A STUDY OF THE EXPRESSED LIVED EXPERIENCE OF PATIENTS WHO FREQUENTLY VISIT AN AMBULATORY CARE DEPARTMENT FOR THERAPEUTIC TREATMENT OF A CHRONIC DISEASE

by

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A STUDY OF THE EXPRESSED LIVED EXPERIENCE OF PATIENTS WHO FREQUENTLY VISIT AN AMBULATORY CARE DEPARTMENT FOR THERAPEUTIC TREATMENT OF A CHRONIC DISEASE

BY

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ABSTRACT

This qualitative phenomenological research study examined the experiences of patients who frequently visit an ambulatory care department for therapeutic treatment of a chronic disease. The purpose of the study was to discover what the experiences meant for the patients. Specific focuses were on: what aspects of the experiences were satisfactory or unsatisfactory; what practices of the nurse contributed to the experience of the visits; what factors in the context of the visits contributed to the quality of life of chronically ill patients; and what factors contributed to stress.

The study participants consisted of seven patients who make frequent visits to ambulatory care for therapeutic treatment of a chronic disease. Data were gathered through two tape recorded interviews. The first interview consisted of the participants' descriptions of the experience. The second interview served to clarify the participants' perceptions of the first interview and to validate the researcher's interpretations of significant statements that were derived from the descriptions. Pertinent details of the researcher's notes that were made after each interview were added to the interview data set.

Colaizzi's (1978) method for analyzing phenomenological data was used to analyze the data. The meaning of frequent visits were identified within nine theme categories that were developed from the participants' descriptions: 1) an historical background of the illness leading to the frequent visits; 2) evaluation of the dimensions of time during treatment; 3) feelings that physical and emotional needs were met; 4) negative experiences related to the frequent visits; 5) impact of the frequent visits on the quality of life; 6) intrusive thoughts about the disease and the treatment in the context of the frequent visits; 7) evaluation of the caring environment; 8) expressed desire for family involvement; and 9) perceived threat to care. The results of the analysis suggest that although patients generally described their experiences of frequent visits to ambulatory care positively, negative experiences were revealed. Suggestions were made for changes. Based on these findings recommendations were suggested for nursing research, education, and practice.

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I wish to extend gratitude and appreciation to the individuals who supported, encouraged, and facilitated the process and the completion of this study. Without their dedication, patience, and caring this project would not have been realized:

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Chapter One

Introduction

Background Information

Hospital-based ambulatory care embraces a continuum of care from individuals requiring acute care needs to individuals requiring long-term management of chronic illness (Hastings & Muir-Nash, 1989). This includes care given in emergency departments, specialty clinics (diabetic, cardiac, renal), and in medical/surgical short stay programs. Ambulatory care services deal with patients over a long period and across a variety of problems (Palmer, 1983). In ambulatory care settings patients are seen by nurses or physicians on a single visit or have many visits spanning months or years for management of the chronic illness.

In recent years as the shift from in-patient care to out-patient care (as a result of cost restraints) gains momentum, ambulatory care facilities are being utilized for medical and surgical procedures that once were performed on an in-patient basis (Hastings & Muir-Nash, 1989; House & Wilkins, 1989; Stacey, O'Rowrke, & Desky, 1990). Nursing responsibilities are now more diverse and more complex. An important feature of ambulatory care is the anticipation and identification of problems associated with the ambulatory care experience (Frisch, Groom, Seguin, Edgar, & Pepler, 1990).

Statement of the Problem

The impact of chronic illness on the patient and the family can be immense (DesRosier, Cantanzaro, & Piller,1992). The experience of individuals who frequently visit an ambulatory care department for treatment of a chronic disease is of interest because of the researcher's work related situation. Since patients frequently visit ambulatory care

for therapeutic treatment, close rapport between patient and the nursing staff often develops. During discussions with patients and through observation, the researcher identified that frequent visits to ambulatory care may produce psychological and/or social disturbances for patients. Some patients undergoing therapeutic treatment lead disruptive and fragmented lives to accommodate the treatment regimen. Disruptions may include interference with personal life such as cancellation of planned vacations and missed hours from work or even loss of job. In addition, some patients experience pain, weakness, and anxiety about the treatment's potential and adverse effects. Often signs of mood swings such as being very talkative and happy during one treatment visit and almost uncommunicative during another visit are exhibited. These positive and negative mood swings may be a result of their disruptive and fragmented lives. Within the context of ambulatory care, nurses may be unaware of issues and concerns that are associated with frequent visits. Awareness of issues and concerns are important because frequent visits to ambulatory care over a protracted period of time may be a major task with which patient and family members must cope in addition to managing the chronic illness.

The literature confirms that chronic illness affects the psychological, social, and physical well-being of individuals as well as affects family relationships (Corbin & Strauss, 1988; Kopp, 1992; Obrien, 1983). Indeed, Perdue (1985) support the contention that the multidimensional experience of chronic illness imposes life long alterations in the biological, cultural, economical, political, and the psychosocial systems of individuals. The broad range of experiences require that nurses have knowledge about the experiences of the chronically ill patient in order to intervene and to implement appropriate caring activities (Perdue, 1985). In addition, current health care providers should not only seek to understand individuals and their health, but also should understand related phenomena in the context in which the phenomenon occurred in order to promote the importance of lived

experiences in care strategies (Hinds, Chaves, & Cypess, 1992). Ray (1985) argues the need for more research in lived experience in all areas of nursing so that lived experiences of illness may be understood.

There is an expanding body of research on lived experiences involving patients with chronic conditions and their families (for e.g., Erickson & Henderson,1992; Forrest,1989; Roberson,1992; Smith,1990; Trice, 1990). Inherent in these studies is the assumption that although professional care providers' perspective of illness and illness conditions are important to treatment interventions, the multiplicity of issues that may be associated with a specific chronic illness can only be revealed by the individual who has lived or is living the experience. No one can give as accurate a description of an illness experience as the person who psychologically reacts to the experience (Woods & Edwards, 1989). It follows that nurses providing care for patients who frequently visit ambulatory care for treatment of a chronic disease, must not only have a working definition of the clinical picture of the illness and the treatment, but must have an understanding of the experience of the frequent visits and the meaning of the visits for the patient.

While many studies related to ambulatory care have been conducted, the majority of these studies have focused on specific aspects of care following single admissions for surgical procedures with attempts to assess quality of care. For example, some researchers used questionnaires and structured interviews to study how patients and families cope at home after discharge (Frisk, Groom, Sequin, Edgar & Pepler, 1990); the effect of nursing care on anxiety levels (Kempe & Gelazis, 1985); the effectiveness of patient education with emphasis on discharge instructions (Icenhour,1988; William & Brett, 1989); and patients' satisfaction with care (Maulding,1984; Noon & Davero, 1987). Other studies have focused on classification systems that investigate nursing needs of patients, assessment of staff requirements, and nursing roles aimed at increasing efficiency of care services

(Hastings,1987a; Miller, & Folse,1989; Murphy, 1988; Parrinello,1987; Pinkey-Atkinson, & Robertson, 1993). As well, investigators have examined trends in ambulatory care with a focus on cost containment, future growth, and direction (Hastings, 1987b; Joseph; 1990; Scehneck,1984; Stacey, O'Rourke & Destky, 1990). However, the quantitative approach to the studies implies that participants' responses were based primarily on variables of interest to the investigator, rather than based on the participants' perception of the experience. More important, studies of ambulatory care to date have overlooked the experience of patients and their families' reactions, attitudes, and concerns related to the ambulatory care experience, specifically, in the context of frequent visits for a chronic disease.

As there is both a paucity of literature on the chronic care dimension of ambulatory care and no published studies that consider the experience of patients who frequently visit ambulatory care, there is a need to study the experience of patients in the context of frequent visits to an ambulatory care department from the patients' perspective. Seeking to understand the lived experience of these patients will enable nurses to better understand the experience and with this understanding, identify the special needs of this population of patients to ensure better management of care. This study is a proposal to examine the common issues and concerns related to the experience. Since each individual's experience is uniquely distinct to his or her particular experience (Woods & Edwards, 1989), the description of the experience of frequent visits will reveal the patient's view point as the frequent visits affect his/her life. The research findings will illuminate concerns and issues associated with the frequent visits.

In order to better understand patients' experiences of frequent visits and the meaning of those experiences, a phenomenological approach to the study will be

undertaken. Phenomenology seeks to describe and to uncover the meaning of experiences as li[illegible] rather than to use categories, explanations, definitions, or interpretations (Oiler, 1982; Salsberry, 1989). Hence, it is an appropriate method to investigate the study of human experience. Without an understanding of the meaning of frequent visits to the patients, although advancement in addressing this issue may occur in some areas, still there will be a gap in what the experience means for the patient.

Purpose of the Study

The purpose of this descriptive study is to examine the expressed lived experience of patients making frequent visits in the context of ambulatory care and in the chronicity of the illness. The research question that will guide the study is: **"What is the meaning of the experience of patients who make frequent visits to an ambulatory care department for treatment of a chronic disease?"**

Sub questions are:

1. **What aspects of the experiences are satisfactory or unsatisfactory?**
2. **What practices of the nurse contribute to the experience of the visits?**
3. **What in the context of the frequent visits contribute to the quality of life of chronically ill patients?**
4. **What contributes to stress of frequent visits?**

Definitions of Terms

The following terms are defined for the purpose of this study:

Frequent Visits

Frequent visits are patient visits to ambulatory care for therapeutic treatment for a chronic disease. The visits range from daily to monthly over a period of months or years and are usually for a duration of one to eight hours.

Therapeutic Care

Therapeutic care is the "delivery of directed physical care to patients following the direction of a heath team member, and the observation and measurement of the results of that care or of the care of others. Examples are surgical preparation, medications, IV [intravenous] medications, blood, and IV therapy"(Murphy, 1988, p.51). Therapeutic care also includes teaching, counseling, and comfort measures.

Lived Experience

"Lived experience is the focus of attention in phenomenology. Experience is not what we think, but what we live through"(Boyd, 1988, p. 65). It is the personal meaning of a phenomenon that involves immediate consciousness of lived situations that are recognized in retrospect and "is the starting point and end point of phenomenological research" (Van Manen, 1990, p. 36).

Perception

Perception "is a totality in which relations are comprised and organized ... It is a totality open to an infinite variety of perspectives, merging, for each individual, into a unique lived style ... Perception presents us with evidence of the world not as it is thought, but as it is lived" (Boyd,1988, p. 69).

Context

Context of a phenomena are the distinct interactive layers of (a) "the extent to which meaning is shared (from totally individualized to almost universal meaning), (b) the dominant time focus (present to future), and (c) the speed with which change within the layer can occur and be perceived .... "(Hinds, Chaves, & Cypess, 1992, p. 65). Context enhances meaning and is the "web of experience that combines thoughts, acts and the past" (Kuhns & Martorana, 1982, cited in Hinds et al. p. 63).

Illness Trajectory

Trajectory is the potential course of a particular chronic illness or condition. The course is uncertain, and although the course cannot be graphed ahead of time, it can be graphed in retrospect. The outcome of the illness is determined by the combined efforts of health professionals, family members, and the individual's actions that are taken to manage the symptoms and the associated disability (Corbin & Strauss, 1992).

Assumptions of the Study

In the phenomenological method no assumptions are made about the experience under investigation (Giorgi,1975; Omery 1983). However, Colaizzi (1978) argues the need for assumptions regarding the topic being investigated. Assumptions provide the researcher with a preliminary basis from which to formulate research questions. Thus, the researcher would adhere to Colaizzi's (1978) assertion that assumptions will broaden the range of the research questions. The study is based on the following assumptions:

1. Understanding the meaning of the lived experience of patients who make frequent visits to ambulatory care for therapeutic treatment of a chronic disease will help identify the diverse and complex health needs of these patients.
2. The experience of chronic illness has various meanings for each patient. Therefore, the study will reveal the uniqueness of the experience for each patient.

3. Descriptions of the experience of the frequent visits will reveal similarities in patients' experiences.
4. Patients who frequently visit ambulatory care have an understanding of the experience and are capable of giving in-depth descriptions of how the experience affects their overall well-being.

Philosophical Framework

The purpose of this section is to discuss and to describe the research framework and its relevancy to nursing research and to this study. A qualitative philosophical framework rather than a conceptual framework is the chosen method to guide the study. The theoretical perspective of the philosophical framework is embodied in the concepts of phenomenology. The framework assists with investigating and solving intellectual difficulties rather than practical difficulties; integrates perspectives of human knowledge and experience through reflection, analysis, assumptions, and clarification of the experience under investigation (Gaut, 1985), and recognizes the complexity of human realities in which the researcher and the participant are involved in a reciprocal relationship throughout the research. The rich descriptive data that are obtained by the researcher help aid understanding of the participant's experiences (Boyd, 1990; Parse, Coyne, & Smith, 1985; Polit & Hungler, 1991).

Munhall (1989) offers a perspective that is helpful in understanding the underpinnings of the philosophical qualitative approach. According to Munhall (1989) the underpinnings of the philosophical qualitative approach reflect values, beliefs, and assumptions. The approach considers human beings, the environment, and the interaction between humans and the environment. Individuals are perceived as active agents with an open perspective and are capable of interpreting and creating inner meanings. Meanings

are based on the perception of specific and varied histories. The world and the individual are considered to be dynamic rather than static. Therefore, since the world is constantly changing, meanings also change. Truth is viewed as interpretation that becomes more meaningful when shared. Interaction between the researcher and the participant does not imply objectivity is held in abeyance. Rather, objectivity is viewed as a subjective discovery that allows for reliability and validity. The focus of the research lies in the description of experiences. The meaning of the descriptions are from the participants; the "meaning is not presumed, assumed or assigned" (Munhall, 1989 p. 23). Experience of the participants will reflect meaning in relation to the participant's language, socialization, and culture. Based on the nature of the philosophical underpinnings of qualitative research, the framework is therefore, the theory underpinning the method (Van Manem, 1990).

Phenomenology is a philosophical, inductive, descriptive method of qualitative research that investigates the experience of man (Giorgi,1971). Phenomenology reaches the deeper layers of life as it exists and focuses on the exploration of what is already known and the expression of what is known linguistically and behaviorally (Thorne, 1991). Historically, phenomenology is credited to Brentano in the 19th century and to Husserl and Heidegger in the 20th century. Phenomenology is derived from the Greek word "phenomenon" which means appearance or that which shows itself. Phenomenology, as put forth by Husserl, is a science of phenomena that investigates objects as they are experienced and as they present themselves in awareness (Misiak & Sexton, 1973). The principal awareness of the experience "brings man into contact with his own loving, hoping, suffering, experiencing self" (Van Kaam,1966, p.304). The goal of phenomenological research is to understand the experience of humans from the view point of the individual (Crossman, 1984a; Knaack, 1984) through a systematic description of the

experience as it is lived (Lynch-Sauer, 1985; Oiler1986) "and from this examination derive consensually validated knowledge" (Lynch-Sauer, 1985, p. 97).

Giorgi (1975) presents philosophical characteristics of phenomenology that provides a comprehensive application of phenomenological concepts. He identified eight characteristics of phenomenological research:

1. "Fidelity to the phenomenon as it is lived". Phenomenon encircles human experience and behaviors and is an aspect chosen from the complexity of life that is studied and understood by the participant and the researcher within the lived context of the experience. The research involves everything as told by the participant and as recorded as data. The researcher states her/his explicit perspective on the descriptions prior to the research investigation (bracketing).
2. "Primacy of life-world". The life-world means "the every day world as it is lived by all of us prior to explanations and theoretical interpretations of any kind" Giorgi,1975, p. 99). It is the life lived before it is investigated and analyzed by the researcher. Emphasis is on the lived experience exactly as perceived by the individual. This reinforces the idea of the life-world as different from the scientific explanation of the same phenomenon. In the quantitative approach, the researcher does not know what the experience is like for the participant.
3. "Descriptive approach". The ability to communicate is important because description is the main method for "circumscribing attitudes, delineating aims and providing adequate contexts for all descriptions" (Giorgi, 1975, p. 100).
4. "Expressions of the situation from the view point of the subject". Some scientific research is structured so that a gap exists that needs to be filled by the participants' opinion. Therefore, the participants' view point of the lived experience is one source from which rich data are obtained to fill this gap.

5. "Situation as a unit of research implies structural approach." The situation being researched has been lived within an interpersonal context that involves the participant. Although the researcher may have ideas about the experience, the experience needs to be made explicit by interpretative procedures. Temporal and lateral relationships between the researcher and the participant will facilitate the weights of the emerging meaning of units of the phenomenon.
6. "Biographical emphasis." The data obtained from the participants are searched for key terms. The data must be biographical and personal to illustrate the temporal, historical, and personal nature of the phenomenon.
7. "Engaged researchers". Presupposionless description (i. e. "a methodology that tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project". Van Manem, 1990, p. 29) is the aim of phenomenology. However, presuppositionless description is not always possible.
8. "Search for meaning". The meaning of the experience is obtained from what is described through a method of a systematic exploration of the data. The value is the direct access provided by interrogating the qualitative aspects of the phenomenon.

According to Giorgi (1975), when these characteristics are combined a certain gestalt is manifested which increases the visibility of a different vision of research. The gestalt assumes that the statement that the whole is more than the sum of its parts. The term is derived from Gestalt psychologists with the underlying assumption that the whole has emerging properties and is not the same as the sum of its parts (Crossman, 1984b). The gestalt is manifested in the phenomenological approach because this approach

combines personal, historical, and biographical factors to study the complete experience (Giorgi, 1975).

Giorgi's (1975) characteristics provide a broad, practical perspective of the dynamics necessary for conducting phenomenological research. Each characteristic relates to the lived experience focus of the research and provides justification for the use of the method. Notably, they emphasize self-descriptions and search for meaning and illustrate both the phenomenological and the philosophical aspects of this qualitative method.

Phenomenology is important to nursing research. Nursing is a humanistic discipline that shares values and beliefs of the phenomenological method. Both nursing and phenomenology are concerned with lived experiences (Thibodeau, 1993) and view human phenomena as holistic and meaningful in which subjective and objective experiences are considered to understand the meaning of an experience (Omery, 1983; Thibodeau, 1993). Phenomenology also shows the interrelationship and the interdependence between humanness and scientific dimensions of the discipline of nursing (Ray, 1985). Phenomenology is therefore considered one of the most effective qualitative methods to the explication of the meaning of lived experience (Ray,1985). Indeed, nurse researchers have used the phenomenological approach in various research projects to capture the subjective experience of patients. For example, the phenomenological method has been used to explore the meaning of post partum depression (Beck, 1992); courage in chronically ill adolescents (Haase, 1987); child birth in later life (Lynch-Saucer, 1985); caring (Reiman, 1986), and the meaning of living with Chron's disease (Spilman, 1975). These are examples of nursing research that reveal new understanding of the experiences of individuals as described by them, illustrate the various methods used to capture lived experiences, and contribute to nursing practice. Brink and Wood (1989) advise researchers

who are interested in the phenomenological approach to look at various phenomenological studies when contemplating their own particular phenomenological study.

Limitations and Strengths of the Phenomenological Method

Phenomenological research offers a new appreciation for human experience and is a new explanation of phenomena that brightens and promotes understanding of experiences that otherwise would be ignored (Giorgi, 1975). The method, however, has both weaknesses and strengths. Barritt, Beckman, Bleckner, and Mulderis (1982, cited in Lynch-Saucer, 1985) present limitations and strengths that are helpful in understanding the phenomenological method. According to these researchers, descriptive studies that are based on experience are difficult to replicate, too subjective, and are based on the informants' memory. The language of phenomenology is too vague and ephemeral; the method is ahistorical, and the researcher's bias may interfere with the results. However, Lynch-Saucer (1985) contends that the limitations also serve as the strength of this type of research approach. She argues that the perceived limitations are the attributes that make the phenomenological approach unique and that distinguish it from the prevailing quantitative methods that investigate selected variables. Qualitative research serves a different purpose than quantitative research and must not be measured against quantitative criteria.

In the qualitative paradigm, the strength of the phenomenological approach is its representation of a shift from the empirical natural science toward a shift to subjective human experience. Whereas the empirical natural science focuses on investigating variables of human experience that are predetermined and in which the meanings are dictated to the participants, the phenomenological approach focuses on the investigation of

the participant's subjective experiences that allows the meanings of experiences to be derived from the interactions of the researcher and the participant (Anderson, 1991).

In summary, phenomenology is a philosophy, a method, and an approach to study descriptions and meanings of human experience (Ray, 1985). More specifically, phenomenology provides a systematic means through which reflections of lived experience are studied. It allows for subjective meanings that are derived from experiences to reveal the humanistic and nonhumanistic values associated with nursing. Most importantly, the meaning of a client's reality through the phenomenological approach will reveal to the nurse the qualities of each individual's existence. The information also will "provide a more comprehensive understanding of the nature of nursing itself" (Ray, 1985 P. 86).

This section provides a presentation of the framework to guide the study. Included in this section are the underpinnings of qualitative research, the concepts and characteristics of phenomenology, and the relationship of qualitative phenomenology to nursing research. From this conceptual framework, the value of the phenomenological method as an approach to this study is supported. Once the experience of frequent visits to ambulatory care has revealed issues nurses may not have considered, it is possible that ambulatory care will offer a more satisfying and fulfilling experience to individuals with a chronic disease who frequently visit an ambulatory care for therapeutic treatment. The information from the participants' experiences will broaden care givers' concepts of the patients' experiences and the experience will be understood from the patients' point of view.

Conclusion and Organization of the Thesis

The thesis will have five chapters. Chapter One provides an introduction to the need to investigate the experiences of patients who frequently visit ambulatory care in relation to the chronicity of an illness. Included in this chapter is a background of

ambulatory care services, statement of the problem, definition of terms, and assumptions of the study. Also included is a philosophical framework as a guide to the study and the literature review, and limitations of the phenomenology method. Chapter Two provides a review of relevant literature, focusing on various aspects of chronic illness to identify various concepts of chronic illness experiences that may be associated with the experience of patients who frequently visit ambulatory care. Chapter Three presents the research methods used in the study. In Chapter Four, the findings of the study will be presented. Chapter Five presents a discussion of the research findings, implications for nursing practice, nursing research, and the research limitations

Chapter Two

Literature Review

Opinions vary about a literature review for a phenomenological approach. Omery (1983) argued that one primary requisite of phenomenological research is that there are "no preconceived notions, expectations, or frameworks be present or guide the researchers as they gather and analyzed the data" (p.61). Conversely, Van Manen (1990) questioned the ability to put aside everything one knows about the phenomenon one has elected to study. For Van Manen:

> it is better to make explicit our understanding, beliefs, biases, assumptions, and theories. We try to come to terms with our assumptions, not in order to forget them again, but rather to hold them at bay deliberately and even to turn this knowledge against itself, as it were, and thereby exposing its shallow or concealing character (p. 47).

The literature review will proceed based on the premise that exploration of various literature will provide a thorough reevaluation of concepts and beliefs related to illness experiences; will enable the formulation of research questions; and will reveal gaps in the literature and in previous research that have not been addressed and that have implications for the study.

Numerous empirical and theoretical literature have addressed the experiences and the perceptions of patients who are chronically ill. Exploration of this literature will be the source of this literature review. This source is chosen as individuals who frequently visit an ambulatory care department suffer from a chronic illness, and therefore, chronic illness issues are most pertinent to this study. The researcher did an extensive computer search of chronic illness anecdotal and empirical literature, as well as conducted a hand search to

cover all possible sources of the chronic disease literature. The review content is based on the most common issues and concerns identified in the literature that are associated with the experience of chronic illness. Thus, the purpose of this chapter is to review the literature that address aspects of chronic illness experiences that may be associated with the lived experience of patients who frequently visit an ambulatory care department for therapeutic treatment of a chronic disease. The review will be primarily guided by phenomenological concepts of experience, meaning, and perception and will be organized as follows:

1. Experiences associated with the characteristics of chronic illness
2. Approaches to managing chronic disease
3. The meaning of quality of life and satisfactory experiences in chronic illness.
4. Factors leading to coping experiences in chronic illness

These perspectives on chronic illness are important sources of information for understanding individual's experience in personal and in situational conditions of chronic illness that may be related to patients' experiences of frequent visits.

Experiences Associated With the Characteristics of Chronic Illness.

Experience in phenomenology refers to events, situations, and to circumstances that individuals live through (Boyd, 1988). In nursing research the phenomenological approach is a way in which situations or events that are real for the patient are revealed. This approach provides a broad understanding of what nurses need to consider in patients' experiences (Ray, 1985).

The characteristics of chronic illness determine the nature of individuals' experiences with the illness process and are reflected in the definition of chronic illness. Chronic illness is defined by the Commission on Chronic Illness as "All impairments or

deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care" (Perdue, 1985, p. 3). Several theories have been developed to explain or to better understand the characteristics of chronic illness. The contributions of Anderson and Bauwens (1981), Anderson and Bury (1988), Masters, Cerreto, and Mendolowitz (1983), Perdue, Mahon, Hawes, and Frik (1985), and Strauss and his associates (1984) are notable. Their literature provides a broad focus on the dynamics of chronic illness, is patient focused, and enables better conceptualization of the course of chronic illness. In particular, Strauss' work has directed much of the thinking in this area.

Strauss and his associates (1984) identified characteristics of chronic illness in medical and psychosocial terms. These characteristics provide a guide for understanding the scope of individuals' experiences with chronic illness and the impact of chronic illness on all aspects of the individual's life which must be considered in treatment regimens. Included in the characteristics are that chronic illness is long term, uncertain, requires great measures at palliation, tends to be multiple, severely intrudes on the lives of individuals, requires many disciplines to manage the symptoms of the disease, and is costly. Inherent in Strauss' work is that chronic illness is an unpredictable process in which individuals experience diverse, complex, physical, and psychosocial problems.

Examination of what is known regarding chronic illness experiences will provide information about the impact of chronic illness on patients and their families. Experiences such as stress, dependency, alteration in lifestyle, and noncompliance to treatment are noted to result from the impact of chronic illness. Each of these characteristics will be briefly discussed in relation to patients' experiences.

The Experience of Stress

Conceptualizing chronic illness as an experience that is associated with many stressors that impact upon the patient simultaneously is a major theme of literature on chronic illness (e. g., Anderson & Bury, 1988; Kopp, 1992; Lamm, Dungan, & Hiromoto, 1991; Strauss, 1984). Stressors necessitate the development of coping skills in the chronically ill individual as well as contribute to altered self esteem and to role-functioning (Kopp,1992; Lamm, Dungan, & Hiromoto,1991). Some situations that evoke stress in chronically ill individuals are specific to the type of chronic illness, and may vary with the severity of the disease. Examples include unemployment (renal failure), stigma from the chronic illness and the treatment (epilepsy and rectal cancer), loss of personal identity (all diseases, specifically psoriasis), and alterations in family life (stroke, multiple sclerosis, heart disease, and arthritis) (Anderson & Bury, 1988). Individuals who frequently visit ambulatory care for treatment of a chronic illness may experience many of these stressors.

The Experience of Dependency

Dependency on family and significant others is often experienced in chronic illness (Burish & Bradley,1983; Diamond & Jones, 1983). Two possible reasons for dependency are the chronically ill individual's inadequacy to accomplish personal and social obligations either completely or partially and their inability to adjust to the illness and to the treatment process (Burish & Bradley, 1983). Chronically ill individuals may depend on family as in the majority of chronic illness situations concerns that impact on the chronically ill individual also may impact on family members (Diamond & Jones,1983). Throughout the chronic illness experience, family members are likely to be involved in treatment, in

exacerbation of the illness, in periods of crises, and in recognizing changes in symptoms (Diamond & Jones, 1983). Family members also assist with personal care demands, contacting outside help, and with forming networks with other support groups (DesRosier, Catanzara, & Piller, 1992). The extent to which chronically ill individuals may depend on their families suggests that the duration of time that family members are involved in caring for the chronically ill individual may be longer than the duration of time that care professionals are involved. Because of this dependency, chronic illness within a family may either be a threat or a challenge to family (Shaw & Halliday, 1992).

Family members may be affected by the chronically ill individual's dependency on them. Psychosocial disturbances such as conflict and anger and physical conditions such as headaches, ulcers, and fatigue (Rosenberg,1991) may occur because of the challenge of caring for the chronically ill individual over a prolonged period of time (DesRosier, et al.,1992). It is possible that if chronically ill individuals become aware that they are a burden to family members they may experience guilt for disrupting the family members' lifestyle and feelings of inadequacy (Rosenberg, 1991).

The Experience of Life Style Changes

The nature of chronic illness forces individuals to make major changes in their life-style. Chronic illness is long-term and changes usually occur in all aspects of the individual's life. Consequently the individual is forced to adapt to changes in social activities, family life, employment, and in recreational activities (Perdue, 1985). In many instances, the roles in family relationships change. Roles of the chronically ill husband and wife, father or mother are often taken over by others (Burish & Bradley, 1983). Life style behavior changes are major adjustments for the chronically ill individuals and are necessary in order for them to cope with the illness conditions (Lamm, Dungan &, Hiromoto,1991;

O'Brien,1983; Perdue, 1985). It is likely that individuals' experiences with frequent visits will be determined by the degree to which the individuals' life style are altered by the effects of the chronic illness.

The Experience of Noncompliance

The characteristics of chronic illness demand that chronically ill individuals be placed on long-term treatment. Noncompliance with the treatment regimen may be associated with the experience of chronic illness particularly in situations in which the treatment involves making uncommon and difficult decisions (Diamond & Jones, 1983). Possible reasons underlying noncompliance are inadequate information about the disease, distorted perceptions about the illness (Lewis, Morisky, & Flynn, 1978; Roberson, 1992), denial of the illness, and difficulty in managing the adverse effects of the treatment (Perdue, 1985).

In an investigation reported by Roberson (1992), a variety of reasons why individuals who are living with a chronic disease and are noncompliant were identified. Twenty three participants with various chronic illnessess (e.g., diabetes, high blood pressure, asthma) were interviewed regarding their compliance to the treatment regimen. Roberson found that, although patients may have adequate information about their treatment, various factors contributed to patients' noncompliance in chronic illness. Noncompliant factors included inadequate information about certain aspects of the treatment regimen, current health status, the association between treatment strategies and the illness condition; lack of trust and confidence in doctors; socioeconomic factors that made it difficult to adhere to the treatment plan; a desire to engage in other forms of behavior; dependence on treatment for health maintenance; religious beliefs; and the patient's observation that others who have not followed a strict treatment regimen have not

suffered negative consequences. Noncompliant factors were consistent regardless of culture.

Roberson (1992) concluded that patients' and care givers' perspectives on treatment modalities differ in that patients and caregivers have different goals for the outcome of treatment. While patients view compliance with the treatment program as only one dimension of their lives, compliance for care providers is viewed as the crucial element in the treatment. Roberson's findings are useful in nursing and, therefore, to the experience of frequent visits. The findings provide valuable, insightful information about the preferences of individuals who are experiencing a chronic illness in their treatment situations. The information also provide insight into the importance of understanding the variety of reasons why individuals are compliant or noncompliant. Because frequent visits are associated with a treatment regimen in which patients may become noncompliant, understanding compliant and noncompliant issues are important to understanding aspects of the experience that may be associated with frequent visits.

This section has provided theoretical and empirical information on characteristics of chronic illness and how the characteristics are associated with psychosocial situations and behaviors. It is evident from the characteristics of chronic illness that individuals with chronic conditions may become anxious, depressed, uncertain, angry, and confused. These attitudes and feelings about the illness and about life in general may vacillate between optimism and hopelessness (Burish & Bradley, 1983). Psychosocial conditions commonly associated with the characteristics of chronic illnessess are real problems that are experienced by chronically ill individuals. Although some conditions are common to many illnessess and some are unique to specific diseases, psychosocial issues can be crucial for some individuals especially in situations when individuals have to shuffle work and family life to fit the treatment regimen. These findings are relevant to the lived experience of

frequent visits in that characteristics of chronic illness are aligned with individuals appraisals of the illness situation. How individuals seek to respond to the characteristics of the illness may be reflected in their experience of frequent visits to ambulatory care.

Approaches to Managing Chronic Disease

Phenomenology focuses on ways of existing in the world (Boyd, 1988). How chronic illness is managed are real situations in which individuals with a chronic disease must experience the world. This section consists of information regarding how care in chronic illness is managed and how frameworks have been used by care professionals to guide much of the treatment decisions. Given that some chronically ill individuals make frequent visits to ambulatory care for treatment of their chronic illness, how care is managed is important to patients' experiences with the frequent visits.

The multidimensional nature of chronic illness demands that nursing management of individuals who are experiencing chronic illness must be comprehensive, multipurpose, diverse, and complex to deal with the perplexity of the illness condition. Management of the illness must include controlling symptoms and assisting individuals to adjust to disability and psychosocial changes (Corbin & Strauss, 1992). Furthermore, an approach to managing chronic illness must look at the realities of living with the illness within the specific illness context. Management of individuals who are experiencing chronic illness must, therefore, encapsulate all aspects of life (Corbin & Strauss, 1991).

Most health professionals provide care for chronically ill individuals based upon medical frameworks that are oriented toward curing acute diseases (Strauss et. al., 1984; Tood & Still,1984). Health professionals also use a categorical approach that addresses specific diseases. Given the multidimensional nature of chronic illness, a more general approach to the problems associated with chronic illness should be

emphasized (Anderson & Bauwens, 1981). Various frameworks have been presented to explain chronic health problems and to direct management of the illness course and symptoms. Some frameworks have focused on the management of individual psychosocial aspects of chronic illness, others have focused on general aspects of chronic illness, and yet others have focused on chronic illness with the inclusion of the chronically ill individuals and their families.

Frameworks that have focused on psychosocial aspects of chronic illness emphasize social and other problems that are common to individuals living with a chronic illness, rather than focused on the overall picture of the chronic condition (Perdue, 1985). For example, the principles of Selye are focused on stress as it relates to chronic illness (Leidy,1989). Harvey's (1992) model is centered on personal and health values on the assumption that an individual's adjustment to illness is related to values such as a sense of accomplishment, secure family support, and inner harmony. Models such as these that have only discussed single dimensions of chronic illness cannot be generalized to other aspects of chronic illness and, therefore, have limited use in the management of chronic disease.

Most early studies on the management of chronic disease also appeared to follow a single dimensional approach. Researchers were concerned primarily with measuring factors that alleviated the clinical manifestation of the disease, altered risk factors, and how to facilitate adaptation factors that were not readily managed by care professionals (Anderson & Bury, 1988; Perdue, 1985; White, Richter, & Fry,1992; Stewart 1992). One possible reason for this single dimension focus to the study of chronic illness is likely the popular tendency for care professionals to manage chronic illness primarily around specific diseases, such as heart disease, Parkinson's disease, and multiple sclerosis

(Rosenberg, 1991). Consequently, information regarding one dimension of chronic illness is provided, but concerns about other aspects of chronic illness are not clarified (Watson & Kendall,1983). Within these approaches the multidimensional nature of chronic illness was not captured.

Frameworks such as "The Adaptation Framework "(Leidy,1989), "The Chronic Illness Trajectory Framework" (Corbin & Strauss,1991, 1992), and the "Three Pronged Framework" (Lamm, Dungan, & Hiromoto, 1991) are general approaches to the management of chronic illness that have addressed the importance of recognizing the ill individual and the family perspectives in the concepts of chronic care. They are promotions in the recognition of a more holistic focus to manage chronic disease. Frameworks that are based on a general approach to the management of chronic illness facilitate individuals' compliance with treatment; promote self respect as they consider the individual's participation in treatment processes; bring about improvement in the individual's and in the family's adjustment to the illness; and reduce or eradicate despair, frustration, anger, and other emotional suffering that is related to the illness (Strauss & Glaser,1975).

In recent years, management of chronic illness that integrates patients' and families' perspectives into the care provided by care professional has gained momentum. For example, a framework of chronic illness that focuses primarily on the family in the chronic illness situation is the "Evolutionary Model of Crisis in Chronic Illness" (Shaw & Halliday, 1992). This framework focuses on the perception of family members during a chronic illness crisis. It attempts to explain the interaction of an illness crisis, beliefs of the family, and chronic illness from a biological and family system nursing perspective. Family members play an integral role in the management of chronic illness. Frameworks that recognize and incorporate family members' perceptions in care

interventions will complement other frameworks on chronic illness and allow a wider range of strategies to be utilized in the management process. The recognition of the stressful experience of chronic illness also has resulted in an increase in research on experiences of illness from the patients' perspective, rather than the professionals' predetermined factors associated with chronic illness (Anderson & Bauwens, 1981; Packard, Haberman, Woods, & Yates, 1991; White, Richter, & Fry, 1992). Nurses must objectively evaluate the strategies that patients select to manage their illness and support those strategies that are effective in the management of patients' care.

Discussions on frameworks to manage chronic illness have led to the identification of trends in the management of chronic illness. Trends in the management of chronic illness have advanced from a primarily single dimensional focus to general approaches that incorporate the patient and family perspectives in the management of chronic care. Recurrent themes in the frameworks posit that professionals hold the primary responsibility for assisting the chronically ill individual and family to overcome the difficulty of physical and psychosocial impairments and that the chronically ill individual and family should be central to care interventions. Although the frameworks address chronic illness in specific and general ways, components specific to frequent visits to ambulatory care are excluded from the frameworks' conceptualizations. The scope of chronic illness frameworks could be improved to incorporate the experience of chronic illness in the context of treatments that are associated with frequent visits to out-patients' departments such as to ambulatory care.

The Meaning of Quality of Life and Satisfactory Experiences in Chronic Illness

The Meaning of Quality of Life

In phenomenology, contact with the world and with oneself is based on individuals' experiences and perceptions of the capacity to make meaning of life's experiences (Boyd, 1988). Since phenomenology attempts to explicate the meaning of described lived experiences that can become known to improve nursing knowledge (Ray, 1985), the meaning of the quality of life in chronic illness is relevant and necessary to the understanding of the lived experience of frequent visits. In this section the meanings of quality of life and the way in which experiences concerning the quality of life for individuals who are enduring a chronic illness are perceived will be discussed.

Quality of life for individuals who are living with a chronic illness, is determined, in part by the degree of physical disability, adjustment to lifelong treatment, and by the degree of social impediments that are associated with the chronic illness (Oberst,.1984). Several writers (e. g., Cowan, Graham, & Cochrane,1992; Laborde & Powers, 1985; Locker & Daunt, 1978; Obrest, 1984; Padilla & Grant, 1985) defined quality of life in the context of satisfaction. Padilla and Grant (1985) found in their study of factors that influence quality of life that satisfaction with nursing care had a positive, significant correlation with psychosocial well-being, social concerns, and with physical well-being for cancer patients. Quality of life "refers to that which makes life worth living and connotes the caring aspects of nursing, because nursing is concerned not only with survival and decreased morbidity, but with the whole patient" (Padilla & Grant, 1985, p.45). Moreover, some researchers (e. g. Allen, 1989; Anderson & Bury, 1991; Cowan, Graham, & Cochrane,1992; Padilla & Grant,1985; O'Brien, 1988; & Stewart, 1992) contend that the care environment and the care giver are important to promoting patients' quality of life. In addition, Locker and

Daunt (1978) and Obrest (1984) postulate that the quality of care provided to individuals who are chronically ill is one determinant of their quality of life.

Anderson and Bury (1988) view quality of life as a complex interaction of subjective health, disability, and the social environment. Using quantitative and qualitative approaches to describe several cases, in which individuals experience living with chronic illness (e.g. stroke, multiple sclerosis, Parkinsons disease), they investigated the social reality of each illness together with the impact of the social environment in which the illness was experienced. Common themes identified from the various lived experiences that impact on quality of life were limitations resulting from physical disability, perceived stigma, dependency on family members, and financial constraints.

Specific chronic illnessess also may determine the degree to which quality of life is compromised. Drawing on the experiences of patients with chronic renal failure, O'Brien (1983) investigated quality of life and "courage to survive" in a nine year longitudinal study of patients with renal failure who were dependent on renal dialysis as a means to survive. The aim of the study was to discover how patients adapt to maintenance dialysis; patients' and family members' concerns, their suffering, and their joys; and how patients cope with the many modifications caused by dialysis therapy. Stressors identified from the shared experiences that were "living realities "of the illness and treatment and took courage to overcome were limitation in physical functioning, pain, fatigue, anxiety, loneliness, disruption of family living, altered social interaction, uncertainty of the present and the future, and diminished support of family and friends.

In another study that showed a specific chronic illness may determine quality of life, Allen (1989) investigated blindness as a chronic condition. Allen found that individuals who are blind reported similar social consequences to other chronic illnessess, as well as consequences unique to blindness. The visually impaired experienced shock,

disbelief, anger, depression, fear of being alone, fear of learning new skills, and experienced difficulty with adjusting to blindness. How patients adjusted to blindness determined the quality of life for the blind person. This study showed that psychosocial similarities and differences that influence quality of life exist within chronic illnessess.

Although most studies on quality of life show that there are some similarities in the experiences of all chronic illnesses, as well as unique experiences that are specific to some diseases, the study reported by Cowan, Graham, and Cochrane (1992) presents a shift in focus. These researchers compared quality of life during chronic illness in patients with myocardial infarction and malignant melanoma to find out if quality of life is generalizable to chronic illness. The focus was on quality of life following chronic illness and not on specific diseases. The results of the study showed that no significant differences were found in perceived quality of life for either group of patients. This finding seems to indicate that there is no difference in how the quality of life is affected in individuals who are chronically ill and suggests that specific chronic illnesses have no influence on the degree to which quality of life is affected. Thus this study challenged other research findings that uncovered the uniqueness of each individual's experience with chronic illness.

Studies on quality of life indicate that there is a trend in how patients who are chronically ill perceive quality of life. Outcomes of discussions suggest that quality of life is a function of beliefs, attitudes, and appraisals of the illness situation by the chronically ill individual. Furthermore, although quality of life may be restricted by environmental, psychological, and physical factors that are required to meet patients' immediate needs, the effect of the caregivers is instrumental in enhancing patients' successful coping with situations of the chronic illness that promote quality of life.

The strength of the studies on the quality of life are in the identification of various physical and psychological factors that affect the quality of life of individuals who are

experiencing a chronic illness. However, no anecdotal or empirical literature addresses quality of life in the context of the frequent visits for therapeutic treatment and little is known about the quality of life in this context. Individuals who make frequent visits to ambulatory care have differing chronic illnessess. It is possible that these individuals may share similar concerns about the impact of the frequent visits on their quality of life. While similar conditions that affect quality of life are recognized, there is much to explore regarding the many questions concerning each individual's quality of life related to the frequent visits. It is anticipated that the caring interaction between the caregivers and the patients who make frequent revisits to ambulatory care, as well as the specific disease, may influence patients' quality of life. These documentations on the quality of life suggest that consideration of patients' quality of life has an important place in the understanding of chronic illness experiences that may be related to the experience of frequent visits..

Satisfactory Experiences in Chronic Illness

Patients' experiences of satisfaction with care are a major concern to care professionals who are interested in monitoring quality of care and studying the effectiveness of specific care interventions (La Monica, Obrest, Madea, & Wolf, 1986; Weiss & Ramsey, 1989). Moreover, satisfactory experiences with care, particularly in chronic illness in which treatment is on-going, influence quality of life (Locker & Daunt,1978), yet only a few studies were found that investigated satisfaction with care in the context of chronic illness. Consideration of patients' satisfaction has an important place in the understanding of the chronic illness experience and this includes the satisfaction of individuals with a chronic illness who make frequent visits to ambulatory care. In this section the meanings of satisfaction with care, research on satisfaction in chronic illness,

family involvement with patient satisfaction, and factors that lead to dissatisfaction are discussed.

Meanings of satisfaction

Satisfaction with care is multidimensional and holds various meanings for individuals (McCorkle, 1984). Satisfaction with care is defined as a subjective outcome evaluation that is based on individuals' perceptions and expectations of care (Abramowitz, Cote, & Berry, 1987; Elbeck, 1987; Gutek, 1978; Harper Peterson, 1988; Hastings, 1987b; Hinshaw & Atwood,1982; Lebow, 1983; Lochman, 1983; Pascoe, 1983; Reeder & Chen, 1990), care providers competence and personal qualities, accessibility to care, the care environment; (Lebow, 1983; Reeder & Chen, 1990), family support, and general satisfaction (Reeder & Chen, 1990). Satisfaction with care is an individual's positive or negative attitude towards the health care received (Elbeck, 1987; Gutek, 1978; Lochman, 1983). It involves dynamic responses and processes in which value judgments, reactions to treatment, and individual differences are modified to fit with patients' expectations and preferences (Strasser & Davis,1991). These expectations and preferences are based on past experiences and expectations of care (Elbeck, 1987; Gutek, 1978; Lochman, 1983). Satisfaction with care also may depend on past, present, and future experiences in which individuals perceive themselves as physically fit, having good interpersonal relationships, and feeling that life in general is good (Burckhardt, 1985). Thus, the more a health care provider's performance agrees with patient's expectations and needs, the more satisfied the patient will be with the care received (Strasser & Davis, 1991).

Pascoe (1983) argued that what constitutes satisfaction with care is difficult to determine. He postulated that a possible reason for this difficulty is related to the absence

of research to explicitly guide a well supported definition or psychological model of satisfaction. He conceptualized satisfaction at two levels: 1) a psychological process that underlies satisfaction and 2) a factor that underlies health related behaviors and treatment outcomes. According to Pascoe, the psychological factors in satisfaction are the patient's evaluation of the process, the context of care received, and the comparison of salient characteristics of the patient's health experience. This comparison is based on what the patient feels he or she deserves and the patient's experiences. As an outcome measure of treatment, satisfaction is related to the degree to which patients understand health behaviors and clinical outcomes. Given these diverse definitions of satisfaction, it may be concluded that satisfaction is a broadly defined concept, and by its very nature, is primarily a subjective evaluation by receivers of care and includes psychological and emotional variables.

Research on satisfactory experiences in chronic illness

Roberts, Pascoe, and Attkinson (1983) argued that satisfaction is associated with a general feeling of well-being or life satisfaction. They investigated the perception of patients with chronic mental illness in various types of health care services using a client satisfaction questionnaire (a direct, micro approach that assesses concrete experiences in health care encounters) and a patient satisfaction questionnaire (an indirect, macro measure of satisfaction with a general conception of medical services and of health care providers). This study found that physical health, mental health status, psychological well-being, personal happiness, and life satisfaction were independent of how satisfied patients were with other aspects of life. A significant relationship was not shown between satisfaction with health care services and life satisfaction and well-being. However, a significant relationship existed between life satisfaction and attitudes towards services.

Research on patients' expectations and perceptions support the claim that patients' expectations and perceptions influence their satisfaction with care. To examine the association of patients' expectations with satisfaction with care in chronic illness and the personal experience for patients, Ferrans, Powers, and Kasch (1987) conducted an exploratory study with 416 hemodialysis patients in which the relationship between satisfaction with care, satisfaction with the quality of life, and satisfaction with other various aspects of life were explored. Findings from this study revealed that patients were generally satisfied with care. Interpersonal relationships with care providers were the primary factor in satisfaction for hemodialysis patients. Internal satisfaction associated with the dialysis nurses were dimensions of nursing care such as understanding of patients' personal needs, sensitivity to concerns, ability to act in emergencies, and interpersonal discussions. Similar findings were reported with satisfaction regarding physicians' interpersonal skills. Patients, however, reported higher satisfaction with physicians' interpersonal skills than they reported with nurses'. Factors that contributed to dissatisfaction with services included waiting time, equipment malfunctioning, mixed up appointments, adverse effects such as pain from the treatment, financial cost for medications and transportation. These appraisals are reflections of satisfactory and unsatisfactory experiences.

When investigating " patients' perception of care" quality and satisfaction, using a self-reporting questionnaire Oberst (1984) investigated 180 cancer patients who were receiving chemotherapy in ambulatory care. Findings from this study indicated that the experience of satisfaction occurred when doctors and nurses gave information about the diagnosis and the treatment. Thus, cancer patients satisfaction was based on the expectation of having information about their condition and their ongoing treatment. However, this study lacked clarity in the dimensions of satisfaction being studied. Because

satisfaction is multidimensional and holds various meanings for individuals, individuals may perceive some aspects of care as unsatisfactory, which may be a misinterpretation of professional responsibility (McCorkle,1984).

In a literature review on satisfaction, Lebow (1983) reviewed and summarized various research studies concerning patients' expectations and perceptions in relation to satisfaction with mental health care services. Lebow concluded from the review that individuals with chronic mental conditions share with medical patients some similarities as well as some unique experiences with satisfactory and unsatisfactory situations in health care. Satisfactory and unsatisfactory experiences were related to "the clinician, outcome, access, confidentiality, medicines, and facilities" (p. 227). Satisfactory predictors were individuals' expectations and aspirations, diagnosis and past history, length of treatment, how treatment was terminated, and individuals' perception of supportiveness. However, in the majority of research that Lebow reviewed, most patients were found to be satisfied with treatment. Only a small percent of patients were dissatisfied with treatment in each study and as Lebow noted, little attention was given to this dissatisfied group. Dissatisfaction with treatment was related to one or many dimensions of the treatment process and was primarily due to certain characteristics of the treatment or due to conflict that involved a specific dissatisfied patient. This finding indicates that care professionals may ignore a group of patients who have needs for professional services as the tendency for professionals is to focus on the larger population of patients who appear satisfied with their care (Lebow, 1983).

Family involvement with satisfaction in chronic illness.

Family support for chronically ill patients as well as family acknowledgment in care decisions are important determinants of patients' satisfaction. Family members play a

crucial role in chronic illness and satisfaction with care in chronic illness involves the patient and the family (Diamond & Jones, 1983). In the majority of cases family members intervene on behalf of the chronically ill individual when they perceive that care does not meet their's and the patient's expectations. They also intervene when they perceive that care providers fail to acknowledge that the experience of chronic illness involves an ongoing relationship between the patient and the family. Inadequate patient and family involvement causes dissatisfaction and leads to distrust, frustration, and disenchantment with professionals in the implementation of care (Thorne & Robinson, 1988). However, some studies (McNeese,1987; Reeder & Chen, 1991; Rempusheski, Chamberlain, Picard, Ruzanski, & Collier, 1988) show that patients and families held varying levels of service expectations that were apart from, yet dependent on, care professionals. Patients with chronic illness preferred attention to personal care needs (e. g. interpersonal communication) rather than attention to other health needs (e. g. teaching). Satisfaction is evident when patient and family members receive care that is satisfying (Thorne & Robinson, 1988).

Factors leading to dissatisfaction with care

Given that patients' preferences and perceptions of health care experiences enhance patients' overall satisfaction, dissatisfaction with health care experiences may have the reverse effect. Dissatisfaction with care in chronic illness leads to non-compliance; promotes attitudes that contribute to poor health habits; and leads to financial, ethical, and social costs to care providers (Thorne & Robinson, 1988). Factors that may contribute to patients' dissatisfaction include insufficient decisions into their care, too much emphasis on care providers' decision when providing care, and lack of recognition that the illness is an ongoing process for the patient (Thorne & Robinson, 1988). These findings strongly

suggest that satisfaction with care for individuals who make frequent visits to ambulatory care may be based on individuals' personal meaning of satisfaction and on their relationship with caregivers.

This overview of satisfaction indicates that patients and families have various expectations of care. Few studies were found that directly investigated patients' satisfaction with care in chronic illness; no studies were found that investigated patients' satisfaction specifically within the context of frequent visits for treatment of a chronic disease. However, the studies reviewed contributed to the understanding of aspects of care that revealed satisfactory and unsatisfactory experiences in chronic illness that may be similar to the experiences of patients who make frequent visits for therapeutic treatment. The studies addressed issues of satisfaction by focusing on the relationship between the patient, care professionals, the care environment, and determinants of satisfaction in specific and in general contexts. Components of the patients' satisfaction represented either positive or negative appraisal based on their expectations and perceptions of care. A phenomenological study would open new doors to the identification of some of the fundamental issues that are based on patients' knowledge, experiences, and perceptions that affect satisfaction with frequent visits to ambulatory care.

Coping Experiences in Chronic Illness

Phenomenology regards an individual's reality in the world as they perceive it and as they are located in it (Boyd, 1990). Coping with the dynamics of chronic illness is a way in which individuals perceive their world and are involved and located in it. It is the individual's adjustment to the long duration of the illness process and to the illness treatment. The process of chronic illness tends to change over time and results in changes in attitudes, inclinations, and changes in physical conditions that necessitate implementation

of various coping strategies (Anderson & Bury, 1988). Individuals who make frequent visits to ambulatory care must cope with various aspects of the visits. This section reviews factors that enhance and hinder individuals' ability to cope with chronic illness that may be related to those patients who cope with the frequent visits.

Factors Enhancing Coping

Successful coping with the dynamics and the limitations of chronic illness is influenced by various psychosocial strategies (Masters, et al., 1983) and support systems ((DesRosier, et al., 1992; Masters, et al.,1983). Values, courage, confidence, hope, denial, and acceptance are notable psychologically strategies.

Values

Values such as family, cherished beliefs, and true relationships enhance one's ability to cope with chronic illness (Chilman, Nunnally, & Cox,1988; Harvey,1992; Mitchell, 1990). Mitchell (1990) investigated the experience of taking life day-by-day in later life. The sample consisted of individuals living with various situations including those needing chronic care. Mitchell found that values such as trust, the opportunity for change, and the ability to cope with and accept life's challenges were important to the enhancement of the quality of life in chronic illness. Rather than focusing on the illness, individuals focused on future possibilities and opportunities despite their limitations.

Harvey (1992) also investigated the role of the patient's value system in chronic illness and suggested that in nursing, when assisting patients to adjust to chronic illness, the value system of the patients must to be recognized. Harvey asserted that if patients' values are assessed and are facilitated by care providers, increased satisfaction with life will result. Values reflect what is important to the patient and are conscious efforts to retain significant values that lead to life satisfaction. Therefore, according to Harvey, the fit between the

value system of the patient and the value system of the nurses is crucial in chronic illness. Values that are maintained bring meaning to the individual's life and enhance coping.

Courage

Courage is another psychological strategy that influences coping in chronic illness. Haase (1987) studied courage in relation to chronic illness and concluded that courage was experienced in various stages and fundamental to the illness experience and to the treatment therapy. Using a phenomenological approach, Haase reported comments from nine chronically ill adolescents who described events when they experienced courage. Haase found that in the initial phase of an illness, the adolescents had difficulty identifying the experience of courage. However, as the duration of the illness advanced, they were able to discuss their experiences of courage in situational contexts such as when physical changes occurred and in altered interpersonal relationships. The adolescence used courage as a defense mechanism and as a coping strategy to deal with undesired situations. The degree to which courage was displayed was dependent and assisted by factors such as the quality of family support, present health status, the care provider, faith, and hope.

Confidence

Confidence was found to enhance an individual's ability to cope with a chronic illness. Padilla and Grant (1985) investigated the role of confidence in cancer patients and found that confidence to cope with the chronic illness correlated with psychological well-being and social concerns for cancer patients. Kirk (1992) used a phenomenological approach to examine the role of confidence as a factor in patients' experiences of coping with arthritis. Kirk asserted that confidence plays an important role in patients' adaptation to chronic illness and is an effective cognitive factor that influences illness and how well individuals' cope with the chronic illness. Patients were found to experience confidence

when care givers informed them about their illness and their treatment and when patients showed interest in themselves and confidence in their abilities.

Hope

Parse (1990) and Raleigh (1992) raised the question about the role of hope and chronically ill patients' abilities to cope with the demands of the illness. Using a qualitative, phenomenological method, Parse investigated the structure of the "lived experience of hope". The experiences of hope were solicited from ten participants (seven men and three women) who were on hemodialysis. Parse concluded that, in general, patients viewed the experience of hope as the anticipation of possible accomplishments despite daily stressors and the discomfort of the illness. She proposed that hope is a common human health and life experience that guides and enhances patients and their families in the everyday discomfort of illness. Patients simultaneously held a vision of the possibility of moving beyond the limiting, disabling effects of the illness. Parse contends that hope should be reinforced in patients and families in order to promote adjustment to the illness and to health.

Raleigh (1992) used a descriptive quantitative study to compare sources of hope as a determinant in coping strategies between 45 cancer patients and 45 patients with other chronic illness. Content analysis was used to analyze the data. The results showed that the level of hope was low in the majority (n=61, 67.8%) of the participants at various times in relation to the illness. Consistent sources of hope in these groups of patients were family, friends, and religion.

Denial

Denial was found to be a common strategy used in the experience of coping in some chronic illnessess. Bradley and Burish (1983) presented theoretical and empirical evidence of ways in which patients cope with chronic illness using contributions from

various authors (e.g., Krantz & Deckel 1983; Kaplan & Wyler, 1983) on coping responses and long term psychological outcomes. Denial was found to allow some patients facing chronic illness to slowly integrate the impact of the severity of the illness and the potential direction of the symptoms. For example, some individuals fail to accept the disturbing realities of living with such conditions as diabetes, kidney disease, cancer, and heart disease so that denial is exhibited. Individuals also exhibit denial when faced with the reality of being personally responsible for their health status and realize that they may become dependent on family and friends.

Acceptance

Acceptance of and adjustment to the illness limitations also enhance an individual's ability to cope. Ability to cope is partly determined by how well the chronically ill individual reorganizes his or her altered life-style and accepts the physical and psychosocial changes in spite of limitations (White, Richter, & Fry,1992). Using a quantitative approach, White and his associates investigated events that produce stress; the impact of stressful events on health; how patients adapt to, and cope with chronic illness; and the nature of support in chronic illness. A 71 item, self-report instrument was administered to a sample of 193 adult women who lived with diabetes for more than one year. The findings from this study supported the researchers' assumption that coping and adjustment to chronic illness depended on patients' perception of factors relating to the chronic illness. These factors include the ability to manage the limitations of the illness; certainty about the future; availability of good, reliable family, and professional social support systems; and availability of effective, palliative strategies. Factors that facilitated coping with chronic illness were independent of the length of time patients had the disease. These researchers emphasized that social influences are important for adaptation to the illness process.

Information on factors that facilitate coping suggests that specific psychological and social situations influence individuals' ability to cope and adapt to chronic illness experiences. Individuals who are experiencing a chronic illness face a variety of interruptions to which they must cope. These perspectives on how individuals cope with chronic illness contribute to the psychosocial experiences that may occur in individuals who frequently visit an ambulatory care department for treatment of a chronic disease.

Factors Inhibiting Coping

In addition to the physical limitations of chronic illness, individuals with a chronic illness will be challenged by various psychological experiences that will inhibit successful coping. These include uncertainty, depression, and stigma.

Uncertainty

Uncertainty is a psychological response that inhibits successful coping in chronic illness. Uncertainty limits individuals' progress to cope with the illness, increases helplessness, anxiety, fear, and creates stress for chronically ill individuals and their families (Strauss et al.,1984). Uncertainty also limits an individual's ability to make future plans (Hilton, 1992; Kopp,1992). Hilton (1992) argues that uncertainty is an inherent, cognitive state in patients with chronic illness with which they must learn to cope and that factors other than the patients' cognitive state are responsible for uncertainty. Two such factors are distortions and incorrect information about the illness. Hilton proposed that caregivers must assess uncertainty in patients to provide a basis for either reducing or eliminating their uncertainties. However, Hilton warns that patients may not want uncertainty reduced because certainty about the illness condition may be more stressful than uncertainty, especially in some chronic illnessess such as serious heart conditions. Hilton, however,

failed to specify why uncertainty affected individuals with different chronic illnessess in different ways.

Depression

Other researchers (Allen, 1989; Moody, McCormick, & Williams, 1991; Learnman et al., 1990; Kopp,1992) found that depression may inhibit individuals' ability to cope with chronic illness. Depression may be the individual's response to the loss of health and well-being and inability to accept the illness. Depression also may be a side effect of the treatment medication and the characteristics of the disease. When in a depressive state, the individual may demonstrate lack of interest in knowing about the status of his/her illness and may be reluctant to participate in his/her own care (Lubkin, 1990). Kopp (1992) proposed that depression may be more severe in some chronic illnessess than in others. Kopp (1992) investigated psychosocial issues related to diabetes and renal dysfunction and reported that depression was the most prevalent psychological factor in patients with diabetes and kidney disease. Given that patients who frequently visit ambulatory care may exhibit signs of depression, nurses in ambulatory must have an understanding of the possible causes and clinical manifestations of depression.

Stigma

Stigma is considered to be an inhibitor to effective coping in chronic illness. Jillings and Alexus (1992) contend that stigma may lead to lowered self esteem and an inability to cope with a particular chronic illness. They argued that not only is the general population responsible for negative attitudes toward some chronic illnessess, but that care professionals often are guilty of attributing negative connotations to some chronic illnessess. Moreover, some categories of chronic illness have social, negative connotations and assumptions attached to them when responsibility is attributed to the individuals for the illness. Negative connotations may be attributed to individuals with AIDS and diseases that are related to

smoking, such as chronic obstructive disease. Jillings and Alexus offered two possible explanations for negative attitudes toward some illnessess. First, these individuals may represent a deviation from society's norm; secondly, these individuals may continue to engage in health behaviors that perpetuate the condition. Consequently, this group of patients become stigmatized. The implications of these findings are that providers of care need to examine their own attitudes, values, beliefs, and sensitivity in order to understand and support both patient and family in appropriate care, coping strategies, and expectations about the outcome of the chronic illness. The degree to which individuals are stigmatized may depend on the specific chronic illness, society, and the caregivers' reaction to the illness.

The studies reviewed in this section have shown that there are several responses to effective and ineffective coping that may be associated with patients who frequently visit ambulatory care for treatment of a chronic disease. The major strength of these studies is the invaluable information they have contributed to the understanding of the psychological and social processes that enhance patients' ability to cope. Some patients who frequently visit ambulatory care for therapeutic treatment suffer from a chronic illness that fits into the category of individuals who may be stigmatized. Since stigma is a negative concept that may be attributed to the attitudes of society and possibly, of care providers, the environment in which individuals live and are treated may be an added challenge with which they must cope in addition to coping with the debilitating effects of the disease. Individuals who frequently visit an ambulatory care department may have similar experiences that may be revealed in this study of frequent visits and add insight into the depth of experiences associated with frequent visits to which care professionals must be sensitive.

Summary of Literature Review

This chapter is a presentation of current theoretical and empirical literature on issues regarding individuals living with a chronic disease. Research on chronic illness and research in nursing have not specifically addressed the frequent visits dimension of chronic illness, therefore, this literature review is broadly based on issues concerning chronic illness that are thought to be most pertinent to the study of the lived experience of patients with a chronic disease who frequently visit an ambulatory care department for therapeutic treatment. The primary focus of the review is given to psychosocial concerns.

The major strength of the studies is that they enhanced insight into the experiences of individuals who are chronically ill and how these experiences influence the life-style of the individual and family. Inherent in all the issues discussed on chronic illness, is that chronic illness is diverse, problematic, and complex and may produce major health concerns for the individual, family members, and professionals. Although there are specific problems and issues that are relevant to each type of chronic disease, several general issues are common to all chronic diseases such as cost, dependency, physical, and psychosocial limitations. Furthermore, it is shown that a medical orientation to manage chronic illness does not provide adequate knowledge of the illness experience and, subsequently, of the frequent visit process.

The literature review illustrates that, despite the vast amount of literature on chronic conditions and acknowledgment by investigators of chronic illness that the treatment process may be life-long, there is a dearth of literature, research studies, and developed positions relevant to the topic of frequent visits for treatment interventions. It is, therefore, evident that the frequent visit dimension of chronic illness is overlooked. If it is alluded to, it is discussed very briefly in the context of the treatment process and not as a potential stressor that becomes part of the lived experience of the chronic illness. This paucity of

literature suggests that researchers have failed to acknowledge the frequent visits aspect of chronic illness as an important dimension of the illness experience. Consequently, the experience of this group of patients have not been adequately investigated. Although the information from this review provides an understanding of what patients who make frequent visits to ambulatory care may experience, investigating the experience of frequent revisits from the patient's perspective is needed.

Chapter Three

Research Method

Design

The purpose of this phenomenological study was to explore the expressed lived experience of patients who make frequent visits to an ambulatory care department for treatment of a chronic disease. The meaning that patients' experiences with the frequent visits held for them was the central focus of the study. The study was designed to answer the question: What is the lived experience of patients who make frequent visits to ambulatory care for treatment of a chronic disease ? The study addressed the following questions: what aspects of the experience were satisfactory or unsatisfactory; what practices of the caregivers contributed to the experience of the frequent visits; what factors contributed to stress associated with the frequent visits and what, in the context of the visits, contributed to the patients' quality of life?

A phenomenological approach to the study was chosen because the experience of patients who frequently visit ambulatory care has not been adequately explored. This approach allows the researcher to establish an understanding of the experience under investigation from the perspectives of the patients. As well, underlying the premise of phenomenology is "because a person himself has been aware of a particular feeling at one time or another, he is able to experience what his fellow man attempts to communicate ... "(Van Kaam, 1966, p. 304). Individuals will be brought into contact with their own loving, hoping, and suffering experiences (Van Kaam, 1966). Therefore, in a phenomenological approach, the researcher tries to describe and to explore subjective experience without preconceived ideas (Omery, 1983) with the primary position that subjectivity permits basic human truths to be revealed (Husserl 1929/1979, cited in Thorne 1991). This is accomplished through an integration and a synthesis of individuals' descriptions of a

phenomenon and the determination of meanings from the descriptions. Phenomenology allows caregivers to combine their observation of patients' experiences with "biological facts about the patient. Caregivers can therefore, assume imaginatively the patient's perspective in the world" (Boyd, 1988, p. 81). Thus, through the phenomenological approach awareness of patients' experiences of frequent visits will bring the complexity of being human to the fore to gain a better understanding of patients' experiences. The principles of phenomenology: bracketing, intuiting, analyzing, and describing (Colaizzi, 1978) were used to guide the design (see Appendix A). This chapter will address the research method and ethical considerations.

Participants

Setting/Participant Recruitment:

The setting for the research was the ambulatory care department of a large tertiary care hospital situated in the city of Winnipeg. The time and place of the interviews were mutually convenient to the participants and the researcher. Interviews were conducted in the participant's home.

Hospital Access/Procedure

After the research proposal was approved by the Ethical Review Committee of the Faculty of Nursing (see Appendix B), the researcher requested permission to conduct the study from the Hospital's Access Committee (see Appendix C). Once access to the hospital was approved (see Appendix D), an explanatory letter and a synopsis of the research proposal was sent to the Head Nurse of the Day Medicine/ Day Surgery Unit, Ambulatory Care where most frequent visits of patients who are treated for a chronic disease occur (see Appendix E). The Head Nurse was asked to identify suitable patients who met the study criteria, explain the researcher's interest in the study, and to give them

copies of the description of the study and invitation to participate (See Appendix F). The Head Nurse was asked to record the names and telephone numbers of patients who received the study information. When the names of patients were obtained, the researcher telephoned potential participants and thanked them for considering participation in the study. The purpose of the study and what would be expected of them also were discussed. When the patient agreed to participate, an interview date and time were determined. The potential participants were advised that they would sign a consent form prior to the first interview as part of the study (see appendix G).

A week prior to the first interview, the researcher contacted the potential participants and confirmed the interview time, place, and date. Participants were advised that it would be essential that the interviews be private with little disturbance so that reflection of their experiences would be facilitated. They were informed that the interviews would last for approximately one hour. The researcher clarified questions and concerns and reminded the potential participants that they might withdraw if they wished and may refuse to answer any questions they did not want to answer without detriment to their care.

A trial interview was conducted with one participant. Polit and Hungler (1991) assert that a trial interview has several advantages. It detects representativeness; ensures the ability of the participants to express articulately about the phenomenon; and provides information that ensures adequacy of the data collection plan and clarity of the questions. After the trial interview, the researcher examined the contents of the transcript and established if the research questions and prompts generated from the participant's responses solicited the desired information (Geissler, 1990). The researcher also solicited feedback from the participant about her overall impressions and reactions about the research and made revisions such as rewording and timing of prompts as was necessary to improve the research (Polit & Hungler, 1991).

Participants/Criteria

The study was centered around seven participants (including the pilot participant) who met the study criteria. The sample size for a phenomenological study is usually small for two reasons 1) the nature of the study yields large amounts of narrative data (Colazzi,1978) and 2) the depth and detail of the phenomenon from each participant is allowed to be revealed (Brink & Wood,1989). However, the sample also must be large enough to be representative of the population being studied (Brink & Wood,1989).

A purposeful sample was used to select the study participants. Thomas (1990) defines purposeful sampling as the selection of individuals who are knowledgeable about the research problem and judged by the researcher to be representative of the sample population. Therefore, the reason for using a purposeful sample was to select articulate informants who would provide rich, in-depth information, be able to express their experiences, relate their responses to the situation, and be willing to share their experiences with the researcher (Morse, 1991). Participants were eligible for inclusion in the study based on the following criteria:

1) able to speak English and to express themselves well,

2) over the age of 18 years,

3) treated for a chronic illness at least once monthly spanning months or years, in the ambulatory care setting.

4) live within the perimeter of Winnipeg and have a phone for contact purposes.

5) able to sign an informed consent.

Appropriateness of the sample was ensured by the purposeful sampling (Parse, et al., 1985) and by adhering to the criteria.

Data Collection

In phenomenological research, data collection is based on retrospective descriptions of lived experience. The participants are the primary source of the information and the researcher is the primary instrument (Sandelowski, Davis, & Harris, 1989). The researcher's questions direct participants to reflect and describe events in which the experience under investigation occurred and how it is currently remembered (Parse, et al., 1985). The researcher enters the context of the participants unbiased and without presuppositions (Giorgi,1975).

Descriptions of the participants' experiences in phenomenology data collection may be written or collected through in-depth interviews (Boyd, 1990). The primary method of data collection in this study was through interviewing informants twice and use of the researcher's notes that were made after each interview. The use of interviews allows thoughts, feelings, and intentions to emerge and gives insight into the research phenomenon in which the interest, needs, and incentives of the participants are understood (Patton, 1987). Interviews in phenomenological research also determine dimensions, themes, images, or words that are derived from participants' responses. Questions asked must, therefore, be clear, specific, singular, and based on what the researcher wants to discover (Patton, 1987). The questions must probe the experience of the participant (Forrest, 1989).

The success of all phenomenological questions will depend on the researcher's ability to address the questions in a way that participants will respond from their lived experiences and not from their theoretical knowledge of it (Colaizzi, 1978). Therefore, the quality of the interview may depend on the researcher and may vary according to the approach taken. The quality of the interview involves skill, sensitivity, mental activity, discipline, neutrality, and rapport as the researcher delves into the inner core of the

participants, to get details and to provide a holistic comprehension from the participants' perspectives (Patton 1987). The researcher attempted to demonstrate these characteristics of a good interviewer throughout the interview process.

The Interview/Interview Questions

Participants were interviewed in their homes in a location specified by them. The initial discomfort experienced by the participants about the interview quickly dissipated after informal discussion unrelated to the interview. Thus, participants appeared to be relaxed prior to the interview questions. Participants were given further explanation of the study and what the researcher hoped to accomplish with the results. They signed the consent form prior to the interview question. Demographic data (see Appendix H) were collected to describe the participants' characteristics (Polit & Hungler, 1991).

The researcher attempted to use Giorgi's (1971) psychological method of data collection as the guide throughout the interview process:

1. Prior to each interview, the researcher attempted to bracket prior knowledge about the experience of frequent visits. This was accomplished by putting aside her assumptions about the study prior to the data gathering and before and during each interview (Parse, et al., 1985; Swanson-Kauffman & Schonwald, 1988) in order to enter the context of the interview with an open attitude toward understanding the participants' experiences. The researcher also attempted to be honest and open about biases. Although the researcher stated assumptions about the experience and put them aside, the researcher considered all data as having equal importance. This ensured that all participants' descriptions of the experience were considered in uncovering the meaning of the experience.

2. The interviews involved asking two open ended questions and listening to and rate recording the answers (see Appendix, I). Participants were asked to reflect and concentrate on the experience of the frequent visits exactly as the questions were asked. This part of the interview involved the participants' intuition, reflection and descriptions. Directions given to each participant were to 1) describe in as much detail as possible your experience of frequent visits to ambulatory care for treatment of your chronic disease, 2) share all your thoughts, perceptions, and your feelings until you feel you have no more to say about the experience.

3. More specific questions (see Appendix J) were asked, as were necessary, as the descriptions of the experiences unfolded. The additional questions served as prompts to clarify and deepen the participants' responses as well as to increase the richness of the data (Giorgi,1971; Patton, 1987). This approach allowed a better understanding of the complete experience. As well, this approach allowed for the experience of the participants to emerge naturally, rather than if aspects of the phenomenon were defined to fit the descriptions (Giorgi, 1971).

Participants attempted to structure their experience chronologically. However, in the initial part of the interviews and throughout the interview, most participants tended to describe their experience with their disease rather than to describe their experience of the frequent visits. The researcher often refocused the participants to the experience under investigation. Of the seven participants, one participant had difficulty elaborating on aspects of the experience. The use of prompts did not solicit much additional information. In this instance, the participant felt that "every thing was great" for him. The other six participants were able to express their experiences more elaborately. The duration of the interviews varied from between twenty minutes to one hour. The seven interviews provided the researcher with verbal and nonverbal data, enabled the researcher to use

interpersonal skills, and encouraged the researcher to facilitate the participants' efforts to express the experience (Colaizzi,1978).

The interview recordings were transcribed verbatim by the researcher. Participants were sent a copy of the transcription of this first interview along with the researcher's interpretation of significant statements and phrases about the experience that were extracted from the descriptions. Participants were asked to add, delete, and to correct information about their descriptions as transcribed. This process ensured that the participants were in agreement with the transcriptions and the researcher's interpretations did not differ from their original meanings. The transcripts, the significant statements, and the researcher's formulated meanings also were read by a committee member who had experience in phenomenological research. The changes that were suggested by the committee member were made to improve the concepts of the formulated meanings.

The second interview was conducted after the participants had received and had reviewed the transcript. It served to clarify and validate the participants' statements about the descriptions of their frequent visits. Participants were asked 1) is there any thing more that you would like me to add to the first interview? 2) do you need any further explanation or clarification of any of the research process or transcript before presentation of the research findings? Prior to this second interview one participant became very ill and required surgery. She was unable to meet for the second interview but indicated during a phone conversation and in person during a hospital visit that the transcript and the interpretations of the significant statements and phrases conveyed her meaning of the experience.

Additional information on one of the participant's personal life was solicited at this second interview, but additional information associated with the frequent visits was minimal and did not extend the data of the first interview. One participant thought that the

transcript was fragmented due to the many interruptions in his thoughts during the interview which were reflected in the transcript. He clarified many of his statements through writing on the transcript and through additional notes made on two sheets of paper. The other five participants made minimal changes to their transcripts. The changes were for clarification of statements that were unclear on the tape recordings. All of the seven participants confirmed that the corrected transcripts and the formulated meanings were consistent with their experiences and they did not request changes. The participants' and the committee member's agreement with the formulated meanings served to validate the researcher's interpretations of the significant statements (Haase, 1987).

In addition to the in-depth interviews, the researcher made notes about specific issues and themes which emerged from the descriptions, variations in participants' responses, and the researcher's personal experience and reflection in the context of the interviews after each interview. The notes were useful for making comparisons between the participants. The entries were in descriptive terms and were added to the interviews to expand the data base (Lynch-Sauer, 1985).

Information Adequacy

Information adequacy, "the sufficiency and the quality of the data obtained" (Morse, 1991, P. 135) is identified when there are no gaps in the participants' descriptions of the experience and nothing new is being described. Information adequacy ensures that the descriptions are relevant and complete and all information has been obtained (Morse, 1991). To ensure information adequacy in this study, the researcher recorded the participants' descriptions until the participants had nothing more to say about the experience of their frequent visits to ambulatory care. It was clear by the fifth interview that common themes were emerging. The additional two interviews proved that saturation

had occurred; no new themes were emerging from the descriptions of the experiences that were pertinent to the research questions. The interviews were terminated at this stage. Participants were reminded that they could contact the researcher at any time if they discovered information that might be important to add to the interviews or if they wanted information removed. If participants had requested removal of information that was correct and relevant to the investigation, the researcher would request the participants' permission to distort the information and present it in a manner that would not identify them. If this request is denied, the researcher would omit the information in keeping within the ethical boundaries of protecting the participants rights.

Analysis

Methods of phenomenological analysis vary. However, faithfulness to the phenomena is the principal aim of all data analysis (Knaak, 1984). Phenomenological analysis is the analysis of specific constituents of data that are obtained from described lived experience of a phenomenon. It is the production of meanings about feelings, attributes, and intentionality of the descriptions (Leininger, 1985). The analysis begins simultaneously with the data collection. Data are analyzed when the first interview is transcribed (Omery,1983) and involve three operations: 1) intuition, 2) analyzing, and 3) describing. These processes are lived simultaneously as the researcher interacts with the participants' descriptions of the phenomenon (Parse, et al.,1985). Colaizzi's (1978) method of analyzing phenonmenological data was chosen for this study because it appeared to be the preferred method used by other researchers (e. g., Forrest, 1989; Geissler, 1989; & Haase, 1987) who investigated lived experiences. As well, the researcher finds the various steps in the analysis clear to follow.

Steps in Analysis

1. Participants' descriptions were read through several times to acquire a feeling for the descriptions and to get a sense of the whole experience of the frequent visit to ambulatory care. The audiotapes were listened to in conjunction with the transcripts.
2. Significant statements and phrases about the frequent visits were extracted from each transcription.
3. Meanings were formulated from the significant statements. During this process, the researcher was careful not to differ from the participants' original description. The purpose of the formulated meanings was to transform the concrete language of the participants into a language of science. The meanings were validated by referring the interpretations of the significant statements back to the original descriptions, verification from the participants' that they were consistent with their statements, and verification from a committee member who is knowledgeable with the procedure.
4. Meanings that were formulated from the statements were organized into themes, theme clusters, and into theme categories. This task was accomplished by organizing clusters of themes from the aggregate formulated meanings. It allowed for the emergence of themes that were common to all participants' descriptions. At this time statements that were repetitious were eliminated.
5. The integration of the result was put into an exhaustive description of the experience in which a narrative integration of all themes, theme clusters, and theme categories was produced. This exhaustive description was developed to gain insight into the experience. It included a description of the process and the meanings derived through the previous steps.

6. A final validity step was achieved by having the committee member validate the meanings of the experience. Information that was added or deleted was incorporated into the final analysis.

The researcher attempted to bracket her prior knowledge and experience about the phenomenon throughout the analysis process.

Ethical Considerations

Researchers who engage in qualitative research that involves human subjects must adhere to ethical principles to protect the rights of participants. To accomplish this task, the researcher gave individuals who agreed to participate in the study verbal and written explanation of the study (see Appendix F) and obtained written informed consent prior to each first interview (see Appendix G). Informed consent involves giving full information to participants about the research and ensuring that participants understood their involvement in the study and their option to withdraw without penalty (Polit & Hungler, 1991). Information given to participants in this study included the nature of the research, the purpose and duration of the interview, the type of information to be solicited, what would be done with the recordings of the interviews during and on completion of the study (e.g., publications, presentations) (Canadian Nurse Association 1983; Boyd, 1990) and potential benefits of the results in influencing care to the participants and other patients.

Additionally, participants were informed about the possible inconvenience and the possible effect to their psychological status that may occur as a result of the interview process. May (1991) postulated that risks in the form of invasion of privacy and space may occur as participants reflect on their experiences. Furthermore, emotional disturbances such as embarrassment and anger are violations of privacy that are brought on either through reflection stimulated by the interview or inaccurate portrayal of the

participants' descriptions. The researcher guarded against emotional problems by telling participants to anticipate this occurrence and ensuring them that the interview would be terminated if the situation occurred. The researcher ensured that participants' descriptions of the experience were clear and accurate by developing and establishing trust and clear lines of communication during the research process. The researcher adhered to these considerations to ensure that participants' rights were protected and to ensure their physical and psychological comfort was maintained during the research. They were reminded that they could withdraw from the study at anytime (Canadian, Nursing Association, 1983; Boyd,1990). This opportunity to speak freely about the experience helped the participants to put their experience into perspective (May, 1991).

Participants were assured confidentiality and anonymity. They were advised that all information given to the researcher would be treated in a manner to maintain confidentiality and information that could identify them would not be given to anyone (Canadian Nurses Association, 1983). However, Munhall (1991) argues that confidentiality of data is difficult in qualitative studies as precise quotations from transcripts are included in publications. Participants were informed that to maintain anonymity, the tapes would be transcribed by the researcher, only the researcher and members of the thesis committee would have access to the transcripts, the information would be kept in a locked filing cabinet, and identifying evidence such as names, would not be on the cassettes or transcripts (Boyd, 1990). Participants were given a copy of the signed consent and the option to receive a copy of the study results.

Conclusion

In this third chapter, the purpose and the research method for this phenomenological investigation of the expressed lived experience of patients who frequently visit an

ambulatory care department for treatment of a chronic illness are outlined. In the following chapters, the research findings and a discussion of the findings will be presented.

Chapter Four

Research Findings

This phenomenological study was designed to uncover the meaning of the lived experience of individuals who frequently visit an ambulatory care department for treatment of a chronic disease. Recorded interviews from seven participants provided the data for analysis. The meaning of the frequent visits was extracted from participants' descriptions following Colaizzi's (1978) procedure for analyzing phenomenological data. During the analysis, the core meaning of the descriptions was maintained. This fourth chapter is a presentation of the research findings as uncovered from the participants' descriptions. In chapter five a discussion of the findings, implications for nursing, nursing education, and for future research and limitations of the research are presented.

Characteristics of Participants

The age of the four men and three women ranged from 39 to 77 years with an average of 56 years; their duration of the frequent visits to ambulatory care ranged from two months to 14 years with an average of 3 years 9 months. At the time of the interviews, one participant was making visits twice daily for three weeks, but had been making frequent visits every three to four months for approximately five years; one was making frequent visits every two weeks for seven months; one participant described the frequency of her visits as twice a week to every two weeks. At the time of this interview, this participant had been attending ambulatory care for approximately two months; another participant was making visits every three to four weeks for nine months. The other three participants were making visits once monthly; one for three years; one for three and one half years; and one for fourteen years. All seven participants were married. Six were

living with their spouse; one was widowed and living alone with the assistance of a personal caregiver. Three of the four men were employed; one was retired. Two of the three women were employed but were unable to work because of their illness situation; one was retired. Six of the seven participants lived in single homes; one in an apartment. Participants described their experience of frequent visits for therapeutic treatment for a variety of chronic diseases: intravenous gammaimmune treatment for hypogammaglobinemia (3 participants); blood transfusions for leukemia (1 participant) and for gastrointestinal bleeding (1 participant); intravenous antibiotics and Ventolin therapy for chronic bronchiectasis (1 participant); and abdominal paracentesis for liver failure (1 participant). It is important to note that this is a study of the lived experience of the frequent visits for therapeutic treatment of a chronic disease and not a study of the experience of living with a chronic disease.

Participants described their experiences of the frequent visits based on their perception of the illness situation and within the context of the frequent visit environment. The cluster of themes that were produced from the descriptions were difficult to categorize because of the variation in the participants' diseases and in their experiences. This variation, however, uncovered the unique experience of each participant. Seven theme categories were developed that were common to most participants: 1) an historical background of the illness leading to the frequent visits; 2) evaluation of the dimensions of the passage of time during treatment; 3) feelings that physical and emotional needs were met; 4) negatives experiences related to the frequent visits; 5) impact on the quality of life; 6) thoughts about the disease and the treatment in the context of the frequent visits; and 7) evaluation of the caring environment. A theme was labeled common if it occurred in most of the descriptions. Two themes: expressed desire for family involvement (extracted from one participant's description) and perceived threat to care (extracted from another

participant's description) that were not common themes will be presented because of their significance to the participants and their relevance to the frequent visits. The seven themes reflecting the meaning of the experience of the frequent visits and the additional themes are described in the following section:

Theme I: An Historical Background of Illness Leading to the Frequent Visits.

One important finding of the study is that all participants gave an historical description of their illness situation that led to the frequent visits. This historical background varied. For example, when asked to describe their experiences within the context of the frequent visits, some participants described the trajectory of their illness; some described prior experiences with health care related to their illness; and others compared and contrasted services of other health care facilities in which they were previously treated. Some participants included all three aspects of historical events. Consequently, recurrent common themes in the first part of the interview centered around participants' illness, treatment of the illness, and how the prior illness situation influenced their anticipation and expectation of the frequent visits.

<u>Illness Trajectory Leading to Visits.</u>

In the initial part of the interview and throughout the narrative, some participants gave a detailed description of their illness and appeared to focus more on the experience of the illness rather than on their experience of the frequent visits for treatment of their disease. Throughout the interviews, there was a sense that participants viewed the visits as another aspect of their illness. To focus only on the frequent visits dimension of the illness was difficult for most participants.

> When I was diagnosed first in May '89, the first two years, they were just watching because the count was so low. And they didn't do any treatment. And the first two years after that, the doctor gave me a drug ... so I was on that for ... about a year or so.

This participant also stated:

> I started going there ... somewhere in December, last year ... after having six chemos ... my hemoglobin went down. Then I started going there to get blood transfusions.

Another participant shared his experience of progression from in-patient care to the frequent visits to ambulatory care.

> First of all, the start of the illness came with recurrent pneumonias through the summer and fall of 1990. They were life threatening pneumonias, so I was extremely ill. And I would have antibiotics, and I would be discharged from hospital, and in two weeks I'll be back again. So I was very ill, ... when they finally hit on the gammaimmune deficiency.

Comparing and Contrasting Services

Four participants compared and contrasted their experiences with frequent visits within the present treatment facility with in-patient care and with frequent visits to other ambulatory care facilities. The first participant compared and contrasted his experience with frequent visits for treatment in the United States; the second with treatment in Oshawa; the third with treatment in Third World countries; and the fourth participant with treatment in another ambulatory care facility in the city of Winnipeg. The following examples further illustrate the participants' perceptions of the differences in the experiences. In three of the descriptions is the concept of cost; in each description were expressions of the difference in care. The first participant made the following two statements about visits for treatment in the United States:

> I spent about four months in the States and I had infusions there. Interesting as a

> contrast, in the States, ... I have Blue Cross/Blue Shield, but they would only allow it for six months and then they would review it even though the Dr. here, ... evaluated it as being something that I would need for the rest of my life.
>
> So actually, overall, the care was much less than it is here - in the States, both in terms of the nurses and the facility. I was under the care of one nurse, she was very good, but the facilities were not that good, ... we didn't feel comfortable with the doctors either. So ... that was the treatment in the States. Here, ... I've been coming in for a number of times.

The second participant who compared and contrasted the difference in the care in Third World countries to care in Canada stated:

> I think, medicine and care, especially giving blood on [ambulatory care], can be affordable for everyone ... In different countries you have to pay quite a substantial out of your pocket, and plus, you are already sort of pressed by the disease. At least, we don't have to worry about the pocket. You just have to worry about your disease. ... I personally like the service, and to a point, all the nurses there. The strength and help I consider I don't think I could get anywhere else in the world.

For this participant, availability and accessibility to care as well as having no financial repercussions as a result of his treatment, meant a great appreciation for the opportunity to be received in a health care system that offers universal care.

The third participant compared and contrasted the experience of home intravenous therapy in Oshawa with that in the city of Winnipeg. She described her struggle with caregivers to maintain self care at home rather than to be hospitalized. This participant lived in the city of Winnipeg prior to moving to Oshawa. She had been receiving intravenous therapy through a home intravenous program for 17-18 years.

> ... And when we were living in Oshawa, they wanted me to go into hospital every time for my medicine, and I just said, "No, you can put a hep - lock in and I'll do it at home". They protested and they said, "no, it can't be done, it's impossible" and gave every excuse in the book, but I finally won my case and gave it at home. Although it was much more inconvenient because we had to pay for the drugs and everything, but I was still able in the end to stay home.

This experience related by the above participant occurred approximately thirteen years ago. However, this is an experience in which the participant derived a sense of personal significance to the experience of frequents visits. Embedded in this experience is the participant's determination of avoiding the inconvenience of having to go to the hospital daily or to be hospitalized and to be firm in decisions that were important to her. As is evident in her reflections, being at home with her family was more important to her than the cost of the medication and the inconvenience of self administration of the intravenous therapy.

Participant four compared and contrasted the experience of frequent visits in a previous location of ambulatory care with the unit within which he is presently treated. The visits were associated with stressful thoughts that surfaced as a result of the physical environment of the unit and the feelings that derived from the experience of being among other patients whose illness conditions were perceived to be more advanced than the participant's.

> ... the environment that I was going into with all the different people there. ... You had the ones that were getting the platelets and ... the hemophiliacs. Some of them aren't there today, you know. These was things that ... kind of works on you. Because you don't know for sure with your disease whether you're going to progress down the road and get as serious as they are. Being in a big group like that, and looking at some of them that were pretty ill, it ... kinda works on you a bit. ... but now they've changed the system. We're into smaller rooms-only six beds, ... They've divided the people up a little bit, who go into the rooms.

He continued:

> It makes me feel a lot easier. ... now I can relate to [other patients] a little bit more because a lot of them are getting the same thing I am. So you know you can talk amongst yourself and discuss how it affects you. ... I think it's a better system. At least, it is for me because it takes some of the pressure off.

The participant relating this experience made frequent visits to ambulatory care for fourteen years. His initial visits were in an older section of ambulatory care. Throughout the narrative, the participant emphasized how stressful this experience was for him. The fear associated with the visits may be the result of uncertainty about the progression of his own illness, fear of suffering, and/or fear of his own demise. This shared experience was one of several references to his earlier experiences. The meaning that this experience held for the participant is his accomplishment of overcoming the anxiety that was associated with previous frequent visits and his perception that the change in treatment locations was more suitable to his emotional status than the previous location.

Past Experiences With Hospitals and With Treatment

Participants' descriptions of past experiences with hospitals and treatment were related primarily to prior hospitalization and treatment of their disease in which negative and/or positive feelings about the frequent visits surfaced. The following quotes from three of the participants best illustrate this theme and the variation within the theme. One participant described feelings of frustration that surfaced as she faces another experience of frequent visits.

> ... now I have to go back on intravenous, I tend to wait until I can't possibly put it off any longer. It's the frustration of once more going back to a hospital situation. It is the frustration of interfering with your life once more. Your whole family has to change their routine for the day until its over. Like my husband has to get up earlier to take me to work, and often has to work a bit later to make up the time that he misses in the morning.

A second participant described contrasting experiences during which he was treated for chronic infections in the early stages of his disease. He emphasized the effect of this initial experience on the present visits.

> When I got that treatment it was amazing. In other words, within hours I was much better. Within a week I was up and around and so on. So, it is ah - actually, a silver bullet kind of treatment. So that experience was - like - given me a new lease on life. So that's the positive thing I went into the treatment with.

Later in the narrative, when describing his feelings about the frequent visits, this same participant stated:

> ... getting back to 1990 when I was in with the pneumonias. The overall aspects of ... being in hospital is not a fun thing, and so, I always have that baggage, if you will, from that time. So if I had a choice I wouldn't be within ten blocks of the [hospital]. Just because that reminds me of the time I was very sick. But that's something I bring with me when I go. But ... that's something that's again, just an experience. But no one can do anything about it. Because its just a matter of being sick and needing treatment. But that aside then, ... since 1990 to now has slowly faded, at least, and now it's a more pleasant experience going to the [hospital] than it was initially.

The feelings described in the first statement are the positive feelings associated with the participant's expectation of the frequent visits. These positive feelings were based on the initial experience with the treatment results. The frequent visits were associated with feelings of well being. This meaning is evident in the statement that the treatment was "a silver bullet kind of treatment". The feelings described in the second statement conveyed the meaning that the participant did not perceive this experience to be life enhancing, but rather, a negative experience that influenced the participant's evaluation of in - patient care. The negative hospital experience can be likened to classical conditioning. The participant associated visits to the hospital with feeling ill as a result of the ineffectiveness of his previous treatment. The positive effect of the present treatment allowed the patient to reframe his negative experience to one of positiveness.

A third participant expressed feelings about the meaning of the frequent visits which were based on her past experiences with health care. The experiences occurred within the context of her early up-bringing, her employment, and within her married life.

> I wasn't afraid because I've been used to hospitals. I've been brought up around the hospital and doctors so I wasn't afraid ...

The lady relating this description was not afraid of the frequent visits and of caregivers because as she stated:

> Throughout the years we grew up on a sanitarium ... and of course, the doctors through the years ... grew up with us.

This participant worked as an xray technician. Her husband was a medical officer of health. These experiences reduced any anxiety that may have been associated with expectations of the visits.

A fourth participant described feelings about the first visit which were based on her minimal exposure to hospitals. Feelings of anxiety were evident in the description. For this participant, the illness situation was a new experience. This part of the description was described in a fearful monotone. The impact of the treatment experience and the participant's psychological anticipation of the visits are reflected in her statements.

> I'm just not accustomed to going for any kind of treatment. I've never been on drugs. I just have never been sick so this was a very new experience for me. We have always been very healthy in my family ... I'm just not accustomed to - to going to medical ... I have had bad experiences with drugs though, which gave me a lot of stress and side effects which really scared me because of what they were doing to me, and that put a lot a stress on me.

From this description, it is obvious that this participant has usually been healthy. However, a short history of illness that required medical attention influenced her anticipation and expectation of the experience of the visits. Later in the narrative, this participant described her perception of hospitals based on her experience as a visitor in which she expressed a dislike of hospitals. This perception may have added to her anxiety:

> I have never appreciated the hospital at the best of times even though I go and visit there. But I guess it's just something that I have to get accustomed to. I'm just not accustomed to going there for anything except visiting other people and encouraging them.

The above historical descriptions provide a background from which the frame of reference within which participants' descriptions of their experiences are influenced. Within the descriptions are psychological impressions that have been evoked as a result of these experiences. These psychological impressions have evidenced that each participant's experience has resulted in the anticipation and the expectation of the frequent visit experience. Additionally, throughout the descriptions, there is a sense that participants created an expectancy of the visits that exemplified the extent to which the impact of prior experiences influenced their perceptions of the caregivers, the care environment, and the physical environment of the frequent visits.

Theme Two: Evaluation of the Dimensions of the Passage of Time During Treatment

Each participant's experience implicitly or explicitly involved an evaluation of the meaning of the passage of time during treatment. Evident in the descriptions was that time had many dimensions. A variety of negative and positive experiences were described. Time for each participant was experienced within a specific context and was based on each participant's experience and perception of the treatment time. In two of the participants'

descriptions, the passage of time during treatment was perceived as time wasted and as a lost day. In another two descriptions, the passage of time during treatment was viewed as a psychological adjustment. For these participants, although the treatment took many hours to complete, they had "psychologically" prepared for the duration of the treatment by anticipating and planning for the time involved in the treatment. Therefore, the passage of time during treatment did not evoke anxiety or was it an issue of concern. In three of the descriptions were statements that implied that participants perceived the time during treatment was analogous to time for self help/supporting others during which participants either read, rested, or interacted with care givers and other patients.

Time During Treatment Described as Lost and Boring

Two participants' described the passage of time during treatment as lost and boring. Their emphasis was on wasted time. This perception of time indicated that participants' experiences of their inactivity during treatment dramatically affected the course of their lives. The first participant made the following comment:

> I guess ... a person just needs a lot of patience to ... be there that long. It just seems that the whole day is gone. Cause when I get home, then I just have to hit the bed. and it just seems like the whole day is shot. It's just ... I haven't accomplished anything much what I'm used to ...

This participant was self employed. Implicit in her description is that she was a very active person who enjoys being busy. She described herself later in the narrative as an active person and not a "bed ridden Queen". Treatment for this participant involved a procedure of abdominal paracentesis along with intravenous albumin. The restriction during the procedure coupled with her physical status immobilized her and limited her activity during treatment. Thus, feelings of boredom and wasted time surfaced. These

feelings were transferred to the home environment on discharge. The participant's ability to perform family activities was already impaired as a result of her illness. Inability to perform family activities as a result of the immediate crippling effects of the treatment further added to the participant's feeling of boredom and wasted time. As she stated:

> ... when I have a paracentesis, I am so painful for days on end ... We make the best of it and we do what we can even if I have to stay in bed."

For the second participant, feelings that the passage of time during treatment was lost and boring were based on the participant's inability to read and to engage in activities that would have eliminated the void during treatment. She related her experience as:

> ... just a lost day because you just lie there and it's as boring as heck. Because I can't read, and if I could read the light is not good enough for me to read. But you can't have bright lights all the time.

The participant relating this experience is elderly and retired. Her vision is gradually decreasing. Feelings of isolation were evident in this experience as she "just lie there". Also evident is that alternative activities that may have provided an occupation with the passage of time during treatment were not a consideration in the description.

The above two participants who described time during treatment as lost and boring share similarities in their experiences. Both women enjoyed an active work and family life. They implied that their inactivity during treatment counter their preferences to engage in meaningful productive activity.

Time During Treatment Described as a Psychological Adjustment

Two participants described the passage of time during treatment as a psychological adjustment. They had anticipated the time necessary for treatment. As one participant expressed:

> I'm nailed to the chair - I'm nailed to that place for about five hours. So how I handle that is a lot up to me. There is not a whole ... lot that the staff can do. If you start watching the clock the time is long, and so, some of it is psychological aspect to the treatment.

This same participant has acknowledged personal responsibility for coping with the passage of time during treatment:

> What I've done is set up time for the treatment, and so when I get there, how long the treatment takes, it doesn't matter because I've set that time. And I always bring reading and paper work. And what I've done is a kind of trick on myself. During the treatment I have something that I never quite get done until the treatment is over. So it is ... a game I play on myself. And it's very effective because if you once look at the clock and say when will this be over, you're lost. Because the infusions drops very slowly, and it's awkward ... it takes about ... four and a half to five hours.

A second participant did not state explicitly what activities he employed to cope with the passage of the time during treatment. However, he was psychologically prepared to cope with the passage of time during treatment evidenced by one of his statements. When asked to comment on how it feels to wait three to four hours for treatment, he responded:

> Not too bad. I know I gotta be there all along and I've already booked that time off work, so its really no inconvenience. It's okay.

Time During Treatment Described as Analogous to Self Help/Support of Others

Implicit in three participant's descriptions were ways in which their time is used during treatment. Their statements during the narrative conveyed the notion that they perceived the passage of time during treatment as a time to rest, read, or to interact with nurses or other patients. Statements extracted from the three participant's descriptions such as "Some days you are up and around more. Some days you lie down", " ... there is no interviews and so forth, and I just have a place to recoup my body", and "Well, I can sit and read now and you're not stopping your reading to be checked ... " suggest that within the treatment situation, time during treatment was utilized by some patients to engage in leisurely activities.

Later in the narrative, one participant described how he interacts with other patients during the time he is being treated. He spoke of his support to patients who are receiving the same treatment that he is experiencing. He described this as one of his most satisfying experiences during the frequent visits in the following two statements:

> ... I'm telling them what's happening to me. They're telling me what's happening to them. So you have a knowledge of what maybe is going to happen.

> There was a girl right across just the last month I was in. She was just starting. She has a different disease, but it's along the same lines. I was getting the same medication. So she was asking me how long I was there, and I told her from when and what was happening with me and she said, "oh, well, that - I'm tired" and I says "yes, well, that happens", "oh, oh, okay". So you know, there is something now she knows is not abnormal, something that goes along with it. It is a little bit different disease she has, but it's still the same medication, so you still get the same side effects. I asked her about the headaches, and she said she gets a very mild one. I said well, that could get a little bit worse if you keep the medication going. Every month it could get a little bit worse. But I say it never gets - with me it never got severe. Well, its a headache - it'll last about two days, and I feel all right. So it's just something that we talked about with hers and mines. Maybe in the end it will help her a little bit ....

The above statements are illustrative of participants' evaluation of the meaning of the passage of time during treatment, and the ways in which participants cope. Five of the seven participants experienced minimal boredom and anxiety during treatment. However, it should be noted that there is a difference in the health status of the two participants who described time during treatment as boring and as wasted and the health status of the five participants who utilized the passage of time during treatment productively. These two participants were limited in their activity during treatment as a result of their physical incapacitation and the nature of their treatment; the other participants were physically independent and not restricted by their treatment. Therefore, the passing of time during treatment perceived as boring and wasted was based on the perception of the women's illness, treatment situation and inability to engage in meaningful activities during treatment.

Theme Three: Feelings That Physical and Emotional Needs Were Met

Within each participant's description were expressions of feelings that their physical and comfort needs were met. Participants expressed these feelings liberally and in a variety of ways as they engaged in reflections of their experiences. The descriptions included feeling secure and cared for, feelings of emotional harmony within the caring environment, and feelings that the treatment environment was a home-like community of warmth. The following examples are illustrative of the variation in participants' expressions of feeling that their physical and emotional needs were met.

Feeling Secure and Cared For

Statements of feeling secure and cared for were related primarily to specific illness situations within the context of the frequent visits to ambulatory care. Participants perceived that care givers' nursing interactions were within and sometimes exceeded their expectations of care. Throughout the narrative, participants gave examples in which they

felt confident with aspects of the nursing process. These feelings represented their trust and confidence in care givers that have been acquired from experiences since their initial visit. They included feelings of certainty that their lives were never at risk even when nurses were faced with role complexity that occurred as a result of increased demands made by other patients.

> I have a great deal of confidence and comfort knowing that if something does go wrong, or if something like that [reaction to the medication] happens, that there is a complete backup. So you don't have to worry about that. So that's basically it. I get a strong feeling of confidence from the staff and attention. So, you know, I noticed that sometimes when all the beds are filled you are quite busy, but nevertheless, you never feel - you're never really neglected.

This patient expressing the above feelings experienced an anaphylactic reaction to the treatment during a treatment visit in the United States. He expressed the "confidence and comfort" in knowing that the caregivers have the skills, knowledge, and technological resource to effectively manage a similar reaction. This feeling is evident in his second statement.

> ... that's the reason I go to ambulatory care. Because there can be a reaction, and it can be a serious one, and so I have no worry because I know I'm comfortable with the safety there.

Two participants reported their meaning of feeling secure and cared for also using examples of crisis situations. Care givers' actions were remembered in detail and illustrated their meaning.

> ... And the other treatment of taking care of the patients, ... I remember first time - this is kind of quite an experience ... I had some sort of reaction from the blood, and I had started shivering after the second pint, and I remember at that time there were two nurses, and they really started- they were standing beside me, both sides, and they were just there giving moral and professional support.

> ... I had two bad reactions, and they were right there and sent me down to ICU one time ... and Dr. [Dr's name] looked after me. Now, they put that filter on for the blood and it helps an awful lot. I have had no trouble since.

Another participant gave a lengthy description of feeling secure and cared for that incorporates the emotional and the physical aspects of care. For this participant feeling secure and cared for meant.

> If you're having a bad day it's them being understanding that it's a bad day, and this isn't the way that you normally are, and it's no big deal. Just making sure that you don't wait around for hours before you get hooked up. They try to accommodate you to fit your schedule and just making sure you're comfortable. Some days you are up and around more. Some days you lie down more. Having a blanket thrown over you when you're lying down. It is really hard to say all the little things that make the big things go around. But the unit, I have never encountered a hospital experience as good as the unit has been, and I'm just very grateful for the love and the concern for the patients even though the staff themselves are in a very bad situation.

This patient continued to express feelings that reflected the depth and the breath of her perception of feeling secure and cared for.

> I feel very fortunate that we have this unit because I really have never, never felt any pressure by it. It has always been very adapting, and the patients isn't just a number who doesn't know anything. The patient is a human being who has feelings, who knows something about her or their condition. What they say is listened to and respected, and I have been amazed at how fast some of the nurses react if there is a problem. They don't kinda say, you know, "it will go away" or 'just let's wait and see what will happen ". Doctors have been called. They have been called sometimes a number of times in the same day.

This participant relaying this description had many frequent visits to ambulatory care as well as was an in-patient. Throughout her narrative, dissatisfaction with previous hospital visits that were related to the treatment and the caring environment were

expressed. At the time of this interview, this participant was receiving antibiotic therapy twice daily for three weeks. She sometimes chose to remain on the unit between the morning and the evening treatments. Within this time she interacted with other patients and with caregivers. Her daily visits to the unit and the duration of each visit made it possible for her to describe explicitly the caring experience.

Feelings That the Treatment Environment is a Home - Like Community

The meaning that the caring environment held for some participants were openly expressed and was illustrative of participants' adjustment to the unit. The participants used the word "community", "family", and "home". These words conveyed a sense of rapport with caregivers and with other patients that represented a home-like environment within the treatment environment:

> ... but here its like a community, in other words, like a family. There is the staff-nurses and so on, and that's sort of infectious with the patients. The patients often are good humored and pleasant. So it makes a pleasant time of it.

This participant continued to describe what he meant by "like a family".

> So in that sense, if a patient wants something, there are six of us in the room. It's like a ward, but if somebody needs something they may have to be told : "if you could just wait a minute", but within a minute, somebody is there to help. So it is a very, very supportive group.

Another participant summarized his meaning of a home-like community.

> ... anything it could do better ... right now for me and my experience, I would say' no. I'm getting pretty good care. It's almost like a personal basis. It's like a family. So I couldn't think of anything off hand to change it to make it any better other than having the pharmacy open earlier in the morning so that I could get outa here quicker.

Comments from other participants such as "when I first came in this time the staff was all very friendly. They made me feel at home" and "it [meeting an acquaintance, a caregiver on the unit] made me feel at home" evidenced that participants' experienced feelings of comfort and warmth within the caring environment which they likened to a home-like community.

Feelings of Interpersonal Harmony Within the Caring Environment

Feelings of interpersonal harmony within the caring environment were disclosed as participants described their experiences of social encounters with care givers. The key perception in these descriptions is that participants felt that the interpersonal interactions were important and helpful to their emotional well being during the visits. Five participants expressed their feelings in the following statements. The first participant described his feelings in relation to the interpersonal interactions of the nurses:

> ... Oh, they're very friendly ... you ask for something they get it for you. They're nice to talk to. It's, just nice going there. I have no trouble whatsoever. Yes, I'm very happy going there and like other patients that I talk to seem to be very happy there also. So as far as I'm concerned, the treatment there and the nurses there are ... doing a very good job.

For another two participants, the greeting interaction is important.

> They say "hello, hi Mrs.---you're back again". And I said "yes, I'm back again". And we started bantering back and forth and it's a happy ... thing. You know, not happy but it's pleasant ... When I see them and they say, "hi Mrs.---"it makes me feel good. That's important to me ...

> They come in, and they always greet you, and they'll kid around with you and like for instance, they knew I had a parking ticket, not a parking ticket, a seat belt ticket. So one of them came out just as I was going and says "make sure you collect your two hundred dollars before you go to jail". It's just the little jokes ...

Another two participants relayed experiences of personal encounters in which they perceived that caregivers were genuinely interested:

> ... I know like last year, I mentioned that we went to Hawaii. I just mentioned that I just came back from holidays and, "oh, so I heard you just went to Hawaii?" "How was your visit?" and that. The same thing, I went to Toronto ... two weeks ago, and came in and ... right away he [the doctor] asked me - I went there [Toronto] to raise some money for our church - "how much money you collected?" and "how is your family?" - I went to visit my father and my brother ... and he asked me all the questions in detail "How did everything go?" So you can feel you know, kind of proud, you know, that you are not ignored.

> Well we just don't talk about the illness. You gone on holiday - "how is your holidays"; I'm going on holidays; "how is the lake going" You know, it's - like I say, it's a family atmosphere. It's more at home. Instead of going into a ... flap and wait situation, ... clinical only, that's not good. This is more casual, more friendly - it's a better system. I enjoy it better, makes it easier to go, cause if you walk in there and it's just - okay put the needle in, bang; gotta take your temperature, good, that's it. It's too cut and dry. This is more friendly. It makes everybody relax a little bit more.

Participants' interpersonal encounters were related to specific events in which there were caregivers' and participants' interpersonal interactions. The personal satisfaction experienced from these encounters were in addition to the participants' satisfaction with the professional role of the caregiver. This meant that patients' biographies are woven into the fabric of the context of the frequent visits. Interpersonal encounters were important to the enhancement of the experience of frequent visits and care givers' interest in participants' personal life conveyed a meaning to the participants that caregivers were concerned with all aspects of their lives.

Theme Four: Negative Experiences Related to the Frequent Visits

The fourth theme, negative experiences related to the frequent visits, represents a set of difficulties that the participants experienced with aspects of the frequent visits. Six of

the seven participants' description of the experience involved a negative experience. The negative experience varied for each participant and was dependent on the extent to which the experience frustrated or inconvenienced the participant. In some cases, the negative experience evoked minimal concern and in others, great concern. Negative experiences include waiting time for treatment; feeling stressed with aspects of the visits; discomfort as a result of the treatment; the inconvenience of parking during the visits; and dissatisfaction with aspects of nursing care. Some participants described more than one aspect of negative experiences.

Waiting Time for Treatment

Three of the participants shared their feelings of frustrations when waiting for their treatment to be established.

> The only thing is the waiting for the IV nurse to come to put the IV in, and that seems ages before she gets there. It will be ten o'clock. I had to be there by nine ...
>
> ... sometimes ... you'll be there 45 minutes waiting for it to come. At one time they were opening the pharmacy at eight o'clock. Now it's gone to eight thirty. So that means they open at eight thirty, but sometimes a quarter to nine to nine o'clock some days before you get your medication up.
>
> So I know that they have very, many obligations, and I understand that. But it's sometimes when you come and have to wait an hour ... before they start you on something, and I could have come an hour later. Now I would appreciate if that could be rectified, but I know sometimes there is an emergency and it cannot be avoided.

Embedded in the above examples is the notion that participants perceived that, in some cases, the waiting could have been avoided. They perceived that if their visits were scheduled at a later time, that the waiting time for treatment would have been reduced. Additionally, implicit in the descriptions is the that participants perceived that there is lack of respect for their time. This perception is evident in their statements regarding the time

when they were scheduled for treatment and the time when they were actually treated, a situation which appears to be habitual.

Stress and Discomfort With Aspects of the Treatment

Discomfort related to the treatment procedure were reported by three participants. For one participant, the discomfort included experiencing pain during the procedure and feeling stressed as a result of traveling to and from the visits (this same participant expressed her negative experience with waiting time for treatment); for the other two participants, the discomfort was associated with insertion of the intravenous device that was a necessary part of their treatment. For these participants, the experience posed a threat to their comfort during the visits.

> ... Yes and the pain that I have to bear when I have to have those visits. They keep me in bed, and I'm not a person - I'm not a bed ridden queen. I like to be up and - so it's very hard for me not to be active.

This same participant expressed feelings of stress related to the going back and forth for treatment.

> Well, it's ... hard to explain, but it ... does put a little bit of stress on me to go back and forth all the time. I have never appreciated the hospital at the best of times even though I go and visit there. But I guess it's just something that I have to get accustomed to. I'm just not accustomed to going there for anything except visiting other people and encouraging them.

Discomfort with the intravenous device was often distressing for a second participant.

> Well, I wish she will come and get it done and over with. Some of them...put it in and it doesn't hurt at all, and others, it just aches all day. It depends on the girl, I think. Whether she is good at it or she is not. Some are, some aren't.

Later in the narrative when asked what it felt like to be traveling back and forth for treatment, this same patient expressed her aversion to intravenous needles. This aversion may have added to her negative experience "I don't like it because I don't like getting that darn IV put in".

A third participant discussed problems with the unsuccessful attempt at insertion of a peripherally inserted central catheter (pic-line) used for some patients who need moderate to long-term intravenous therapy:

> My veins are all now no good. They have to put in a pic-line. The first day they tried to put in the pic-line-I have never fussed about an intravenous, but I couldn't [stand it] - it was so bad I finally said "enough! Quit! I'm not having anymore!"

<u>Reaction to the Treatment</u>

Reaction to the treatment represented a different kind of negative experience. However, the participant relating this experience acknowledged that the reaction is a potential complication of the treatment. When describing negative experiences during the frequent visits, this participant stated:

> The only negative thing is reaction to the treatment, which again, is something that can't be avoided or anything done for it.

This participant explained his meaning of reaction to the treatment as a negative experience.

> In terms of the treatment itself, within about six to eight hours after starting the infusions, I have about a two day reaction .... Usually, after the treatment, I'll sleep about 12-14 hours. And - it's about two days before I can do anything. So I always say a long weekend starts with my treatment. But that's a negative side that I always know is coming even though I feel not too bad when I go in for an infusion. I know I've got that two days recession to go through.

The Inconvenience of Parking

Difficulty with parking was expressed as a problem by another participant. However, this was not a major issue of concern. Often parking difficulty was due to no available space in long term parking facilities. To find and to use an alternative parking facility such as public parking meters was not an appropriate choice. Delay in treatment beyond the anticipated time may have resulted in parking fines. In addition, searching for parking availability increased the participant's time away from work and delayed the implementation of treatment. The cost of parking over a prolonged period was another consideration in the inconvenience of parking. When discussing this experience, this participant described how he solved the parking dilemma:

> Well, the only problems I did have was with the parking there. I know you had to park, but I usually get somebody to take me down there, drop me off, and then I phoned them when I'm finished and they come and pick me up. But no, no there is no trouble at all to get down there and do it.

Dissatisfaction With Aspects of Nursing Care

One participant described two nursing situations that caused her concern: waiting to be made comfortable in bed and an unsanitary act that was performed by a caregiver in which she immediately voiced her concern to the caregiver.

> ... there was a couple of days they didn't have time to put my bed up. I had to wait a long time ... One gave me a pillow that a man had his foot on. I did not appreciate that and I questioned it and she took it and put a clean pillow case on, so I thanked her for that. But that has only happened once.

Two participants voiced concerns about waiting for meals/fluids to be served:

> Sometimes you have to wait for your lunch till three o'clock - three thirty. It's a little bit too long. I think they have forgotten about me but I can understand that.

> ... I think the (...) didn't really think I needed to be there too much for a while,

> and for the first few days, I didn't get asked if I wanted a drink or anything else. I thought, "have I done something wrong?". But then one day I decided, this is crazy, and I just asked ... for something and after that there was no problem.

Within these descriptions are events in which the participants felt that aspects of their care were neglected by caregivers. Also implicit in the description is the participant's feeling that she was responsible for the lack of care. Although the participants voiced their displeasure about the events, they were quick to cover up their displeasure. Their positive comments that were associated with the descriptions of the negative experience indicated that the participants perceived that the situation no longer existed or that they minimized the extent to which the experience affected them. It may well be that the participants were trying to avoid making negative comments about the unit. It is also likely that negative experiences were minimized because the research was conducted in the researcher's place of employment where the participants are known to the researcher. Participants may have perceived that speaking candidly about their concerns may have jeopardized their care.

The above examples of participants' descriptions evidenced the negative experiences that were associated with aspects of the frequent visits. The meaning that the experience held for each participant ranged from minimal to great concern and was dependent on how the participant defined the negative experience.

Theme Five: Impact on the Quality of life

Impact on the quality of life constitutes the fifth theme in the experience of frequent visits. Each participant's description involved conditions of the visits that impact on dimensions of his or her quality of life. In some cases, the impact was related to alteration in family life, alteration in work life, feelings of dependency, and inability to make plans for the future. Participants described how they and their significant others coped with the disruptions that arose within the demands of the frequent visits.

Alteration in Family Life

For two women, the themes reflecting alteration in family life were based on their experience of the limitations placed on them and on their families. The limitations were a result of the illness coupled with the experience of the frequent visits. The first participant described the difficulty experienced when adjusting to the sudden changes in the family situation.

> We like to entertain them [her grandchildren] and play games and that ... it's just come almost to a halt ... unless we do just one or two at a time once in a while. So it's just that it is such a change of pace that all of a sudden it has just fallen into our lives unexpected ... so naturally, it does wear you considerably; not being able to be free to do the things that you would like to do with your family.

The following two statements were made by another participant. She described the difficulties encountered as she coped with the activities of daily living.

> And things like the laundry is always done, and put away isn't being done. So this is sort of a lot of frustration in everybody's pot because you're going on for so long, and then you're right back to it [the illness situation].

This participant is describing the back and forth adjustment to the illness situation that she and her family must endure. For this participant, the frequency of the visits are interspersed with periods of remissions in the chronic illness. During the periods of remissions, the participant is able to resume the activities of daily living. Family life regains normality. In periods of crises that necessitate frequent visits to ambulatory care for treatment, family life is once again disrupted. Disruption in family life was not only experienced within the context of performing household tasks, but also within the context of family meal time. The participant described situations in which the family resorted to restaurant meals which the family could not afford. Also described are situations in which

the participant felt concerned that her child's nutritional needs were not met. The feelings generated from this experience represented the depth of the participants' frustrations with the time demands of the frequent visits.

> And sometimes I don't know if some of us even eat ... we were going out to restaurants when we shouldn't be going out to restaurants. And my son ... doesn't eat a good breakfast, or if I'm not home, he tends not to take a lunch (to school), so that means he eats breakfast rarely and then doesn't eat until he comes home from school.

Throughout the descriptions, there was a sense that the women relating the above examples felt totally responsible for what they perceived to be the disarray of the family unit. For these women, thoughts about their inability to meet family demands were the center of their focus. They appeared to be more concerned about the services they could no longer provide for their families rather than concerned about the impact of the illness on their quality of life. Consequently, these women presented an appearance of struggling to fulfill the demands of daily family life in addition to coping with their incapacitation and personal difficulties.

Inability to Make Future Plans

Inability to make future plans is a second impact on participants' quality of life that participants found to be a source of difficulty. They shared their feelings of the conditions of the frequent visits that were directly attributed to their adaptation to the patterning of the illness and to the frequent visits situation. Additionally, participants discussed a sense of disruption in their social and personal lives that were situations in which feelings of being trapped in a decision dilemma surfaced. Three participants shared their experiences. In the first description the participant described limitations on traveling and planning vacations.

> ... I'm essential tied to Winnipeg. There was a time when I spent two month in South America or Europe. I can't do that now ...

This same patient continued to describe an event in which the schedule of the visit made planning difficult.

> ... for example, planning - We [were] going ... to see my mother this month, but I have a treatment in the middle of the month, and I need those two days, so my wife was just talking to my sister on the phone: "Well, we can't come that week because of ... the treatment". So we had to juggle things when we can go and when we can't go places.

In the following three statements this inability to plan vacations is further described. Feelings of ambivalence and personal discomfort by intentionally missed treatments in order to accommodate personal preferences for the participant and family are at issue:

> Sometimes it [the frequent visits] cuts into your plans a little. That makes it a little tough ... I'm cheating this time myself. ... I would say that ... is probably the one that bothers me most. It's having to go a little bit longer so that I can do something that I want to do.

> Well technically, I'm due to go in for an infusion right in the middle of my wife's holidays. So that would mean that I would have to come in from the lake. So what I'm doing, which I shouldn't, I'm postponing it one week longer. I'm going to go five weeks this time instead of four. I take a chance by going the one week longer, but I'm doing it so that I can go to the lake for two weeks with my wife.

> ... Well, I guess it does kinda make you a little bit stressed because I'm worried I'm going to get sick because I'm making it go a little longer. But then, I don't want to split the holidays in the middle to come in for it. And ... it happens a few times a year, about three times .... Christmas time is a bad time trying to figure it into your holidays. Where I work, they shut down for the one month. I try to get ... the infusion as close to the shut down date so that I don't have to come back in on my holidays to get the next one. We shut for one month, so I try and get it ... the day the shop shuts down, I get the infusion so that the day I'm going back I get the next

one.

Feelings of frustration associated with inability to make future plans were also expressed. The frustrations are intensified when the spouse's and children's life course are disrupted by the demands of the treatment process. The following statements express this aspect.

> It frustrates me that it affects - the inconvenience affects not only me. It affects my husband, it affects my son. The inconvenience - you can't plan very much. Most of the time, I wouldn't even plan a week ahead because you don't know

> I am frustrated because its not something that you share and that's it. It's something that is not going to get better, it's going to get worse. It's something that isn't - you can't say, "well, I've had the treatment, this is it now, we can start planning again, we can start doing what most families do." You know, that isn't the case. You know that you'll just start getting involved in something and bang, you don't know how long you're going to be involved.

Feelings of Dependency on Others and on the Treatment

Participants' quality of life also were affected by thoughts of dependency on the treatment and on others such as family members and caregivers. Family members were involved primarily with the transportation of participants to and from the visits. The following examples from five of the participants' descriptions reflect the various meanings of dependency and participants' feelings of dependency.

> But ... for me, it's a bit of a trauma ... not because of people, it's just going for therapy, and I can't do any other things that I would like to do with the family or do my own work at home. I have to depend on other people which has been very difficult for me. I have always helped people. I have enjoyed helping people. I like to be a server rather than to be served.

> Well, my sister would bring me in and she'd see that I was in good hands, and then she would leave, and then they would phone her when I was ready to go home, and she would come and get me. She would take me up in a wheelchair. She would come to the admitting office with me and have me admitted, and [take]

me up in a wheelchair.

Dependency associated with the permanence of the treatment was reflected in the following statements.

> ... and I think since this is a long term care - I have to go through transfusions every four weeks, the overall feeling is one of permanence. In other words, it's not like, maybe we wouldn't be here next time. So there is the confidence in it as well.

This same participant summed up his meaning of dependency on the treatment as he stated:

> The visits only remind me of the need for the treatment. So it isn't the people but it is ... dependency on the treatment. I don't know if that makes it fair, but there's nothing, there's nothing you can do about it because I just have to do it.

In this next example, not having a choice is notable. The link between the visits and the frequent visits was perceived to be an extension of the participant's life.

> Well, once you know there is not much choice - either to take transfusion, and there is nothing, so I have no choice to go there. And ... the feeling I ... get sometimes - if you have a choice. In my case I didn't have a choice, and ... either you have to visit, or ... not ... go ... and I want to get extension to my life ... so that's why I sort of went along with the doctor's. recommendations

Underlying these statements from the participants' descriptions is the notion that dependency on the treatment and others are intrusive thoughts that coexist with thoughts of the treatment situation.

Alteration in Work Life

How participants managed the frequent visits in the context of their work was dependent on how flexible they were allowed to be in their working environment. The effect of the visits on participants' work life had varied meanings for each participant.

They included planning visits around working hours so that missed work time was made up later ; missing wages because of missed hours from work to accommodate the visits; and feelings of being ostracized at work as a result of frequent absences from work that were necessary when the participant required treatment. The following participants' responses illustrate the differences in the work related experiences:

> I plan such a way that I have to take on Friday and I have Saturday and Sunday off, so in that way, I rebook my self, and in case of any sort of infection, or some other - let's say, fever or something like that, so then I'm back to normal after the weekend.

> I usually go in the morning, around nine o'clock in the morning, usually on a Wednesday of that week. I leave work to do that, and I don't have no problems at work. The reason is that I make my time up. I either work later or start earlier and it usually takes between three to four hours for the whole treatment.

For the above two participants, the rescheduling of work hours to accommodate the visits was not perceived to be stressful. Participants were able to combine the treatment visits with their work life. However, two other participants expressed their experiences of the impact of the visits on their work in terms of financial loss due to missed hours from work and feelings of being punished by the participant's employer for frequent absences from work.

> ... You lose work ... I lose a day's pay by coming in. That sometimes bothers me. You know, when you're short of dollars a few times in a year and you got to lose it because of the illness. But ... I guess, over the years ... you kinda mellow a little bit on it, ... you take it as a fact of life and go on from there.

> It's the ... interference with work ... you miss and you don't get the same treatment at work. I was treated like dirt at work because she [her employer] knew I was a good worker, she didn't want me to go, but she would hold it over my head because I had missed this day or that day or this time. And even if you point out to them, well, I haven't missed every weekend, they have it on you that you missed and that's it, and that's the same with my husband's job. You can put in as much extra time as you want, but if you take off time on a regular basis it goes against you.

This participant continued to express thoughts about how doctors blindly make arrangements for visits without consideration of patients' personal lives:

> Doctors continue to amaze me. I think it's because they are so busy they have no idea what a regular life involves. And they know how much times they see you, they know how many doctors they send you to, they know how many times you're sick, but they don't always put it together in how it affects your working life, your family life, and you as a person. And my doctor is a very understanding man. ... when he has been called, he has always been there. If he's in the city he - I couldn't ask for any better treatment. I still get frustrated because I don't think he realizes how employees react to somebody with a long-term condition. If you have a short term condition like a hysterectomy, well, that's fine.

The above experiences illustrated the meaning of alteration in work life for each participant. The impact on work life appeared to be dependent on the participants' ability to alter the work conditions to meet the frequent visit schedule, how well the participants' economic status is affected by the loss of wages that resulted from missed hours from work, and employers' tolerance of employees who have frequent absences from work because of illness. There is also the notion that doctors who are arranging visits for patients show insensitivity to the patients' personal agendas and the impact of their insensitivity to the patients' quality of life.

While the impact of the frequent visits on the participants' quality of life cannot be exactly the same for each participant, the descriptions of the experiences have illustrated that several factors associated with the frequent visits impact on patients' quality of life in similar ways. These include the interactions of caregivers as they relate to the frequent visits schedule and, consequently, to the patients' family life, work life, and social life in terms of future planing; the treatment itself as a source of dependency since it is viewed by

the participants as their means to survival; and the participants' family and personal ability to adjust to the dynamics of the frequent visits situation.

Theme Six: Thoughts about the Disease and the Treatment in the Context of the Visits

Most participants' description of the experience involved thoughts about the disease progression and the effectiveness of the treatment.

Thoughts About the Progression of the Disease

In most of the descriptions there was a sense that participants' thoughts were focused on questioning the future of their disease. A major concern for one participant who had been receiving treatment for 14 years was that his disease had progressed, as had been predicted, to a malignancy. Intrusive thoughts about the disease outcome was constantly in his awareness during the frequent visits.

> It's not going to get better, and over the years - even in '78 when I was diagnosed with it at that time, they said I am susceptible to lymphoma. They told me that. From 1978 until '93, or actually '94, I didn't have it, but it's always in the back of your mind. And now I have lymphoma. So, you know, for 14 years you kinda think about it, and you don't try to think about it, but every once in a while it comes and just pops into your head, and you know, you're lying there and you're getting your infusion and you're thinking well, you know, what's going to happen next, ... this is a chronic thing, you have to have it for the rest of your life ...

This part of the description was delivered in an emotional tone with the indication that the participant had many concerns about the disease outcome. Throughout the description, the participant had a facial expression of resignation. However, despite his deteriorating health status, he maintained a positive attitude as was reflected in his statement "But I've come to a point now where I've decided I'll fight this. ..." Finally the dreaded prediction had become true. There was no longer any uncertainty to fear and he

will fight the disease and hang on to life. This next participant has insight that his disease is incurable. He expressed gratitude for the improvement in his condition and hope for the future. He perceived the treatment as life saving and described the limitations, opportunities, and courage derived from the extension to his life that is afforded him by the treatment.

> Well, I guess as you know, this disease, we know there is no cure. I guess it is only to sort of extend your life because I sort of read some books on this, and that's what it is. But I think that this support of professional help from doctors and hospitals, I think each day extends my life. I thank God everyday, in the morning when I wake up I thank God that I'm seeing one more day, and in ... that way, I feel happy and so far, like I say, in the past five years - who knows? maybe another fifteen or twenty years?

Thoughts About the Treatment

For some participants, there was a perception that the treatments were temporary means to alleviate the symptoms of the disease. They were aware that the disease would progress to a point where surgery may become necessary. Other participants perceived that the present treatment was the only treatment for their disease, and that treatment would be life long. Within participants' descriptions were expressions of uncertainty about the future:

> The only other thing they can do is surgery, and nobody wants to do the surgery because I'm in congestive heart failure. I had a mitral valve replacement in 1984, and ah, I get short of breath on exertion. So they are treating that as well so they can proceed ... to operate, to find out where this bleeding is coming from. So when the blood drops, they send me in for a transfusion.

Uncertainty about the treatment effectiveness is reflected in the following participant's emotional description of her illness situation.

> It is frustrating because every time you come in ... this might be the last time

> before they have to do surgery ... I seem to react to more and more of the drugs. I mean a couple of times I was really sick ... Lung surgery isn't as uncommon as it used to be, but lung surgery is lung surgery. You don't feel happy about it and as long as I have a spot on my lung, I'm going to get infected.

In the above examples participants described the pervasive intrusions of thoughts about the progression of the disease and about the adequacy of the treatment. These thoughts occurred within the context of the frequent visits and coexisted with participant's uncertainty and questioning about future care.

Theme Seven: Evaluation of the Care Environment

Most participants' descriptions involved thoughts that reflected an evaluation of the general context of the visits. These thoughts were expressed in many different ways. They included a positive evaluation of the care environment and of the care givers; thoughts about future visits related to the illness trajectory; and thoughts about desired changes that participants believed would improve the quality of their frequent visit experiences.

Caring Environment and Caregivers Evaluated Positively

The care environment and the caregivers were evaluated positively by all participants. Feelings about participants' physical, emotional, and interpersonal care were summarized in the following statements:

> I think the experience of the ambulatory care is a very positive one. The staff are very helpful and very attentive to the needs we have. The thing is, that I've noticed both myself and other patients are very well treated. The only thing I would add, and I mentioned earlier as well, and that is that a lot of problems that I may have or not have is nothing to do with you. It is a pleasant surrounding, it's comfortable ... but as far as what the staff can do in a positive way, I think it's 99 percent done. So I think that covers most of the things that I have to say about it. It is a positive experience. It works well.

> I think the attitude there - even all the patients, just talking to them, they say "it's a good - this is not a bad place to go". Now, compare to some places in the hospital,

> it's - it's not a bad place to be. You have to be there, it's not bad. Other than that, I think, that's all I can say on it.
>
> Well, I feel very important and let's say, when the patients ... require assistance or when the service is available. ... I think they sort of treat you properly. In other words, I feel that if somebody visits there, it's not annoying ... and I'm quite happy with the way the unit is run.

The following two statements were made by one participant who described her reluctance to seek medical attention in illness crises until her condition was critical. Additionally, she expressed appreciation for the presence of an ambulatory care facility that meets her psychological needs more than an in-patient facility.

> Well, it certainly encourages you to go and get treatment when you need it. There have been lots of times I just haven't gone in until you collapse or something, because you just don't want to be anywhere near a hospital.
>
> I feel very fortunate that we have this unit, because I really have never, never felt any pressure by it. It has always been very adapting, and the patient isn't just a number who doesn't know anything. The patient is a human being who has feelings, who knows something about her or their condition. What they say is listened to and respected, and I have been amazed at how fast some of the nurses react if there is a problem. They don't kinda say, you know, it will go away or just let's wait and see what will happen. Doctors have been called. They have been called sometimes a number of times in the same day.

Another participant succinctly summarized his thoughts about the care environment "I would say it is very excellent care ... I have no complaints".

Included in the above evaluations of the context of the care environment are participants' perception that other patients also evaluated the care environment positively. To include other patients' perceptions of the environment conveys the impression that participants were validating their positive evaluation of the caring environment.

Desired Changes

Three participants expressed their desire for changes relating to the frequent visits and their care. These changes were not always explicitly stated, but the meanings were reflected in their descriptions. One participant identified a need for three changes: 1) a different treatment schedule, 2) patients to be better informed about the treatment that they are receiving prior to its administration, and 3) measures that will reduce waiting time for treatment. The two other participants also expressed their desire for measures to reduce waiting time for treatment.

> I think the nurses maybe, when somebody is first starting some of this treatment could explain some of the side effects that could happen to them. Not necessary that it is going to, but this could happen. Maybe not right away, but down the line this can develop. And then when it does, the person doesn't worry that there is something going wrong.

This patient explained how he derived information about the medication that he was receiving for 14 years.

> ... you see, I ... just took the pamphlet up and I started reading it, and that's where I found out that this can cause you to get headaches and that you can get chills from it, you can get fatigue ... it's in the pamphlet that comes with it. But this was only a couple of years ago that I read the pamphlet. When I started having some more-like little things were just starting - really different, so then, that's when I pulled the pamphlet out and I read it, and oh, well, okay, these are things that are going to come - oh well, if that's how it's going to be, that's okay then.

This participant emphasized this lack of information giving several times during the interview. This indicated the importance of being informed to the participant. Additionally, during the interview, this participant explained why a different treatment schedule would benefit him.

> Over a year I lose thirteen day's wages in a year. Because of the four weeks, it

> works out to thirteen days or fifteen days, that I lose in the year. If you could change the hours or something and have me come in the evening to get it instead of during the day it would help.

This example shows that the treatment schedule impacts upon the participant's work and his finances. The following statements relate to the desire for changes that participants believe will reduce waiting time for treatment.

> ... it's running good for me right now - the way it seems now. If they could improve pharmacy, good.

> ... But ... sometimes when you come and have to wait an hour ... before they start you on something, and I could have come an hour later. Now I would appreciate if ... that could be rectified ....

> The only thing is the waiting for the IV nurse to come to put the IV in and it seems ages before she gets there. It will be ten o'clock. I had to be there by nine.

The above statements portrayed participants' meanings of change with aspects of the frequent visits. The waiting time for treatment as previously noted, was one source of negative experience. When evaluating the care environment, time surfaced within the participants' descriptions of aspects of desired changes. Consequently, participants' descriptions of time overlap in both themes. Some complaints that were related to time seems to be just waiting, whereas, others had valid reasons such as waiting to get started by the IV nurse or for the pharmacy to be opened. These changes were important to participant's psychological and financial adjustment within the context of the frequent visits.

Additional Themes

Two themes that were not included in the most common themes because they were not part of most participants' descriptions are : 1) an expressed desire for family involvement and 2) perceived threat to care. The forcefulness and emphasis with which

these perceptions were expressed by the participants conveyed the importance of the meaning for them.

Expressed Desire for Family Involvement

One participant who has been making frequent visits to ambulatory care for many years spoke about his wife's and two sons' reluctance to be involved in his experience of the frequent visits. He attributed his family's apparent disinterest as their way of coping with his disease, their uncertainty of the future, and their fear of being afflicted with the disease. Two in-depth statements are illustrative of his thoughts about his wife's and sons' lack of involvement:

> ... the family, the wife - well, I would say, she knows what I've got, but I never really explain too much to her. She never comes to the hospital. She hates the hospitals. So I just don't encourage her to come. I guess I should, to show her what goes on, but she doesn't want to come, ... She has never been to [the unit]. She went to [the one before] when I was there back then in '78. When I first went in, she went once; and in 14 years, she has never been in since. So - the only time she does come to the hospital is when I was in on the ward, when I had my spleen out. She came then but that was it. I think if she seen the system, she'll probably settle down a little bit, cause I think it does bother her, but we don't talk about it because she doesn't want to talk about it.
>
> ... The boys, they're the same. They hate the hospitals. They won't go. ... And they worry about it, but they won't talk about it either. So I pretty well just keep it to myself ... when they told me that I had lymphoma, well then, I had to try to explain everything to them. ... But still, they wouldn't even come to the Cancer Foundation to look around there either - they don't want to see that either, so I just do it. But I don't know how I could change it either, you know, cause they just don't want to go in ... they're afraid to, well, especially the boys. I think ... they figure they might catch it too. See, the youngest one just went in and got tested for the same thing that I have. It turned out that he's all right so now he's happy. But he was pretty down there for a quite a while, because he wanted to talk to me but he didn't know how. I tried to explain to him what goes on, but I finally got him into the hospital to be checked. This is as far as I could get. At least he was all right, so he doesn't have to go back, but trying to get him there was a job. ... I think it's putting more pressure on them, more stress on them than they would need,

> because I think if they come and see what actually goes on, it would ease their minds, but how do you make a person do that? You know, it's hard. They're-they're just as happy, I think, right now, to let it ride. Because if they don't know, I guess, they figure it's not going to hurt them, but I think it would help them in the end. But to get them to come, I think, I wouldn't want to do that...it's been a lot of years now and I can't get them to come ...

The above lengthy statements were expressions of the personal family stress that this participant experienced simultaneously with coping with his illness. Within his descriptions is the desire for family involvement in his illness situation. Furthermore, there was a sense that this participant was unable to express conditions of his illness and the frequent visits within the context of the family. His thoughts about the progression of his illness and uncertainty of further treatment are kept to himself. This shared experience is significant since it was evident from the descriptions that involvement of the family would help the participant maintain a more positive and meaningful perception [of his family in the context of his illness and the frequent visits] and content with the burden of suffering with this chronic condition.

Perceived Threat to Care

In this second theme, perceived threat to care, the participant spoke of her concerns about the possibility of her home intravenous program being deleted or available only at a cost to the recipients. She also spoke about hospital workers' conversations concerning job insecurity that she overheard during her treatment visits. The relevance of this concern to the experience of frequent visits for this participant lies in the possibility of increased visits to ambulatory care in the advent of the deletion of this home program. As well, threat to the quality of her frequent visits is anticipated because of hospital's staff insecurity about their job situation:

> Well, you listen to the government and they say, "put more home care in, get

> people out of the hospital." But in fact, they cut home care. They have cut services in home care. At this point they are in the midst of changing the whole home IV program, and this will affect me greatly. In Toronto, we couldn't go on home IV, because we had to pay for the drugs - when I was on home IV so that meant I had to go in the hospital when I was on. Here, if I'm on home intravenous, I still have to go in the unit for a while, but then, I can do it at home. But I don't have to worry about the cost of it. ... And if they change the whole program when they are preaching put home care in, get people out of the hospital. Well, if they put somebody else in charge of the whole intravenous program, then long term patients are the ones that will suffer. We have hoped that we can live a half decent normal life. I've gone to work with a pic - line in, I've gone to work with a hep-lock in and then give the medicine when I got home. But if they muck around with this program, it's going to be the long-term patients again who take the bulk of the funding cut.

In regards to nurses' conversations about their job situation this participant stated:

> You can feel the tension because - the nurses that go for coffee with each other, they don't know if their job is going to be taken away by that same nurse the next day or the next week. It's not that they ... are miserable or anything, but you just can't help picking it up. People coming from another unit, what are they talking about? they are talking about somebody being bumped. It doesn't matter what unit it's coming from. Whether it's the IV nurse, whether it's a tech. ... like aids, attendance pushing the stretchers, nurses from other floors, you're hearing the same thing all the time.

Embedded in the above descriptions are the participant's fears of losing more of her independence. Important to this participant is the opportunity to engage in self - care, an experience during which the participant perceived life as meaningful. The meaningfulness extends to the importance of being able to work despite coping with the treatment and the limitations of the disease. A feeling of despondence pervaded the experience of uncertainty and is associated with thoughts about increased frequent visits, a situation that may pose additional difficulties for her and for her family. The patient also shows concern for the potential reduction in health care workers and for nurses' job insecurities as a result of budget constraints which may adversely affect the environment of the frequent visits.

The additional themes are the unique experiences of two individuals associated with the frequent visits. Each of these experiences are meaningful for the participants as evidenced by the depth of detail in their descriptions. The meaning of these experiences appear to be that the participants perceived that they are not achieving the family and health care support which they value within the context of the frequent visits.

Summary

This fourth chapter has presented the analysis of seven individuals who frequently visit an ambulatory care department for treatment of their chronic disease. This analysis demonstrate that the participants defined seven dimension of meanings related to their experiences. Participants defined the meaning of frequent visits by reflecting on the history of their illness which, for these participants, formed the basis for what they anticipated and expected within the context of the frequent visits. Participants defined the time spent within the frequent visits as an important dimension of the visits. However, it was evident from the participants' descriptions that the time during treatment had various meanings. This variation in meanings determined the way in which participants perceived the importance of time and determined ways in which participants coped with the passage of time during treatment. Participants defined the meaning of the frequent visits based on their perception of the care provided and of the caregivers. They assessed whether the care met their emotional, physical, and interpersonal needs.

Throughout the descriptions, there was the notion that participants felt that their interpersonal needs were just as important as their physical and emotional needs. When all three needs were satisfied, participants felt that care providers promoted a home-like environment within the caring environment which included care givers, study participants, and other patients. Another meaning that participants derived from the frequent visits were

negative experiences with aspects of the frequent visits. Six of the seven participants described a negative experience. For most of these participants, the negative experience was not a major concern. The meaning of impact on the quality of life also was identified within the context of the frequent visits. For some participants, the impact on their family life, discomfort from the treatment that limited participants' activities, and the impact on their work life were sources of stress or frustration. Finally, participants evaluated the general context of the caring environment. They expressed their thoughts about the care givers, the care environment, and about desired changes with aspects of the visits. Throughout the descriptions, there were a number of similarities and differences in the way in which each participant derived the meaning within each dimension of their experience. This variation reflected the unique experience of each participant in living with his or her specific disease. Chapter five will present a discussion on the findings of the study, implications for nursing, future research, education and the limitations of the study.

Chapter Five

Discussion of Findings

The analysis of descriptions of data from patients who frequently visit an ambulatory care department for therapeutic treatment of a chronic disease has resulted in the description of the meaning that the experience hold for the participants. Each participant views the frequent visits experience in the context of his or her illness and the caring environment. Thus, different perspectives about the experiences are gained.

From the data, the researcher concluded that the meaning of the frequent visits is broad and encompasses many dimensions that result in the theme categories. The common theme categories are related to: 1) an historical background of the illness leading to the frequent visits, 2) evaluation of the dimensions of the passage of time during treatment, 3) feelings that comfort and emotional needs were met, 4) negative experiences related to the frequent visits, 5) impact on the quality of life, 6) thoughts about the disease and the treatment in the context of the visits, and 7) evaluation of the context of the care environment. In addition, two theme categories desire for family involvement and perceived threat to care are unique experiences for two participants. These meanings were expressed as participants moved through the initial experience of their illness and treatment to the experience of their frequent visits to ambulatory care. This chapter presents a discussion of the findings as they relate to the literature and to the researcher's perspective, implications for nursing practice, nursing education, and future research. Similarities in the experiences of patients who make frequent visits for a chronic illness with those who make single visits for acute procedures and a conclusion of the research interpretations are presented also.

An Historical Background of Illness Leading to the Frequent Visits

Experiences of the chronic illness leading to the frequent visits are common among the descriptions of all participants. This finding supports the literature that the lived experience of an individual is primarily determined by the individual's history which forms the basis of his or her experiences (Chang, 1980; Oiler, 1986; Pascoe, 1983; Van Manem, 1991). Embedded in experiences are meanings that stem from the individual's existence in the world (Oiler,1986). Thus, an individual entering a hospital may base his or her current judgment of care on prior experiences, characteristics, and attitudes towards the care provider and the care facility (Obrest, 1984).

In this present study, it is discovered that the participants' experience of frequent visits is determined by their prior experiences of health care. In addition to the present context of the visits, participants' perceptions of their illness and experience with other health care contribute to the definition of their experiences. This historical background not only forms the basis from which participants judge the care providers and the care environment, but the historical background provides the researcher with a way of understanding the differences in the participants' experiences. Furthermore, as Lubkin (1990) contends, in chronic illness, the patients' multiple hospital experiences give them a fuller sense of their disease, its management, and progression. Since patients' biographies are an integral part of their history, without an awareness of patients' experiences and biographies, inadequate care may result. It is important for nurses to listen to patients' opinions and reflections about prior health services as these are evaluations of the effectiveness of nursing care. Determining patients' preferences and expectations of current care could lead to open communication between the nurse and the patient in deciding on expectations of care that could be met or those that are unrealistic.

Evaluation of the Dimensions of the Passage of Time During Treatment

Participants assigned various meanings to the passage of time during treatment. The different meanings to the passage of time suggest that participants' perceptions of the passage of time emerge out of their awareness of the significance of their time spent during treatment, how they define time, and how they cope with the passage of time. This finding fits well with other studies that revealed time to be an important factor in chronic illness situations (Shields, Morrison, & Hart, 1988; Thibodeau, 1993). Time was found time to be a factor in the study conducted by Shields and his colleagues (1988) regarding consumers' satisfaction on a psychiatric unit. These researchers found that how time was spent during the hospitalization period was a factor in patients' satisfaction. Feelings of boredom when patients were not actively involved in treatments was one source of dissatisfaction. Thibodeau (1993) studied the experience of an adult child who assumed live in care for a parent and uncovered that time was an important dimension in chronic illness situations. Time was either a factor that resulted in increased energy levels for the caregiver (if conditions of the live in situation involved shared responsibilities of household tasks) or a component of stress (if the responsibilities were not shared). Stress and reduced energy levels were a result of the increased demands on the caregiver's time to meet the demands of the situation.

Patients having control over various aspects of their treatment as it relates to time was very important. Those patients who find it difficult to cope with the passage of time during treatment are not in control of their situation. They are restricted either biologically (decreased vision) or physically (inability to be ambulant because of their physical incapacity or confined because of the nature of the treatment, such as, having an abdominal paracentesis or six hours of IV therapy) from engaging in activities that they

perceive would utilized the time during treatment` (reading, walking around, watching television). Those participants who are concerned with the passage of time during treatment, but are able to manage the passage of time effectively (able to walk around, read, or work on projects that are brought in for the purpose of absorbing time) feel they are in control of the situation. It is likely that those participants who were prepared for the duration of the time during treatment are exhibiting a higher level of self care and personal responsibility for the time involved in the treatment than those who were not. In view of this difference nurses need to promote the abilities of those patients who are not prepared to manage their treatment time effectively and assist them in making choices that will help fill the void during treatment. For example, having a volunteer sit and talk with the patient during treatment or a family member accompany the patient may be options. As well, providing information to patients that will make them understand that some negative experiences (being confined to bed during an abdominal paracentesis) are unavoidable may increase their tolerance of the treatment time. Thus, participant's psychological status, physical status, and their ability to influence use of the treatment time are important considerations in their perception and description of the meaning of the passage of time during treatment.

These aspects of meanings of time are important to an understanding of the feelings that patients experience and the strategies they employ to cope with the passage of time during treatment. Important consideration to these findings must be acknowledged in nurses' plan of care. Care givers may not consider the time during treatment to be important to the experience of living with a chronic illness in which frequent visits are associated. Yet this study found that all of the participants reported experiences in dealing with the time during treatment or how they perceived the passage of time. Roberson (1992) and Lubkin (1990) point out there is difference in caregivers' and patients'

perceptions of illness situations. The evaluation the patients' time spent during treatment should be an important aspect of nursing. The support of caregivers, their acknowledgment, and their implementation of measures aimed at considering the effect of what time means for the patients could improve time demands in chronic illness situations (Thibodeau, 1993).

Feelings That Physical and Emotional Needs Were Met.

Participants' perceptions of their physical and emotional needs being met suggest that, although participants find that there are aspects of the frequent visits that are not synchronized with their psychological status, they feel that their physical and emotional needs are met. Many participants believe that aspects of caregivers' interactions have enhanced their quality of life in the context of the frequent visits. Within participants' descriptions, the feelings that physical and emotional needs are met, appear to be the bridge between their preferences, their expectations of care, and the caregivers' interactions. As Oberst (1984) and Handly (cited in Blancett, 1992) theorized, patients have prior knowledge about what they expect of professional care. This knowledge not only enables patients to define their care, but also to identify their need for care. Thus, patients hold expectations of the outcome of their care, caregivers' interactions, and the dynamics of the health care environment. These factors are the basis from which care is evaluated with respect to the degree to which it meets patients' needs and expectations.

Participants spoke of specific nursing interactions in which caregivers provided physical, social, and emotional support. In discussing this experience, specifically important to the participants was the feeling of comfort which is derived from within the care environment and which is central to the experience. From these findings the researcher concluded that when care meets the patients' physical and emotional needs in

which there is a meaningful, important relationship with the care providers, caregivers are helping patients to deal with their situation (Corbin & Strauss, 1991; Holmes, 1989). The care professionals with whom patients are in contact and their professional care interactions are important for patients' physical and psychosocial well-being.

Also embedded in the participants' descriptions of feeling that their physical and emotional needs are met is the notion that they experience satisfaction with the care received. This finding is reflected in the conceptualizations on satisfaction. For example, Noon and Davero (1987) stated that satisfaction is the degree to which the health care experience matches the patient's prior expectations. Strasser and Davis (1991) asserted that satisfaction is the patient's reaction to stimuli in which value judgments are modified by individual differences and "involves the relation between stimuli, value judgments, reactions, and individual differences" (p. 56). The positive evaluation by all patients suggests that it is likely that most participants are satisfied with their experience, caregivers, nursing care, and the care environment. This finding fits with Handly's (cited in Blancett, 1992) argument that patients will express their satisfaction with care when they perceive that care professionals are responsive, demonstrate a willingness to provide care; are reliable, dependable, and accurate; promote trust and confidence in them; and provide caring, individualized attention. Most importantly, since patients' satisfaction has been acknowledged as a legitimate indicator associated with patients' perceptions of their care, patients' descriptions of the outcome of their care should be of interest to care professionals in ambulatory settings (Nelson, Hays, Larson, & Batalden, 1989). Participants' feelings that their physical and emotional needs are met indicate that care professionals play an important role in the experiences of patients. These aspects of care that participants identified within their experiences of frequent visits must be maintained. It is evident that

nursing functions of providing physical, interpersonal, and emotional care strongly enhance the patients' experiences with the frequent visits.

Negative Experiences Related to the Frequent Visits

Participants descriptions reflected negative experiences related to aspects of the frequent visits. Five categories of negative experiences emerged: 1) waiting for treatment, 2) stress and discomfort associated with the treatment, 3) reaction to the treatment, 4) the inconvenience of parking and 4) dissatisfaction with aspects of nursing care

Waiting time for treatment is especially a source of frustration for some participants. In these cases, the frustration occurs from such experiences as missed hours from work or having to wait an extra hour after arriving on the unit for treatment to be implemented. Participants are aware that the negative experiences are not always directly related to aspects of care within the immediate care environment, but rather to factors external to the immediate caring environment, such as having to wait for the IV nurse to establish the IV for treatment or for the pharmacist to dispense the treatment medication. Some participants indicate that some of the negative situations (waiting time) could have been avoided, whereas others perceive that some negative experiences (inconvenience of parking, reaction to the treatment) are unavoidable aspects of the visits and the treatment.

Koerner (1987) discussed the waiting aspect that is associated with visits to ambulatory care. Although some aspects differed, some similarity to situations that participants in this research have described apply. Koerner stated:

> ... although the appointment card has a definite time, everyone knows it is first come, first served. The physicians do not arrive until 9:00 a.m., so the patient is weighed by the nurse, has his or her blood pressure taken, and is put in one of the examination rooms. ... The patient then waits anywhere from 1 to 2 hours until the physician appears to do an evaluation and prescribe or modify the treatment (p. 1).

Negative experiences that are similar to findings in this study also were reported in a study which examined the demands on women who were experiencing a chronic illness (Packard, et al., 1991). These women reported negative experiences that included waiting for treatment and tests procedures to be implemented; financial cost; and negative effects of the treatment that were socially, physically, and psychologically disruptive. As well, these women reported that having to accommodate the treatment regimen were limitations that were problematic to them and to their families.

The finding of negative experiences in this study suggests that some sources of negative experiences of individuals with a chronic illness may not be the direct effect of the disease on the individual's physical and psychosocial life. External, interpersonal, and environmental factors such as time, the nature of the interactions, the relationship between the caregiver and the patient, and the setting of care may accompany the experience and may prove to be disruptive and challenging. Therefore, nurses should identify and collect data on factors that negatively impact on patients' experiences so that negative experiences may be reduced and if possible, be eliminated. Such data should include finding out patients' concerns about their care and soliciting their opinion on what should be done. This information could be useful for coordinating patients' care. For example, nurses could arrange with the pharmacist to dispense patients' medications on the evening prior to their admission. As well, nurses could inform the intravenous nurse about the expected admission time of patients who may require an intravenous in order to reduce waiting time for treatment. Nurses also should be alert to and maintain nursing interactions patients identify as conducive to promoting their physical and psychological health.

Impact on the Quality of Life

Impact on the quality of life relates to factors of the frequent visits in which stressful events are revealed. The assertion that stress (Lamm, et al., 1991; Kopp, 1992; Strauss, et al., 1984), dependency, (Burish & Bradley, 1983; DesRosier, et al.. 1992; Diamond and Jones, 1983; Shaw and Halliday, 1992), and alteration in life style (Lamm, et al., 1991; Strauss, et al., 1984) are associated with chronic illness were borne out in this study. Additionally, the popular assertion (e.g. Rolland, 1987; O'Brien, 1983) that managing the treatment regimen in chronic illness is a complex situation also supports the findings in this study. Rolland (1987) pointed out that the family and the patient have to be able to adapt to and be flexible with the changing nature of the disease as it moves back and forth from episodes of stabilization, remission, and progression. This back and forth adjustment is stressful for the family. O'Brien's (1983) also asserts that the nature of the treatment regimen includes modifications in social activities, family and work life, and in recreation. Moreover, Leahey and Wright (1987) argued that it is difficult for the family of the chronically ill patient to maintain a normal life within the 'abnormal', heightened, uncertain situation of a chronic illness.

The impact on the quality of life in this present study is associated with significant aspects of the participants' lives such as their family life, work life, and future planning for family vacations, and uncertainty about maintaining employment. Gender is noted to be an important factor in the interpretation. The two female participants who worked focused more on their inability to care for their families than they focused on their ability to work outside of the home. As the women expressed these concerns, their emotions were aroused to reveal that they had difficulty adjusting to their perceived inadequacies to meet obligations to their families. In contrast, the men who worked focused more on altered

work hours than on family matters. This difference may relate to the type of family obligation or work. From the women's descriptions, it was evident that their work was important and meaningful to their personal lives. This indicate that they viewed their work as a career, rather than just a job. However, both women were employed in moderate salaried positions. They did not appear concerned with loss of salary. Thus, in this study it appears that the women are concerned with nurturing responsibilities, whereas the men are concerned with financial obligations.

Gender specific differences in illness situations were reported in other studies. For example, Lucas, Morris, and Alexander (1988) found a significant relationship ($r = .3329$, $p = .03$) between the male and female participants in their study on self care agency and satisfaction. These researchers suggested that nurses should plan care specifically to reflect the differences in genders. They asserted that men may need more assistance with ways to identify and eliminate deficits in self-care agency and promoting of the abilities they have than females. Anderson (1988) also demonstrated a gender difference in his study on the quality of life for the carers of stroke victims and their perception of the help they received. The family carers were either men or women. Anderson implied from his findings that, although participant characteristics such as age, sex, and social class did not influence the carers' assessment of the help they received, gender difference influenced the participants' perceptions of help. Of the men 44 % reported that increased help caused problems and difficulties in the illness situation as compared to 79 % of the women. Anderson implied that the results

> ... may be that women carers were doing more and more work than men, or that they were stretched by other commitments to home, work, and family. But perhaps also they were more inclined to identify and respond to problems ... ; or it may be that contrary to stereotypes, the men who took on the role of the carer were less troubled about this than the women (p. 22).

Reports on gender differences support that gender differences in this study may account for the differences in how the participants' quality of life is affected within the context of frequent visits.

Loss of salary due to the time of the visits' schedule was a major problem for one participant; perceived threat to job security for another. Financial costs and job loss are reported to be a major concern for some patients and their families in chronic illness. Strauss and his colleagues (1984) and Nordstrom and Lubkin (1990) have noted that chronic illness is expensive and the impact on the family income as a result of the illness is tremendous. They assert that if the patient does manage to remain employed, the employer may perceive the patient to be either permanently disabled or concerned about recurrence of the illness and the resultant absenteeism. Furthermore, if the patient is unable to work or if there is alteration in his or her work activity due to the frequent absenteeism to accommodate the demands of the illness, job loss may result.

While most of the participants in this study did not consider the frequent visits to have major impact on their quality of life, they report how they cope with the frequent visits. Feelings of dependency on the treatment and on others is notable. Dependency on the treatment is a result of the incurable nature of the disease and the illness crises that necessitate frequent visits for treatment. The women express that dependency on others is an undesirable experience for them. This finding is supported in the literature as it relates to long-term care. "A long - term dependency on the formal health care system for medical maintenance and disease monitoring may be an important dimension of the experience of chronicity" (Packard, cited in Packard, et al., 1991, p. 435). Nordstrom and Lubkin (1990) advocate that health professionals should recognize and accept dependency as an inherent part of chronic illness. They contended that it is the business of nurses to help the

patient deal with his or her inadequacies and proposed that it is the dependent nature of the illness that requires patients to become dependent on others. They also argued that when patients are dependent on medication or on other people, such as family members and caregivers, this dependency may conflict with the patient's values, preferences, or personality so that the patient may experience low self esteem and helplessness.

In this study, despite the impact of the frequent visits on the participants' quality of life, the researcher concluded from the meanings that they struggle to maintain as normal a life as possible by balancing work life and home life with the frequent visits. This attempt at normalizing life in chronic illness has been documented in other studies. For example, O'Brien's (1983) indicated from the results of her study on chronic dialysis patients that dialysis patients attempted to normalize their lives simultaneously to managing their dialysis regimen. While some patients were successful, others were not. Some patients were able to blend their professional activities with their illness, whereas other patients were unable to maintain their jobs as a result of the physical limitations and the treatment regimen. Based on her findings, O"Brien posited that patients who were able to maintain their professions were those patients who were able to adapt satisfactorily to the alteration in their lives that was necessary to meet the treatment regimen. Those who found difficulty adapting were those whose future and goals were uncertain. Kelleher (1988) found in his study on coping with diabetes that when adapting (normalizing) to the diabetic situation, some participant's gave up social activities, such as eating out or engaging in other activities that were restricted by their illness. As in the O'Brien's study, patients with diabetes who adjusted to the alteration in their lives had accepted the adaptation required in lifestyle.

Bramble (1990) discussed the factors that influence adaptation to chronic illness. Her examples included aspects of the patients' personality that are based on previous and present coping mechanisms; prior experience with illness and hospital care; and the

reactions of the patient's family, caregivers and social groups. In particular, she proposed that acceptance of the patient by the health professional is crucial and emphasized that knowledge of adaptation is not enough. She contends that caregivers must acknowledge the various factors that influence adaptation. If nursing interventions are to be successful in enhancing adaptation nurses must become aware of and develop an understanding of how patients cope with the demands of the chronic illness to facilitate patients' adaptation to the illness situation.

In this study some participants who met difficulties in their quality of life as a result of the frequent visits are able to consider their experience in a positive way. Some participants view the experience as an opportunity to expand their life expectancy in a caring environment in which they have grown comfortable. Thus, the impact of the frequent visits on the participants' personal life are linked to how participants perceive they and their family were able to adjust their personal life, their work life, and their psychological status to the frequent visits situation. This indicates that in patients with chronic illness, they, and their families make many sacrifices and decisions to cope with the frequent visits.

The importance of the family's and the professional caregivers' role to patients' quality of life is emphasized (Corbin & Strauss, 1991; Lamm, et al., 1991; Leidy, 1989; Shaw & Halliday, 1992). Corbin and Strauss (1991) contend, that although the home environment within which the chronically ill individual lives should be the center of his or her care, health care facilities should provide a suitable backup resource in which home care is supplemented. According to Corbin and Strauss (1991) important to this care are the nurses who "... of all the health professionals ... have the skills, knowledge, and the vision to organize and provide for the comprehensive and the technologically complex care that chronically ill clients require" (p. 167). Thus nurses must acknowledge the impact of

chronic illness on the patients' quality of life. When evaluating and making decisions about care, nurses must consider significant aspects of the patients life such as facilitating independence and promoting a caring environment that is conducive to the patients' attempts to meet life challenges.

Thoughts About the Disease and the Treatment in the Context of the Visits

As participants described their meanings of frequent visits, the narrative was interspersed with positive thoughts such as hope, confidence, and courage, as well as negative thoughts such as uncertainty and insecurity about the progression of the disease and possible ineffectiveness of the treatment. Positive thoughts were evident in those participant's descriptions who are in periods of remission and stabilization of their disease. The assertion that hope (Parse, 1990; Raliegh, 1992), confidence (Pallidia & Grant, 1980) and courage (Haase,1987) enhance an individual's ability to cope were reflected in the participants' descriptions of ways in which they cope with the illness situation.

Even as more and newer treatment are being introduced, negative thoughts related to uncertainty about the future of their health status are particularly a concern for one female and one male participant who are obviously exhibiting signs of disease progression. They perceive their situation to be potentially life threatening. Uncertainty is found to limit patients' ability to cope with the conditions of the illness, induces helplessness, anxiety, fear, and stress for the patient and the family (Strauss, et al., 1984) and limits the patients' ability to make future plans (Hilton, 1992; Kopp, 1992). It is evident from the differences in the participants' concerns about the disease and the treatment that their perception that their condition is deteriorating is a factor in the pervasiveness of the intrusive thoughts about the disease outcome.

Support for this finding that intrusive thoughts about the disease and treatment pervade the minds of patients who are undergoing treatment for a chronic illness has been documented. For example, in the study conducted by Packard and his colleagues (1991) on the demands of illness among chronically ill women, illness reminders were troublesome situations which evoked a recurrence of thoughts and fears about the illness.

Kahn (1990) posited that thoughts about the illness and treatment are a common emotional response that cause patients to perceive, evaluate, and defend against their loss of health. Kahn proposed that the intrusive thoughts result from fear and grief. She described fear as the result of the anticipation of potential threats to life brought on by the exacerbation of symptoms that are characteristic of chronic illness. The fears may include fear of death; loss of body parts; withdrawal of friends, loved ones, and family; pain; and hospitalization and the competency of strangers to implement the correct care. Grief was described as a normal process that occurs at the initial diagnosis of a chronic illness that, if used effectively, will help the patient and family come to terms with the illness and illness demands. Kahn cited denial, anger, mourning, and acceptance as the processes of grieving in patients with chronic illness. These are coping strategies necessary for effective adaptation to the physical and psychological adjustments to the chronic illness. She advocates that because emotional responses may vary with the different stages of chronic illness and treatment, health professionals should have an understanding of the causes of intrusive thoughts in order to be aware of patients' individualized needs and provide the appropriate care. Such care may include recognizing the patients' thoughts about the treatment; reinforcing hope, confidence, and courage as factors in coping; distinguishing those who are prone to cognitive problems and providing reassurance and support for the thoughts they experience to alleviate their apprehension. The opportunity for the

participants in this study to share intrusive thoughts about their treatment and their disease with the researcher may help them to come to terms with their situation.

Evaluation of the Context of the Care Environment

Participants explicitly and implicitly described aspects of the visits that they liked and aspects that needed improvement. They spoke about their perceptions of the care environment, the caregivers, and about aspects of care within the unit. As they spoke it was evident that their evaluations of the context of care were being judged by what was important to them.

Participants described feelings of gratitude for ambulatory care. They frequently commented on the caring attitudes of the care givers and on their prompt responses to their needs. Most participants expressed desired changes that they perceive will resolve some of their negative experiences with aspects of the frequent visits. The one participant who repeatedly referred to the lack of information available to him during his early experience with the treatment identified a need for patients to be better informed about the treatment they are receiving. This finding shows some consistency with Shields, Morrison, and Hart (1988) study on consumer's satisfaction on a psychiatric ward. They reported that persons who are coming into hospital desired more information about their treatment and progress. Patients suggested that they be provided with information about the outcome of tests, type of drugs taken and why, side effects of the drugs, and the length of usage. Nail, Jones, Green, Schipper, and Jensen (1991) found in their study on the information of the side effects of chemotherapy and the effectiveness of self - care activities that patients need to be informed of and be prepared for the side effects of medication in the likelihood of side effects appearing. Given, Given, and Simoni (1979) examined the relationship between process outcomes and satisfaction with ambulatory care in patients with hypertension.

They reported that knowledge of the treatment were an important factor in the patients' health outcomes.

Researchers (Prehn, et al.,1989) emphasized that it is important for caregivers to integrate patients' perceptions (attitudes and beliefs) about their health status and care received into nurses' plans for care. They asserted that such things as caregivers' attentive behavior, courteousness, appropriateness of the care environment, and the serving of meals are factors in patients' appraisals about their care that increase the validity of their perceptions. These researchers emphasized that caregivers must pay attention to patients' perceptions when identifying the status of patients' needs and what they believe should be modified. Considering it is difficult to assess care without the patients' opinion, data about patients' descriptions about the outcome of their care should be the sole mechanism to evaluate quality outcome (Prehn, et al., 1989; Shields, et al., 1988).

Although patients may express satisfaction with their care, unsatisfactory experiences may be expected within the context of nursing care and should be investigated to enhance the experience of caring (Eriksen, 1987). This theme is important to caregivers understanding about what patients need to know about aspects of their care.

Additional Themes: Expressed Desire For Family involvement and Perceived Threat to Care

Expressed desire for family involvement and perceived threat to care have supported the researcher's assumption that the investigation of the lived experience of frequent visits will reveal the uniqueness of the experience for each participant. The finding also has shown that chronic illness poses different problems for each individual (Lubkin, 1990; Masters, et al., 1983).

Expressed desire for Family Involvement

The participant who expressed a desire for family involvement with aspects of his care based his judgment on the fact that his wife and children were not involved with his frequent visits and that they appeared disinterested. He attributed their attitude towards his illness situation as their way of coping with his chronic illness or their (his children) fear of getting the disease. As researchers (Burish & Bradley, 1983; Diamond & Jones, 1983; DesRosier, et al., 1992) who have investigated the family in the context of chronic illness have asserted, chronic illness is the concern of the patient and the family. Family members, in particular the spouse, play an integral part in patients' treatment process and in their coping with the illness.

Following their investigation on marriage and family circumstances in coping with heart disease Schott and Badura (1988) suggest that a life threatening illness causes stress for the patient, spouse, and family. They also assert that patients and their families may experience shock, fear, and uncertainty. Although in the majority of cases the well spouse is supportive to the ill partner, some marriages do deteriorate after the advent of a chronic illness. They found that in relation to the quality of married life after a heart attack, 46 % of the women felt the relationship with their husband was changed, 48 % felt the relationship was unchanged, and 6 % felt there was a deterioration in the marriage. The extent to which the wives worried about their husband's health was determined by the wives' concern for their own health and their perception of the state of their husbands' health.

Thus, it is likely, that in this study of frequent visits the participant's illness may have impacted on the marriage adversely or that the wife of this participant does not perceive the participant's chronic illness to be serious enough to warrant her full support. This may be based on the wife's perception of how well the participant appears to adapt to

the illness. It also is likely that the wife may have concerns of her own. This latter interpretation may also be the reason why the participant's children are reluctant to be involved with the frequent visits.

Perceived Threat to Care

Perceived threat to care, the second additional theme, is another participant's description of her feelings about the wide spread and popular health care restructuring. The media reports on budget cuts that are targeted at care professionals and their discussions on cuts to specific programs, such as the intravenous program that allows the patient to maintain some degree of independence, have led the participant to conclude that her care is threatened. This concern is coupled with the participant's observation during her frequent visits that there is a reduction in the number of care professionals and that uncertainty of jobs security have permeated discussions among staff. These observations have further induced fears about the quality and the accessibility of her future care.

As was previously noted, uncertainty is a factor that inhibits coping in chronic illness (Hilton, 1992; Kopp, 1992) and induces stress (Curtin & Lubkin, 1990). The uncertainty that clouds the participant's future may not only be the result of the illness condition, but also the result of the intricacies of the health system (Curtin & Lubkin, 1990). This finding should alert care professionals that their attitudes toward their work and work environment may negatively affect patients. Care professionals should be aware that the environment they create within their work setting may influence the patients' attitude toward the health care resources in the management of their chronic illness. They should provide an environment

that will encourage fuller life experiences and expectations (Curtin & Lubkin,1990). Furthermore, it is easier for patients to accept the limitations and to cope with the illness if they are certain about the future, have available, good family and professional support, and access to effective, palliative treatment (White, et al., 1992).

Similarities in the Experiences of Patients Who Make Frequent Visits to the Experiences of Patients Who Make Single Visits.

Although the aim of this study was to examine the experiences of patients who make frequent visits to ambulatory care for treatment of a chronic disease, discussion about the experiences of patients who make single visits to ambulatory care for acute procedures is helpful to the understanding of how these experiences are similar or different. This knowledge will help nurses to be sensitive to the needs of different populations of patients in ambulatory care. As Harper Peterson (1988) contends, different populations such as patients who are seen on a frequent outpatient basis and those who are seen on a very brief basis will have different expectations and experiences in their care.

This study showed that similarities and differences in experiences do exist in single and frequent visits to ambulatory care. For example, in Williams and Brett's (1989) investigation about patients' satisfaction with their care after surgical procedures in ambulatory care, the scheduling of the procedure, extended waiting periods, lack of privacy, and the noise level were sources of dissatisfaction. When Frish, Groom, Sequin, Edgar, and Pepler (1990) investigated patients' and their helpers' expectations and preparation for surgery following an ambulatory care experience, they found that whether the responses were from the patients or helpers, patients were satisfied with their nursing care. Common sources of dissatisfaction were pain, discomfort, anxiety, and weakness. Other sources of dissatisfaction were inadequate teaching about the expectation and

preparation for treatment, and difficulty with carrying out usual activities after the procedure. The researchers also found that previous surgical experience affected what patients expected regarding their care and recovery. Kempe and Gelazis (1985) investigated the effectiveness of nursing care on the anxiety levels of patients. They found that patients having single surgical procedures in ambulatory care were less anxious and stressed during the same day experience when nursing interventions, such as providing information on the preoperative and post operative care was given, than if this personalized care was not given.

In another study regarding single visits, Noon and Davero (1987) investigated patients' perceptions in regards to the convenience of the ambulatory care system and the nursing care provided following surgical procedures. They found that 100% of the patients were satisfied with the physical environment, 89.3% were extremely satisfied with the nursing care received, and 98% were satisfied with the affective behavior of the nursing staff. The finding that the majority of patients evaluated the ambulatory care system and the nursing care positively are similar to findings in this study.

Thus, from the above studies, similarities between the experiences of single and frequent visits appear to be related to both the positive and the negative aspects of the visits. The positive experiences relate primarily to satisfaction with the nursing care. Negative experiences were related to time, specifically with the treatment schedule, waiting for treatment, and to discomfort associated with the treatment. Also similar is the impact of previous hospital experiences on the patients' current visits as was found in this study.

The important differences that are unique to those who make frequent visits is evident in these patients' need for a secure and home-like environment in which the caregivers are familiar with the patients at each visit. As well, rapport with the caregivers is important to the patients who make frequent visits psychological comfort within the context

of the visits. Although the interpersonal aspect of nursing care is valued across the participants in the single and frequent visits, it appears to be one of the most valued dimensions of care in this study. This need for the interpersonal interaction between the caregiver and the patient may be a result of the nature of the patients' treatment and duration of time that patients who make frequent visits are in contact with the caregivers. Other important differences specific to frequent visits are the cost to the patient that are associated with missed hours from work over a prolonged period time, uncertainty about their health and employment, and prolonged disruptions in family life.

. However, despite the kind of ambulatory care encounter, patients were found to value prompt, courteous, and effective care (Harper Petersen, 1988; Noon & Davero, 1987; Rempusheski, et al., 1988; Williams & Brett, 1989). Harper Petersen (1988) asserts that it is common to have very positive results with nursing care even if specific aspects are unsatisfactory. She postulates that those patients who experience satisfaction with their care will have their positive experiences reinforced. However, the small percent of patients who are dissatisfied is significant as they may be representative of a larger number of patients who prefer not to complain. Caregivers need to pay attention to issues of dissatisfaction in order to make changes in the delivery of care and improvements in the facility for patients who make single visits as well as for patients who make frequent visits.

Researchers in the above studies that examined patients' experiences with single visits to ambulatory care used quantitative measures to describe the experiences. Furthermore, researchers investigated specific aspects of care that were of interest to them rather than what the experience meant for the patient. Therefore, other aspects of the participants' experiences that may have been revealed through the participants' descriptions of their experiences are likely to have been excluded from the data.

Summary

In the above section, seven common themes and two additional themes that were derived from the participants' descriptions of their frequent visits to ambulatory care for therapeutic treatment of a chronic disease were discussed. Also discussed were the similarities and differences between the experiences of patients who make single visits to ambulatory care for acute procedures and those who make frequent visits for long-term care. The discussion was in relation to the aim of the research investigation with reference to the literature. Exploration of the meanings of frequent visits showed that certain aspects of the frequent visits are consistent with findings in other research and theoretical perspectives of chronic illness. However, none of these studies on chronic illness and ambulatory care or theories of patients' experiences were associated with the frequent visits dimension of a chronic illness.

The results of the study indicate that the research questions aspects of the experience that were satisfactory or unsatisfactory; practices of the nurses that contributed to the experience of the visits; factors in the context of the visits that contributed to the patients' quality of life; and factors that contributed to stress were answered. Furthermore, participant' descriptions of their experiences indicate that the researcher's assumptions about the experiences of individuals who make frequent visits were verified. The participants in this study were eager to discuss their thoughts and feelings about their experience; the experience of the chronic illness revealed the uniqueness of each participant's experience, as well as similarities; the participants exhibited an understanding of their experience and were able to describe how the experience affected their over all well-being. Within the discussions were many important issues that have implications for nursing, future research, and for nursing education.

Implications for Nursing

Important inferences may be drawn from the findings that are pertinent to nursing practice. If nurses are committed to providing holistic care, nursing care for patients who frequently visit an ambulatory care department for treatment of a chronic illness can be enhanced if care providers pay attention to the interpersonal, psychosocial, and physical care that are associated with the illness situation. Nurses may not typically attribute these aspects of care to the frequent visits or they may not even identify them. They may be difficult to identify because of the episodic nature of the clinical encounter in ambulatory care. For example, some patients appeared to have coped effectively with their treatment, but other aspects of the frequent visits (e.g. waiting time for treatment, scheduling of treatment, insufficient information about treatment) of which caregivers may be unaware were evident in the participants' experiences.

The results of this study also provide additional insight into the various factors that may impact on the experiences of patients who frequently visit ambulatory care. The nurse should be aware that the outcomes of patients' experiences could differ depending on their previous experience with treatment, their employment status, their expectations, and their plans in preparation for the treatment. It is possible for nurses with this knowledge to become sensitive to each patient's experience by incorporating and/or adjusting aspects of nursing care in response to the patients' needs and circumstances.

In phenomenology, human experiences are assessed based on how situations or events are perceived (Oiler, 1986). The findings in this study suggest that the extent to which the patients adapted to their personal disruptions and the demands of the illness over time was a result of their perceptions of the situation. Nurses acknowledgment and assessment of these factors and experiences may be useful when planning nursing interventions in order to help patients deal with the many disruptions in their family and

personal lives. Measures to reduce waiting time for treatment and providing more information to patients about their treatment and disease may make the frequents visit a more positive experience for the patients and for their families. If caregivers follow these recommendations from participants it may indicate to them commitment of the ambulatory care staff to enhance their experience with the frequent visits.

The findings of this study are consistent with the assertion that chronic illness is multidimensional (Packard, et al., 1991). Therefore, nurses need to view chronic illness and the associated frequent visits in a broad context that considers all aspects of the experience. The various meanings of the frequent visits could be useful in providing a framework to form the basis for the development of ideas, policies, and services that are relevant and sensitive to the changing needs of this population of patients.

When looking at patients' experiences with regards to specific aspects of their care, health care organizations must become expert at determining what patients need and expect. In order to gain general information on patient's views of care, every patient must be given the chance to have his or her voice heard in order to identify unsatisfactory care and correct the problem. Patients' feedback could teach nurses about patients' needs and expectations. The experiences can be used to shed light on ways to produce better outcomes (Nelson, et al., 1991). Moreover, if patient satisfaction is considered a worthwhile measure in the provision of medical care, then emphasis should be put on providing the highest possible level of care in keeping with the hospitals' commitment to provide quality, continuous care. This will include acknowledgment of the patient and family in nursing intervention, nursing assessment, diagnoses, and treatment that considers social support, psychological stability, and knowledge about their disease and treatment that meet the patients' needs. Putting these efforts into effect will help health care researchers

further refine continuous care as well as delineate aspects of care that promote satisfaction (Weiss & Ramsey, 1989).

Given the diversity of patients' needs, identification of what patients' experiences mean for them is important. There is need to have an understanding about what patients' experiences mean to them and from this information determine what information patients need to know about his/her illness, the treatment regimen, and how caregivers' affect their experiences in order to provide care that includes patients' perceptions of their experiences and caregivers' contribution to the outcome of care (Given, et al., 1979).

Implications for Future Research

Identification of the meaning of frequent visits for treatment of a chronic illness provides direction for future studies. The method was effective in uncovering the meaning of the lived experience of individuals who make frequent visits for therapeutic treatment of a chronic disease. However, further phenomenological studies of the patient, the family, and the caregivers' perceptions of the experience of frequent visits to ambulatory care and how the experience impact on their lives are needed. Such studies may identify aspects of frequent visits that may confirm factors identified in this study or may find other factors that were not identified. Additional information on how the frequent visits affect the patient; family members' life; and daily activities such as, leisure, work, family interaction, and alteration in role function as a direct result of the impact of the frequent visits may be revealed. "Studies of long-term health outcomes could be more informative if they address the ways in which a person manages the personal and environmental demands of illness rather than the effects of the disease" (Packard, et al., 1991, p.451).

In the initial part of the interview the participants had difficulty adhering to the research question and tended to discuss their experience with the chronic illness. It is

therefore likely that research that focused on the disease in addition to the frequent visits will expand the understanding of the patients' experiences.

Four of the seven participants in the study were men. Further research should specifically consider gender differences. The men and the women in this study had varying perceptions of the visits that were based on the difference in gender and differences in the roles each played within their personal lives. In addition, the type of disease, the age difference, the educational status, and the employment status of participants may be considered in future studies to enhance a better understanding of the influence of these factors and the meaning of the experience for each participant.

The researcher also recommends that similar research be conducted in an environment where the participants are not known to the researcher in an effort to minimize insider's bias. It is possible that additional information may have been gained had the researcher not been known to the participants.

The findings from this study also show strong support for the phenomenological method to investigate the meaning of patients' experiences as a way of knowing how experiences are lived. The descriptions illuminated the participants' perspective that could not be achieved by quantitative methodology (Ray, 1985). Although the quantitative approach is important to nursing research, a major limitation is that the quantitative method reduces human experience to a few concepts which are defined in advance by the researcher rather than by the participants. The use of the phenomenological method enables the researcher to capture the human experience holistically, emphasize the complexity of the participants' experience as it is actually experienced, and collect the information without a formal structured process (Polit & Hungler, 1991). Furthermore, "nursing has advanced a philosophy that embraces the whole of the human condition. It professes values that include respect for each individual and their cultural interpretation of

meaning and events ... A qualitative perspective of nursing not only as a research design but also for actual implementation of a holistic, empathic, individualized delivery of nursing care" (Munhall, 1989, p. 27) is essential from the perspective of nursing.

Implications for Nursing Education

The context of frequent visits from the patients' perspective raises important questions for nursing education. What percentage of nursing education is focused on the complexity of chronic illness? What do nurses know about the psychosocial aspects of chronic illness? How can nurses who are entering the work environment be made aware of the importance of the patients' perspectives about their illness situation in the implementation of their care? A review of the literature on chronic illness and the researcher's personal observation have revealed that there is minimal content on the frequent visits dimension for treatment of a chronic illness. All aspects of chronic illness that impact on patients' quality of life must be considered in nursing interventions (Anderson & Bury, 1984; Corbin & Strauss, 1991). Chronic illness is therefore a necessary part of nursing education particularly, if health care professionals must be accountable for personalized care (Lubkin, 1990). However, although the effect of chronic disease on patients and family members is recognized in nursing education, it appears that the meaning of the experience for the patient and the family is not emphasized. Nursing education should include information on coping strategies and social support systems. Nurses could use this information as a resource to enhance patients' and families' hopefulness during a chronic illness and long - term treatment regimen that is specific to each patient's needs.

Moreover, the frequent visits aspect of chronic illness is important to nursing education as the complexity involved in a patient's long - term management and hospital

experiences can lead to a great psychosocial adjustment in the life of the patient and family members who play a role in helping the patient. Thus, the nurse who is educated in all aspects of patients' illness will not only focus on the physical maintenance of the patients' condition, but will become more involved in the psychosocial aspects of the patient's care to identify the amount and type of support that the patient may need.

Curtin and Lubkin (1990) have commented on the lack of comprehensive programs that include chronic illness in nursing schools. They propose that nurses' clinical experiences be related to the complexity of issues in chronic illness and that the curriculum reflect techniques to improve communication between the patient, family, and caregiver. They advocate that classes in chronic illness be made a major focus in nursing curricula. Furthermore, professional caregivers must have knowledge about how to empower patients through the promotion of assertiveness and self-care skills. "To be effective, we as professional caregivers must be part of the involvement. A partnership of care requires information exchange and mutual decision making and offers the opportunity to share part of a courageous, creative life" (Curtin & Lubkin, 1990, p. 18). This can be accomplished through educating nursing students about all aspects of chronic illness and the importance of patients' experiences to treatment planning and intervention.

Additionally, the benefits of phenomenological investigation to understand patients' experiences should be emphasized in nursing education. Both phenomenology and nursing deals with aspects of patients' experiences. "The meaning of a client's reality through the phenomenological approach will reveal to the nurse the qualities of each individual's existence, which subsequently will provide a more comprehensive understanding of the nature of nursing itself" (Ray, 1985, p. 85).

Limitations of the Study

This study has some limitations. Aspects of the methodology such as the purposeful sampling, the differences in patients' diseases and varying health status, the selection of participants from the researcher's place of employment, the participants' accuracy of recall, and the short duration of frequent visits of one participant may have introduced some methodological issues.

The purposeful sampling method used to select participants is recommended for a phenomenological study (Thomas, 1990). However, the purposeful sampling may have resulted in more knowledgeable, articulate participants who may have higher education than the population of patients that are to be represented in the study. Experiences for these participants may differ from those of other patients and the results of the research may not be widely representative of all patients' who make frequent visits.

The sample was made up of patients with varying diseases and varying health status. Although the research aim was to examine the experience of frequent visits and not the experience with the disease, the degree to which the disease limited the participants was seen to influence their experience of the frequent visits so that there was considerable variation within a particular theme. Rogers (1983) states that investigations that use different samples can produce very different results. Artinian (1991) also argued that there is more to be learned about the experience of chronic illness by identifying the differences among similar disease states, rather than by prematurely attempting to find similarities among dissimilar disease states at a general level. Thus, the differences in the diseases may well contribute to the dissimilarities among the participants. The variations in the experiences also may be viewed as a strength of the study as it evidenced the uniqueness of each participant's experience and showed similarities across participants.

The selection of participants from the setting in which the researcher is employed may have produced insiders' bias. Harper Petersen (1988) warns that participants may not express themselves candidly if the researcher is a direct patient care provider. However, Field (1991) and Stephenson and Greer (1981) have discussed the advantages and disadvantages of the researcher in one's area of work where the participants are known to the researcher.

As an insider, the researcher has the advantage of having a better understanding of the verbal and non verbal data (Field, 1991; Stephenson & Greer 1981) and will therefore be able to adapt the research in a manner that will promote trustworthiness of the results. The data may also be easier to interpret and there may be less chance of misinterpreting the meanings of the participants (Stephen & Greer, 1981). On the other hand, some of the subtleties of the data may be missed because they appear common place. Being an insider also is economical because less time is needed to become comfortable in a different research setting, to access participants, and to gain rapport with the participants (Field, 1991; Stephenson & Greer, 1981).

The disadvantages of an insider may include selecting informants with whom the researcher feels comfortable, influencing the informant to provide information that is unrelated to the research question, and identifying with the values and the perspectives of the participants. Maintaining confidentiality also may be difficult as information may be traced back to the participants or may be excluded from the results particularly in some settings where information may be easily traced (Stephenson & Greer, 1981).

However, Stephenson and Greer (1981) contend that if the researcher has knowledge of the disadvantages of doing research in an environment where the researcher is known, the researcher must develop strategies to address the effect of the insider's issues. Although one strategy that is advocated to overcome the insider's issue is to conduct the

study in another setting where the participants are not known to the researcher (Field, 1991), the insiders' issues will still be problematic as the researcher is in the field of nursing and will have knowledge of the experience (Scanlan, 1992).

Strategies the researcher have used to manage the insiders' issues include masking the participants identity; addressing the issue of coercion and confidentiality through recruitment of participants by the Head Nurse; and withholding the names of participants who were selected from the list of names from the Head Nurse. As well, the researcher did not provide direct care to the participants during the research process. The researcher stressed to the participants that the interview would not be discussed with the Head Nurse, other patients, or anyone one else on the unit. Furthermore, the interview questions were innocuous and addressed what the frequent visits meant for the patients rather than fault finding about specifics about the unit.

Although the participants appeared to be true to their descriptions, they may have felt obligated to participate in the study or may have withheld information that they thought may have affected them personally, especially if the information was negative. For the same reason, participants may have felt the need to over-state the experience positively. The finding that all participants evaluated the context of the care environment positively and focused more on those negative experiences to events that were external to the unit (the waiting for pharmacy to be opened and for the IV nurse), rather than internal to the treatment unit may be because they were familiar with the researchers and believed that their care may be jeopardized.

This study required that participants recall an experience that occurred over many months or years. The participants' ability to recall the experience may not have been as accurate as the experience occurred. However, the purpose of phenomenology is to explore the perceptions of the participants.

One participant was making frequent visits for only two months prior to the research investigation. This short time period may not appear to be sufficient to identify aspects of the experience that are meaningful to the study. However, the researcher believes that the frequency of every two to three weeks within which this participant made frequent visits increased the participant's reflection of the experience and was meaningful to the results of the research.

Conclusion

The aim of this study has been to uncover the meanings of the experience of patients who frequently visit an ambulatory care department for treatment of a chronic disease. The study was conducted with a purposive sample of seven participants. The research was phenomenological in character in an attempt to discover from the patients' experiences what the experience meant for them from their perspectives. Overall, the results were encouraging. The findings indicated that patients were generally satisfied with their experiences in ambulatory care. This conclusion was based on their high evaluations of their experience with the caregivers, the care provided, and the climate of the caring environment. Participants' descriptions highlighted similarities and differences in the experiences. These similarities were evident despite differences in the distinct disease for which the participants were treated. What appeared to be the difference between the participants' experiences were the nature of the demands of the frequent visits, the degree to which the participants were affected by the disease, and gender differences. For example, various experiences either restricted or enhanced the participants' experience with the frequent visits while they simultaneously coped with the physical aspect of their disease.

The results of this study demonstrated that participants perceived the frequent visits as a two way interaction between themselves and the caregivers through which both

benefit. They also perceived that the past, present, and future uncertainties that characterize the experience with respect to the illness and care environment are evaluated against the support and care they received. Thus, the study is an important means to understand the psychosocial factors that are involved in the experience that patients face and their coping skills within the frequent visits. Strong support was provided for studying chronic illness from a phenomenological perspective regardless of the diagnosis and as a multidimensional, complex, and dynamic experience.

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Appendix A

Bracketing

Bracketing is the researcher's attempt to put aside assumptions about the reality of the phenomenon prior to the data gathering and before and during each interview. The researcher also reduces her/his influence on the subjects. Bracketing is also the bridge to close the gap between the researcher's own experience, what is being studied and what exists in the world of the researcher. Bracketing is therefore a tool used to meet the essence of a phenomenology investigation because it allows for portrayal of the phenomenon as accurately as described by the informants (Swanson-Kauffman & Schonwald, 1988).

Intuiting

> Intuiting...is the process of coming to know the phenomenon as described by the subject. It is a demanding activity requiring concentration and strict adherence to the surfacing meaning of the phenomenon as it shows itself in the descriptions of the subjects...The idea of intuiting is to grab the uniqueness of the phenomenon by openly looking, listening, and feeling (Parse, Coyne & Smith,1985, pp. 19-20).

Analyzing

> Analyzing...is the process of investigating a phenomenon, is the strict intentional tracing of elements and structure of the phenomenon revealed through intuiting. It explores the distinguishing characteristics of the phenomenon and its connections and relation to other phenomena. It is an attempt to uncover the constitutional elements of the phenomenon in order to come to know the whole of it, to shape its meaning as a lived experience (Parse, Coyne & Smith,1985, p. 20).

Describing

> Describing is an integral part of intuiting and analyzing. It is the process of affirming a connection between the phenomenon and everything which is denoted or connoted by way of the terms used in reference to it. Describing focuses attention on the major characteristics of the phenomenon, setting forth essences and pointing beyond them. It is not an exhaustive process, but rather a selective one, which culminates in an elaboration from the meaning of the elements and structure of a lived experience (Parse, Coyne & Smith, 1985,p. 20).

Appendix B

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#94/15

Proposal Title: "THE EXPRESSED LIVED EXPERIENCE OF PATIENTS WHO FREQUENTLY VISIT AN AMBULATORY CARE DEPARTMENT FOR THE TREATMENT OF A CHRONIC ILLNESS."

Name and Title of Researcher(s): MERLINE P. MORRIS, RN
MASTER OF NURSING GRADUATE STUDENT
FACULTY OF NURSING UNIVERSITY OF MANITOBA

Date of Review: JUNE 06, 1994.

APPROVED BY THE COMMITTEE: JUNE 06, 1994.

Comments: APPROVED WITH SUBMITTED CLARIFICATIONS/REVISIONS OF JUNE 14, 1994.

Date: June 14, 1994

Linda J. Kristjanson, PhD, RN — Chairperson
Associate Professor
University of Manitoba Faculty of Nursing

Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

Appendix C
Request For Hospital Access
Description of Research To Director of Health Sciences Centre Research Committee

Winnipeg, Manitoba
R
May 27, 1994

Director Research Committee
Health Sciences Centre
820 Sherbrook, MS-7
Winnipeg Manitoba
R3E 1X2

Dear Director:

I am a Master of Nursing Student at the University of Manitoba. As part of my Masters program, I am conducting a research study on the expressed lived experience of patients who frequently visit an ambulatory care department for treatment of a chronic disease. I am writing to request permission to recruit research participants from the day medicine/day surgery unit, ambulatory care at the Health Sciences Centre.

I have worked in ambulatory care for 15 years and am interested in understanding the meaning that the frequent visits holds for the patients from their perspective. Many studies have been conducted in ambulatory care. However, it is interesting to note, that although frequent visits to an ambulatory care department for treatment of a chronic illness is a dimension of ambulatory care, this aspect of care has not been studied. The research is guided by the view that frequent visits to an ambulatory care department are health experiences that need to be studied from those living the experience. The study will involve interviewing participants on two occasions about their experience with the frequent visits. The interviews will last for approximately one hour each. It is hoped that the results from the study will benefit the participants indirectly through a better understanding of issues and concerns associated with the frequent visits by participants and will contribute to the improvement of their care. I have enclosed a copy of the proposal for your perusal.

Once you have given me approval to conduct the study, an explanation of the study will be sent to the head nurse of the day medicine/surgery unit, ambulatory care. The head nurse will be asked to identify individuals who meet the criteria as set out in the description of the study, to give potential participants a copy of the invitation to participate in the research, and to keep a list of names of these individuals. After receiving the list of names from the head nurse, I will telephone the potential participants to thank them for

considering to participate in the study and to further discuss the research plan and elicit their participation. Participants will sign a consent form and may withdraw from the study at any time. Following the study, participants will be debriefed about the results and given a summary of the results, upon request. Information resulting from the research will be treated with respect to the ethical principles of confidentiality and anonymity

I have applied for ethical approval from the Ethical Review Committee, Faculty of Nursing, University of Manitoba. Please contact me at any time with questions concerning the research. I may be reached by phone at (home) or (work). If you wish to speak with my advisor, Judy Scanlan, she may be reached at .

Thank your for your time and consideration of this request.

Yours sincerely

Merline Morris

Health Sciences Centre

Appendix D
Hospital Acess Approval

820 SHERBROOK STREET
WINNIPEG, MANITOBA R3A 1R9

DIAL DIRECT (204) 787-4587
FAX (204) 787-4547

OFFICE OF THE DIRECTOR OF RESEARCH

June 20, 1994

Ms. M. Morris
Day Surgery
MS3

Dear Ms. Morris:

RE: A Study of the Expressed Lived Experience of Patients Who Frequently Visit an Ambulatory Care Department for Treatment of a Chronic Illness.

ETHICS #: N#94/15

The above-named protocol, **has been evaluated and approved** by the H.S.C. Research Impact Committee.

If your study is receiving funds, please contact the H.S.C. Finance Department for an application for a Specific Purpose Account. It is imperative that you submit a copy of this letter along with your application to: Supervisor, Ancillary Services, Finance Division, so she is aware this has been approved by the H.S.C. Research Department.

PLEASE NOTE: THIS SPECIFIC RESEARCH ACCOUNT NUMBER CAN ONLY BE USED FOR THIS PARTICULAR STUDY.

My sincere best wishes for much success in your study.

Sincerely,

Lui S Oppenheimer, MD, FRCSC
Director of Research
Health Sciences Centre

cc: Supervisor, Ancillary Accounts
Finance Division
791 Notre Dame Avenue

LO/lls

Appendix E
Letter to Head Nurse

Dear Head Nurse:

I am a Registered Nurse and a Master of Nursing student at the University of Manitoba. I have fifteen years experience working on the Same Day Admission Unit of ambulatory care. I am conducting a study of "The expressed lived experience of patients who frequently visit an ambulatory care department for treatment of a chronic illness" in partial fulfillment of the requirement for the Masters program. I am interested in interviewing patients who attend your department at least monthly over months or years for treatment of a chronic illness. Patients who agree to participate must be able to speak and understand English, express themselves well, be over the age of eighteen, and live within the perimeter of Winnipeg. Any patients fitting into this category may volunteer for the study since the actual visits are the focus of the research, not the type of disease. Please find enclosed a copy of the study proposal and copies of letters requesting patients to participate in the study.

I would appreciate it if you would invest the time necessary to identify patients who meet the criteria, explain the researcher's interest in the study, and present them with a copy of the description of the study which requests their participation. The description provides information regarding the study and ethical considerations. I would also appreciate if you would obtain the names and telephone numbers of those individuals who are willing to consider volunteering so that I can contact them by phone to discuss the study process and their expected involvement should they decide to participate.

I would be happy to provide more information about the research. Please do not hesitate to contact me with any questions or concerns. I can be reached at (home) or (work). Thank you for your time and consideration. I will contact you next week to discuss this request.

Yours sincerely,

Merline P. Morris, R. N., B. A., M. N. (C)

Appendix F
Description of the Study and Invitation to participate

Hello, my name is Merline Morris. I am a Registered Nurse and a Master of Nursing student at the University of Manitoba. I have fifteen years experience working on the same day admission unit of ambulatory care where I am currently employed.

At the present time, I am nearing completion of my Master's program. As part of the program, I am conducting a research study on the experience of patients who frequently visit an ambulatory care department for treatment of a chronic illness. I am interested in talking to individuals with a chronic disease who have been attending an ambulatory care unit at least on a monthly basis spanning months or years. I have asked the head nurse of this department to provide a list of patients who fit the study criteria and who may be interested in volunteering to be a participant in the study.

If you agree to participate, I will ask you to share your experience with me in an interview at a place and time that is mutually convenient. You need to be able to understand English, live within the perimeter of Winnipeg, and have a telephone so that I can contact you. You will be asked to take part in two interviews which will last one hour each. At the first interview, I will outline the study and you will be asked to sign a consent form. The interviews will be audiotaped and transcribed. Your name will not appear on the tapes or on the transcriptions. The tapes will be labeled with a code and will be kept locked in a filing cabinet. All information shared with me will be confidential. Only I and the members of my thesis committee will have access to the transcription. If publications are made from the results, your name will not be identified. At the end of the study, the tapes will be kept secured for ten years, after which they will be erased.

I will be contacting you by phone to discuss this request and answer questions you may have. Participants may withdraw from the study at anytime since involvement in this study is voluntary. Participants may also receive a summary of the study. My telephone number at work may be found at the end of this letter if you wish to contact me. It is hoped that the information from the study will result in the implementation of more flexible and improved care that will benefit you, other patients, and the nursing profession.

Thank you for considering this request. Your time is greatly appreciated.

Sincerely,
Merline Morris
Telephone _____ (work)

Appendix G

Consent to Participate in the Study

This is to confirm that I----------agree to participate in the study entitled "The Expressed Lived Experience of Individuals Who Frequently Visit an Ambulatory Care Department for Treatment of a Chronic Disease." I understand that the study proposal has been approved by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba. I am informed about the following conditions:

1. That the study will be conducted by Merline Morris, a Master of Nursing student at the University of Manitoba and will be supervised by three faculty members: Professor Judy Scanlan, Faculty of Nursing (chair), Dr. Erna Schilder, Faculty of Nursing (internal member), and Dr. Brian Penner, Associate Professor with the Department of Medicine and Pharmacology and Director of Sherbrook Center Dialysis Unit (external member).

2. I understand that the purpose of this study is to investigate what it is like for individuals with a chronic disease to be frequently admitted to an ambulatory care department for treatment over months or years. This information will assist doctors and nurses to better understand what type of needs and concerns are associated with the frequent visits.

3. I have been given verbal and written explanations about the study and understand the purpose and the process.

4. I understand that my involvement in the study requires that I be interviewed twice by Merline Morris at a mutually agreed time and place and that I will be asked to share my experiences about the frequent visits I make for treatment to ambulatory care. The interviews will last approximately one hour and will be audiotaped and recorded. An additional interview may be necessary. I understand that the researcher will keep a journal in which she will note specific information about the interview.

5. I have been assured that I may withdraw from the study at any time with no penalty, and I can refuse to answer any questions I choose not to answer.

6. I understand that the information from the study will be kept confidential and that only Merline Morris and the committee members will have access to the transcripts. The transcripts will be locked in a filing cabinet for ten years.

7. I understand that the information may be used for presentations or publications and that I will not be identified individually.

8. I have been given a copy of this consent form, and am aware that I will not benefit directly from participating in the study.

9. I understand that the only risks of participating in this study is that I may become distress during the interview and I can request that the interview be stopped.

10 I may telephone Merline Morris or her advisor at any time regarding the study. Her telephone number is (work), and Judy Scanlan's, her advisor number is

Date---------- Date----------

Participant---------- Researcher----------

I would like a summary of the results of this study.

Yes_____
No _____

If yes: Name_____
Address_____
_____
_____
_____

Appendix H
Demographics

1. Age
2 Address
3 Marital status
4. Type of disease being treated
5. Type of treatment
6. years of illness
7. Commencement of visits to ambulatory
8. Frequency of visits/months or years attending ambulatory care
9. Employed/not employed

Appendix I
Interview Guide

In the first interview, the following questions will guide the interview:

1. Please describe in as much detail as possible your experience of frequent visits to ambulatory care for your chronic illness.
2. Please share all your thoughts, perceptions and feelings until you feel you have no more to say about the experience (Parse, Coyne, and Smith, 1985).

In the second interview, the participants will be asked:

1. Is there anything you would like to add, delete or correct to the descriptions?
2. Do you need further clarification of any of the research process or transcripts before presentation of the findings?

Appendix J
Interview Prompts

-Please elaborate on that point.
-Will you please tell me more about----
-How do you feel about----?
-I would like you to clarify what you mean by----
-Is this what you mean to say?
-What do you mean by----?
-I would like you to describe exactly the way you feel about---
-Please describe how you felt in that interaction