stressor for the participants and expanded into meanings of powerlessness and hopelessness. As a factor which negatively effects the illness experience, further research needs to be done to explore this characteristic which is inherent within the diagnosis of leukemia. Such studies could be guided by Mishel's (1988; 1990), Theory of Uncertainty in Illness. A further understanding of how one balances hope and fear may also be gained from such studies.

**Researcher's Personal Comments**

Conducting this study has proven to be a very worthwhile endeavour for the researcher. While the benefits are felt in both an academic and professional sense, the most significant result has been the personal journey. Listening to the participants' stories was a humbling experience - after all, having worked on a BMT/Leukemia unit for a number of years the researcher felt she had a clear understanding of what an individual experiences throughout the illness experience. However, what the researcher realized during, and upon completion of the research project was that during our encounters with patients we hear and understand a very small portion of what our patients are telling us. The researcher surmises that a part of this can be contributed to the
organizational structure of health care institutions. With limited time and limited staffing it is erroneous to assume that all patients will receive a level of care which is congruent with and respectful towards their needs, concerns and beliefs. More importantly however, are the personal barriers which prevent health care professionals from truly hearing and understanding their patients. Prior to the onset of this study and as an on-going process of her professional practice the researcher explored her own explanatory model of health and illness in an attempt to not only understand her own beliefs more clearly, but also to be cognizant of how her beliefs affect her practice. While this personal exploration has proven to be helpful, it pales in comparison to the impact of the thoughts and feelings the participants shared during the course of this study therefore stressing the importance and crucial necessity of health care professionals to elicit and incorporate a patient's explanatory model of health and illness into the health care plan.


APPENDIX A

Information Letter to Participants

LEUKEMIA AND BONE MARROW TRANSPLANTATION: PERSONAL MEANINGS AND PERCEPTIONS OF THE ILLNESS EXPERIENCE

Dear Potential Participant,

My name is Debra Richards and I am the social worker on the Leukemia/Bone Marrow Transplant (BMT) unit of Vancouver General Hospital. I am presently completing studies at the University of British Columbia towards my master of social work degree. I am conducting a research study for my course requirements exploring the illness experiences of leukemia. Your personal experience with leukemia can provide the valuable information that is required to complete this study.

The purpose of the study is to collect information that will allow health care professionals a clearer understanding of the meanings one gives to their illness. This in turn may provide a basis upon which health care professionals can better individualize the delivery of health care. Although this study will provide no direct benefit to you, it will assist us in future program development of the Leukemia/BMT unit.

If you agree to participate, I will interview you one or two times about your personal experience with leukemia. I would like to tape record our discussion which may last one and one half hours per interview.

Your participation is completely voluntary. Deciding not to participate will in no way affect your future medical or nursing care. The staff of the VGH Leukemia/BMT program will have no knowledge as to whether you participate or not. If you agree to participate, you may withdraw from the study at any time, or refuse to answer any questions.

All information that you share will be confidential. To ensure confidentiality all notes will be identified by a code, and only I will know your identity. Your name and any identifying information will not be used in the study, nor revealed in the final report or any published material resulting from this study.

If you would like more information regarding this study, please feel free to contact me at 875-4957. If you choose to
participate, I will obtain your written consent prior to the interview. This research project will be guided and supervised by Elaine Stolar, professor of the UBC School of Social Work at 822-6622.

Sincerely,

Debra Richards
Consent to Participate

LEUKEMIA and BONE MARROW TRANSPLANTATION: PERSONAL MEANINGS AND PERCEPTIONS OF THE ILLNESS EXPERIENCE

Client Consent Form

I understand that the purpose of this study is to share how I perceive my illness and the personal meaning of my illness experience.

I understand the study will involve the investigator visiting with me in my current place of residence one or two times in order to interview me about my illness experience and each interview will last approximately one and one half hours. I understand our conversation will be taped on an audio recorder.

I understand that my name, and any identifying information will not be used, or revealed in the study. The investigator will ensure confidentiality by identifying her notes by a code name. No one other than the investigator will know my true identity. If the information discovered in the study is published, my identity will not be revealed.

I understand that some questions and the questioning process may prove to be stressful and that I am under no obligation to participate in the study. I understand that choosing not to participate will have no effect on my future medical care. If I do agree to participate, I may withdraw from the study, or refuse to answer any questions at any time.

I understand that if I have any further questions regarding the study, I can contact the investigator, Debra (Merritt) Richards, at 875-4957.

I understand the nature of this study and I give my consent to participate. I acknowledge receipt of a copy of this consent form.

Signature ____________________ Witness_________________________
APPENDIX C

Sample Interview Questions

1. Tell me about your illness.
2. What do you call your illness?
3. How do you feel about your illness?
4. What do you think your illness is a result of?
5. Why do you think it started when it did?
6. What does your sickness do to you? How does it work?
7. How serious is your illness?
8. How long do you feel your illness will last?
9. What do you fear most about your illness?
10. What are the main problems your illness has caused for you (personally, in your family, and at work)?
11. What kind of treatment do you think you should receive?
12. What other treatment did you seek out?
13. Do you think the treatment changed the way your body works?
14. What does having your illness mean to you?
15. What have you been doing to get yourself better?
16. Tell me how you felt when you first came to hospital.
17. Tell me how you felt when you first came home from the hospital.
18. What concerns you about being out of hospital?
19. What do you hope is the result of your treatment?

Adapted from Kleinman, Eisenberg, and Good (1978, p. 256).