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UNIVERSITY OF ALBERTA

LEARNING TO LIVE WITH UNCERTAINTY: THE ROLE OF HOPE AND MEDICATION COMPLIANCE IN CHRONIC ILLNESS

BY

© CHERYL LYNN MARIE NEKOLAICHUK

A THESIS
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UNIVERSITY OF ALBERTA

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The undersigned certify they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled LEARNING TO LIVE WITH UNCERTAINTY: THE ROLE OF HOPE AND MEDICATION COMPLIANCE IN CHRONIC ILLNESS submitted by CHERYL LYNN MARIE NEKOLAICHUK in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION in COUNSELLING PSYCHOLOGY.

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Date: August 7, 1990

"In Memory of My Parents"

to my dad, whose love for learning inspired me,

and to my mom, whose love for life showed me how to hope

Abstract

Traditionally, studies of medication compliance have been based on medical or behavioral models which emphasize the objectives of prediction, explanation or cause-effect. In contrast to the quantitative elements of traditional compliance research, the purpose of this study was to gain a greater understanding of the relationship between hope and medication compliance in the chronically ill, from the individual's perspective.

The design for this study was qualitative in nature, consisting of in-depth interviews with eight chronically-ill individuals. The participants ranged in age from 25 to 65 years, represented a wide variety of chronic illness experiences and were receiving medications as one form of treatment for the illness. The data were analyzed using the constant comparative method of data analysis.

Two separate, concurrent processes emerged from the participants' experiences, the process of hoping, that is, maintaining the hoping self, and the process of coping, that is, learning to live with uncertainty. These two processes, although separate, are interconnected through the common theme of uncertainty. The role of medications and medication compliance within the chronic illness experience is embedded within these two processes and linked through the theme of uncertainty.

The general discussion includes a review of the interrelationship of hoping, coping, uncertainty and compliance in chronic illness. A second theme for discussion is the importance of relationships within this experience. Implications for practice and suggested areas for future research are also highlighted.

The concepts of hope and medication compliance in chronic illness are complex; and are difficult to fragment, simplify or study in isolation. The results from this study suggest that these concepts may be better understood within the multifaceted coping process of learning to live with uncertainty.

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CHAPTER I

INTRODUCTION

A. Statement of the Problem

The concept of health care is changing. This may be related, in part, to alterations in patterns of morbidity and mortality, as well as shifts within social values towards healthier lifestyles. The evolution of the health care concept is reflected in transitions within definitions of health, health care trends, health promotion and roles of health care providers.

Definitions of health are expanding beyond the traditional view of physical health to include mental, emotional, intellectual, social and spiritual dimensions of human functioning. The conceptualization of health as being much more than the absence of illness was advanced by the World Health Organization some forty years ago. It defined health as "a state of optimal physical, mental and social well-being and not merely the absence of disease or infirmity" (in Health and Welfare Canada, 1988, p. 4)). It is only recently, however, that this definition has been incorporated within national policies in which health is viewed as more than the result of treating and curing illnesses (Health and Welfare Canada, 1986).

Health care trends are shifting from an emphasis on treatment and cure to that of quality of life and prevention. Current trends focus on wellness and quality of life; health promotion, illness and injury prevention; and patient rights, including the advocation of greater accessibility, choices and control.

In response to these current health trends, a framework for health promotion has been proposed (Health and Welfare Canada, 1986). Within this framework, three challenges which are of prime importance to the health of Canadians have been identified. These include reducing inequities in health in varying socioeconomic groups; increasing efforts to prevent injuries, illnesses and chronic conditions; and enhancing the individual's ability to cope with chronic conditions, disabilities and mental health conditions.

Accompanying the transitions in health trends and health promotion, the roles and expectations of health care professionals are changing. In a recent report by the Premier's Commission on Future Health Care for Albertans (1989), the need for active involvement of the patient in health care was stressed. The traditional roles of health professionals may need to be adjusted to accommodate the patient's active role in the health care process.

The segment of the health promotion framework which is of greatest interest within this study is the challenge of enhancing the individual's ability to cope with chronic conditions. The impact of a chronic illness is not limited to physical disabilities, but may influence many facets of the individual's life, such as the social, financial and emotional spheres. Often, individuals lack sufficient internal resources for coping with the illness process.

A fundamental resource for the chronically-ill individual is the health care system. In order to effectively assist in the coping process, this system must be sensitive to the needs and perspectives of the individual. Health care professionals need to understand the concepts of illness and health from the individual's frame of reference, based on the broader definition of health which includes psychological and social factors. Quality of life, as opposed to longevity, is of prime importance to the chronically ill.

This study will focus on the interactions between the health care system and the individual's psychological responses to illness and health. Specifically, this study has been designed to explore the relationship between an expectation of the health care system, that of medication compliance, and the psychological variable of hope, within the context of coping with a chronic illness.

Compliance

Noncompliance has been cited as a serious health care problem (Becker & Maiman, 1975; Sackett, 1976a). It has been estimated that 50% of patients do not take their medications as prescribed (Sackett, 1976a). Considering that the level of compliance to a prescribed medication regimen may determine the overall effectiveness of therapy (Given & Given, 1984), the issue is of concern to those charged with prescribing, administering and providing education regarding medications. Compliance rates tend to decrease the longer the regimen must be followed (Gerber, 1986), thus posing special problems for individuals with chronic illness. Noncompliance in the chronically ill may intensify complications associated with the chronic condition.

Traditionally, compliance studies have focused on the effect of an individual's personality or behavior patterns on the treatment regimen (Leventhal, Zimmerman, & Gutmann, 1984). It has been suggested that these traditional approaches ignore important aspects of an individual's quality of life (Barofsky, Sugarbaker, & Mills, 1979), which may greatly influence the degree of compliant behavior, especially in long-term chronic illness (Gerber, 1986). To better understand the issue of compliance, attention must be given to the personal meaning attached to the individual's chronic illness experience and the impact of this condition on everyday life (Bury & Wood, 1979). Thus, one might question, "What are the experiences of the chronically ill and how do these individuals adapt, especially with respect to treatment regimens?"

Chronic Illness

In pursuit of the above question, one must first understand the extent of chronic illness. Chronic illness represents a major threat to health care and society. As early as the 1940's, epidemiologists identified chronic diseases as a new area of concern for public health, due to their economic and social impact, as well as their enhanced effect on morbidity, mortality and disability (Balram, 1989). In a recent survey, approximately 13% of adult Canadians reported some level of disability in daily functioning due to a long-term physical condition, health problem or mental handicap (Statistics Canada, 1984). A number of reasons for the increased prevalence of chronic disease have been cited: (1) a general increase in population (Bright, 1966); (2) an increase in the proportion of the elderly population (Strauss, 1975); and (3) the elimination and control of infectious and parasitic diseases (Strauss, 1975). Although it is more prevalent amongst the geriatric population, chronic illness affects individuals of all ages (Strauss, 1975). It is currently the number one health problem in the United States (Forsyth, Delaney, & Gresham, 1984).

The nature of chronic illness is a second key in understanding the experiences of the chronically ill. Chronic illness is a long-term, potentially debilitating condition, which may have a profound and prolonged impact on an individual's self-image, sense of identity and lifestyle. The onset of chronic illness is often insidious, leaving the individual with feelings of uncertainty regarding the future (Bury & Wood, 1979). The progression of the condition is unpredictable, although it tends to follow a downward pathway, characterized by intermittent remissions and plateaus (Craig & Edwards, 1983). In contrast to acute illness, there is no cure for chronic illness. Rather, the goal of treatment is to assist in the alleviation of symptoms and control of the illness process. Thus, medical treatment is often lifelong, requiring long-term medical follow-up.

A third factor which is important in understanding the chronic illness experience is the concept of coping. The long-term, unpredictable, progressive nature of the illness process presents the chronically-ill individual with ongoing adaptive tasks. To cope with these many adaptive tasks, individuals develop unique management strategies (Strauss, 1975). The types of strategies vary and some may be better for coping than others (Viney & Westbrook, 1982).

The management of medication regimens has been identified as one of the key adaptive tasks of the chronically ill (Craig & Edwards, 1983; Strauss, 1975). Coping with

with prescribed medication regimens is an issue for the chronically-ill individual. Compliance to these regimens may be conceptualized as a form of coping (Weisman, 1979). The individual's potentially lifelong dependence on medications may, however, pose special problems. The medication regimen may have limited effectiveness and significantly disrupt the individual's daily routine (Reif, 1973). Therefore, the ability to comply with the prescribed regimen would be affected.

Coping is a fundamental component of the chronic illness experience. Although the individual is confronted with many adaptive tasks, and the nature and effectiveness of management strategies may vary, it has been suggested that the concept of hope plays a central role in the coping process (Forsyth et al., 1984).

Hope

Hope has been linked to the essence of human existence. Descriptions of hope as a powerful resource for life and restoration of being; vital to the human spirit; and fundamental to the survival of an individual have been cited in the literature (Korner, 1970; Lynch, 1974; Marcel, 1962; Vaillot, 1970). Some researchers have identified hope as an important factor in the quality of survival. It has been suggested that a loss of hope and a narrowing of expectations and goals for life reduce quality of life (Pierce, 1981; Stoner & Keampfer, 1985; Stotland, 1969).

There is a basic assumption that a positive relationship exists between hope and health (Lange, 1978; Obayawana & Carter, 1982; Proulx, 1972; Watson, 1979). The absence of hope can have a profound impact on psychological well-being, response to therapy and recovery from illness (Engel, 1968; Frank, 1975; Gottschalk, 1974; Jourard, 1970; Orne, 1968). Loss of hope results in "giving-up" behavior which may lead to physical and emotional imbalance (Lange, 1978). In contrast, the presence of hope may have a predominant influence upon the healing process (Bruhn, 1984; Frank, 1975; Laney, 1969). One might then question, "What role does hope play in the chronically-ill individual, where complete healing or a cure is not probable or possible?"

It has been suggested that a relationship exists between hope and the ability to cope with illness (Herth, 1989; Korner, 1970; Weisman, 1979). Based on a review of the literature, the investigator identified three ways in which hope has been related to coping, namely, as an adaptive task (Craig & Edwards, 1983); as a prerequisite to effective coping (Weisman, 1979); and as a coping strategy (Craig & Edwards, 1983; Jalowiec & Powers, 1981).

B. The Relationship Between Compliance, Chronic Illness and Hope

The rate of compliance to medication programs could be classified as a type of coping behavior and related to one of the adaptive tasks of the chronically ill, specifically, the management of medication regimens. The concept of hope has been linked to coping in chronic illness and may affect coping behaviors. Further, noncompliance has been recognized as a problem amongst the chronically ill. Thus, one might question, "What effect, if any, does the concept of hope have on a specific coping behavior, compliance to medication regimens, in the chronically ill?"

C. Purpose of the Study

This study will explore how an individual's constructions of the illness and medication experiences, in relationship to hope, affect medication compliance. It is the investigator's hope that this research will provide a greater understanding of the issue of hope and compliance in chronic illness, from the chronically-ill individual's perspective.

To aid in this understanding, the conceptual framework of hope proposed by Dufault (1981) is expected to be useful. Dufault conceptualized hope as consisting of two spheres, generalized and particularized hope. These two spheres share six common dimensions, affective, cognitive, affiliative, behavioral, temporal and contextual. The process of hoping is characterized by changes within and among the dimensions of hope, and is reflected in an individual's hope profile. A hope profile is a unique pattern of hope objects, sources and threats, which change over time

Using Dufault's (1981) conceptual framework of hope, the following questions will be addressed in this study:

(1) How does the individual's perception of the chronic illness and medication experiences affect hope?
  (a) What are the individual's hope sources, objects or threats?
  (b) What factors contribute towards the individual's perception of medications as hope sources, objects or threats?
  (c) What factors contribute towards the individual's perception of the illness experience as hope sources, objects or threats?
(2) How does the individual's perception of the medication and illness experiences as hope sources, objects or threats affect compliance?

D. Significance of the Study

Health care providers are continuously searching for new ways to enhance effectiveness of therapy, by improving patients' compliance with medication regimens. To effectively influence medication-taking behavior, health care workers must consider the patients' perceptions of the illness and medication experiences.

Thus, there is a need to study both medication compliance and the chronic illness experience from the perspective of the individual. It is the investigator's belief that this study will provide greater insight into the complex nature of compliance. It will help illustrate the impact of chronic illness and medications on an individual's level of hope; and the effect of hope on compliance. If a relationship between hope and compliance does indeed exist, then unique, patient-centered strategies for the effective use and enhancement of hope in the area of medication compliance could be developed.

This study is not intended to identify effective coping strategies; or to show that high levels of compliant behavior provide an effective method of coping. Nor is it the investigator's intent to pass judgment on the participants regarding their degree of compliance. Rather, it is the investigator's intent to focus on the process which leads to differing levels of compliant behavior, with the recognition that a specific level of compliance or noncompliance may indeed be an effective method of coping for that individual. This novel approach to the issues of compliance and hope may help generate hypotheses for further research.

E. Definition of Terms

A number of terms have been adopted from the literature and incorporated within the study design. To aid in the clarification of these terms, the following definitions have been included.

Chronic illness: 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 (Mayo, 1956);

Compliance: The extent to which a person's behavior coincides with medical or health advice (Haynes, 1976). For the purposes of this study, compliance will be examined in relationship to medication management only;

Coping: Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984);

Generalized hope: A general sense or an aura that the future will bring beneficial but indeterminate developments; broad in scope and not linked to any particular concrete or abstract object of hope; a "hope umbrella" (Dufault, 1981);

Hope: A multidimensional, dynamic life force characterized by a confident yet uncertain anticipation of realistically possible and personally significant desirable future good having implications for action and for interpersonal relatedness. Hope is not a single act but a complex of many thoughts, feelings and actions that change with time, and has as its object not only indeterminate future good but various concrete and abstract particular outcomes (Dufault, 1981);

Hope object: That toward which hope is directed; a personally significant favorable future outcome, good, goal or state of being which the hoping person perceives or believes is possible yet uncertain (Dufault, 1981);

Hope profile: Construction of patterns of hope objects, sources and threats, at given times, and monitoring changes over time (Dufault, 1981);

Hope source: An agent that gives rise to hope or influences the person to hope (Dufault, 1981);

Hope threat: A person, thing or condition that (a) interferes with, inhibits or weighs against the possibilities for maintaining hope, or for attaining the hope object and (b) weakens or eliminates the source of hope (Dufault, 1981);

Particularized hope: Confident expectation of a personally significant future good for oneself or others; associated with a particular positively valued outcome, good, goal or state of being (i.e. an object of hope) (Dufault, 1981).

CHAPTER II

LITERATURE REVIEW

A. Compliance

The issue of compliance and the problems associated with noncompliance are well-recognized within the health care setting. Health care providers first became interested in this concept when it was discovered that noncompliance could result in ineffective treatment outcomes, as well as the confusion of results in clinical trials.

Although compliance is a concern within the health care community, there is a lack of consensus amongst health care providers regarding the definition of this concept. **Compliance** has commonly been defined as "the extent to which a person's behavior coincides with medical or health advice" (Haynes, p. 2-3, 1976). This traditional view of compliance implies an attempt to change patient behavior to align with health care team treatment goals (Bury & Wood, 1979). The patient assumes a passive role, with the physician in the position of authority (Turk, Salovey, & Litt, 1986). Turk et al., (1986) offer an alternate cognitive-behavioral approach, replacing the term compliance with "**adherence.**" The term adherence refers to the assessment of actions and behavioral patterns, based on specific standards. The relationship between the patient and the health care professional is collaborative in nature. A third term, "**therapeutic alliance,**" has been discussed in the compliance literature (Barofsky, 1978). A therapeutic alliance involves the negotiation of a mutually satisfactory agreement between the patient and the health care provider, based on a positive social relationship.

Barofsky (1978) suggests that these three terms occupy different positions along a continuum of social control, and that any patient-provider relationship contains elements of all three perspectives. The relationship between the patient and health care professional is thus characterized by the degree of external control over the patient's life. According to

Barofsky, a therapeutic alliance would offer the greatest degree of flexibility and patient involvement in this relationship.

For the purposes of this study, the term, compliance, and the traditional definition by Haynes (1976) have been adopted and applied to the management of medication regimens. The investigator has remained open to Barofsky's (1978) concept of a continuum of social control; and has attempted to explore the unique, individual experiences of compliance which may involve varying degrees of collaboration, patient participation and adherence to regimens.

Models of Compliance

Models of compliance have been developed from three major perspectives: (1) biomedical, (2) behavioral and (3) self-regulatory. These three perspectives will be reviewed and analyzed with respect to their significance to this study.

The Biomedical Model

The biomedical model supports the traditional view of compliance in which the expert view of the physician is readily accepted by the patient. It is designed to diagnose diseases; define risks; and suggest treatment and prevention regimens. An external or observer frame of reference is incorporated within this model. Emphasis is placed upon examining the characteristics or personality type of the "noncompliant" patient. Neither the patient's behaviors nor perspective is considered (Leventhal et al., 1984).

The Behavioral Model

In contrast to the biomedical model, the behavioral perspective shifts the focus away from the individual's personality to the environment, emphasizing actions and behavioral patterns of patients. The general goal of this approach is to develop methods to shape individual behavior, with measurement of success based upon the performance of specific actions. Behavior is not conceptualized as goal-directed or future-oriented (Leventhal et al.,1984).

Models arising from the behavioral perspective are based on three classes of behavioral theory: (1) operant behaviorism, (2) cognitive behaviorism, and (3) communication or attitude change theory. The basic difference amongst the behavioral models is the degree to which they adopt an external (i.e. observer) or internal (i.e. individual) frame of reference. Operant approaches are externally-oriented, focusing on the regulation of rewards for behavior, with little regard for the patient's perspective (Leventhal et al., 1984). In contrast, the cognitive-behavioral approach of the Health Belief Model (Becker, 1974; Becker & Maiman, 1975) places greater emphasis on the patient's perspective, in which attention is given to the individual's perceptions (i.e. perceived susceptibility to, seriousness of and threat of disease; perceived benefits and risks). Models of communication (for example, Weiss, 1969) and attitude change (for example, Ajzen & Fishbein, 1980) lie somewhere in between the operant and cognitive-behavioral models on the external-internal reference frame continuum, focusing on the communication process between the sender and receiver.

Of all the behavioral models, the Health Belief Model (Becker, 1974) places the greatest emphasis on the individual's perspective. This model is designed to describe the internal cognitive processes operating between communication and action, with an emphasis placed upon action expectations or beliefs (Kirscht, Becker, & Eveland, 1976). However, this model tends to ignore exactly how an individual views a problem (i.e. how an illness or an illness threat is experienced) and the actions needed to solve it (i.e. how required responses are viewed and understood).

The behavioral models have been effectively applied in the research field. These models have contributed to the development of behavioral response shaping; skill training; and modification of compliance techniques. With respect to compliance, a number of techniques which attempt to change health attitudes or behavior have been developed. These include modeling, changes in goal setting, education and persuasion. All of these techniques involve a one-way transfer of information from the health care professional to the patient. The primary goal, which is behavior modification, is most readily achieved in short-term compliance programs (Leventhal et al., 1984).

In spite of their usefulness in research, the behavioral approaches do not provide a complete or comprehensive understanding of the compliance issue. Although effective for short-term programs, these approaches are insufficient for maintaining long-term behavioral patterns. In addition, these models provide minimal insight into the ways in which individuals perceive or define health problems; and have not examined how to integrate behavioral change into an individual's lifestyle (Leventhal et al., 1984).

The Self-Regulatory Model

The self-regulatory model (Leventhal et al., 1984) has incorporated specific behavioral skills or action plans within its framework, but moves beyond the behavioral approaches. Within this model, the individual is perceived as an active participant with self-selected goals. These goals are selected based upon the individual's perceptions of the illness and the treatment setting; the selection of responses to reach these goals; and self-evaluation of progression towards goal attainment (Schulman, 1979).

There are three major phases within the self-regulatory model, representation, coping and appraisal (Haynes, Mattson, & Engebretson, 1980). Representation refers to the individual's perception of an external event in the environment related to the illness. This perception is represented as the degree of threat to oneself. Within the coping phase, the individual develops and implements a plan of action in response to the illness threat. The success of the strategies which are implemented in the coping phase are monitored and evaluated by the individual during the third phase of appraisal. The value of self-regulation is reflected in the opportunity for experimentation within these phases. The experimenter aspect of self-regulation helps in understanding how individuals develop a wide range of actions to treat and prevent illness, without medical advice (Leventhal et al., 1984).

The self-regulatory model differs from the medical and behavioral models in its emphasis on the individual's perspective (i.e. internal frame of reference) and the active role of the individual. In contrast to the behavioral models, self-regulatory behaviors are perceived as goal-directed and selected by the individual. The self-regulatory model provides support for the investigation of compliance from an individual's perspective. The first two components of this model, representation and coping, have received the greatest emphasis in this study. The individual's perceptions or representations of the chronic illness experience and the impact of these perceptions upon a specific aspect of coping, compliance, have been stressed.

Compliance as a Coping Behavior in Chronic Illness

Chronically-ill individuals and their families are continuously challenged by the long-term, unpredictable, progressive nature of a chronic illness. Adjustments may need to be made in many aspects of one's life due to the pervasive nature of the illness process. Coping strategies are developed to aid in adjustment and adaptation. The impact of the illness and the extent of adaptation may be complex. Thus, it may be difficult to fully appreciate or understand the impact of this disease process upon the individual's lifestyle.

Strauss (1975) proposed a framework to aid in understanding the daily experiences of the chronically ill. This framework consists of the following components: (1) identification of key problems; (2) development of coping strategies; (3) involvement of family or organizations; and (4) appraisal of consequences of actions.

The first stage of Strauss's (1975) framework involves the identification of key problems. One of the key problems described by Strauss was the "carrying out of prescribed regimens and the management of associated problems" (p. 7). Similar to Strauss's concept of "key problems," Craig and Edwards (1983) developed a model for adaptation in chronic illness which included the identification of adaptive tasks. "Dealing with treatment procedures" was identified as one of the psychological adaptive tasks of the chronically ill.

The second component of Strauss's (1975) framework involves the development of coping strategies to deal with the many "key problems" or "adaptive tasks" accompanying the disease process. There are a variety of coping strategies which have been used by the chronically ill. Feifel, Strack, and Tong Nagy (1987), in their study of medically-ill patients, identified three primary methods of coping: (1) confrontation, (2) avoidance, and (3) acceptance-resignation. Alternatively, Viney and Westbrook (1982) identified six primary coping strategies (i.e. action, control, escape, fatalism, optimism and interpersonal coping), in a study in which chronically-ill patients assessed their own coping preferences.

The degree of compliance to a medication regimen could be conceptualized as a type of coping strategy or behavior, for the adaptive task of medication management. Using Feifel et al.'s (1987) framework, high levels of compliance could be viewed as an acceptance-resignation strategy, whereas low levels of compliance may be perceived as a form of confrontation. Alternatively, using Viney and Westbrook's (1982) categorization, high levels of compliance could be viewed as an action strategy, whereas low levels of compliance could be considered a method of control.

This proposed relationship between compliance and coping has been alluded to in the literature, but the nature of this relationship remains unclear. Weisman (1979) viewed "cooperative compliance" as an effective coping behavior. Forsyth et al. (1984), in their study of chronically-ill, hospitalized patients, provide an alternate perspective of compliance and coping. They suggest that the patients interviewed in their study made decisions regarding treatment adherence or continuation, based on their own risk-benefit assessment of the situation. The investigators did not interpret decisions to discontinue treatmen [illegible] [illegible]ant behavior, but rather as behavior which was directed toward winning--v[illegible] [illegible] the disease.

Copin[illegible] integral component of the chronic illness experience. The development of unique and effective coping strategies is an important part of this experience. Although the types and effectiveness of strategies may vary amongst the chronically ill, it has been suggested that the concept of hope is a common underlying theme and plays a central role in the coping process (Forsyth et al., 1984).

B. Hope

The concept of hope is multifaceted and complex. For the purposes of this study, this concept will be reviewed primarily from the perspective of its goal-directed and multidimensional qualities. A more extensive description of the model of hope proposed by Dufault (1981) will be presented, particularly with respect to its applicability to medication compliance. Finally, the link between hope and coping will be described.

Conceptualization of Hope

Hope is a complex, multidimensional, dynamic construct (Dufault, 1981; Hinds, 1984; Miller, 1986; Owen, 1989). No single definition for hope exists. It has been described as an illusion, a virtue, a feeling, a psychological state, knowledge, a life force, a coping strategy, an expectation, a belief, a trait, a disposition and a gift for transcendence (Miller, 1986). The elusive quality of hope has been addressed in the literature (Korner, 1970; Marcel, 1962). Marcel (1962) referred to the nature of hope as a "mystery," "super-rational" and "super-relational"; and was reluctant to restrict the concept to a set definition.

There are many ways of looking at the concept of hope. The disciplines of theology, philosophy, psychology, sociology and medicine, particularly psychiatry and nursing, have offered their unique perspectives. Attempts have been made to define the concept by contrasting it with related terms (eg. desire, wishing, expectation, optimism) or opposing terms (eg. despair) (Lange, 1978). Some have attempted to reduce the concept to a singular definition (eg. Stotland, 1969), while others have developed comprehensive models of hope, which emphasize the multidimensional nature of this construct (Dufault, 1981; Korner, 1970; McGee, 1984; Obayawana & Carter, 1982). The following review is a brief summary of some of the proposed conceptualizations of hope, with particular emphasis on the goal-directed nature of hope and its multidimensional aspects.

The Goal-Directed Nature of Hope

A number of definitions, which emphasize the action-oriented nature of hope, have been proposed. Using a theoretical framework of goal-attainment, Stotland (1969) described hope as "an expectation greater than zero of achieving a goal" (pp. 2). The degree of hopefulness is based on the individual's perceived probability of achieving a goal. Thus, different persons who encounter similar situations may have varying degrees of hopefulness. Lynch (1974) defined hope as "a sense of the possible," implying that hope has an action orientation. Similarly, McGee (1984) described hope as futuristic, motivating, action-oriented and involving expectancy, based on her summary of the literature. These definitions, although functional, are narrow in their conceptualization, with primary emphasis on goal attainment or motivation towards action.

A more comprehensive definition of hope is offered by Miller and Powers (1988). They identified ten critical elements of hope based on a summary of the hope literature: (1) mutuality-affiliation; (2) sense of the possible; (3) avoidance of absolutizing; (4) anticipation; (5) goal attainment; (6) psychological well-being and coping; (7) purpose and meaning in life; (8) freedom; (9) reality surveillance and optimism; and (10) mental and physical activation. Although Miller and Powers (1988) acknowledge the goal-directed or action-oriented nature of hope, as proposed by Stotland (1969), they move beyond this single element to a more multidimensional view.

The Multidimensionality of Hope

Rather than reducing the concept of hope to a singular definition, other researchers have attempted to study the construct in terms of its multiple dimensions. Most have addressed some aspects of the cognitive, behavioral and/or affective domains of human functioning.

For example, Stotland (1969), who focused primarily on the behavioral dimension of hope (i.e. goal attainment), also emphasized the cognitive domain. Within this domain, schemas are acquired based on personal perceptions or communication with others.

In contrast to Stotland (1969), Korner's (1970) model of hope stressed the affective and cognitive domains. Hope was conceptualized as consisting of four components: purpose of hope, affective component, the cognitive component or rationalizing chain, and the hope equation. Korner's view of the purpose of hope is to defend against despair. The affective component involves the emotional attachment to the hoping process; whereas the rationalizing chain or cognitive component emphasizes the reality of a situation. Korner's concept of the hope equation represents the dynamic relationship between the affective component, the rationalizing chain and external stresses. Korner did not attempt to include the goal-oriented behavioral dimension as described by Stotland.

Similarly to Korner, Lange (1978) described the concept of a hope structure (i.e a process by which hopes are maintained) in terms of affective and cognitive components. She arranged the affective components on a faith-doubt continuum. Emotional elements of hope included faith; trust; confidence in self and others; and fortitude. According to Lange, a weakening of faith would lead to doubt and despair. The cognitive components referred to the way in which a person perceived and processed reality, similar to Korner's concept of the rationalizing chain. In addition to a hope structure, Lange identified four tasks of hoping: reality surveillance, encouragement, worrying and mourning. She also provided an operational definition of hope based on a hoping-despair continuum. Although Lange did not directly refer to a behavioral dimension of hope, she did provide an outline of hoping behaviors, part of which included "activation" behaviors.

In contrast to previous works, Dufault (1981) attempted to incorporate all three domains - cognitive, affective and behavioral - into her model of hope. She conceptualized hope as consisting of two spheres, generalized and particularized. These two spheres share six dimensions, specifically, affective, cognitive, behavioral, temporal, contextual and affiliative. The process of hoping is characterized by changes in emphasis within and among the dimensions of hope.

Support for the inclusion of all three domains in a conceptual framework of hope is offered by McGee (1984). She defined hope operationally in terms of responses to stimuli. The responses could include feelings, thoughts, expectancies or actions. The types of responses which are selected are determined by a desire or need for a future "state of being."

Although the investigator acknowledges the multidimensionality of hope, the behavioral dimension and the goal-directed nature of hope are of greatest interest, within this study, as these two elements most closely relate to the concept of compliance. Dufault's (1981) model of hope acknowledges these two elements, but incorporates them within a much more comprehensive framework than some of the previous works. Thus, for the purposes of this review, the significance of specific components of Dufault's model, that is, hope spheres, the hope profile and the behavioral dimension of hope, will be addressed.

Dufault's Model of Hope

Hope Spheres

Dufault (1981) conceptualized hope as being composed of two spheres, generalized hope and particularized hope. These two spheres are related, in terms of function, yet they exist independently of each other. Individuals fluctuate between the two spheres.

Within the sphere of **generalized hope**, there is a general sense of some future beneficial good. This sphere is broad in nature and is not linked to any particular hope object. Generalized hope provides the atmosphere for developing particular hopes and becomes more evident when particular hopes are threatened (i.e. development of hope threats); during times of uncertainty and change; and when particular hopes become identified, more abstract or more general.

In contrast, within the sphere of **particularized hope**, there is a confident expectation of a positive or "good" future for oneself or others. It is associated with a particularly valued outcome, good or state of being, that is, a hope object. The objects of hope may be concrete or abstract, explicit or implicit (Dufault, 1981). Medications, treatments and therapies could be classified as concrete hope objects.

Particularized hopes encourage commitment towards a future-oriented object or goal, similar to Stotland's (1969) conceptualization of goal attainment. Hope within the particularized sphere encourages constructive coping with obstacles, the development of alternative strategies and evaluation of progress toward the object (Dufault, 1981). These elements are similar to the coping and appraisal stages of Leventhal et al.'s (1984) self-regulatory model. One might question whether or not there is some relationship between hope and compliance, due to the similarity between these two models.

The Hope Profile

Dufault (1981) proposed the concept of a hope profile, a construction of patterns of hope objects, sources and threats which change over time. A **hope object** is a personally significant, favorable future outcome, good, goal or state of being which the hoping person perceives or believes is possible yet uncertain. Hope objects are characteristic of the particularized hope sphere and are most prevalent during times of stability. A **hope source** is an agent which gives rise to hope or influences the person to hope. A **hope threat** is a person, thing or condition that interferes with the maintenance of hope or the attainment of a hope object; or reduces the hope source. Hope threats are more likely to emerge during times of uncertainty or instability, and may coincide with an individual's transition from the particularized to the generalized hope sphere.

Various components of the illness and the medication experiences have been identified as potential hope objects, hope sources and hope threats (Dufault, 1981). Some of these components include diagnostic tests, treatment, symptom control and behaviors of significant others.

Elderly cancer patients who were interviewed in Dufault's (1981) study identified "hopes regarding illness and functioning" as **hope objects**. Within this category, specific hope objects related to the illness included hopes for favorable outcomes of diagnostic tests or medical evaluation; symptom management; symptom relief to achieve another hope object; and independence in functioning. Specific hope objects involving medications included "hope that a specific agent or action would provide symptom relief" and "hope for prevention of symptoms."

Dufault (1981) identified two **hope sources** which relate to the illness and medication experiences, specifically, the behaviors of significant others, including health care providers; and the means of achieving symptom relief or disease control. The methods for achieving symptom relief or disease control included evaluative tests; therapies, medications and equipment; and actions on the part of patient. Medication compliance was identified as a specific action, by the individual, to help relieve symptoms or control the illness.

The experiences which were classified as **hope threats** were related to other individuals, treatments and the progression of the illness. In addition to being a hope source, the "behaviors of significant others" could also represent a threat to hope (Dufault, 1981). This reinforces the powerful influence that health care providers may have over an individual's hoping process. Three other hope threats relating to the medications or illness included negative effects of therapies, treatments, tests and hospital environment; the evidence of diminished health; and the lack of information and ambiguity.

The Behavioral Dimension of Hope

This dimension focuses on the action orientation of the individual with respect to hope. Actions to achieve an outcome may be classified into one or more of the following four realms: psychologic, physical, social and religious. Within the physical realm, specific, visible, personal actions are selected by the individual either to achieve hope or as a consequence of hope. Compliance has been identified as a specific action to achieve hope, for example, "taking vitamins and other medications as scheduled" was described as a specific action to achieve the hope object of symptom relief (Dufault & Martocchio, 1985). The converse, that is, the effect of hope on compliance, was not directly addressed in Dufault's (1981) study. However, one might question whether or not compliance could be a consequence of hope; and more specifically what effect hope threats or hope sources might have upon compliance.

Summary

Dufault's (1981) model helps support the concept that a relationship may exist between hope and compliance. However, the nature of this relationship remains unclear. It is important to note that Dufault's conceptual framework for hope was based upon elderly cancer patients. Thus, there are a number of unanswered questions which apply to this study: (1) Is this conceptual framework unique to elderly cancer patients or can it be applied to any individual with chronic illness? (2) Are the hope sources, objects and threats different for individuals with chronic illness than for cancer patients? (3) Are the medication and illness experiences of the chronically ill different from those of elderly cancer patients?

The Relationship Between Hope and Coping

Hope has been identified as playing a central role in the individual's ability to cope with a chronic illness (Forsyth et al., 1984). Based on the review of the literature, the investigator identified three perspectives of hope within the coping process: (1) as an adaptive task; (2) as a coping strategy; and (3) as a prerequisite to coping.

Maintaining Hope as an Adaptive Task

The chronically-ill individual is confronted with a continual adaptation to the disease process, and is challenged with the task of maintaining hope in the face of adversity (Greene et al., 1982). The adaptive task of maintaining hope in spite of an uncertain or downward course has been addressed by other researchers (Craig & Edwards, 1983; Forsyth et al., 1984; Miller, 1983).

In Craig and Edwards (1983) adaptation model for chronic illness, "preservation of hope" was identified as one of the psychological adaptive tasks of the chronically ill. Forsyth et al. (1984), in their study of hospitalized patients with unpredictable, progressive chronic disease, suggested that by maintaining hope, patients perceived themselves as adopting a winning position over the disease process. Similarly, Miller (1983), in an analysis of nursing diagnoses of 115 chronically-ill adults, identified the maintenance of hope as a coping task.

Hope as a Coping Strategy

The chronically-ill individual develops many coping strategies. These strategies assist with achieving the adaptive tasks or adjustments within the illness process. Lazarus (1966) identified two classes of coping strategies, specifically, direct action tendencies and defense mechanisms. Hope was classified as a direct action tendency, strengthening an individual's protective resources against harm. As a method of coping, hope aids in the management of unpleasant stressful situations, by reinforcing a future positive outcome (Korner, 1970; Lynch, 1974).

The use of hope as a coping strategy has been cited in the literature. In Craig and Edwards' (1983) model for adaptation in chronic illness, hope was identified as one of four commonly-used coping behaviors. Similarly, in a study of 25 emergency room patients (Jalowiec & Powers, 1981), "to hope that things will get better" was the most frequently-used coping strategy of the seven methods identified.

Hope as a Prerequisite to Coping

Hope has been considered as an important determinant of behavior, serving as an activator of the motivational system (Korner, 1970, Lynch, 1974). Lynch (1974) suggests that hope is an aspect of motivation which leads to action, providing empowerment and greater self-control. In his theory of hope, Stotland (1969) acknowledged the relationship between hope and action, suggesting that hope is an essential part of motivating action, movement or achievement. The importance of hope in influencing behavior has also been addressed in the nursing literature (Dufault, 1981; McGee, 1984; Miller, 1985; Stoner and Keampfer, 1985). Coping involves the development of action or behavioral strategies. Thus one might question, "What role does hope play in the coping process?"

According to Forsyth et al. (1984), hope plays a central role in the coping process of the chronically ill. It has been considered as a "key" or "prerequisite" to effective coping and adaptation (Craig & Edwards, 1983; Obayawana & Carter, 1982; Weisman, 1979). In a study of 42 adults with brain tumors, Hung (1975) identified hope as the primary factor responsible for effective coping. It has been suggested that a reciprocal relationship exists between hope and coping, with one building on the other (Gottschalk, 1974).

This positive relationship between hope and coping is further supported by Herth's (1989) study of adult oncology patients undergoing chemotherapy. This study was designed to explore the relationship between hope, coping and a number of environmental, interpersonal and illness-related variables. A significant positive relationship ($r=0.80$, $p=0.001$) was found between level of hope and level of coping response.

The design of Herth's (1989) study was based upon Herth's (1985) Coping Process Nursing Model (CPNM), which incorporates Lazarus and Folkman's (1984) conceptualization of coping and Stotland's (1969) theory of hope. According to Lazarus and Folkman, coping involves both a primary and a secondary stage of appraisal. The primary appraisal is a cognitive determination of the degree of threat of a stimulus to an individual. Secondary appraisal involves the use of existing or development of new coping mechanisms by the individual. These two appraisals mediate between the stimulus and the outcome response (i.e. coping effectiveness). Stotland's conceptualization of hope is action-oriented, which enables the mobilization of coping resources. Thus, hopefulness is perceived as a prerequisite to action.

Herth's (1985) model for coping (i.e. CPNM) bears some resemblance to the self-regulatory model for compliance proposed by Leventhal et al. (1984). The primary appraisal component of the CPNM is similar to the initial phase of Leventhal et al.'s model (i.e. representation of the illness threat). Similarly, the concept of secondary appraisal in the CPNM coincides with the second and third stages of the compliance model (i.e. coping and appraisal). The similarity between these models provides further support for the conceptualization of compliance as a coping behavior and for the possibility of a relationship existing between hope and compliance.

C. The Relationship Between Hope and Compliance

If hope is considered to be a prerequisite to action or coping, and compliance is conceptualized as a type of coping behavior, then one might question, "What is the relationship between hope and compliance?" Although this relationship has not been directly studied, it has been addressed in the literature. However, differing views regarding the nature of this relationship have been proposed.

Some have viewed the relationship between hope and compliance as positive and linear. Perley, Winget and Placci (1971) examined hope scores and discomfort scores of 27 psychiatric patients in an emergency department. They found that compliant patients had higher hope scale scores than noncompliant patients. The positive relationship may also be inferred from Ajzen and Fishbein's (1980) model of attitude change, which suggests that the more positive one's attitude is toward a particular behavior (for example, taking medications), the more likely one is to comply with the behavior. Maintaining a positive attitude could be conceptualized as a component of hope. In addition, Craig and Edwards (1983) viewed compliance of medical regimens as evidence of a realistic and hopeful perspective of the situation, providing further support for a positive relationship.

As opposed to a positive, linear relationship, McGee (1984) proposed a curvilinear relationship between hope and acceptance of health care. In this type of a relationship, individuals who are at the extremes of a hopefulness-hopelessness continuum (i.e. "totally hopeful" or "unjustifiably hopeless") have a low acceptance of health care, which could be interpreted as a low level of compliance.

A third perspective for describing the hope-compliance relationship involves Dufault's (1981) concepts of hope objects, sources and threats. Dufault directly linked compliance to specific hope objects and sources. A direct relationship between compliance and hope threats was not addressed. The following is a summary of the relationships between compliance and hope objects, sources and threats, based on Dufault's framework.

The relationship between compliance and hope objects. A positive relationship may exist between compliance and specific hope objects. For example, high compliance rates have been associated with the maintenance of the hope object, symptom relief (Dufault, 1981). A second example involves the representation of medications as hope objects. Patients may try new or experimental drugs and treatment in an effort to maintain hope (Forsyth et al., 1984).

A number of questions arise from these observations. Is the relationship between compliance and hope objects always positive? Are there any hope objects which may result in noncompliance? How do these relationships develop?

The relationship between compliance and hope sources. A positive relationship may also exist between compliance and hope sources. For example, the achievement of symptom relief through compliance with medications may offer a source of hope (Dufault, 1981). Similarly to the compliance-hope object relationship, one might question whether or not any sources of hope result in noncompliance.

The relationship between compliance and hope threats. The relationship between compliance and hope threats remains unclear. Although compliance has not been directly linked to hope threats, various aspects of the illness and medication experiences have been implicated (i.e. negative side effects of medications; evidence of diminished health; and lack of information and ambiguity). One might speculate that the emergence of hope threats might reduce an individual's level of compliance, although this has not been directly discussed in the literature. Support for a potential relationship between compliance and hope threats is offered by Given and Given (1989). Based on Mishel, Hostetter, King and Graham's (1984) work on uncertainty, Given and Given suggest that uncertainty regarding a diagnosis (which could be classified as a hope threat) may deter hope and positive beliefs about effectiveness of therapy, resulting in lower levels of compliance.

D. Summary

The issue of reduced medication compliance rates amongst the chronically ill is a major health care concern. Unfortunately, traditional behavioral approaches to compliance have been ineffective for maintaining long-term adherence to treatment programs. These approaches ignore a critical aspect of the patient's perspective, that is, the impact of the medication and illness experiences on lifestyle, which can have a profound influence on compliance, especially in the chronically ill. In contrast to the behavioral approaches, the self-regulatory model focuses on the individual's perspective. This model provides a more comprehensive approach to the exploration of the phenomenon of compliance.

The management of medication regimens has been identified as an important adaptive task of the chronically ill. The conceptualization of compliance as a form of coping for this adaptive task has been proposed by the investigator. However, the precise relationship between compliance and coping remains unclear.

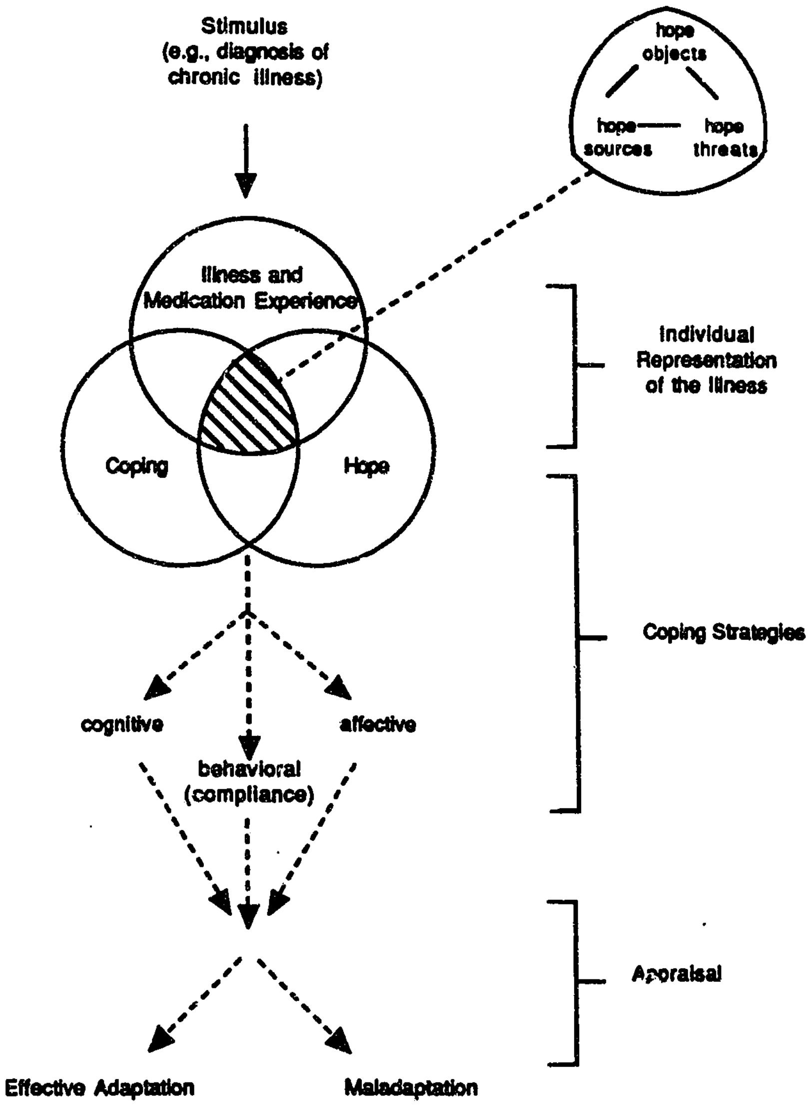
Coping has been accepted as an integral component of the chronic illness experience. It has been proposed that hope plays a central role in this coping process. The relationship between hope and coping can be viewed from three perspectives: hope as an adaptive task; as a coping strategy; and as a prerequisite to coping.

The conceptualization of compliance as a coping behavior, and the recognition of the importance of hope as a prerequisite to coping, raises the question of whether or not there is some relationship between hope and compliance. The possibility that a relationship exists has been addressed in the literature, although the nature of this relationship remains unclear.

Thus, this study has been designed to further explore the nature of the relationship between hope and compliance in the chronically ill. Particular emphasis has been placed upon how an individual's perceptions of the illness and medication experiences as hope objects, sources or threats affect medication compliance.

A conceptual framework of the research question has been developed by the investigator (see Figure 1). This framework incorporates components of Dufault's (1981) model of hope, Herth's (1985) Coping Process Nursing Model and Leventhal et al.'s (1984) self-regulatory model of compliance. The shaded area within the figure refers to the identification of the individual's hope objects, sources and threats, particularly as they relate to the chronic illness and medication experiences. Of the three types of coping strategies outlined in the figure (i.e. cognitive, behavioral and affective), this study has been designed to focus specifically on the behavioral coping strategy of compliance.

Conceptualization of the Research Question



CHAPTER III

METHODOLOGY

A. Methodological Considerations

The Quantitative-Qualitative Debate

The current debate regarding the merits of quantitative versus qualitative research has significant historical roots. The quantitative and qualitative methods originated from two philosophically opposed paradigms, positivism and idealism, which existed within the social science field in the late nineteenth century (Smith, 1983).

Positivism was rooted in the scientific or empirical method of the basic sciences. It supported the existence of an independent or objective social reality. Facts were viewed as separate from values; thus, knowledge was considered value-free. The quantitative approach, which evolved from positivism, focuses on explanations, predictions, cause and effect. The researcher adopts the role of observer (a "subject-object" position). Truth is defined in terms of a comparison of the data with a single, objective reality.

Idealism developed in opposition to positivism, and was based on the Kantian philosophy. Within this paradigm, reality was viewed as "mind-dependent," that is, dependent upon the individual's interpretation of an experience within a given context. In contrast to positivism, facts were interwoven with and inseparable from values, suggesting that knowledge was value-laden. The qualitative approach originated from idealism. This method is descriptive, as opposed to the explanatory or predictive nature of the quantitative design, and focuses on gaining an understanding of the individual's perspective. A "subject-subject" position is adopted, in which the researcher becomes a part of the descriptive process. Truth is viewed within the individual's social context.

Researchers continue to debate the merits of quantitative versus qualitative methods (Firestone, 1987; Smith & Heshusius, 1986). There are many positions held within this debate. At one extreme, the polarized position acknowledges major differences between these two approaches. Individuals have set up two separate camps, with little recognition or regard for each other. At the other extreme, a cooperative position has been assumed. Individuals, in this position, disregard or minimize the historical distinctions, suggesting that there are no significant differences between these two approaches. The qualitative approach has essentially been assimilated into the quantitative design, with an emphasis on quantifying qualitative experiences (Goodwin & Goodwin, 1984; LeCompte & Goetz, 1982). A third position, within this debate, is the acknowledgement of the differences, accompanied with an appreciation of the distinctiveness, of both of these approaches. Some individuals, who have adopted this perspective, are suggesting that the combination of these two approaches may result in the enhancement of a study's design (Howe, 1985).

The debate regarding the value of quantitative, as opposed to qualitative methods, surfaced during the design phase of this study. The quandary regarding which approach to use became a significant issue. It is the investigator's belief that the quantitative and qualitative paradigms, although philosophically opposed, offer equally valid and distinctive perspectives.

The ultimate decision regarding the selection of a research method is predominantly dependent upon the research question and the topic. Questions which focus on cause and effect, predictions or explanations are well-suited for the quantitative design. In contrast, questions which emphasize the understanding of a topic from an individual's frame of reference are more appropriate for qualitative methods. Further, Field and Morse (1985) suggest that qualitative approaches are indicated when knowledge regarding a domain is limited; existing knowledge and theories are biased; or the research question focuses on the understanding of an obscure phenomenon.

Ultimately, a qualitative research design was selected for this study. This decision was based on two primary factors: (1) the limitations of existing theories, models and measurements for both compliance and hope; and (2) the focus of the research question.

Existing theories, models and measurements for compliance are restricted in their applicability. A number of compliance models which do exist have been developed within the quantitative framework. Leventhal et al.'s (1984) self-regulatory model was adopted for this study due to its emphasis on the representation of the illness experience from the individual's perspective. Accepted measurements for compliance, such as self-report, behavioral, biochemical and clinical outcome measures, have attempted to objectify the experience. A standardized questionnaire has been developed (Sackett, 1976b), but is quantitative in nature, and is based upon the Health Belief Model (Becker, 1974). In response to Leventhal et al.'s (1984) self-regulatory model, interviewing styles which focus on the patient's perception of the experience have been promoted for the enhancement of the patient-health care provider relationship (Meichenbaum & Turk, 1987). However, few research studies have attempted to incorporate this framework within the research design.

Similar to compliance, theories, models and measurements for hope have been developed but are restricted in their usefulness. Dufault's (1981) model of hope was adopted for this study due to its multidimensional focus . Attempts have been made to measure hope, using hope instruments (Erickson, Post, & Paige, 1975; Gottschalk, 1974; Herth, 1989; Hinds, 1984; Miller & Powers, 1988; Nowotny, 1989; Stoner & Keampfer, 1985). Some of the difficulties in applying these instruments to this study are that they are based on unidimensional or limited multidimensional models. They have been developed for use with adolescents, healthy adults, bereaved individuals or cancer patients, but not specifically for individuals with chronic illnesses. At the present time, an instrument which is based upon Dufault's multidimensional view of hope does not exist.

The second reason for selecting the qualitative research design is related to the focus of the research question, which addresses a previously uninvestigated topic from the perspective of the individual. Although the topic of compliance has been researched extensively, it has not been studied in relationship to the concept of hope. Further, the understanding of this relationship from the individual's frame of reference is best achieved through a qualitative paradigm.

The Study Design

The design for this study was qualitative in nature. The primary source of data collection was formal, in-depth, semistructured interviews with chronically-ill individuals, without participant observation. An interview guide was used as a conceptual framework within the interview process. All sessions were audio recorded and then transcribed into written format for data analysis. Additional sources of data included biographical information from the coresearchers; and the investigator's field notes and memoes. The data were examined for descriptions, patterns, common themes and relationships, using the constant comparative method of analysis, commonly used in grounded theory methodology.

The research design for this study, although qualitative in nature, does not fit into any of the familiar classifications of qualitative research, such as ethnography, phenomenology or grounded theory. The lack of participant observation, and the inclusion of a detailed interview guide, excluded this design from the ethnographic and phenomenologic approaches, respectively. Although this study draws from the grounded theory methodology, in data analysis, the proposed outcome of this study was not necessarily theory-generating and therefore was not initially classified as grounded theory.

The difficulty in assigning a name to certain types of qualitative research, particularly unstructured or semistructured interviews which do not include participant observation, has been addressed (Morse, 1989). The term "interactive interview" has been suggested as a category for this type of interviewing process in which concepts are explored within an audio-recorded interview, and transcriptions are reviewed, without the inclusion of participant observation as a data collection procedure.

An alternate term to describe this type of qualitative research is the exploratory, descriptive method (Parse, Coyne & Smith,1985). The exploratory design is used to investigate the meaning of an experience, which has been shared by a number of subjects, using the interview process. This method enables the discovery of common themes and patterns within a given experience.

The exploratory, descriptive method differs from the descriptive methods of quantitative research, such as the survey and observational methods, with respect to the structure of data collection and analysis. Within the exploratory, descriptive method the interview process is semistructured. The number and types of questions vary from one individual to the next. The goal of data analysis, as mentioned previously, is to identify common patterns and themes. This is in contrast to quantitative, descriptive research in which the data collection procedures are much more structured, using standardized questionnaires or observational procedures. Data analysis is quantitative in nature. Thus, the design for the data collection segment of this study could be classified as an "interactive interview" without participant observation. An alternate categorization is that of an exploratory, descriptive qualitative method.

B. Sample

The Sampling Dilemma: The Heterogeneous Sample

One of the most difficult aspects of this study design was the selection of a sample and the development of criteria for selection. A number of questions were raised during the design of the selection process: (1) Should the sample be preselected, based on levels of hope and compliance, and then divided, arbitrarily, into high and low groups?; (2) Should the sample be restricted to individuals who are in stabilized situations, or expanded to include individuals in life-threatening or unstable situations?; and (3) Should the sample be restricted to a single disease state as opposed to a heterogeneous, disease-state sample?

The Preselection of Individuals Based on their Levels of Hope and Compliance

If individuals are preselected according to hope and compliance levels, then the assumption is made that this preselection would contribute to the heterogeneity of the sample, representing different views of hope and compliance. This assumption is supported by those who view the relationship between hope and compliance as positive and linear: the higher an individual's level of hope, the greater the compliance (Ajzen & Fishbein, 1980; Craig & Edwards, 1983; Perley et al., 1971). One of the difficulties of this procedure, however, would be the lack of a reliable prescreening tool. Further, if one adopts the view that the hope-compliance relationship is curvilinear, as indirectly proposed by McGee (1984), then the division of the sample into extreme groups (i.e. high and low levels hope) may result in a biased, as opposed to heterogeneous sample, in which most individuals would have low compliance rates. In further opposition to sample preselection, if one adopts the view that compliance is in some way related to Dufault's (1981) concept of the hope profile (i.e. hope objects, sources and threats), then the preselection of a sample based on levels of hope and compliance would serve no direct purpose.

The Restriction of the Sample to Stabilized Phases of the Illness

Restriction of the sample to individuals with stabilized conditions would enhance the homogeneity of the sample and simplify the selection procedure. Support for the restriction of the sample to a specific phase of the illness process is offered by Forsyth et al. (1984). They suggest that the illness experiences of individuals are different, depending upon the nature and phase of the illness. In their study of chronically-ill, hospitalized patients, they identified three phases: (1) progressive, with an unknown course; (2) stabilized, controlled by medication or diet; and (3) untreatable end-stage. For the purpose of their study, Forsyth et al. restricted their sample to those with an end-stage chronic illness.

In contrast, the different phases of the illness process may provide a more comprehensive and meaningful representation of the illness experience, as well as hope and medication. The dynamics of Dufault's (1981) concept of the hope profile are dependent upon the stage of the illness process. For example, hope objects are characteristic of the particularized hope sphere and are most prevalent during times of stability. Hope threats, on the other hand, which interfere with hope objects or sources, are most likely to emerge during times of uncertainty or instability. Thus, in order to examine all three components of the hope profile (i.e. hope objects, sources or threats), in relationship to medication compliance, it may be necessary to interview individuals who are in a state of transition or instability, as well as those in a state of stability.

Restriction of the Sample to a Single Disease State

If the sample were restricted to a single disease state, then the issue of compliance could be studied within a more uniform setting. This would have simplified the selection process. However, this approach would have limited the diversity of experiences. It would have been more difficult to capture the common themes of the chronic illness experience which exist irrespective of the type of illness.

In further support of a heterogeneous sample, the restriction to a single disease state may result in a biased compliance sample. It has been suggested that certain disease states have been associated with specific rates of compliance. For example, compliance rates for hypertensives (McKenney, Slinning, Henderson, Devins, & Barr, 1973), diabetics (Turk & Speers, 1983), and renal dialysis patients (Nehemkis & Gerber, 1986) are relatively low. In contrast, reported compliance rates amongst cancer patients is less clear and inconsistent, ranging from as low as 23% (Itano, Tanabe, & Lum, 1983) to as high as 98% (Carey, Sohier, & Kaufman, 1979). If the sample were restricted to a single disease state, such as hypertension, then a skewed view of the compliance issue might be obtained.

Summary

With the consideration of all of these issues, the investigator rejected the idea of a preselected, homogeneous sample, opting, instead, for a heterogeneous sample, consisting of individuals with varying types and phases of chronic illness. The heterogeneous sample has its own inherent problems. Firstly, the selection process is more complicated with this type of sampling. Multiple contacts may be required for the identification of potential participants. Secondly, the identification of common themes may be more difficult due to the diversity of experiences. Although the global process of coping with an illness may be similar, the specifics are quite different. In spite of these potential difficulties, the heterogeneous sample was still selected, as it is the investigator's belief that it offers greater diversity and richness of data than the homogeneous sample.

Criteria for Selection

The following criteria for selection were established for this study: (1) English-speaking; (2) minimum age of twenty-one years, with no upper maximum; (3) diagnosis of a minimum of one chronic illness; and (4) the prescription of a minimum of one medication, by a physician, for treatment of the illness. These criteria were developed, taking into account the research design; the potential relationship between age, hope and compliance; the heterogeneity of the sample; and role of medications in treatment. The following is a summary of the justification for each criterion:

(1) English-speaking. The nature of this research design, with an emphasis on data collection through the interview process, necessitates the selection of individuals who are expressive and can articulate their experiences.

(2) Minimum age of 21 years. The age restriction is important, particularly with respect to the concept of hope. It has been suggested that children and adolescents have a different, less mature perspective on hope, than adults (Wright & Shontz, 1968). Thus, this sample was limited to adults aged 21 years and older. The concern regarding the relationship between age and compliance has also been addressed, but results have been inconsistent. Some researchers have hypothesized that compliance rates increase with age. Others suggest that there is no relationship between these two factors. At the present time, it has been suggested that the relationship between demographic variables, including age, and compliance remains inconclusive (Haynes, 1976; Meichenbaum & Turk, 1987).

(3) Diagnosis of a minimum of one chronic illness. As mentioned previously, a heterogeneous sample of disease states was selected. The minimum requirement was that an individual have one disease state, but was not necessarily restricted to a single disease. A potential pool of chronic illness experiences was identified, specifically, diabetes, rheumatoid arthritis, Parkinson's Disease, renal disease, chronic pain, hypertension, migraines, breast cancer, heart disease and epilepsy. These diseases were selected based on a number of factors. These include the rapidly progressive nature of some of these conditions; the lack of symptoms (eg. diabetes, hypertension, breast cancer); the persistence of symptoms (eg. chronic pain, rheumatoid arthritis); the potential for complications (eg. diabetes, breast cancer, heart disease); the varying rates of compliance associated with specific illnesses; the lack of recognition of the illness (eg. epilepsy, migraines); and the potential treatment with medications.

(4) The prescription of a minimum of one medication. To understand the compliance issue, individuals who were currently receiving medication were selected. This criterion would have eliminated individuals with certain disease states which, although chronic, may require minimal medication treatment (eg. certain neurological disorders, including multiple sclerosis). It would have also potentially eliminated those individuals, with chronic illness, who selected forms of treatment other than medication.

The Identification Process

The process for the identification of coresearchers was complex. Rather than preselecting the sample, participants were identified and selected sequentially, based on the purposeful sampling (Morse, 1989) was used in this study to assist with this identification process.

Theoretical sampling involves the selection of a sample based on the needs of the study and the subjects' knowledge of the research topic. Initially, individuals with broad, general knowledge of the subject area or who are considered to be typical may be selected. Then, as data are collected and analyzed, individuals with more specific information may be interviewed. Finally, an attempt is made to select individuals who are atypical, to ensure that a broad range of experiences are represented.

The process for identifying potential candidates for this study involved a number of phases. These included the initial contact, gaining entry and making contact.

Phase I: The Initial Contact

A variety of sources for the sample pool were identified, specifically a physician with a private family practice, selected institutions (i.e. Edmonton General Hospital, Cross Cancer Institute, Royal Alexandra Hospital) and support groups (i.e. Alberta Migraine Assistance Association, Edmonton Epilepsy Association, Arthritis Society of Alberta, Parkinson's Disease Society). The appropriate administrators or physicians were contacted by phone, or in person, by the investigator and provided with a summary sheet of the study design (see Appendix A). In some cases, a more extensive copy of the proposal was also submitted.

Phase II: Gaining Entry

Approval for this study was obtained directly from the family physician and the executive directors of the support groups. Formal ethical approval was required from the Edmonton General Hospital, the Cross Cancer Institute and the Royal Alexandra Hospital. A proposal for this study was submitted to the Ethics Review Committees of the Edmonton General Hospital and the Cross Cancer Institute. Due to time conflicts and constraints, a submission was not made to the Royal Alexandra Hospital. Ethical approval was obtained

from the Edmonton General Hospital. Again due to time constraints, the [illegible]
Cross was withdrawn.

Phase III: Making Contact

Once approval was obtained, a contact person (or persons) within each organization was identified to help with the selection process. This person was then contacted by the investigator and provided with information regarding the study. This contact person served as a link between the investigator and the potential coresearcher. In most cases, the study was explained to the potential coresearcher by the contact person. An information sheet was provided to help explain the study (see Appendix B). Once an individual had tentatively agreed to participate, the contact person provided the investigator with the individual's name. Each potential coresearcher was then contacted by phone, or in person, by the investigator, to explain the study; to obtain verbal consent to participate; and to schedule an interview appointment.

Description of the Sample

The investigator purposefully selected a sample which was heterogeneous with respect to basic demographics including gender, age and educational level. The sample consisted of eight coresearchers, four males and four females. The age range of the sample was 25 to 65. The educational level varied from Grade 12 to a doctoral level of education.

This sample was also heterogeneous with respect to the illness experience. A wide range of disease states was represented, including rheumatoid arthritis, epilepsy, migraines, hypertension, chronic renal failure, breast cancer with metastases, cancer of the uterus and cervix, polymyalgia rheumatica, osteoporosis, Hodgkin's lymphoma and diabetes. The number of illnesses per individual varied from one to four. The time since diagnosis of the illness ranged from one to 29 years. The illnesses varied in severity from a single stabilized illness to severe, multiple illnesses to end-stage disease. The total number of medications per individual ranged from two to eleven.

C. The Interview Guide: The Compass

An interview guide (see Appendix C) was developed by the investigator to aid in the interview process. This guide consists of questions relating to three major areas: (1) the illness experience; (2) the medication experience, including compliance; and (3) hope.

The questions within this guide were developed from a number of sources, specifically, the literature, the investigator's experiences and existing research tools. The first two sections of the guide, the illness and medication experiences, were primarily derived from the literature and the investigator's experiences. The third section of the guide relating to hope was derived from Dufault's (1981) conceptualization of hope. Dufault describes hope as consisting of two spheres, generalized and particularized, and six dimensions, affiliative, cognitive, affective, behavioral, temporal and contextual. She further describes the concept of a hope profile, which consists of a pattern of hope objects, sources and threats. For the purposes of this study, both hope spheres, the behavioral dimension of hope, and the concept of a hope profile were emphasized. Questions for the third section of the interview guide were derived from two of Dufault's research tools, the interview topics guide and the hope profile assessment.

Two approaches were used to ensure relevancy and clarity of questions included in this interview guide. The first approach was to distribute this guide to a panel of reviewers prior to the initiation of the study. This panel consisted of two psychologists with doctoral degrees, two physicians, one nurse and one individual with a chronic illness, specifically breast cancer. Each panel member was asked to review the questions within the guide in terms of relevance to the research question and clarity. For further elaboration of the requirements for review, see Appendix D. The second approach was to test the interview guide using a pilot sample of two coresearchers. Based on the panel reviewers' responses, the guide was further revised prior to the initiation of the pilot study. The guide was not study.

D. Data Collection

There were four primary types of data: (1) biographical descriptions of the coresearcher; (2) written transcriptions of the interview process; (3) the investigator's field notes: and (4) the investigator's memoes. The following is a summary of each type.

Biographical Descriptions

Biographical descriptions consisted of demographic variables such as age, gender, marital status, ethnic background and level of education. Additional information regarding the nature, onset and duration of the illness, as well as the medication regimen was documented (see Appendix E). This information was documented by the referral source, the investigator or the coresearcher. The sources for this data included the coresearcher, the contact person or the individual's medical records. The rationale for the documentation of this type of information was to thicken the data, in the event that a particular theme regarding some of these variables might emerge. It was also helpful in describing the heterogeneity of the sample.

Written Transcriptions

The second source of data, the written transcriptions, were obtained from semistructured interviews involving the coresearcher and the investigator. This was the primary source for data collection. All sessions were audio-recorded. The locations for the interviews varied. They included a medical setting (i.e. outpatient clinic, physician's medical office, inpatient nursing unit), a university clinic setting and the coresearcher's home.

interactive interview, termination of the session and clarification of the written transcript. The majority of the interviews were completed in one session. In two cases, two sessions were required. The first session consisted of meeting the coresearcher and introducing the study. A second session was scheduled for the interactive interview.

Within the first phase of the interview process, the study was explained and a written consent form to voluntarily participate was signed (see Appendix F). The issue of confidentiality of all information was reinforced.

The second phase, the interactive interview, consisted of an informal discussion of the coresearcher's experiences, using the interview guide as a conceptual framework. The number and sequence of questions which were asked by the investigator varied from one coresearcher to the next. As the interviews progressed, the questions became more focused, particularly with respect to the research question. To ensure adequate and appropriate data collection within the interview, the investigator incorporated basic elements of a "good interview" within each session. Adequate measures were taken to ensure privacy. The investigator attempted to develop rapport and build a trusting, supportive, nonjudgmental relationship with the coresearcher, to encourage freedom of expression. Open-ended, reflective, paraphrasing and clarifying questions were used to gain a greater insight into the coresearcher's personal experiences and perspectives. The investigator's recent training in counselling was an asset.

In the third phase, a short time was spent terminating the session, once the formal interview was completed. Arrangements were made to contact the coresearcher by telephone or in person to discuss the written transcript of the interview session.

The final phase consisted of clarifying the written transcript with the coresearcher. The audio-recordings of the sessions were transcribed by an official transcriber into written format. The written transcript was compared with the audio-recording, by the investigator, and then forwarded to the coresearcher for clarification or elaboration of any issues. Seven of the eight coresearchers were contacted by phone or in person to discuss the transcript. One coresearcher stated that he trusted the investigator and did not feel it was necessary to review the transcript, although he did request a copy for his own reference.

Field Notes and Memos

Field notes, which comprised the third type of data, were documented on a worksheet (see Appendix G), within 24 hours of each interview session, by the investigator. Field notes consisted of the content of the interview; nonverbal behavior of the coresearcher; and the investigator's impressions and analytical processes.

The fourth type of data, the investigator's memoes, were maintained throughout the entire study. Memoes consisted of the investigator's impressions; the metacognitive process relating to the study design; and the emerging patterns and themes from the data analysis. These memoes were always dated and linked to specific parts of the transcripts, whenever applicable.

The documentation of field notes and memoes provided the investigator with an opportunity to reflect upon the research process and to heighten self-awareness regarding personal biases. At the outset of this study, the investigator identified a number of factors which could potentially interfere with the analysis. These included the investigator's scientific or quantitative background and experiences as a hospital pharmacist. An additional factor was the development of the research questions based upon specific models and the potential for adopting a narrow view of the coresearchers' experiences. Although these factors were acknowledged at the beginning of the study, they surfaced at varying times, during the study, often beyond the awareness of the investigator. A discussion of the investigator's metacognitive process, within this study, will be presented in the concluding chapter.

E. Data Analysis

The data were analyzed for descriptions, patterns, common themes and relationships, using the constant comparative method of grounded theory. Two coding systems were used to help categorize the data and identify relationships, specifically the ethnographic approach of domain analysis (Spradley, 1979) and Glaser's (1978) concept of theoretical codes. The following is a summary of the constant comparative method, the two coding systems and the application of these processes within the data analysis phase of this study.

The Constant Comparative Method

The constant comparative method was advocated as a method of analysis for the discovery of grounded theory by Glaser and Strauss (1966). This method provides an avenue for the identification of conceptual categories which may result in a generation of a theoretical framework, grounded in or based upon the data. Hypotheses for further research may also emerge. Within the grounded theory model, the comparative method facilitates the discovery of processes, transitions and phases; and identifies the characteristics, dimensions and conditions under which they occur.

Using the constant comparative method, data collection and analysis occur concurrently, as opposed to a linear progression within the quantitative paradigm. Data analysis begins with data collection. It is interwoven throughout the collection process and continues during the final stages of report writing. Stern (1980) described this interwoven process as working "within a matrix in which several processes are in operation at once" (p.21). The investigator begins to analyze or code the data as soon as it is collected. Subsequent data is compared with previous data and coded with consideration for emerging themes. Conceptualizations regarding the final report are documented from the beginning of the study.

The interwoven process of data collection and analysis is difficult to describe. Maxwell and Maxwell (1980) offer a five-step description of this process:

(1) Collection of empirical data (coding and categorizing). Data are collected and coded according to an open system of coding. The data are analyzed line by line, using a variety of codes (eg. characteristics, processes, strategies, functions). These codes are referred to as substantive codes, as they are grounded in the data, and often use the precise words of the coresearchers. The data are coded and compared with other data. Coded data which appear to form clusters or groupings are assigned specific categories.

(2) Concept formation. In this phase, categories which appear to be of significance to the coresearchers are identified. A tentative conceptual framework, which incorporates these significant categories, is developed.

(3) Concept development. The tentative conceptual framework is expanded and solidified in this phase. This occurs through three steps: (1) Reduction. The categories are linked together and collapsed into higher order categories or major processes. These major processes are referred to as "core variables" by Glaser and Strauss (1967). (2) Selective sampling of the literature. A review of the literature is used as data, which is incorporated within the matrix of coded data, categories and conceptualizations. (3) Selective sampling. Concepts are further delineated through testing, expansion and qualification using the process of theoretical sampling. This process results in the saturation of categories. Through the process of concept development (i.e. reduction, sampling of the literature and selective sampling), the core variable, which is central to the data, emerges.

(4) Concept modification and integration. During this phase, the emerging theory is strengthened and integrated, using two major processes, theoretical coding and memo writing. Theoretical codes assist in linking the coded data (i.e. the substantive codes) with the theory. A number of theoretical coding systems exist (eg. Glaser, 1978; Spradley, 1979). Memo writing is a system for documentation of tentative concepts, hypotheses and theoretical components. Memoes are conceptual, but are grounded in the data. The coding and organization of memoes provide a framework for writing the final report.

(5) Production of the research report. The underlying process or theory is presented in the final report, and is substantiated or supported by data from the study. References from the literature are woven into the theory to provide further support.

Coding Systems

A variety of coding systems are offered as a structure for linking the coded data with theory. For the purposes of this study, two coding systems were accessed, domain analysis (Spradley, 1979) and theoretical codes (Glaser, 1978). Domain analysis was particularly useful in identifying the characteristics, dimensions and classes of the data. The theoretical codes assisted in the discovery of an underlying process.

Domain Analysis

Domain analysis (Spradley, 1979), which evolved from ethnography, is a strategy for exploring and discovering the larger units of cultural knowledge referred to as domains. The identification of domains is built upon the discovery of semantic relationships, which are the linkage of coded data in a meaningful way. The number of semantic relationships in any culture is quite small. For example, Casagrande and Hale (1967), in their study of Papago Indians, discovered thirteen semantic relationships. Further, certain semantic relationships appear to be universal.

For the purposes of this study, a number of universal semantic relationships were selected as a foundation. The following relationships were selected to aid in the characterization of data: (1) strict inclusion (X is a kind of Y); (2) spatial (X is a part of Y):; (3) cause-effect (X is a result of Y, X is a cause of Y); (4) sequence (X is a step or stage in Y); (5) attribution (X is an attribute or characteristic of Y); (6) contingency (X is defined with relation to an antecedent or concomitant of Y); (7) function (X is defined as the means of effecting Y); (8) operational (X is defined with respect to an action Y of which it is a goal or recipient); (9) comparison (X is defined in terms or its similarity and/or contrast with Y) ; (10) exemplification (X is defined by citing an appropriate co-occurrent Y); and (11) circularity (X is defined as X).

Theoretical Codes

Theoretical codes assist in linking the substantive codes together in the form of hypotheses, which are further integrated within a theoretical framework (Glaser, 1978). Glaser identified eighteen coding families, representing a variety of theoretical codes. These families are not mutually exclusive, having some degree of overlap. Five of Glaser's (1978) coding families assisted in the identification of an underlying process. These included the "six C's," "process," "degree," "strategy" and "identity-self."

Within the **six C's family**, four of the six codes were used, specifically, "contexts," "conditions," "contingencies" and "consequences." The context is the setting or environment in which the other components interact. Glaser (1978) referred to it as the "ambiance." The conditions are the specific factors which help set the stage. They have been referred to as "qualifiers" and could be viewed as the restrictions or limitations. Contingencies are the factors or processes upon which specific variables are dependent. Consequences are the outcomes, efforts, functions, predictions and anticipated or unanticipated consequences. Consequences which are separate, yet exist concurrently, may be conceptualized as co-varying consequences.

A **process** consists of changes which occur over time. These changes may be represented in the form of phases, stages, transitions, steps or subprocesses. A process must have at least two phases or stages.

The **degree family** represents the variability of a category. Categories may be represented in terms of limits, ranges, intensities, polarities, continuums, levels or probabilities, to name but a few.

The **family of strategies** includes any techniques or methods which have been developed to assist in problem solving or gaining control over a situation. A common example within this family would be coping strategies.

The **identity-self family** refers to the different parts of the self. These include, but are not limited to, self-image, self-concept, self-worth, self-realization, identity and transformations of self. This category was not used extensively, but did help isolate some components of the self.

The Process of Analysis

All of the collected data were included in the analysis. This data consisted of the written transcripts, summaries of telephone conversations with the coresearchers, the biographical descriptions, field notes and memoes. The data collected from the pilot sample were included in the analysis. The interview transcriptions from this sample were reviewed by the investigator's supervisor for effectiveness of interviewing style and relevancy of the research questions. At this point, it was decided to include this data in the final analysis. To aid in the analysis process, a summary profile was prepared for each participant. These profiles are included in Appendix H.

Using the constant comparative method, the data were analyzed both inductively and deductively, as they were being collected. An open coding system was used for the first three transcripts, in which data were analyzed line by line without any preset codes and compared from one transcript to the next. This resulted in a proliferation of codes which became difficult to manage. It was at this point that the codes were collapsed into ten separate categories, specifically, illness, medications, environment, relationships, feelings, coping strategies, events, hope, philosophy and self.

As the coding continued, some of the categories were broadened and terms, which were more meaningful to the coresearchers, were adopted. For example, the category "illness" was changed to "problems," in which "medical problems" was just one of many problems. The category "medications" was broadened to "medicines" which included many forms of treatment other than medications.

Using the ten general codes as a framework, the first three transcripts were re-coded and the remaining five transcripts were coded for the first time. Coded excerpts from the transcripts were reorganized into ten separate units, according to the general codes. This was facilitated through the use of the computer program, Factfinder. Once the data had been reorganized according to the ten codes, they were reanalyzed and recoded, line by line, using an open coding system or substantive codes. All other data, that is, the biographical descriptions, telephone conversation summaries, memoes and field notes, were also reorganized or coded according to the ten general categories. The data were further coded, within each category, again using substantive codes.

Two coding systems were used during the coding process, domain analysis (Spradley, 1979) and theoretical codes (Glaser, 1978). Domain analysis was helpful in categorizing data, resulting in two common categories, characteristics (or "attributes") and components ("strict inclusion," "kind of"). The theoretical codes assisted in the identification of two underlying processes, the hoping process and the process of learning to live with uncertainty.

A number of individuals were involved in the coding process. The investigator was the primary coder for all of the data, which included the biographical descriptions, interview transcriptions, field notes and memoes. Secondary coders were accessed at different levels of data analysis of the written transcripts. A total of four secondary coders were used: the investigator's supervisor, a family physician and two graduate students in the Department of Educational Psychology. The family physician was indirectly involved in the study as a contact person, whereas the two graduate students were not previously involved.

The involvement of the secondary coders in data analysis varied. The investigator's supervisor reviewed all of the uncoded transcripts and provided suggestions regarding coding. At certain points during the coding process, she reviewed the investigator's coded transcripts. In addition, with the first three transcripts, she provided feedback regarding interviewing style. Adjustments were made based on this feedback. Two of the coders, the family physician and one of the graduate students, reviewed a total of five transcripts, uncoded, for common themes (the graduate student reviewed three transcripts and the family physician reviewed two). The other graduate student was asked to review three transcripts and compare them with the investigator's codes. The student was given the ten general codes as a framework.

F. Reliability and Validity

The consideration of reliability and validity stems from the quantitative paradigm. These issues will be addressed from the qualitative perspective, using the concepts of auditability, credibility and fittingness (Guba & Lincoln, 1981):

Auditability

Auditability is related to the consistency of qualitative findings and is parallel to the concept of reliability in quantitative research. If a study is auditable, then a second researcher should be able to follow the primary investigator's research path and arrive at similar conclusions.

In this study, auditability was achieved primarily through the comprehensiveness of the final research report. This report includes accurate descriptions and explanations of the development of the research question; selection of the sample; and collection and analysis of the data. The documentation of comprehensive field notes, coding procedures and memoes assisted in the compilation of the final report. In addition to the final report, a detailed work plan, which outlines the phases of the study, was prepared (see Appendix I).

To strengthen the audit trail, a secondary coder was used to review the investigator's coding procedure for consistency and accuracy. The secondary coder reviewed three transcripts, using the ten general codes as a guide. Any additional codes or discrepancies in coding were documented and discussed.

Credibility

Credibility is used to evaluate the truth value of qualitative research and is similar to the quantitative concept of internal validity. A credible, qualitative study accurately depicts the experiences under investigation, such that individuals would readily recognize these experiences from the study's descriptions and interpretations.

To maintain credibility within this study, a number of approaches were used: (1) review of the interview guide by a review panel and a pilot sample (similar to the quantitative concept of content validity); (2) incorporation of basic elements of a "good interview" within each session; (3) transcription of the interview into written format; (4) comparison of the audio-recordings with the written transcript, by the investigator; (5) review of the investigator's interviewing style by the supervisor; and (6) review of individual transcripts by the coresearchers for clarity and elaboration.

Fittingness

Fittingness is used to evaluate the applicability of qualitative research. In contrast to the quantitative concept of external validity, which focuses primarily on representativeness and generalizability of the sample and findings, fittingness primarily refers to the representativeness of data. Specifically, the fittingness of a study refers to the application of findings to areas outside the study situation; the meaningfulness and application of findings to individual experiences; and the relationship between the findings and the data.

The concept of triangulation may be used to increase the fittingness of a study. There are four different types of triangulation: data, investigator, theoretical and methodological (Mitchell, 1986). A triangulated study combines different theoretical perspectives, data sources, investigators or methods within a single study.

For the purposes of this study, the concept of fittingness was achieved through three types of triangulation, investigator, theoretical and data. With respect to **investigator triangulation**, the following methods were used: (1) The investigator's supervisor reviewed the eight, uncoded transcripts and offered suggestions regarding coding. (2) Two secondary coders independently reviewed a total of five uncoded transcripts for general impressions and themes. The investigator met with each of these coders individually to discuss their secondary analysis. This discussion included a comparison of the selected transcripts. (3) Three individuals reviewed the model prior to the final report. They included one participant from the study, the investigator's supervisor who has a substantial amount of clinical experience with chronically-ill individuals and a physician. (4) The findings from this study were reviewed by three individuals who were not directly involved in the study, two women with breast cancer and a family physician. A summary of the individuals' responses to the model and findings of the final report is provided in Appendix J. **Theoretical triangulation** was achieved through the integration of the literature within the final results. A form of **data triangulation**, in this study, was the collection of data from two different sources, that is, from the coresearcher within the interview process, and from the contact person for the biographical descriptions. One of the difficulties which arose was that, in some cases, the source of the two types of data was the same, that is, the coresearcher. In addition, the biographical data were more peripheral to the study, than the data from the interview, itself.

G. Delimitations

This study was delimited in a number of ways: (1) restriction of the sample to chronically-ill adults who are receiving medication; (2) limitation of data collection to the interview process and biographical descriptions; (3) focus of the research question on understanding the research topic, as opposed to proving the models of hope (Dufault, 1981), coping (Herth, 1985) and compliance (Leventhal et al., 1984); and (4) focus of the study on a nonjudgmental understanding of compliance from the perspective of hope.

The restriction of the sample to chronically-ill adults receiving medications eliminated the inclusion of children, as well as certain individuals with chronic illnesses. This age restriction was particularly important in the examination of the concept of hope. The experiences of chronically-ill individuals who are not on medications or who have elected forms of treatment other than medications may be valid as negative or atypical cases. The inclusion of these individuals may be a consideration for further research. However, for the purposes of this study, these individuals were not accessed.

The primary source of data collection was the interview process with chronically-ill individuals, which was supplemented by the biographical data. Participant observation was not considered in this study due to the focus of the research question, which did not lend itself to this form of data collection. Additional interviewers and data sources other than the participant were considered in the research design, but were not included due to manpower and time constraints.

The focus of this study was to explore the concept of medication compliance, in relationship to hope, amongst the chronically ill. The investigator's conceptualization of the research question (see Figure 1) integrated components of models of hope (Dufault, 1981), coping (Herth, 1985) and compliance (Leventhal et al., 1984). Only certain components of these models were abstracted and applied to the conceptualization of the research question. It was not the investigator's intent to prove any of these models.

Compliance is a complex concept. Many factors have been related to compliance in other studies. This study, however, was restricted to exploring the relationship between compliance and a single factor, hope. Further, for the purposes of this study, compliance was conceptualized as a method of coping. This study identified many coping methods used by the chronically ill, which included medication compliance. However, it was not the investigator's intent to judge the effectiveness of these coping strategies. Rather, this study was limited to gaining a greater understanding of the process which leads to varying levels of compliant (coping) behavior.

H. Ethical Considerations

The principal ethical considerations for this study included informed consent, voluntary participation and confidentiality. A proposal for this study, which highlighted these ethical considerations, was submitted to the Ethics Review Committee of the Department of Educational Psychology for approval and clearance. Ethical approval was also obtained from the Ethics Review Committee of the Grey Nuns-Edmonton General Hospital.

The coresearchers were appropriately informed of the general purpose of and their involvement in this study. They were required to sign a written consent form prior to participation. Participation was voluntary. Coresearchers were given the option of not answering specific questions, and were free to withdraw from the study at any time, if they so chose. Results were shared with those coresearchers who showed an interest and requested a summary of the study's findings.

The coresearchers' participation remained confidential throughout and after the study. To maintain confidentiality, code numbers were used on all data sheets. The transcriber of the audio recordings and the secondary coders were required to sign an oath of confidentiality (see Appendix K). All information in the final report has been presented without identifying the coresearchers. Any information which may contribute to their identification (eg. names, places) has been removed. In addition, all audio recordings and raw data which may be directly linked to the coresearchers will be retained for a period of 5 years after the study and then destroyed.

CHAPTER IV

A. CONCEPTUAL OVERVIEW

The primary objective of this study was to gain a greater understanding of the relationship between hope and medication compliance, in chronically-ill individuals. The method for reaching this objective was initially determined by the content-oriented nature of the research question. The initial research questions focused on the characteristics of hope, in relationship to medication compliance, based on Dufault's (1981) concept of a hope profile, consisting of hope objects, sources and threats.

As the study progressed, however, based on the data, it became apparent that the initial focus needed to be broadened. The objective remained the same, but a shift occurred within the framework of the research questions, moving from an emphasis on content (i.e. What are the characteristics of hope objects, sources and threats?) to process. The following additional questions, which primarily focus on process, emerged from the data:

(1) What are the components of the hoping process?

(2) How do the components of the hoping process interact?

(3) What are the phases of the hoping process?

(4) How does the hoping process relate to coping?

(5) What is the relationship between the hoping process, coping and medication compliance?

There were three factors which contributed to this shift in the research questions. These included the limitations of coding the data according to Dufault's (1981) concept of a hope profile, the investigator's initial bias regarding hope sources and the process-oriented nature of the participants' experiences.

At the outset of this study, Dufault's (1981) framework of a hope profile, consisting of hope objects, sources and threats, was adopted as part of a model of hope. Preliminary coding included categorizing data according to these three theoretical concepts.

During the data collection and analysis process, it became apparent that these conceptualizations were not always personally meaningful to the participants. It was at this point that there was a shift in coding, which built upon, but was more extensive than, Dufault's framework. The research question broadened in focus from "What are the characteristics of hope objects, sources and threats?" to "What are the components of the hoping process?"

The second factor which contributed to the shift in the research questions was related to the investigator's initial bias regarding hope sources. Initially, hope sources were envisioned as originating from sources external to the self (for example, from the environment, other individuals or medications). From the data, it became apparent that there were two primary origins of hope sources: an internal source, from within the self, and an external source, from outside of the self. These two types of hope sources were reclassified under two new categories, the hoping self and hoping resources.

The third factor which contributed to a shift in the questions and assisted in the identification of a hoping process was the process-oriented nature of the participants' experiences. The discovery of process codes helped link the components of the hoping process together, to help answer the question, "How do the components of the hoping process interact?" Further, these codes helped identify the relationships between the hoping process, coping and medication compliance.

In the discussion of the results, within Chapters V, VI and VII, it is the investigator's intent to address the initial research questions, but to broaden the view of this complex issue within the framework of the additional questions which emerged from the data. A greater emphasis will be placed upon the underlying process relating to the concepts of hope, compliance and coping.

The concepts of hope and medication compliance in chronic illness are complex; and are difficult to fragment, simplify, or study in isolation. The results from this study suggest that these concepts can be integrated within a multifaceted, interactional or systemic framework of coping with chronic illness.

The process of coping with a chronic illness is complex and may involve many adjustments in one's life. In addition to the many medical problems which result directly from the illness itself, the individual may experience changes in financial status, social status, work and relationships. The participants' illness experiences and the strategies which were used to cope with these experiences were diverse. In spite of this diversity, however, a common underlying theme related to coping with a chronic illness emerged from the data. This common theme was the basic process of "learning to live with uncertainty."

Uncertainty is an integral component of the nature of a chronic illness. From the outset, the emergence of undiagnosed symptoms and alterations in normal routine may propel the individual into a period of instability. The discovery of a diagnosis may bring some relief, albeit temporarily. The chronic, unpredictable and progressive nature of the illness process presents the individual with new challenges and uncertainties. The lack of a cure, the difficulty in controlling symptoms and the insidious development of complications may further contribute to the uncertainty of the situation.

The individual must learn to adjust to or cope with the many changes which occur as a result of a chronic illness. One of the most difficult and challenging adjustments is learning to live with the uncertainty of the illness process.

The process of learning to live with uncertainty consists of three phases: (1) experiencing and assessing uncertainty (the initial reaction); (2) reacting to the uncertainty (the transition or adjustment phase); and (3) mastering the life of uncertainty (learning to live with some degree of uncertainty, acceptance or tolerance phase). The amount of time which an individual spends in each phase is highly variable and is dependent upon turning points within and between phases.

Turning points are marks of transition within a phase and from one phase to another. They are points at which uncertainty is either reduced or increased. These turning points may be preceded by a "crisis" (eg. uncontrollable symptoms including lack of effect from medications, confrontation by a support group, admissions to hospital). They may be highlighted by an increase in self-awareness or a sense of relief. Some specific examples of turning points, within the chronic illness experience, include the discovery of a diagnosis; controlling symptoms (eg. finding the proper medication); finding a cause for the illness; asking for help; self-realization of not being responsible for the illness; acceptance of the illness; and awareness and acceptance of one's limitations.

To assist in this process of learning to live with uncertainty, a second concurrent process emerged from the data, the process of hoping. These two processes are separate, yet interconnected through the underlying theme of uncertainty. The hoping process, which is best described as the process of maintaining the hoping self, can be viewed as a means for bringing some certainty into one's life. The coping process, as mentioned previously, can be viewed as a complex process of learning to live with uncertainty. Thus, the hoping process plays a fundamental role within the complex framework of coping.

The hoping process consists of three phases: (1) assessing hope and the hoping self; (2) strengthening the hoping self; and (3) maintaining the hoping self. These three phases covary with the phases of the coping process.

There are four components within the hoping process, specifically, the hoping self, hoping resources, hoping inhibitors and hoping objects. They can be described within five contexts, the self, relationships ("people," "supports"), environment ("the living environment," "facilities"), medicines and problems.

These four components are interconnected and can be represented in the form of a hoping network. The primary objective of the hoping self is to attain specific hoping objects. The hoping resources assist in this process. Thus, these two components are interconnected, functioning as a team. Hoping inhibitors interfere with the objectives or functions of the hoping self and resources. Hoping objects provide a sense of direction within the hoping network, although the precise pathway remains obscure. The hoping network is dynamic and undergoes many changes as it advances through the phases of the hoping process.

Medications and medication compliance are linked to the hoping and coping processes through the theme of uncertainty. Directly, medications can alter the uncertainty in an individual's life by serving as hoping resources, inhibitors or objects. Indirectly, medication compliance or noncompliance can effect uncertainty by acting as a coping strategy which enhances hoping resources, minimizes hoping inhibitors or assists in the movement towards hoping objects.

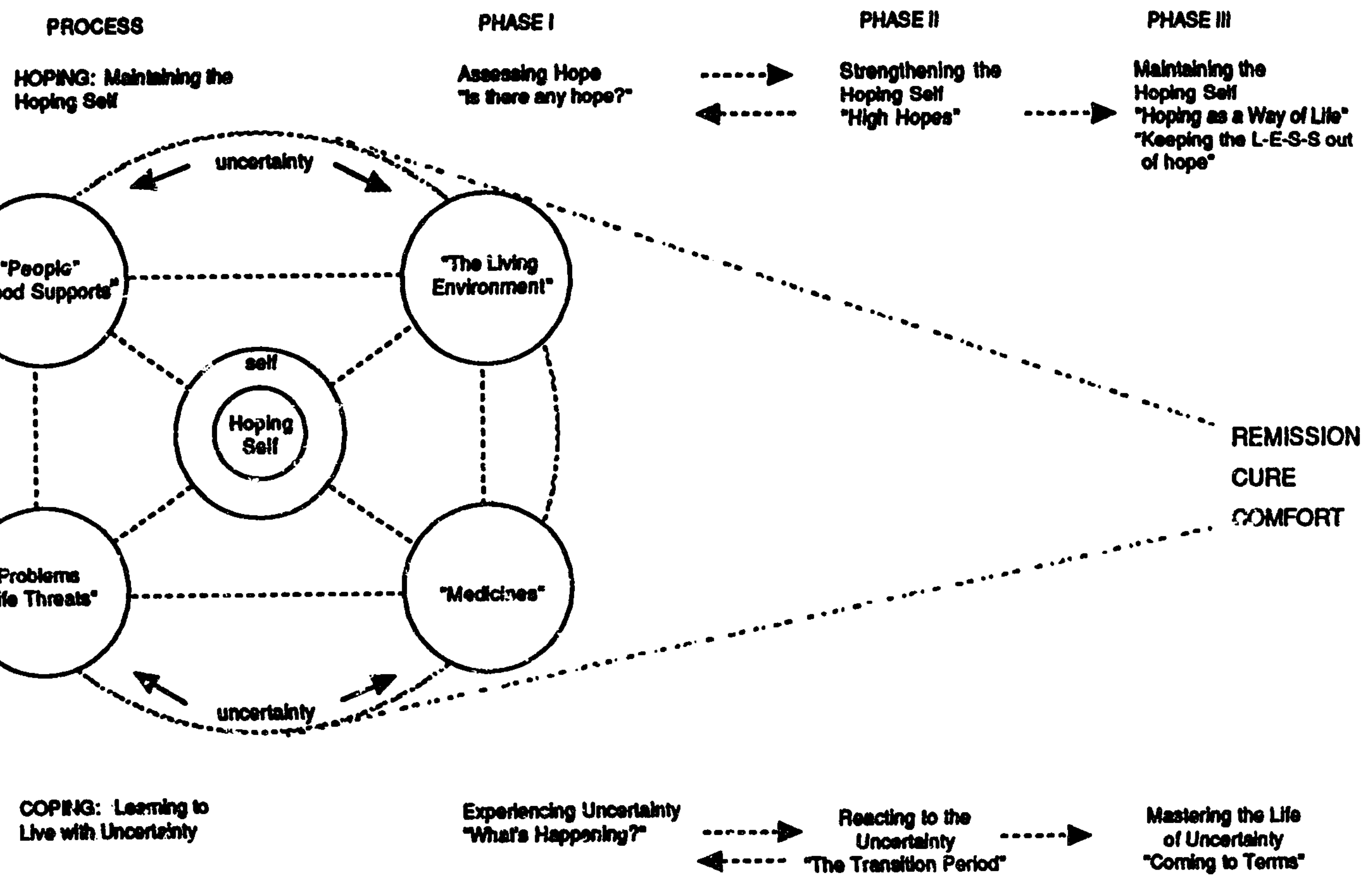
Two coding systems, domain analysis (Spradley, 1979) and theoretical coding families (Glaser,1978), were used to link the preliminary data, the substantive codes, to the theoretical concepts and underlying process. Using domain analysis, the coding system of semantic relationships was used to help characterize the components of the hoping process. To assist in the identification of an underlying process, five of Glaser's coding families were used. These included the "six C's," "process," "degree," "strategy" and "identity-self." Within the "six C's family, four of the six codes were used, namely, contexts, conditions, contingencies and consequences.

A summary of the results will be presented in the next three chapters. Chapter V consists of a review of the components of the hoping process and interactions within the hoping network. These components will be described, based upon the coding system of semantic relationships. In Chapter VI, the relationship between the hoping process and the coping process will be reviewed. This chapter will include a discussion of the phases of these two processes, using Glaser's (1978) coding family, "the six C's," as a framework. Chapter VII will focus on medications and compliance. It will highlight the inter-relationship of medication compliance, hoping and coping.

An overview of the phases of the hoping and coping processes is represented in Figure 2. This figure illustrates the concurrent nature of the two processes which are linked together through the common theme of uncertainty. It also displays the interconnectedness of the hoping self with other components of the hoping process, based on the five contexts. The role of medications is represented within the context of medicines.

Figure 2

The Phases of the Hoping and Coping Processes



CHAPTER V

THE COMPONENTS OF THE HOPING PROCESS AND THE HOPING NETWORK

As mentioned in Chapter IV, the hoping process can be viewed as a process of bringing some certainty into one's life. It is an interactive process, consisting of four primary components which advance through three phases. These four components are inter-related in the form of a hoping network. The dynamics of the hoping network fluctuate, over time, with the level of uncertainty. The following is a review of the components of the hoping process and the interactions of these components within the framework of the hoping network. The three phases of the hoping process will be discussed in Chapter VI.

A. The Components of the Hoping Process

Four components of the hoping process emerged from the data, specifically, the hoping self, hoping resources, hoping inhibitors and hoping objects. These four components evolved from Dufault's (1981) concepts of hope objects, sources and threats. The coding system of domain analysis assisted in the differentiation of these four components. Each of these components can be categorized through the identification of semantic relationships, which is part of the process of domain analysis. A summary table, highlighting the semantic relationships for each of these components, is included as an introduction to each of the following sections.

Although domain analysis was used as an initial framework for data analysis, a different format was adopted for the presentation of the results. Each of the components of the hoping process will be discussed according to the following categories: (1) overview of the concept; (2) identification of the concept; (3) characteristics; (4) functions; and (5) dynamics. The semantic relationships have been subsumed within these categories.

The Hoping Self

("An Inner Strength" "An Indomitable Spirit" "A State of Mind")

Overview

The hoping self is that part of the self which gives rise to hope. In relationship to the self, it can be viewed as the inner, central core. The hoping self is difficult to describe or explain, but has been referred to as an "inner strength," a life-oriented source or a "state of mind." It more readily manifests itself through other parts of the self. The hoping self serves three primary functions, specifically, the development and realization of hoping objects; the monitoring of progress within the hoping process; and assuming the role of a hoping resource for others. It exists in the present, but possesses a forward-moving future orientation. It is dynamic and has the capacity to enlarge or diminish in size over time. The hoping self appears to be influenced by one's perspective of and past experiences with hoping. It may also be affected by the uncertainty of a situation. An overview of the hoping self, based on its semantic relationships, is presented in Table 1.

Identification of the Concept

The concept of the hoping self evolved from the initial identification and coding of the self as a hope source. Most individuals acknowledged that their primary source of hope came from within.

> Q. Is there anyone who gives you hope or who you might see as a hope model?
>
> A. You mean like someone who says well things aren't that bad? No, I think it's more from myself. I can't see someone I would look up to.

Table 1

Semantic Relationships of the Hoping Self

RELATIONSHIP	EXAMPLES
circularity: X is defined as X	The hoping self can be defined as that part of the self which gives rise to hope.
spatial: X is oriented spatially with respect to Y	The hoping self can be viewed, in relationship to the self, as the inner, central core. It may also be described, in relationship to time, as existing in the present but with a forward-moving, future orientation.
attributive: X is defined with respect to one or more attributes of Y	The hoping self has been described as an "inner strength," a life-promoting source or a "state of mind."
exemplification: X is defined by citing an appropriate co-occurrent Y	The hoping self can be manifested through other parts of the self such as one's view of self, view of others, view of life, view of the illness and spiritual beliefs.
function: X is defined as the means of effecting Y	There are three primary functions of the hoping self: (1) the development and realization of hoping objects; (2) the monitoring of progress within the hoping process; and (3) serving as a hoping resource for others.
contingency: X is defined with relation to an antecedent or concomitant of Y	The hoping self may be influenced by one's perspective of hope, one's past experiences and the degree of uncertainty in one's life.
comparison: X is defined in terms of its similarity and/or contrast with Y	The hoping self is unique. However, it can be compared with or evaluated against other individuals (other hoping selves).
class inclusion: X is defined with respect to its membership in a hierarchical class Y	The hoping self is a component of the hoping network.

> Q. Were there any people who were influential in helping you with the acceptance or in coping?
>
> A. In my disease state do you mean? Nobody at all. No person helped me. Unless if I think, maybe deep down, I could always say, gee, I know people who have worse situations than me......But no person really, even a religious person, helped me.........[It came from within] from my personality. And when I go back I must have been like that since my youth.

During the coding process, it became apparent that certain parts of the self, such as one's beliefs or view of life, were related to hope. This resulted in a further differentiation in coding in which specific components of the self were coded as a hope sources, as opposed to the self as a whole.

> I have never believed and I do not believe today that I am going to die. I have no intention of dying. Someday I will die but I'll determine when. I am sure cancer will kill me but I will be the one that says when. So I think it is a case of 'I'm not ready'. So I am going to continue as long and as hard as I can to fight every ounce of this......I never believed I was going to die and I still don't. If I die, it is going to be a shock to me.

> I just think that if it's meant to be, it's meant to be. But you can't give in to it and give up.......Life was always a challenge to me.........I know I got bad days and good days, but you got to look, tomorrow is another day. Tomorrow you might have hope.....Life has been a challenge to me and a lot of disappointments but......take it with a grain of salt.

The different parts of the self, which were related to hope, appeared to be linked together through an inner, central component. This central component was identified as the hoping self. The view of the hoping self as an "inner strength" or "indomitable spirit" is reflected in one of the participant's comments.

> I'm a very strong person. In a lot of ways I might not seem to be........But I have always had a lot of inner strength......I'm very optimistic and even at the lowest point in my life, I feel optimistic. There is something......I always feel, you know, that something - that there's benefits that come out of some things.

> I had an indomitable spirit that I wanted to know what was going on and why couldn't I get better........I'm a very hopeful person. My husband knows a lot of people because of his business. We all know a lot of people. And he's never known a more optimistic person than me in his whole life.......And it always amazed me that I had this because of the bad home life that I had and the bad growing up experiences. There was a spirit inside me that nobody could flatten. And nothing has. I've always been extremely optimistic. And it's just a gift I guess.

The description of the hoping self as a central component is further supported by two of the participants' definitions of hope. Within these definitions, there is a focus on life or living, in which hope is described as "a hope for living" or "the art of living.....just to keep on going." The hoping self could be viewed as a life-promoting source.

> [I would describe hope as] a hope for living. Like I say, I've always enjoyed life. To me life has been good. I don't look back and say 'life has been bad to me.' There's no way I can feel that way cause I really don't feel it has. I've had a lot of pain and I haven't been sick a great deal. And there's a difference between being sick and having pain. I'm very fortunate with friends, family, work, and people I associate with and everything. I like them all. I always liked what I did. I've always been a very independent person. Life's been good actually. There are other people out there that haven't had it as good as I have.......I like to get up every morning and say, 'Hey here's another day.' The old saying, 'Don't say good God, morning. Say good morning, God.'

> I guess hope is the art of living to me. That is what I would call hope.....Well, there is two ways to look at where I am at now.......I can take the easy way out tomorrow and die. Not going to be hard. All I have to do is give up fighting and I will die. There is no doubt in my mind. So that is one level - without hope there is no hope. The other is that I can continue to do - work towards a normal life which I hope to have one day soon - and that is what

> wins the game.......hope is just to keep on going.

An alternate view of the hoping self as a "state of mind" is proposed by one of the participants. It is interesting to note that the life-promoting quality of the hoping self (i.e. "hope.....keeps a person going") is also reflected in this definition.

> Hope really is a state of mind which through influence, through religion, through beliefs, through whatever, keeps a person going, although he has a detrimental condition.......Really hope to me is the coping process. It translates in the coping process.

Each of these interpretations is unique, representing individual perspectives. The importance of individual differences is reinforced in a number of the participants' comments.

> Adalat is the drug for me. Cause I've talked to other people that have the same problem and I mean, Adalat don't do nothing for them but they have other drugs. I guess we're all different make-up.

> Each person, as I understand it, your body make-up is so different. They say there are no two, is it DNA's that are - they're like snowflakes. There are no two the same.

> Everybody's different. That's life. Just because I have it and somebody else hasn't. I mean there are people that I know, play basketball, play professional baseball and play professional hockey and they have epilepsy and they have no problems. Professional football too. And they handle it. But everybody's got a different ... It's all different.

In spite of the individual differences, a number of common themes can be identified. These will be discussed under the categories of characteristics, dynamics and functions.

Characteristics

Although the concept of the hoping self emerged from the data, it was difficult to elucidate. The hoping self may be difficult to describe as it is not tangible and does not display itself outwardly. It may be a more private than public self. This difficulty is directly reflected in two of the participants' comments.

> Your hope is kind of hard to explain.

> I'm very good in crisis situations. I just, I don't know, I just seem to be. I can't really explain that very well except that I never really give up on anything.

Expressing hope in words was difficult for the participants. A more effective approach for understanding the concept of the hoping self might be through metaphors. The following is an example of a participant's view of hope, using the metaphor of color.

> A. [If I could put a color to hope [pause]. It would have to be a bright color.....I love colors so it's hard for me to choose but it would have to be a bright color. Nothing wishy washy......no pastels.....It would have to be a bright color. It could be any color as long as it was bright.
>
> Q. What would that brightness mean to you?
>
> A. It's fun. I suppose - it's fun. That's all. It's a lifter. It's not a downer.

The hoping self may be characterized through other parts of the self which are more tangible, objective or measurable. These include one's view of self, view of others, view of life, view of the illness and spiritual beliefs. These parts of the self appear to be linked together through one's belief system. One's beliefs are, in turn, more openly manifested through a variety of means, including one's attitudes, behaviors and feelings. These beliefs help the individual persevere or cope during times of uncertainty. The representation of the hoping self in relationship to one's belief system is outlined in Figure 3.

The following is a summary of the different views or beliefs held by the participants. Some of the quotations, which were selected, may directly express an individual's beliefs. In other quotations, one's beliefs may be indirectly expressed through an attitude, feeling or behavior. It is important to note that not all eight participants had similar views. However, these are some of the common themes which emerged.

View of Self. Many of the participants described their hope in terms of their view of the self. They identified a number of personal qualities which helped them in the hoping process. These included confidence, perseverance, patience, courage and being "tough."

(1) Confidence. Having confidence in oneself, as well as others, helped the individuals persevere and not give up hope.

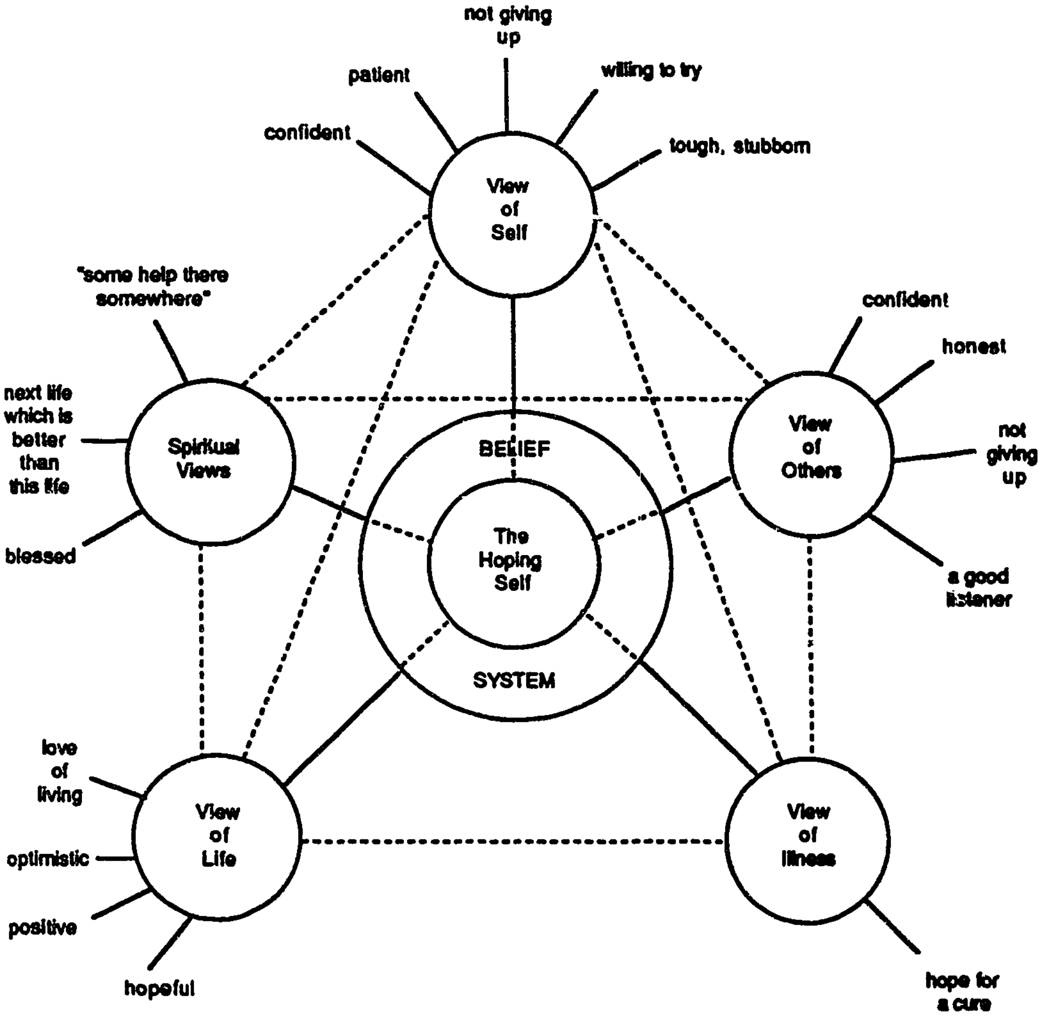
> But to me, like I have a lot of faith in my doctors. I have a lot of faith in everything else, myself. But you should never give up hope and that's pretty much it.

> Well....I know that I'm gonna make it......I'm not gonna lay down and die. There's hope.......You know your capabilities and what you can do, you know, not give up.

This confidence was not limited to oneself, but extended towards confidence in others, as well as in treatments for the illness. There appeared to be an interconnectedness of confidence, which was labelled the "confidence connection." This interconnectedness in relationships, as well as treatments, will be discussed further under the hoping network.

(2) Perseverance. The themes of "not giving up" and "willingness to try or experiment" exemplify the underlying quality of perseverance.

The Hoping Self in Relationship to One's Belief System



> I'm constantly researching, and not on behalf of my group [support group], but for myself too......I always feel that something, that there's benefits that come out of some things.

> You just can't sit around, say well I can't do this. You've got to try. If you don't try........just don't give up.......I'm not one to give up.

> I was always, anytime I went to the doctor's office there, I'd try and grab that new medical [journal] - trying to read the new ones [medication] or watch anything new on blood pressure. And I was always game to them to experiment with anything that came along.....To hit the right one.

> Well, I have a choice because nobody can do anything for me. So I might as well try little experiments myself.

> I'm trying desperately to get onto the AISH [Assured Income for Severely Handicapped] program.....I hope to do so sometime next year. With all this fiestiness I'm gonna do it.

The quality of "not giving up" is reflected in the behavior of one of the participants, shortly after the discovery of cancer and is consistent with the life-oriented quality of the hoping self.

> I'm out of the operating room [after an exploratory operation for cancer]. I've got a nurse there that is supposed to be 24 hours a day and I am out making tea for myself. And she is looking for me. She said, 'What the hell? You are supposed to be here [in bed].' And I said, 'I want that chemo.' You know what they do when they sew you up, you know. They look at it and sew you up and send you back to die. I'm not ready to die.....The surgeon told me to come back in two weeks.....they would have brought me back in a box. I wouldn't have been there in two weeks.

> I was rushed in a couple of times and I was in the hospital for quite some time. Of course, I couldn't walk. I had no skin on my feet [as a result of the chemotherapy]......I insisted, I insisted I have to walk.....So the physio, God bless her heart, she made moon boots for me......And I'd walk up and down the hallways - in terrible pain - but I'd walk.....I wasn't flat.

(3) Patience and courage. To assist in the process of perseverance, two of the participants emphasized the value of patience and courage.

> You have to be patient. You can't rush things. It's not like taking a pill and the headache goes away. I mean when you have something like this you take a lot of pills and you have the headache for a lot of days and maybe eventually it'll go away if you keep working on it.

> And by and large I think there's always a solution to everything. If you have the patience to go after it, patience and courage.

> But I got through that one [making an apple pie using a special gadget for peeling apples due to decreased mobility in arthritic hands]. Now I can peel potatoes, carrots, but you got to have patience.

(4) Being tough. The view of the self as "strong," "tough," "stubborn" and a "fighter" also played an important role for some participants.

> Q. I'm wondering how you're able to keep that kind of an attitude [never giving up hope] or what's your secret?
>
> A. I don't know myself. It's me. I've been stubborn since the time I was little. That's part of the nature. It came with the body.......It was part of the bargain. When I was little, before I went to school, my mom still laughs - she says, "you used to stand there [and say] 'I don't have to. You can't make me'." I guess it was a good attitude for a kid wasn't it.......It worked well for me I guess so maybe I needed it.

> But I don't let things get me down. I'm a fighter you know.

> The way I feel personally is that......I feel I'm tough. I'll get by.

The view of self may be reflected in the expression of one's feelings. For some participants, the ability to control or manage these feelings, particularly negative feelings, was an important aspect of hoping and dealing with the coping process.

> I've never had chronic depression with this [illness] ever....I've never had deep depression or deep anxiety or anything like that so I really can't say what that is like. Or I've never felt where I was never gonna get well. I've felt okay there's hope that I'm gong to get well.

> I never really react negatively to something I have analyzed and know that I couldn't control.....And that helps me cope with it. I don't become depressed. I don't feel bad. I may feel bad, you know, temporarily or something.

View of others. The individual's view of others was important in two respects: first, as a form of evaluation of oneself and second, as a screening method for identifying potential hoping resources. The comparison of the self with others could serve as a source of motivation. It could also assist in the hoping and coping processes by helping the individual put things in perspective, as indicated in one of the participant's comments.

> No person helped me [with the acceptance or in coping] unless if I think maybe deep down, I could always say, 'Gee, I know people who have worse situations than me.'

Comparison with others is an important role of the hoping self and will be discussed further under the "functions" section.

With respect to hoping resources, the participants tended to identify with individuals who had similar qualities. The elements of confidence and trust were fundamental for the development of effective, working relationships. These issues will be discussed further under the topics of hoping resources and the hoping network.

View of life. The individuals' perspectives on life seemed to help stabilize the situation or act as a form of motivation. Some individuals saw their own love for living as a driving force.

> Q. Is there anyone at this time that is helping you to give you that hope?
>
> A. Your family always. Your family always. You always feel part of your family. Your own love of living. Cause to me like, life's fun.......Always at the top end of the thing. Yeah. I see life as the top end of the thing. Just plain living is you're at the top end of the scale. If you aren't you should be working to get there.

> Q. So what kept you going [after the diagnosis of the illnesses]?
>
> A. Love of life.

For others, there was an emphasis on acceptance of and adjustments within their situation, without giving up their inner spirit.

> The way I feel, I'm gonna live. But you gotta change your way of living.

> I've accepted my limitations in life.......And also you can make such a difference in small ways, so what's the big deal if you never did it in a big way. We can't all be Mother Theresa or whatever. So I just do what I can in small ways. I'm not really disappointed that I didn't make those big goals [from my youth]......I just do the best I can and I accept what I have. And I just go on and live my life you know. I've just been blessed with a real optimistic [view].

An individual's view of life can be expressed in terms of an attitude. Most participants described themselves as having a positive, hopeful attitude or outlook on life.

> The way I feel now, I've got a positive outlook. I'm gonna make it, unless I get run over or get in a hunting accident or something like that. But I figure I'll sure - that I'll survive as much as the next guy.

> You have to feel positive all the time. Always feel positive. There's going to be times you can't. But at least you'll keep them to a minimum length and you won't start dwelling on them where they become part of your life and focussing on negative things. I'm not gonna get better. It's not gonna work. Isn't it awful. Throw those thoughts out. Throw all those thoughts out. Work on everything positive. If you're laying there thinking about taking you medicine, your medicine's gonna help you. If it's relaxation, the relaxation is gonna help you. Whatever you do is going to help you. Drill that into your head. And by and large it often does.

Spiritual beliefs. An individual's spiritual beliefs can assist in the hoping process by bringing some certainty into one's life, for example, knowing that "there had to some help there somewhere."

> I am a very spiritual person. Also, I think a fairly intelligent person. And I knew there had to be some help there somewhere........You have to look for the good as well as the bad and I feel that maybe in some ways God wanted me - as I said I'm a very spiritual person - maybe God wanted me to have an appreciation of these things [enrichment of life as a result of the illness].

One's beliefs may also assist in the hoping process by enabling the individual to make the assumption that not everything is under one's own control.

> I believe that God will determine when he takes me. And I am not going to make it very easy for him. But he will decide when it is my time to go. And I have not the slightest fear of death at all, not the slightest. I know full well that the next life is better than this life, so

have any fear of dying.

Views about the illness. One's beliefs may be directed toward the illness and the effectiveness of treatment. These beliefs may reflect a hopeful view regarding the future.

> I believe that someday they are going to find a cure for a lot of these medical problems, and I guess I'll keep believing in it.

> I think they've made so many advances in the last few years with migraine that I always think, well may be there's gonna be something in the next year or two and I always look like that.

Functions

There are three basic functions of the hoping self which help reduce the uncertainty in one's life. These include the development and realization of hoping objects, monitoring progress within the hoping process and acting as a hoping resource for others.

The hoping self is responsible for **the development and realization of hoping objects**, within the hoping process. The hoping self provides the driving force or "strength" to persevere, to "keep going" and to "not give up" along the pathway to specific goals. This persevering function of the hoping self is of great importance within the coping process.

> But after they did surgery, I tried everything to make it a success. I think it has a lot to do with the patient. If you're going to give up hope, you're going to give up hope.

> And what you try to do [when the blood count drops], you try to make sure you eat well. You try to make sure you rest well, and get yourself built up again.

The hoping self can serve as a type of **internal evaluator**, being responsible for monitoring progress within the process of hoping. In this capacity, it has two basic functions, the comparison of the hoping self with individuals external to the self and decision-making regarding coping strategies. The hoping self can be compared with or evaluated against other individuals. This form of comparison can serve as a source of motivation.

> You meet different people [in the hospital]. Then I thought - I was always health conscious - and I thought I don't want to get to be like them. Try and look after yourself.

> As I lay in the [hospital], time after time, when I was in there, I felt so sorry for people that didn't even know how to hope.......There was a number of us in there [in hospital] and they're all gone.....But I felt some of them didn't fight very hard either. They had to have somebody there holding their hand and running for water and wiping their brow. And that is giving up. You have to do that yourself as long as you can lift your arm. No matter how hard it hurts, you have to do it I think.

> I'm a bit more likely to take risks than other people, just because, I don't know, maybe I'm a bit more optimistic that there is something out there. I never seem to lose hope that there'll be something someday......And I don't seem to be afraid to try too much.

> If you look you always find somebody worse off than you are. Which tells you to give yourself a kick and get going.

In its role as an internal evaluator, the hoping self is also responsible for decision-making. Decisions regarding the selection of coping strategies are based upon whether or not the strategy will interfere with the hoping process.

I had read at that time the annual report of the Canadian Kidney Foundation.......which has the full statistics of all the people who are on dialysis for the previous period of 4, 5 or 6 years. And according to that statistics, it said that those with diabetes, 25% of them are still living after 4 years. So I said to myself and I said to [my physician], okay, I have a chance to live up to 4 years and maybe more than that. And I will accept that. I'm accepting that very much. And I don't want the transplant. And the statistics about the transplant was no better......So I figured that one is giving me 4 years, maybe more, with the inconvenience of taking [dialysis] 3 times a week, spending 6 hours here. The other is giving me the same survival rate but with the side effects of the continuous anti-rejection drugs. And I was already beginning to adapt to this thing. Getting some energy back. So logically, mathematically to me, it made sense to stay this way.

And after that [receiving a back injury secondary to treatment from a manipulative physiotherapist] I really made sure that I knew what was going on with my body. It's my body and I want to know what drugs are going in to it and what the side effects will be. And I feel much better knowing that. And then I can make an educated, decision on whether or not I want to try something.

But that night at work, the night I was told to come back and see my doctor the next day because they had found something [a lump in my breast] - in my own mind that night the mastectomy was done mentally.......It was done. Like I went in there and I told him, I said, 'The only thing you have to do now is physically remove it. In my mind it's totally done. It's accepted. It's been finished.' I said, 'All you have to do is put me to sleep and actually do it'. So it was complete in my head at that time.......You don't duck the issue. You go into it straight head along. Like one of my expressions are "I was here before it was." And that's the way you have to treat it........[My sense of hope at that time was] recovery. I said I don't need a breast to eat with. I don't need it to think with. I don't need it for any particular reason. And so be it - take it. That's it. I can live with one or I can die with two. So you take - there really was no choice. You turn around and say there's your line, you just step the way you have to step. There's no choice. Because you, like I said, I could have kept that breast on and probably been dead years ago.

This may occur directly through helping others or indirectly through modelling of hope.

> I don't usually confide in other people. They usually confide in me and the only thing I can do is, say, try this or do this. I went through it and see if they could, give them hope, you know. Not just to give up. Try something else or try and do something else.

> I've seen people sit in the aisle ways at [the hospital], women who would probably be their first visit over there, or they've been diagnosed for having cancer. Crying. Crying pitifully. And you don't know whether to stop and talk to them or not. You don't know whether to leave them that space to let them cry out their feelings. Or to sit down and say, 'Hey, you know, this isn't the end.' And I have opted for, sometimes, not to talk to them thinking maybe they need that little space. Maybe they need that little time.

> Maybe you can help someone who.....has something else wrong in their life and they are feeling sorry for themselves......You can maybe help someone else deal with something they are going through, by saying.....that you are not limited by.....diabetes. Like you don't have to lock yourself away and not do anything and dream of being a mountain climber or whatever you want to do. If you want to and have the drive to do it you can really.

> If I can be of any help to anybody who is suffering a chronic illness, I would very much like to be......I really feel that people like myself - who've had an experience and have managed to find good out of it, or managed to handle it in a good way - if they can help anyone else, that's really what I think we should be doing. And that way it will be easier and easier for people who come on in the next generation to have help. It seems a pity that you have to go and find all of this for yourself.

Dynamics

In relationship to time, the hoping self exists in the present, but possesses a forward-moving, future orientation.

> want to do in the future and being able to enjoy them. I guess hope, for me, is maybe not being totally damaged so I don't have to go through all the terrible complications. I realize I probably am more of a realist - that I probably will have to - and I don't to me I still have hope in the future because that hasn't happened yet.

> It is dynamic and has the capacity to enlarge or diminish in size over time.

> I always feel less hopeful just when I'm having a migraine. That's quite natural. And after I've had one I don't feel as hopeful, but they're small differences in hopefulness. It's only natural when you don't feel well that you have gone downhill in all ways, a little bit. And then you slowly come back up again. And you're not immediately gonna just get better like that.

Relationship with uncertainty. For some individuals, the hoping self may be influenced by the degree of uncertainty in one's life. For others, it appears to be less affected by the uncertainty of a situation. These variations in response to uncertainty may be dependent upon one's perspective of hope (i.e. general and specific hopes versus a continuum of hope) and one's past experiences (i.e. enlightenment, life experiences). This will be discussed further under the hoping process.

Hoping Resources

("Enhancers" "Lifters" "Uppers")

Overview

Hoping resources, as defined in this study, are those assets, external to the self, which contribute to the hoping process. Some of the desirable characteristics of hoping resources, which were identified by the participants, include trustworthiness, honesty, perseverance, realism and empathy. The primary function of these resources is to assist the hoping self in the realization of hoping objects. Hoping resources increase the certainty in one's life and thus also assist with the coping process. Similar to the hoping self, hoping resources fluctuates throughout the hoping process and may be influenced by varying levels of uncertainty. An overview of the hoping resources, in terms of their semantic relationships, is presented in Table 2.

Identification of the Concept

The concept of hoping resources evolved from the investigator's difficulty in coding the data according to Dufault's (1981) concept of hope sources. Hoping resources include, but are not limited to, hope sources. In addition to giving rise to hope, as with hope sources, hoping resources may provide other functions. For example, rather than giving an individual hope, directly, they may emulate the possibility of there being hope. This is similar to the concept of hope models (Jevne, 1990).

> They [historical religious leaders] don't give me hope but when I look at their life, they must have had hope and therefore I tell myself, there is hope.

Further, within the classification of hoping resources, hoping sources have been recategorized according to the specific manner in which they provide hope, for example, as hope believers and hope supporters.

> I started my own [support] group. And we have a very tight group......We are very close and very, very supportive of one another. We can call each other at any time. We exchange medical information. And we give each other a lot of common sense advice.

Characteristics

Hoping resources can be characterized in a number of ways. Two classification systems which emerged from the data are the categories of contexts and attributes.

Semantic Relationships of Hoping Resources

RELATIONSHIPS	EXAMPLES
circularity: X is defined as X	Hoping resources are those assets, external to the self, which serve as resources to the hoping self.
spatial: X is oriented spatially with respect to Y	Hoping resources are external to the self. They exist in the present, but tend to be forward moving and future oriented. However, these resources may originate from the past.
attributive: X is defined with respect to one or more attributes of Y	Some of the characteristics of hoping resources include trustworthiness, honesty, perseverance, realism and empathy.
exemplification: X is defined by citing an appropriate co-occurrent Y	Individuals may serve as hoping resources through their beliefs in themselves and others.
function: X is defined as the means of effecting Y	Hoping resources assist in the realization of hoping objects and increase the certainty in an individual's life through the functions which they provide. These include enhancing hope, modelling hope, providing support, believing and caring enough to confront.
contingency: X is defined with relation to an antecedent or concomitant of Y	Hoping resources may be influenced by varying levels of uncertainty. They also covary with hoping inhibitors and the hoping self.
comparison: X is defined in terms of its similarity and/or contrast with Y	Hoping resources can be compared with Dufault's (1981) concept of hope sources and contrasted with hoping inhibitors.
class inclusion: X is defined with respect to its membership in a hierarchical class	Hoping resources are one of the components of the hoping network.

specifically, relationships ("good supports," "people"); environment ("good facility," "the living environment"); problems, including medical problems ("good science"); and medicines ("proper" medicines). Each participant had a unique set of hoping resources derived from a variety of these contexts. The importance of "good supports" and a "good facility" are described in the following quotation.

> But they are wonderful people, the cancer people, they are wonderful people!.....They know everything about you. They are great people.....Knowing that I had the best......[This city] has the best cancer treatment in the world. So if you got to have cancer, geez what better place to have it than here.

Hoping resources can also be described in terms of specific attributes. It is interesting to note some similarity between the characteristics of the hoping self and those of hoping resources. Some participants strived to find hoping resources who possessed qualities similar to themselves. The following is a partial list of the attributes of hoping resources which were preferred by some of the participants.

(1) Trusting, honest

> I don't know, it has got a lot to do with doctors and their attitude......I like a doctor that can sit down and talk to you, give you good advice, gives you hope, but not lie to you, be honest.

> If he [my physician] is not sure about something he'll even say well leave it with me, and I'll talk to you about it once I've researched it. It's very valuable for me that he will sometimes say, 'Well, I haven't heard of this. Or this is new to me.' I can trust him then, because I know that he's being very honest.

As long as there is good science, good doctors and, that they will not give up.

He'll do his best for me. He'll find out about it [new treatments]. Also, if he finds something new, which he always does try.....he's very good at just talking to me about what's new in the market and what he's heard recently.

And friends - I know people all over the world, because I travelled the world - and they send me stuff......because they want me to live.

(3) Being realistic

Every doctor I've had....[was] not letting me down as far as medication, as far as surgery. They didn't build up my hopes and say, well, we're going to do this surgery and you're going to be perfect. They'd tell me what the side effects are or what could happen, or.......maybe it is not going to be a success, maybe you're going to be crippled up.......Everyone [physician] that I've had, never, built up my hopes and let me down.

(4) Being empathic (being a good listener, attempting to understand the individual's point of view)

I find the best thing with him [my physician] is that he will listen to me......I feel that when I meet with him, I have information sharing and that's great.

He was the first physician that I'd ever spoken to, who knew the pain that I suffered, who knew the disruption of the family life that could occur with nonunderstanding. And he encouraged me to let everyone in the family know my problem and how it worked......But he had real empathy. He had actually been there.

> [My family] They've been good - very, very good. They know the problems I go through. Like I can say to them, well, if I'm really owly today, understand why. I don't feel that great today and I'm a bit grouchy. And that's it. It's not you. It's me......Being open enough to tell them when you aren't feeling well.

Most of the participants, either directly or indirectly, identified physicians as potential hoping resources. The significance of the physician-patient relationship will be discussed in Chapter VIII.

Functions

The primary objective of hoping resources is to assist the hoping self in the realization of hoping objects. They are able to bring some certainty into the individual's life, thereby assisting with the coping process.

> I have always been quite hopeful.....I don't think that it [confrontation by support group members] made me feel that I was not going to have migraines anymore. So it didn't really make me anymore hopeful. It just made me feel that.....I could cope with it better. That I was going to manage the headaches, they weren't going to manage me. That was like a role reversal.

Hoping resources can be categorized according to the functions which they provide to the individual. These include hope sources, models, helpers, believers and confronters.

(1) Hope sources or enhancers are the same as Dufault's (1981) concept of hope sources. They are perceived as a source of hope by the individual and give rise to hope.

> But health.....there was no problem [in my family history]. I always figured well, surely, you must take a few genes here and there.

> Every day they're [medical science] discovering new things. Every day.

(2) **Hope models** offer hope in an indirect manner. Rather than giving an individual hope, directly, these resources model or emulate the possibility of there being hope.

> [I would see] Leaders [as models of hope]. Be it prophets of any religion, saints who did things and became saints, contemporary religious leaders who try to defy certain things. I must be a religious person myself, deep down, because the closest that comes to hope to me or a hope model to me, really is through religion. Any religion. Doesn't matter what. I consider all religions the same. Historical religious leaders, more than today's fake religious leaders.........They [historical religious leaders] don't give me hope but when I look at their life, they must have had hope and therefore I tell myself, there is hope.......And it impresses me that people could live comfortably, even suffering.......history to me shows that hope can work.

> People have been known to have cancer, have it go into remission and not have it reoccur and die of some other disease when they're older.....you can go on for years. You can have people - it's even disappeared. Which is the importance of never giving up hope. Never give up hope.

(3) **Hope helpers** may be considered a special type of hope source, by offering support and help. This support may be provided in a variety of ways. Some assist by sharing similar experiences and information.

> Q. Was there anyone or anything that helped you through that time [when blood sugars were out of control]?
>
> A......I had forgotten how to be a diabetic sort of thing. I had forgotten all the basics......So I had forgotten all the basics and so I went through their program [diabetic teaching program at the hospital]. And that sort of - I knew in the back of mind, knew what I had to do and that reinforced it.

Others provide a monitoring role and help the hoping self evaluate progress.

> I do that. I do that myself [monitor own blood pressure]. Then when I go see a doctor......it confirms the reading. Sometimes your own machine - mine's the old mercury type, but it's still a good machine. But just the same, you like to see what the other one's do, you know.

> Q. What role do you think your physician plays in your diabetes and your hypertension?
>
> A. My watch dog, I guess.....I need someone to keep reminding me, telling me, 'You are not doing so good or you are doing good, you know. Watch this. Do that.' We need all the encouragement here and there.

Some participants emphasized the importance of having individuals who were understanding and caring.

> I spent a great deal of time laying on the floor by the toilet [vomiting from the chemotherapy]. My wife was so sweet, she used to bring a pillow in - because there was nothing else she could do - and put it under my head.

> You know everyone needs to be loved and accepted and that is what my family [gives me].....I might get more, from the diabetic centre, get more push to do better, but maybe some more understanding too from my family.

> My husband was extremely understanding.....He was always there for me. My church was always there for me.

Hoping helpers can also assist the hoping self by serving as a motivator, either directly or indirectly.

> Q. Was there anything or anyone who helped you maintain that level of hope [following the diagnosis of cancer of the uterus and cervix]?
>
> A. Well, your family always does if you're secure in your family. Probably the greatest thing would be your child. Like our boy, he was just into kindergarten at that time. So he was at an age where he would need a mother. That becomes a very important thing. Having, not only having someone there that you need, somebody who needs you, which is probably more important.......So I think the thing goes in to the caring for someone else rather than your caring for you. That's what gives you the courage to go on. Because nobody really wants to be babied.

(4) **Hope believers (affirmers)** serve as hoping resources through their beliefs in themselves and others.

> Q. What effect might their [the physicians'] influence have on your hope?
>
> A. Well, if they [the physicians] are honest, like I said, and if they believe in this medication 'cause it helped somebody else, I would try it.

> People like [my psychologist, my physician] [helped me get through the chemotherapy]. I had the support of my three daughters and my grandchildren - and my wife never, ever once believed that she was going to lose her husband. You could ask her today and she'll tell you herself that she just didn't. Most people in this town believed it and if you could see that picture you would believe it. But I didn't and neither did she. And she was seeing me in those times when I looked like - I was swollen, bald-headed, bald everywhere, puking all the time. She never once, to this day, believed that I was going to die and neither did I.

(5) **Hope confronters** care enough to constructively confront and challenge the individual.

> Q. So what is it about her [your psychologist] that gives you hope?

> the bucket. Give up. Don't bother me if you are going to be whining around. You want to fight, let's fight.' And she shoots it - I love her - and that's the way you have to. You can't give up. She is gentle and she's kind and she's sympathetic. But she knows when to pull the cord too.

> They [the support group members] were quite ruthless. They said, 'You're so angry at yourself.' And I said, 'No I'm not.' But they were right on you know. And I felt like they attacked me. But it was so true, you know. It was so true. And it was like a light going on because I kind of realized these people really cared and that they had been there.

Figure 4 is a representation of hoping resources according to the functions which they provide. The inner circle refers to the four contexts within which these resources can be described.

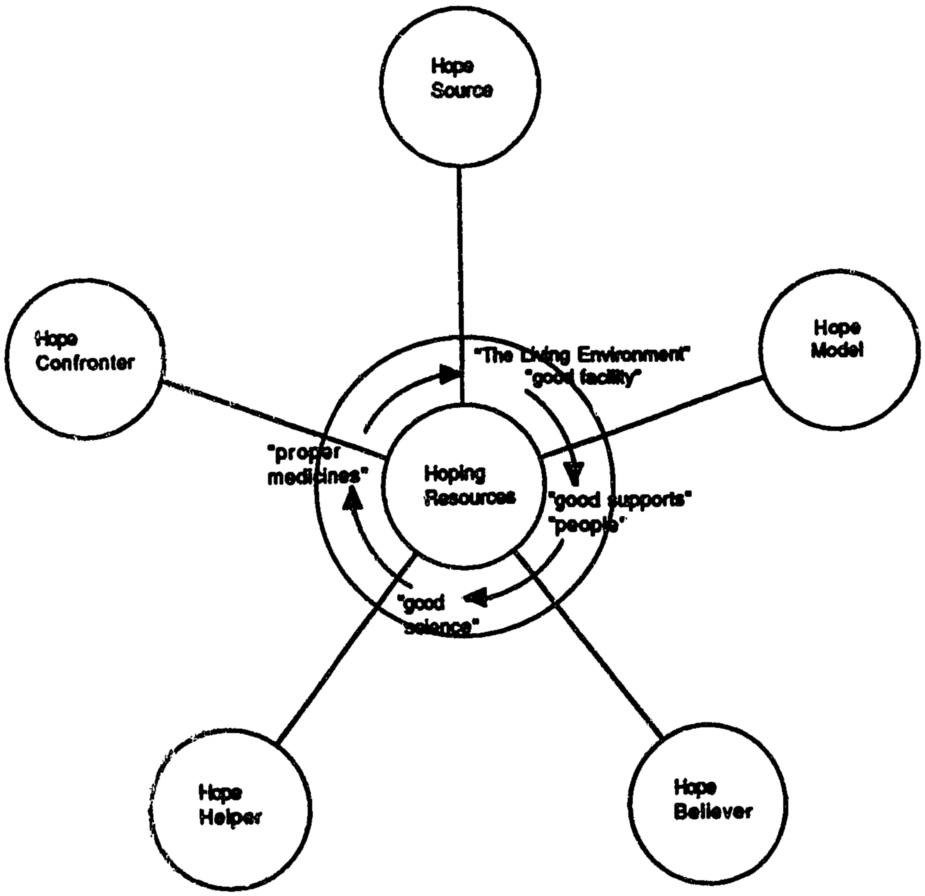
Dynamics

Hoping resources can be defined, in relationship to the self, as being external to the self. They may also be described in relationship with time. Hoping resources exist in the present and, similar to the hoping self, tend to be forward-moving and future-oriented. Even though they exist in the present, these resources may originate in the past, for example from family history or historical figures.

> But right now, I feel good. And, you know, the outlook actually I'm not so worried about it anymore. I got it [hypertension] and like I say I always go to the fact that my mother was 93 when she died.

> So if you tell me who influenced you in terms of hope, or who would be your model, I go for especially the historical figures more than the contemporary ones.

The Functions and Contexts of Hoping Resources



fluctuate with varying levels of uncertainty. This will be discussed further under the section of the hoping process.

Hoping Inhibitors

("Blockers" "Downers" "Barriers" "Delays")

Overview

Hoping inhibitors are obstacles or "blocks" which interfere with the hoping process. From the data, these inhibitors can be categorized according to five contexts, specifically: the self, relationships, medicines, environment and problems (which include medical problems). They can also be described on three continuums, that is, uncertainty, change in normal routine and feelings. Hoping inhibitors interfere with the hoping process by impairing the movement of the hoping self and resources towards hoping objects. They exist in the present or the future. These inhibitors appear to be influenced by the degree of uncertainty in one's life and may be more prominent during times of great uncertainty. A summary of the hoping inhibitors, within the framework of semantic relationships, is presented in Table 3.

Identification of the Concept

Hoping inhibitors are similar to Dufault's (1981) concept of a hope threat with respect to their function as obstacles or blocks to the hoping process. In contrast to Dufault's term, however, hoping inhibitors are more expansive. They include, but are not limited to, hope threats.

Semantic Relationships of Hoping Inhibitors

RELATIONSHIPS	EXAMPLES
circularity: X is defined as X	A hoping inhibitor is anything which inhibits or interferes with other components of the hoping process.
spatial: X is oriented spatially with respect to Y	Hoping inhibitors are spatially oriented between the hoping self and hoping objects. They exist in the present or future and tend to move in a direction opposite to or different from the hoping self and resources (i.e. away from hoping objects). They may also be viewed as blocks which don't alter the direction, but which impair forward movement.
attributive: X is defined with respect to one or more attributes of Y	Hoping inhibitors can be described on continuums of uncertainty, change in normal routine and feelings.
exemplification: X is defined by citing an appropriate co-occurrent Y	Hoping inhibitors are like "blocks" or barriers.
function: X is defined as the means of effecting Y	Hoping inhibitors interfere with the hoping process by blocking the movement of the hoping self and resources towards hoping objects.
contingency: X is defined with relation to an antecedent or concomitant of Y	Hoping inhibitors may be more prominent during times of uncertainty.
comparison: X is defined in terms of its similarity and/or contrast with Y	Hoping inhibitors can be compared with Dufault's (1981) concept of hope threats and contrasted with hoping resources.
class inclusion: X is defined with respect to its placement in a series or spectrum that also includes Y	Hoping inhibitors are one component of the hoping network.

participants. For some, the word threat was replaced by other terms such as "detriment," "slow-up periods" or "delays." These terms imply a sense of temporariness and an ability to get around the obstacles.

> But as far as permanent threat, no.......It [the discontinuation of active treatment] seems like a slow-up period. When you say threat or that, not really as a threat but there's another little slow-up period to get everything balanced out again.

One of the participants reframed the hoping inhibitors as "blocks" or "challenges" which tested oneself.

> Another challenge, like you say, it's [the illness is] a block that blocked my wheel. [It] was another challenge. Can I cope with it, can I go on or will I give up?

For some, however, the potential obstacle may have a more permanent effect and may be viewed as a real threat.

> Q. Did you feel at any time that anything might be threatening your hope [after car accident in 1965 and diagnosis of cancer in 1966]?
>
> A. .....Well, I think you always do when you're hurt. Cause you couldn't tell the extent of the injury at that time. And until an injury like that heals it out, you can't say that it really threatens your hope, but it does make you wonder - I wonder if this thing will heal out where I'll be back where I was before. Not as a threat but as a comfort thing.......Because you need to think of yourself as going around partially, maybe paralyzed. Some nerves don't heal out or you don't want to look at yourself being handicapped. And it's not that it's a big issue, but it does, it does play a part in it. It's the same as if you broke your leg. You would hope that leg would heal, especially if that leg was aching over a period of time. You'd say, 'Well, gee, I hope that leg's going to heal properly. There isn't gonna be a permanent injury here.'

one extreme and temporary "slow-up" periods, annoyances or delays at the other.

Characteristics

Hoping inhibitors can be characterized in a number of ways: (1) within contexts; (2) as degrees of uncertainty; (3) as degrees of change in one's routine; and (4) in terms of the feelings associated with the inhibitor.

Contexts. From the data, hoping inhibitors could be categorized within five contexts, the self, relationships, medicines, environment and problems, including medical problems. These contexts are similar to the four contexts of the hoping resources, with the addition of the self as a fifth type. It is interesting to note that these five contexts can serve dual roles, that is as contributing to or interfering with the hoping process.

Degree of uncertainty. Different levels of uncertainty or unpredictability may be attached to hoping inhibitors. For some inhibitors, there is no way of predicting when they might occur.

> Q. What might cause you to lose hope?
>
> A. Well if I was on the floor right now [having a seizure], I might be a little upset. You know, That's the thing about it, you never really know.

For other inhibitors, the uncertainty is related to the frequency of occurrence. Some may have a very low probability, whereas others may have a higher probability, of occurrence.

> Things like that [the danger of some medicines] could threaten hope, Everything else is working fine. But here I have to take that medication. Yet we know that there is that possibility, although it doesn't happen to everybody and it happens very little.

> the high blood pressure, it's more of a factor. It is more of a possibility so I worry more about it, and you know, what's going to happen when my kidneys go. Not that I want to know.

Even though some inhibitors may have a high probability of occurrence, the timing of their occurrence remains unpredictable or uncertain. Further, some of these unpredictable inhibitors are not necessarily perceived as threats, but rather as something which is expected, "a part of the whole game."

> Q. Would you see those s [to insulin] affecting your hope in any way?
>
> A. No. It is just part of.....It is part of the whole game.

> A. I feel I am now getting older. I'm not even---even my organizational abilities are not the same as previously. But again I accept that too. I mean, my limits, the threshold of my limits is shorter a bit. But within that I try to cope and accept it.
>
> Q. Would you see that as threatening your hope?
>
> A. No. Not really. I see that as a process that is going to happen and if I can control it I would have controlled it. In other words, I have to accept it. The fact that I am less organized, I must accept it.

Degree of change. Hoping inhibitors can also be viewed in terms of the degree of change in one's routine. They can be viewed on a continuum from temporary delays to permanent changes.

> With the white cells [when the white cells were low and the chemotherapy had to be interrupted]....I can't say that it affected my hope on a long-run basis because usually if I had an extra week between chemo injections my blood would come up again. I just needed that extra time cause it affects the bone marrow and every thing.

> I always said that if I was ever confined to a bed that I'd give up hope then. Because I wouldn't be able to do what I've always done. Like you say, there are things that I cannot do anymore in sports, but I tried something else........But I always did say that. That if I ever got to a point that I was bedridden, that's where I would give up hope. I don't say I couldn't be bedridden for a couple of weeks or something.....after surgery.

Feelings associated with inhibitors. Hoping inhibitors can be described in terms of the feelings associated with them, for example, "downers," "fears," "concerns" or "annoyances." These feelings can range from safety and connectedness at one extreme to feelings of fear and isolation at the other extreme.

> Well, gee, I figured I'd survive, but I was always scared of a stroke......I was scared to be left crippled. And that's what scared me more about the blood pressure I think......I like to be quite active. I do a lot of hunting there in the fall, for a month and that. And I thought, boy, if something happened to me that I couldn't get out on my own, what are you living for?

> A. I think, well, if I can get back to something [work], great. But if the tension and the pressure, if somebody there rubs me the wrong way, that's all there is to it. I'm out the door again.
>
> Q. It's almost an overriding cloud or would you call it -- a fear?
>
> A. No, no, no, no, no. I mean, well maybe a fear, phobia, whatever. It depends what type of work it will be.

> Q. What was threatening your hope at that time [prior to diagnosis of the illness]?
>
> A. Well, I thought that number one, I was the only one. This is unrealistic but this is how you feel. I was the only one who was suffering this because I felt alone.

> It's disappointing that if you can't get your shots [when the white blood cells are low] 'cause like I say, you always figure it puts you a week behind. But as far as putting the damper on things, no it doesn't do that.

The three continuums of hoping resources are illustrated in Figure 5. The inner circle refers to the contexts within which these inhibitors may be described.

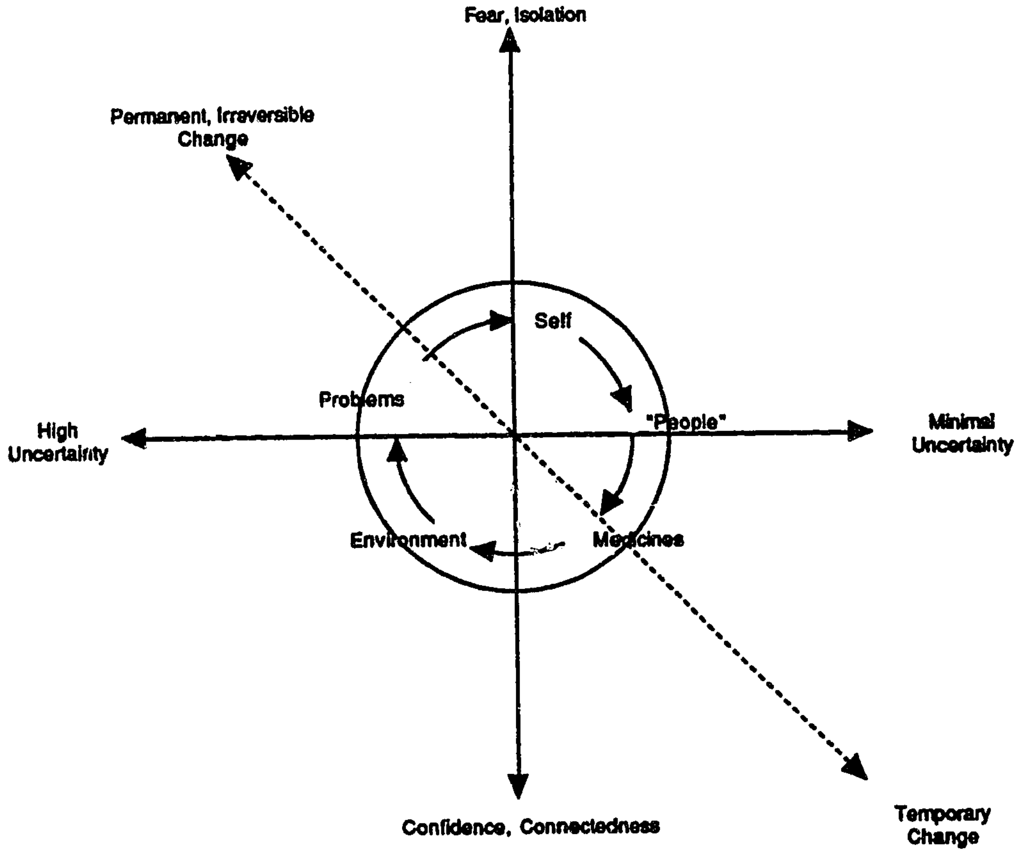
Functions

Hoping inhibitors interfere with the hoping process by blocking the movement of the hoping self and resources towards hope objects. This interference may be directed towards the hoping object, itself, or towards other components of the hoping process. At times, the inhibitor can directly interfere with a specific hoping object. For example, for one of the participants, potential complications of the illness, such as kidney failure, could interfere with the individual's hopes for having a family some day.

> I know that if you don't watch it then your kidneys are going to get worse and worse and worse and that will mean dialysis and more strict diets and things will get worse. And you won't always feel so good......Maybe I was just thinking here I am what 20 some years old and in five years I could be on a machine three times a week, limiting myself. I might not be able to work, I won't be able to have a family and I think that really scared me because those are things that I wanted.

> It [the increased probability of developing renal failure] does threaten your hope. It makes sense that you know it is going to happen so you sort of well, sometimes it might hold you back like - like you won't get involved with this person because they won't be able to handle this or you won't do that sort of thing. That might be, that's a detriment to your hope.

The Continuums and Contexts of Hoping [illegible]



For another participant, the onset and progression of the illness interfered with many things, including work.

> Life was always a challenge until this [the illness] really block, put a block in my wheels and now you can't do dentistry no more. You can't do this, you can't do that. But I don't sit around and mope about it. I figure, well maybe tomorrow is another challenge for me to do, try something else.

At other times, the inhibitor may not be linked to the hoping object itself, but may be directed towards other components of the hoping process, such as the individual's patience.

> Q. How would that "not knowing" affect your hope [time period during which diagnosis of bone metastases was suspected, but not confirmed]?
>
> A. Hope. I don't think it affected my hope. It just, I don't know how to put it. See, I've never been of the opinion that I wasn't gonna get better no matter what came. So you couldn't say it affected your hope and I'm trying to think of the right word to use here and I can't get what I want. It affected my patience. I think probably.....I wanted to know what was going on and let's get at it and do something about it.....But not the overall hope, scope of the thing. It was just hey let's find out now what it is and get after it, instead of sitting here another 2 months and not knowing......Let's get on with it and find out or treat it or see what we're gonna do here. Get going in a direction and get it looked after.

> Q. Is there anything that is threatening your hope at this time?
>
> A. Not threatening it, but I can tell you there is times when my patience runs a little thin. I mean three years and ten months is a long time to suffer pain. It's a long time to suffer pain. Sometime you think it would be easier to take the other route. And I would be lying if I didn't tell you that, you know.

Hoping inhibitors are spatially oriented, within the hoping process, between the hoping self and hoping objects. In relationship with time, hoping inhibitors exist in the present or the future, and tend to move in a direction opposite to or different from the hoping self and resources (i.e. away from hope objects). They may also be viewed as blocks which don't alter the direction, but which impair forward movement.

> Q. Okay. So during that slow-up period I sense that you still have the same level of hope.
>
> A. Oh yeah...No, that hasn't changed. Just like you say, I'm going to Calgary but I'm gonna have to wait 'til next week. You're still gonna go but it's gonna take a little bit longer.

Relationship with uncertainty. As mentioned previously, hoping inhibitors can be characterized on a continuum of uncertainty. They appear to fluctuate with the degree of uncertainty in one's life and may be more prominent during times of great uncertainty. This will be discussed further under the section of the hoping process.

Hoping Objects
("The Field Goal That Wins the Game" "The Rainbow")

Overview

Hoping objects are the goals towards which the hoping self and resources are moving. Similar to hoping inhibitors, they can be characterized in terms of five contexts, the self, relationships, problems, medicines and the environment. The attributes of hoping objects can be described on five continuums, specifically, degrees of abstractness, specificity, realism, uncertainty and importance. Hoping objects provide a sense of direction for the hoping self and resources. They may also assist with the coping process by acting as an incentive, giving the individual a goal to work towards, while they are

Some objects appear to be interrelated in a chain-like or hierarchical fashion. They are dynamic, changing over time. The re-evaluation of hoping objects may be influenced by varying degrees of uncertainty. A summary of the qualities of hoping objects, based on semantic relationships, is presented in Table 4.

Identification of the Concept

This concept is the same as Dufault's (1981) term, hope objects. The term "hope objects" was changed to "hoping objects" to emphasize the process-oriented nature of this component. Using the metaphor of a football game, hoping objects can be viewed as the points scored in a game. This was described by one of the participants in the following manner: "Hope is to get to the point, to kick the field goal that wins the game."

Characteristics

Hoping objects can be characterized in a number of ways. Similar to hoping resources and inhibitors, they can be classified according to certain contexts. They can also be viewed on continuums.

Similar to hoping resources, hoping objects can be described in terms of five contexts, the self, relationships ("people"), problems (including medical problems), medicines and the environment. The four latter contexts are the same as the contexts for hoping resources. In some cases, these objects may be directly related to the illness. This is reflected in one of the participant's comments.

> I don't know, I think with any illness is to have the hope someday you're going to be cured, or they will come out with a drug that will help kill the pain, or that they got good doctors.

> I don't think there is actually a cure for rheumatoid arthritis. There is a lot of medication that could help but I'd like to live long enough to say well, try me. See if it's going to cure. Then I'll believe you.

RELATIONSHIPS	EXAMPLES
circularity: X is defined as X	A hoping object is a goal towards which the hoping self and resources are moving.
spatial: X is oriented spatially with respect to Y	Hoping objects are perceived as being in the future. They tend to be defined in terms of a time frame.
attributive: X is defined with respect to one or more attributes of Y	Hoping objects can be viewed on a number of continuums: concrete versus abstract; general versus specific; realistic-unrealistic; definite-improbable; frivolous-essential.
exemplification: X is defined by citing an appropriate co-occurrent Y	A hoping object is like a field goal in the game of football.
function: X is defined as the means of effecting Y	Hoping objects provide a sense of direction for the hoping self and resources. They may assist with the coping process.
contingency: X is defined with relation to an antecedent or concomitant of Y	Hoping objects are dynamic and may be redefined, based on varying degrees of uncertainty.
comparison: X is defined in terms of its similarity and/or contrast with Y	Hoping objects are similar to Dufault's (1981) concept of hope objects.
class inclusion: X is defined with respect to its placement in a series or spectrum that also includes Y	Hoping objects are one of the components of the hoping network.

In other cases, the hoping objects were directed towards other parts of the individual's life.

> I always said I want to live to be at least in my late sixties, to see her [daughter] grow up and to see if she goes to university.......I'd like to see her make something out of her life.

Some of the attributes of hoping objects may be viewed on continuums, specifically, concrete-abstract, general-specific, realistic-unrealistic, definite-improbable (i.e. a continuum of uncertainty) and frivolous-important.

(1) concrete versus abstract

> I don't look that far in the future to think, 'Well what am I looking for?.' I don't expect all that wealth and fame and fortune, that's not hope.

> Sometimes, especially late at night when you think about it [the threat of kidney failure], that's the time when it bothers you. Maybe - I'm not a worrier so I don't - whatever happens happens. I'll take each day at a time. I'm not promised tomorrow......I only have right now so I don't look too far in the future. But I sort of, 'Well, this would be nice.' And so if I can keep myself healthy in order to look forward to it, well, all the better.

(2) general versus specific

> Well, you hope to live to, you know, a ripe old age but you can never tell.

> And I want to see my grandchildren graduate and get married......and teach them the importance of financial sound structure.....So I want to teach my grandchildren. So that is

(3) realistic-unrealistic

Hope to me does not deny facts. It's not denying a fact. It is rather helping me to cope with the fact. So if you tell me you're very hopeful, I will tell you, yes, of course. But hopeful for what? That the disease will go away? No, in fact, you could say, for example, that a cure for diabetes may happen in my lifetime. I don't even hang on that. If it happens, it happens, but I know as an educated person, that even if it happens in my life time, it might not be really applicable to me.

But I would like to have children, although I don't know whether that is a realistic hope. Like that's one thing that would be because of my high blood pressure and my kidneys. They will probably say you shouldn't. Like I know they are going to say that. That's to me a little disappointing because I would like to but that won't, you go maybe through the monthly cycle, get depressed about it occasionally. It is not something that - I don't look at it as a necessarily horrible thing either.

(4) definite-improbable (continuum of uncertainty associated with hoping objects)

I believe in, there is a life after this life and I trust in God that the life after is going to be perfect. So maybe my hope really isn't totally centered on just what's here, but what's in the future in Heaven with God. So I have that perspective. I don't worry if I know He is there taking care of me and whatever happens, that through it all, that I don't have to worry. I can depend that come the next life I will be free of this. To me that is a definite hope.

(5) frivolous-important

Well I am hoping, I guess, I don't know, in this life, I guess I, there are things that I would like, but I guess you call that hoping for. I like to travel and I like to do that sort of thing and that's maybe a

> [Today I am hoping] that my husband gets home safe and sound.....and that my daughter, she is with a friend right now, that she is okay. That is the only hope I've got, that everything, I don't know.......My dad said he'd be back.....when he was eighty years old. I'm hoping that he is going to live that long.

> Right now, with my condition, I hope to live comfortably, to work as long as I can, to make things easy for my family, as easy as possible, while I am still living and after I go. That's it. That's basically it.

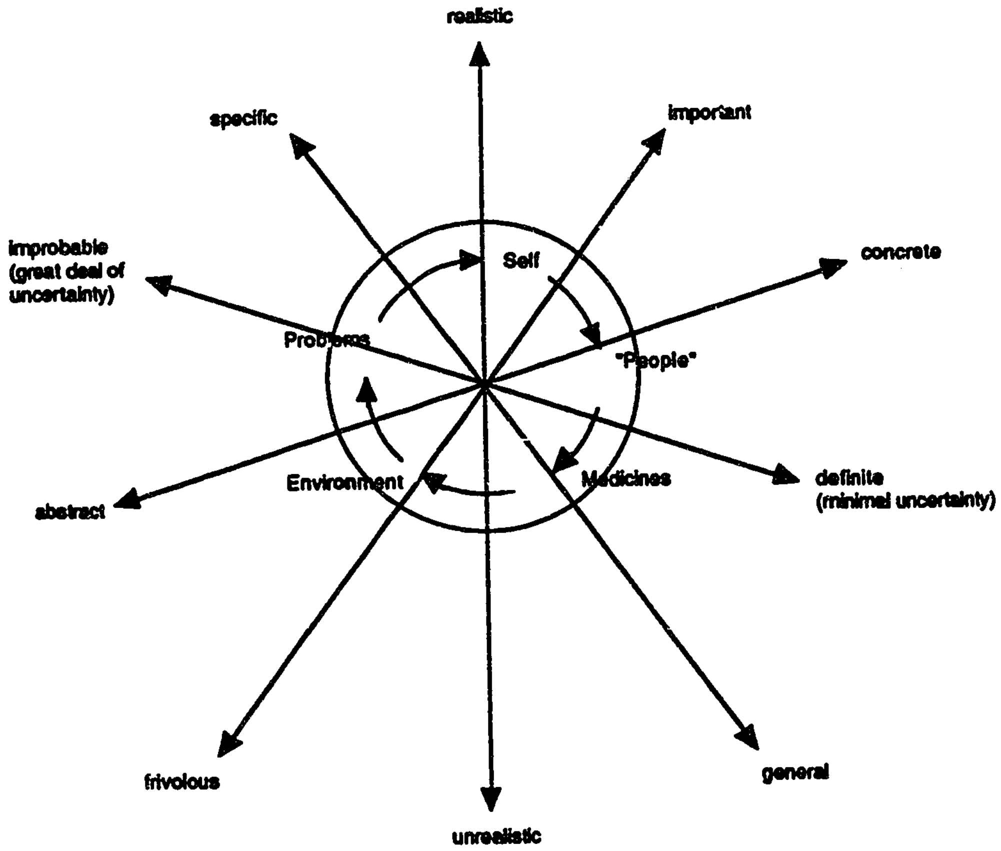
The continuums of hoping objects are illustrated in Figure 6. The inner circle represents the contexts within which hoping objects can be described.

Functions

Hoping objects provide a sense of direction for the hoping self and resources. They also provide the individual with an incentive or goal to work towards. In this sense, they may assist in the coping process by acting as a source of motivation to "keep going." The individual is more able to cope, in anticipation of achieving the hoping object.

> The only hope I have, in reading the literature on polymyalgia rheumatica, it runs its course usually somewhere between one and - I thought it was four years, but now I find it's one and ten years. And then it will just, it is known just to disappear as fast as it comes......and that's what I am shooting for - for that day when I wake up without any pain. That's the day I am waiting for.

> I have hope that they are going to find a cure. But being aware of that, I'd like people not to give up.


realistic
specific
important
improbable (great deal of uncertainty)
concrete
Self
Problems
"People"
Environment
Medicines
abstract
definite (minimal uncertainty)
frivolous
general
unrealistic

of a specific time element, for example, a hope to get out of bed by next week or hope for survival for 8 to 10 years.

> Q. What was your sense of hope at that time?
>
> A. The same as I'm talking to you now. I never gave it - a hundred per cent, a hundred per cent hope of survival. I never gave it a thought that I wouldn't survive. And I don't say survive forever, but I'm looking at an 8, 10 year period. Because nobody can say they're gonna survive forever, regardless.

Other hoping objects are defined in the future without a specific time frame. There is a greater degree of uncertainty attached to these objects.

> Q. What role do you think hope plays in your life?
>
> A. Hope there is a cure some day. [Slower pace, more serious tone of voice]. Not only for rheumatoid arthritis, for cancer. They come up with a lot of cures for cancer but not enough.

> If things go well as they are now, I'm going to live comfortably, as comfortably as can be in my condition, for whatever number of years are left for me. And then I hope that nothing interrupts that.

Some hoping objects tend to be inter-related. For example, they may be inter-connected in a hierarchical or chain-like fashion, in which a subsequent goal is dependent upon the achievement of a preliminary goal.

> You never know, maybe someday they'll come up with something where I'll have no migraines. And maybe I will still be able to go into palliative care or take a degree or whatever it is that I want to do.

> get back some of my what shall I say independence. To do things like go to the bathroom. To do the little things. Brush your own teeth. Just to have that little independence to know when you're going to go to the washroom to know that you can get up and take your walker and walk out to the lobby. Who knows? And you build on those 'til you progress up to the independence and you take it from there. I mean you just work on it slowly and keep on going.

Hoping objects are dynamic and change over time. Some hoping objects are attained. Others may be unattainable and thus be redefined. The redefinition of hoping objects is part of the hoping process.

Relationship with uncertainty. The redefinition of hoping objects may be influenced by varying degrees of uncertainty. This will be discussed further under the section of the hoping process.

B. The Hoping Network

("The Confidence-Connection" "Working Together")

The inter-relationship of the hoping self, hoping resources, hoping inhibitors and hoping objects is represented in the form of a hoping network. This network is dynamic, undergoing many changes as it advances through the phases of the hoping process.

The following is a description of the hoping network, outlining the interactions of the hoping components. The interactive nature of this network will be further illustrated using two metaphorical approaches.

Interactions of the Hoping Components

Each of the components of the hoping process interact with one another within the hoping network. The following is a summary of these interactions.

The concept of "working together" is fundamental to the success of this construct. This team approach is important in working towards common goals within the hoping process, and as such, assists in coping.

> Q. Is there anyone at this time that is helping you to give you that hope?
>
> A. Your family always. Your family always. You always feel part of your family. Your own love of living. Cause to me like, life's fun. And well just in general - the people you have, the friends you have, the family you have. All these things all tie in together. Same as doctors, medications and stuff tying in together. All these other things all tie in together.......The whole thing works together. You work at the whole thing together.

> Q. How do the medications relate to your hope?
>
> A. Well, again, coping, I mean, how am I coping for example? Number one, with my psychological state of mind. Number two, my doctor and the treatments available to me. Number three, the medications I'm taking. So taking the medications - I'm still the same person I used to be - very meticulous, very organized and so on. It's part of the complex of coping. Medication, treatment, good doctor, good family support, good facility. And my psychological state of mind.

One individual went so far as to say that if a particular hoping resource, in this example, a physician, is not helping or is not "working together," then it's time to find a new resource.

> If you're not working together with your doctor, get a different doctor because you don't want anybody hanging onto you that brings you down. You fight to stay up and they bring you down, where are you?

which developed varied amongst the participants. Some individuals saw their relationship as reciprocal and collaborative. The participant and physician shared the roles of advisor and consultant and were equal team members.

> I did at some time in my life, not look on a physician as an equal, which I do now, but as an authority figure......There has to be [information sharing] for me. If there wasn't I would find another physician because I really feel that - I'm so grateful for what they can do for me - but they also have to listen to how I am. And it should be a shared thing. And often I think it's not.

> We [my physician and I] see eye to eye. He's got a sense of humor and I can bounce things......off him and he throws them back at me. And there's no problem there.

> I want to know what is in it [the medication]. And if something happens to me, I come back and say, 'Doc, would you get your medical book out there and check and see if [it] causes this or that.'

> I consider myself more lucky because I read. So from the first diagnosis of the first disease I would read about, and the second one and so on.......then I ask questions of my doctor.......It helped me. It helped the doctor also......Some doctors wouldn't accept that. They have no time for you telling them what about medicine and so on. But with [my doctor] it was, he accepted that right away and it became a two-way process. I do my share and he does his share of treating me.

Others saw a definite distinction between the role of the patient and the doctor. Although collaboration was still an important component of this relationship, the degree of collaboration and negotiation was much more restricted. Both the physician and patient were team members, but the physician was in a better position to influence the game plan.

> Well, I always left it in the hands of the doctors. Especially if you go to the cardiologist and if he doesn't.....know the proper medication for me I don't know what.

> [Medications] That's the one area where a layman has to totally depend on the medical profession. And I was very fortunate, from my rheumatoid people, to my cancer people, who would phone me at home and say, there is something new out. I want you try it.

In spite of this variation in team structure, there was a common underlying theme regarding the relationships between the hoping self and hoping resources, that is, the significance of confidence. This confidence was not only in oneself, but was also interconnected with the level of confidence of others. This interconnectedness of confidence was labelled the "confidence-connection."

> It's got to do with the patient and doctor. If the patient doesn't have confidence in the doctor, well, they haven't got confidence in theirselfs and they're just going to give up.

> Because to me if I didn't have confidence in my doctor, I'm wasting their time and I'm wasting my time. That doesn't mean the doctors not good. It means that I have to feel confident on a one-to-one basis with that person. He might be the greatest doctor in the world, but if I don't have that feeling about that person, it's not gonna help me none.....I had a lot of confidence in my doctors. If I did not have confidence in my doctor he would not be my doctor for long.

The interconnectedness of "working together" and the "confidence-connection" provides [illegible] cohesion, courage and strength; and enables the individual to move in the direction [illegible] hoping objects.

Hoping inhibitors serve as blocks or barriers on the hoping object pathway. They may directly interfere with the hoping object or the interference may be directed towards other parts of the hoping process. The relationship between hoping resources and hoping inhibitors could be viewed as antagonistic, as these two components serve opposite functions. Hoping resources assist in the hoping process, whereas hoping inhibitors interfere with this process. The relationship between hoping inhibitors and the hoping self could also be viewed as antagonistic, as the inhibitors can affect parts of the self which contribute to the hoping process, for example, one's patience.

Hoping Objects

Hoping objects give some sense of direction to this network. These objects function as a definite endpoint or goal. The pathway to reach this goal, however, is uncertain and unique for each individual. Not only is the pathway unclear, the time required to reach a specific hoping object is also uncertain. As mentioned previously, some objects are more predictable or certain than others, that is, they have a greater probability of occurrence.

Representation of the Hoping Network

The interactive nature of the hoping network can be represented in a number of ways, using a metaphorical approach. This network will be illustrated using two metaphors, the metaphor of a game and the metaphor of a constellation.

Metaphor of a Game

Some of the participants saw their illness or life experiences as a game.

> That would probably help the game [having active treatment with chemotherapy]. So you have to sort of sit that spell out.

> Hope is to get to that point, to kick that field goal that wins the game.

> it [the insulin reactions] is part of the whole game.

It is interesting to note that some individuals saw themselves as always being on the defense, always "pushing," struggling or fighting.

> But before [in the past, prior to stabilization of the blood pressure] you're pushing and.....truthfully, too much medication, I don't go for that. And you just, it has some effect on you, you know. But it wasn't bringing down the blood pressure and I was saying, well, 'Jesus, am I one of those cases where you know, nothing can be done?' That's the way I'd feel.......Another thing that always alerted me was the fact, you know, that they always called it the silent killer.....I'm quite concerned about it and like now, with this machine [blood pressure monitor] and I take it and say well, everything's fine you know. [But] I'm always on the defensive.

> I am at it all the time [trying to regulate blood sugars]. It is a constant battle.

> [Regarding changes in financial and social status related to the illness] ....This discrimination and I've taken it a step, too, down in society. That's all there is to it. I'm basically fighting every day.

> I am going to continue as long and as hard as I can to fight every ounce of this.

The conceptualization of the hoping network as a football game is illustrated in Figure 7, using the contexts of the self, relationships, medicines, problems and environment. If one thinks of the game of football, then there are two teams, an offense, a defense, goals or points and plays of the game. In the game of life, the hoping self and the hoping resources could be viewed as being on one team, the hoping inhibitors on the other team and the hoping objects as the point or goals which are scored. Either team may be on hoping self, in one of its roles as internal evaluator, could be compared to a linesman or referee, determining whether or not the team is getting closer or further away from the goal. The hierarchy of hoping objects could be envisioned as the progression from scoring a field goal or a touchdown within a game to winning a game within the regular season; then, ultimately, to winning the Grey Cup.

Metaphor of a Constellation

An alternate view, proposed by the investigator, is that of the hoping constellation. The hoping self is at the core of this conceptualization and the hoping resources are attached to this core, to form a unique, three-dimensional configuration. Each component on this configuration is interconnected, reinforcing the importance of the theme "working together" and the "confidence-connection." This configuration is constantly rotating upon itself, and moving in the direction of selected hoping objects. The hoping inhibitors are circling around this hoping configuration. These inhibitors obstruct or interfere with the pathway of the configuration. The conceptualization of the hoping network as a constellation is illustrated in Figure 8, within the contexts of the self, relationships, medicines, problems and the environment.

Figure 7

The Conceptualization of the Hoping Network as a Game

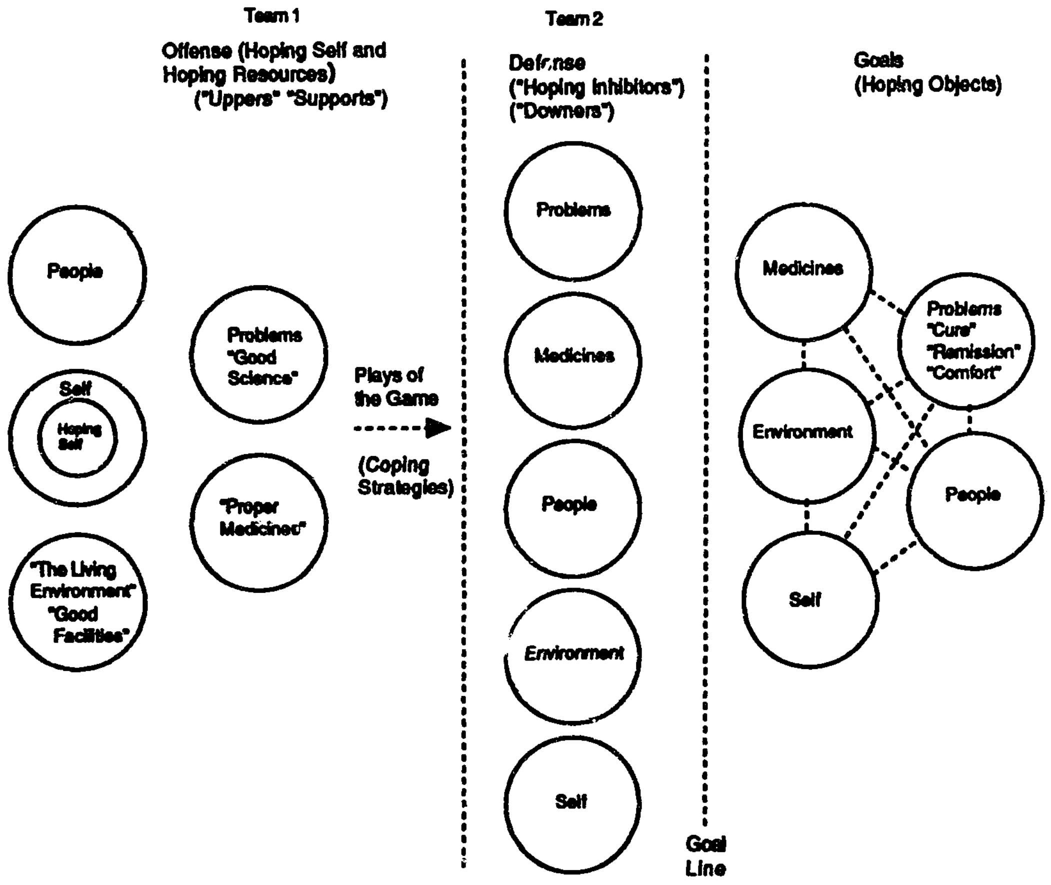
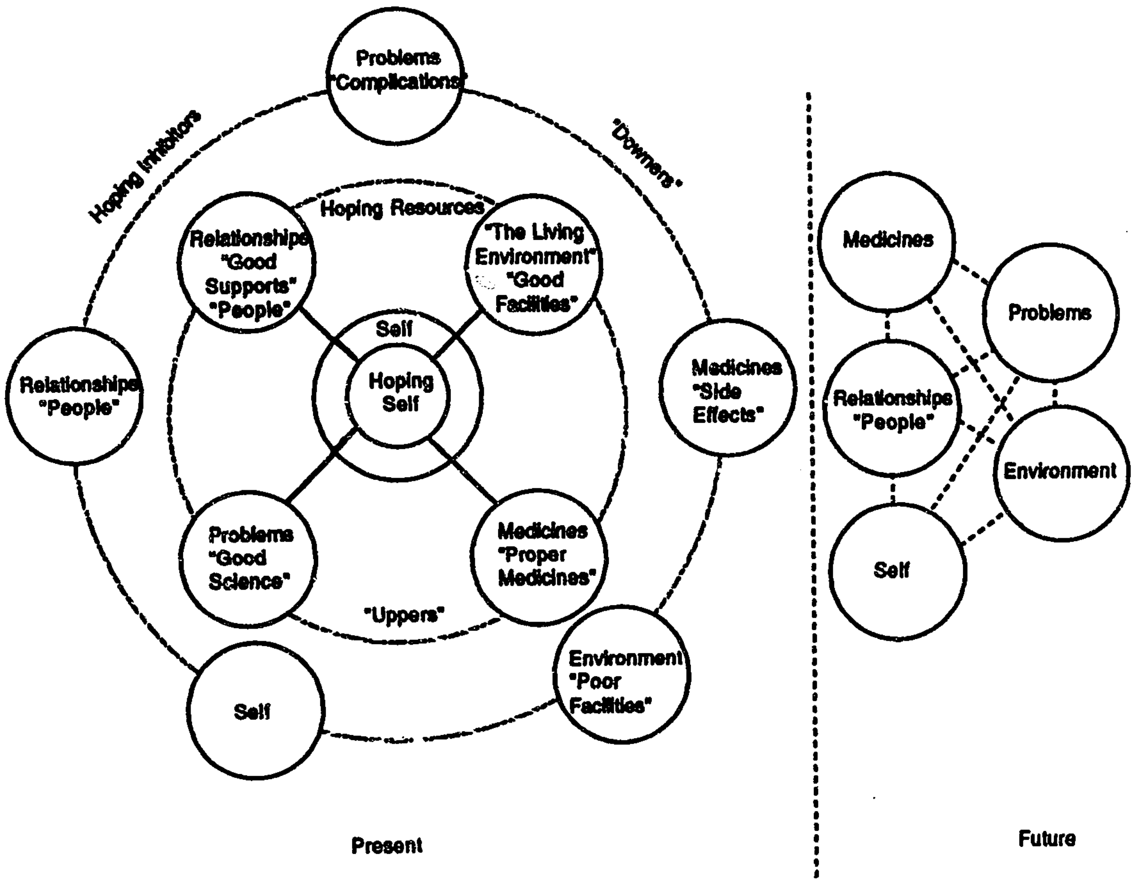


Figure 8

The Representation of the Hoping Network as a Constellation



A. Overview

As mentioned in Chapter IV, two processes emerged during the data analysis, a hoping process, "maintaining the hoping self," and a coping process, "learning to live with uncertainty." They can be viewed as two separate, concurrent processes which interact.

These two processes are interconnected through the underlying theme or intervening variable of uncertainty. The hoping process can be viewed as a means for bringing some certainty into one's life. The coping process can be viewed as a complex process of learning to live with uncertainty. Thus, the hoping process plays a fundamental role within the complex framework of coping.

Within the coping process, there is an emphasis on the development of specific strategies to deal with the illness process, for example symptom control. The hoping process is there to maintain hope, while the individual experiments with different coping strategies. As one participant stated, "hope keeps a person going......although he has a detrimental condition."

> Really hope to me is the coping process. It translates in the coping process.....The reason I cope easier is because I have hope. Now that hope doesn't mean that the disease is going to go away. But the hope means that, okay, if the disease is going to kill me in 5 to 10 years, I will live them with comfort. In other words, hope to me does not deny facts. It's not denying a fact. It is rather helping me to cope with the fact......But with all the disease factors, my hope is that within the fact of that disease, I don't want to be a burden. I don't want to be depressed......I want to be as comfortable as can be. That's the way I really mean, when I say I'm hopeful.

> I guess hope is the art of living to me......without hope, there is no hope.......Hope is just to keep on going.

"hope for being able to cope until the end."

> It's a mathematical game to me. If I'm not gonna live 10 years, I'm gonna live five. What can I do? I always worry about - I just want not to become a burden. Not to become really disabled and still living. This is the only thing that when I meditate by myself, I say God, just, I have enough. I don't want this too, to become ill to the extent of becoming a burden on somebody. To my family. Not that that works on my mind all the time, but when I sit back and think what do I want. What do I hope for now, is I tell myself, that I just go on like this, accepting all that. I don't want something more serious to happen, so that, you know, it would affect my family and so on........See, to me, hope is hope for what. So as I said, to me, I define hope as hope for being able to cope until the end which is suppose to happen. So rating hope that way, that hope to be able to cope without becoming a burden is 70 percent, 7 on your scale [hope scale ranging from 0, no hope, to 10, a great deal of hope].

The hoping and coping processes were developed using three of Glaser's (1978) coding families, the "six C's," "process" and "strategies." Within the six C's family, four of the theoretical codes were used, specifically conditions, contexts, contingencies and consequences. These two processes will be described in terms of these three coding families.

Using Glaser's (1978) theoretical codes, it is possible to demonstrate the similarities and differences between the hoping and coping processes. These two processes are similar in that they share common conditions, contexts and contingencies, which can be described within the framework of uncertainty. Although they share common conditions, contexts and contingencies, the major difference between these two processes is related to contrasting consequences. The consequences, within each process, may be described in three ways: impact on the self, impact on the hoping network and strategies. These consequences exist concurrently. Thus, rather than assuming a causal relationship, which

This chapter has been subdivided into three separate sections, the nature of uncertainty, the phases of the hoping process and the phases of the coping process. Within the first section, the common contexts, conditions and contingencies of the two processes will be discussed under the nature of uncertainty. The next two sections will highlight the phases of the hoping and coping processes, with primary emphasis on consequences. Any additional contexts, conditions and contingencies which are specific to the given process will be included within the respective section. A table, summarizing the phases of each process, will be included within each section.

B. The Nature of Uncertainty

The concept of uncertainty can be described within four coding categories, that is, degrees, contexts, conditions and contingencies. These categories have been adopted from two of Glaser's (1978) theoretical coding families, the "six C's" and the "degree" family.

Degrees of Uncertainty

Uncertainty can be viewed on a continuum, ranging from minimal or no uncertainty to a great deal of uncertainty. The perception of the degree of uncertainty, within a given situation, is highly individualistic. This perception can be influenced by a variety of factors, which will be discussed under contexts, conditions and contingencies.

Contexts

Similar to the components of the hoping process, uncertainty can be described within five contexts: problems, environment, relationships ("people"), self and medicines. The conditions and contingencies of uncertainty will be discussed within these contexts.

participants. They can be primarily categorized within three contexts: problems, relationships and the environment.

Within the context of problems, the conditions related to the illness, itself, included undiagnosed symptoms, unpredictable course, uncontrollable symptoms and the discovery of complications. For some participants, the uncertainty began prior to the diagnosis with the onset of unexplained symptoms.

> And until they [the migraines] were properly diagnosed and I got support from the doctors and a clear understanding of what was going on, it was quite difficult.

For others, the initial diagnosis was not a concern. Rather the uncertainty developed when the illness followed an unpredictable course.

> I just seemed to be going up and down and up and down [with my blood sugars]. And I got so frustrated, I said, 'Why bother?' Or I would follow my diet perfectly and I would have blood sugars of 20 or more. And I go, 'Well, what am I doing wrong?'........I think I got angry that it wouldn't work. The frustration and anger kind of went hand in hand, you know. If I am going to have this disease.....it better follow something so I can take care of it. It had better follow a pattern.

The difficulty in controlling symptoms could also increase the uncertainty of the situation. This might include the ineffectiveness of treatment, including medications.

> You'd go down or phone the.....doctor's office. Nurse there would take it [the blood pressure] and gee, it's up again. You know, maybe increase the medication but it's still up. How long am I gonna last?

> That's the time [the adjustment period for the dialysis] when I thought I may not - that the dialysis may not work.

Conditions, which are indirectly related to the illness experience, may be described within other contexts. For example, a change or loss in relationships may result in some degree of uncertainty. Within the environmental context, uncertainty may be associated with changes or losses in employment, social or financial status. The concern regarding financial problems is reflected in one of the participant's comments.

> How would you like to be broke, flat and in my health?.....I don't know how you could do it. You must be worrying all the time. What is going to happen to [my wife]? Where is she going to get.... Who's going to make the payments when you go? Anything like that.

Contingencies

The contingencies associated with each of the five contexts include the following: (1) problems: the rate of onset, duration and intensity; with respect to medical problems, the nature or profile of the problem; (2) environment: the degree of change in one's normal routine; (3) relationships: the perceived uncertainty of others; (4) self: one's previous experience with and level of tolerance for uncertainty; and (5) medicines: the degree of effectiveness. The following is a summary of the conditions of uncertainty, described within each of the five contexts.

Problems

The rate of onset, progression and intensity of the illness. The rate of onset, intensity and progression of the illness may contribute to the uncertainty of the

From the data, it appeared that the degree of perceived uncertainty could be directly related to the rate of onset of a particular situation, that is, the more sudden the onset, the greater the perceived uncertainty. For some participants, a sudden onset was associated with a great deal of uncertainty.

> My first disease, as you were asking, is polymyalgia rheumatica which comes on instantly. It hit me on July 4th, at 7:30 in the morning with massive body pain. It is a disease where my own immune system is attacking my muscle system. There is no known cause or no known cure......no warning whatsoever........I didn't know what was happening. I just didn't know, the pain was so excruciating.

This could be compounded by the rapid progression of complications, which intensify the uncertainty. For example, one of the participants developed four different illnesses over a three-year time period.

> One day I will wake up and it [the polymyalgia rheumatica] won't be there, that part of it. But I don't know what is going to happen to all of the other ones that came as a result of it - the osteoporosis, the rheumatoid arthritis and now the Hodgkin's Disease, which of course is large cell lymphoma cancer, which I am living with now.

For others, the uncertainty was not as prominent if the onset and progression of the illness or complications were gradual.

> In my case, I think things came gradually, step by step, and I had enough time to absorb being a diabetic. And it didn't affect me that much. Then I became hypertensive and that didn't affect me that much.

lower the degree of uncertainty. Some participants did not initially view their illness as being serious, partly because their symptoms were minimal.

> When it [the diabetes] started it wasn't that serious.....it was not serious, made to me serious, when it was first diagnosed......Until now all the disease I had to me was problem that has to be coped with. But it did not really show that this problem was serious. That if you slack a little bit it could be dangerous later on.

> And I took it [the diagnosis of hypertension] really lightly. I wasn't that scared at first. Then years later, you start getting more exposed to the media and telling you what it's really all about. And saw a few cases of your own that they had a stroke. And the thing is anytime you hear about somebody having a stroke, did he have high blood pressure? You always want to combine them......As you get older there's more concern I mean. Concern. Let's not joke around with it. This is serious.

For others, the seriousness of the illness was manifested in the severity of symptoms.

> And it took two weeks to diagnose it [sudden onset of massive pain] and that is two weeks without one minute's sleep because it is just massive pain.

Profile of or stigma attached to the illness. The profile or stigma of the illness may affect the degree of uncertainty. For example, some illnesses, such as cancer, have a high degree of fear associated with them, which may add to the uncertainty of the situation.

> So many people when you're dealing with cancer - I don't know what other diseases, but when you're dealing with cancer - the first thing when they hear the word cancer, they throw their arms up in the air. It should be renamed. It should have a different

> should be renamed. Should find a family name for it

> Two things are the worst part of medicine - one is worry that you have accommodated your family, if you are a man, and the other is the word cancer. Even you don't say it. Everybody is afraid to say cancer. I haven't got leprosy, I have got cancer. But they will avoid you. They will go on the other side of the street. They will go around you because - not that they don't love you - they are just petrified of that word cancer and they shouldn't be, but they are.

Other illnesses may contribute to the uncertainty of the situation due to their low profile and the lack of public awareness and knowledge regarding the illness process. This is reflected in the comments of two of the participants.

> There needs to be more recognition of this [migraines] as being an illness or condition. There needs to be more information given out to people.

> I kept ending up in the emergency ward. What am I doing here again?....Between that and my parents confronting him [my physician], a combination of the two, he says you got epilepsy.......If somebody walks up to you and says you got epilepsy. What is it?.....What is it? Is it like leprosy? Am I gonna fall apart or what?

> I just wish that doctors themselves were more clued in so they could themselves help this association [support group] educate the public. I mean they've got the pamphlets in their office, but that's not enough. I mean if somebody has a head injury or a cut or whatever, they should be told the possible effects. That's a major concern now a days. Now it is. Now it's a major concern.

versus global changes, may influence the uncertainty of a situation, that is, the greater the change in one's normal routine, the greater the perceived uncertainty. Some participants were able to integrate their illness into their normal routine with little if any adjustments.

> And I lived with it [the diabetes and the hypertension]. It's just a part of my, an extra part of my routine.....I didn't even have to sacrifice that much the lifestyle, in terms of eating out, going out for example with my wife. And measuring the food. I would measure the food at the beginning, but then I would estimate after that....As close as possible to accurate compliance, but without again sacrificing too much of the lifestyle........In fact, it [the diabetes] was diagnosed and then I had to go away to do my research for my master [degree]. And that was in the desert.......I was in the field for nine months and it didn't even bother me. I was taking my pill.

One participant described her life as being more complicated and requiring some advance planning.

> It [the diabetes] means there are certain limitations, in that....when I have to travel, we have to stop. I have to eat....you have to plan ahead......and so it makes life a little more complicated in that I have to make sure that I remember this, when I go somewhere, I got to have that insulin, I got to have my medication and I have to remember this.

For another participant, the illness resulted in "massive" changes within the individual's life, over and above the medical concerns.

> I did not like to quit work. I am a workaholic. I have always been a workaholic and I'll continue to be a workaholic......I've had a very massive change. I had a very high profile. I was general manager of the largest [business organization] in Canada. I was in the media every day and television most weeks and most everybody in the community knew me. My salary was excellent, if I might say so,

> Not until it hit the joints. Then I had to retire. I could work up until that point, because I could stand the pain. But I couldn't stand the pain when both of it hit [the osteoporosis and Hodgkin's lymphoma]. And then the osteoporosis, I couldn't even have a shirt......the shirt couldn't even touch my ribs.

Another participant described the disruption in her life during a migraine attack.

> Well, when they [the migraines] were at their worst, I was in bed for 24 hours. And leading up to that I wouldn't be feeling that well.......Then it would take me about three days to recover.

Relationships

The level of uncertainty which is experienced by the individual may be affected by other individuals who are also experiencing uncertainty. This is especially true if these individuals are perceived as being dependable or knowledgeable; or being in positions where they "should have known."

> I didn't know what was happening [experience of massive body pain, prior to diagnosis of polymyalgia rheumatica]. I just didn't know, the pain was so excruciating and I couldn't lay to take the x-rays because the pain was so vicious. I almost had to tie myself down for everything. Then I didn't know what was happening and the more they [the medical people] didn't know of course, the more it made me worry what the heck was going on.

> I went to the Mayo Clinic twice.......They went through everything they could possibly do to help me and there is no cure for this thing [Hodgkin's Lymphoma]. Of course, they didn't know I had cancer [at that time], which they should have known. Two days later [after I had returned from the clinic] I found the cancer.

> They call it essential hypertension. That's what the doctor's term is.......[There is] no cause. And truthfully, they [the medical people] don't know what the heck is causing mine.

The influence of relationships will be discussed further in Phase I of the hoping process, under the topic of reduction in hoping resources.

Self

Previous experience with uncertainty. The level of perceived uncertainty may be related to one's past experiences with uncertainty. For some participants, they had never before experienced a situation which was so disruptive and uncertain.

> I had never been sick a day in my life - from digging coal mines, to swinging sledge hammers - I had never been sick a day in my life......What the hell's happening here? Tomorrow, well, it'll be over tomorrow. But it wasn't over tomorrow or the next tomorrow's.....I didn't know what was happening to me. I was wrapping my arms and strapping my legs and hammering them and kicking them and slapping them with boards and - because I didn't know what was happening to me because they were just hurting so bad.

In contrast, for one of the participants, who had had a number of previous experiences with uncertainty, the illness was viewed as another "challenge."

> [The illness was] another challenge.....it's a block that blocked my wheel, was another challenge. Can I cope with it, can I go on or will I give up?

personality factors such as patience and perseverance.

> And it was hanging up and not knowing. Not knowing is the rough thing to go through. The knowing isn't near as bad as the guessing.......[The "not knowing"] affected my patience......I just said, 'Hey, let's find out now what it is and get after it, instead of sitting here another two months and not knowing.'

Some individuals may have a strong need to know or to be shown. This is reflected in one of the participants' comments.

> I had to prove why I was choking on it [the medication].....That's what life is with me, I got to prove everything. Just don't take my word. I got to prove to you why I can't take it.

Medicines

The degree of effectiveness of medicines or treatment can influence uncertainty. A lack of effect may be associated with a higher degree of uncertainty.

> They [the medications] weren't working. And I'd get panicked and I'd say, 'What's the matter with me?' And I think probably that alone would make me feel all riled up.

> It was very difficult until I got them [migraines] diagnosed. And I didn't know what was wrong with me. I would take headache pills and they weren't doing any good and the headaches got worse and worse.

The hoping process is a dynamic, interactive process, which helps bring some certainty into one's life. Its dynamic, interactive nature is reflected in changes in the hoping self and other components of the hoping network which occur over time. This process is best described as a process of maintaining the hoping self.

The origins of the hoping process, and specifically of the hoping self, are difficult to ascertain. Some of the participants speculated that their hope may have originated in their youth, although they themselves weren't sure exactly when it all started.

> You were asking me where I got hope from......I don't know. I've just always been that way.......I have always been quite hopeful.

> I don't know how I do that [being aware of my limitations].......I've tried to work hard but to reach that limitation, not go beyond.....Now, how I became like that, I don't recall. Maybe as a child there was influence on me that way. If that happens through childhood, then there must have been influences on me - my dad, people surrounding me or something in my culture. But I can't put my hand on this.

Although the origins of the hoping self remained obscure, the dynamics of the hoping self and other components of the hoping network became apparent within the context of the chronic illness experience. Thus, the hoping process will be viewed within this framework.

The process of maintaining the hoping self during a chronic illness consists of three phases: (1) assessing hope and the hoping self; (2) strengthening the hoping self; and (3) maintaining the hoping self. A summary of these three phases, outlining the contexts, conditions, contingencies and covarying consequences is presented in Table 5.

Table 5

The Hoping Process: Maintaining the Hoping Self

Phase I: Assessing hope ("Is there any hope?")

Conditions	Contexts/Contingencies	Covarying Consequences
Problems Undiagnosed symptoms Unpredictable course Uncontrollable symptoms Discovery of complications	**Self** Past experiences with hope and uncertainty Tolerance for uncertainty Perspective on hope	**Impact on the hoping self** Depletion of hoping self for those w view hope on a continuum; maintena of a general sense of hope for those who view hope in general and specif terms
Relationships Change in or loss of relationships	**Relationships** Influence of others Degree of change in relationships	**Impact on other parts of the hoping network** Increase in hoping inhibitors Reduction in hoping resources Development of generalized hoping objects or loss of previous hoping objects
Environment Change in or loss of employment, social and/or financial status	**Environment** Degree of change in routine	
	Problems Rate of onset, intensity and progression Profile of the illness	
	Medicines Effectiveness of treatment	

Phase II: Strengthening the Hoping Self ("High Hopes" "Enhancing Hope")

Conditions	Contexts/Contingencies	Covarying Consequences
Problems Undiagnosed symptoms Unpredictable course Uncontrollable symptoms Discovery of complications **Relationships** Change in or loss of relationships **Environment** Change in or loss of employment, social and/or financial status	**Self** Reaction to the uncertainty (i.e. ranging from rejection to acceptance) Tolerance for uncertainty **Relationships** Degree of trust and confidence in others **Environment** **Problems** Duration of the conditions **Medicines** Length of trial period	**Impact on the Hoping Self** A drive to strengthen the hoping sel **Impact on Other Parts of the Hoping Network** Enhancement of hoping resources Minimization of hoping threats Redefinition of hoping objects with greater specificity or adoption of previous hoping objects **Strategies** **(1) To develop hoping resour** relationship building (working toge building trust); learning about the illness **(2) To strengthen and protect hoping self:** comparison with oth drawing upon past experiences; introspection; self-discovery and education; helping others **(3) To minimize hoping inhibitors:** maintaining a positive attitude, staying away from downer

Phase III: Maintaining the Hoping Self ("Keeping the L-E-S-S out of Hope")

Conditions	Contexts/Contingencies	Covarying Consequences
Problems Undiagnosed symptoms Unpredictable course Uncontrollable symptoms Discovery of complications **Relationships** Change in or loss of relationships **Environment** Change in or loss of employment, social and/or financial status	**Self** Awareness and acceptance of limitations Greater tolerance for or acceptance of uncertainty Perspective on hope Past experiences with hoping	**Impact on the Hoping Self** Strengthening the hoping self Shift within the belief system (eg. change in view of life, finding new meaning or purpose; redefinition of problem) **Impact on Other Parts of the Hoping Network** Enhancement of hoping resources Acceptance of some hoping inhibit Redefinition of hoping objects in te of uncertainty **Strategies** Further development of strategies t strengthen the hoping self and resources Development of strategies to tolerat accept certain hoping inhibitors

Contingencies

Two additional contingencies which were not discussed under the nature of uncertainty include one's perspective of hope and one's past experiences with hope. Hope can be viewed from two perspectives: (1) on a continuum, ranging from minimal or no hope to a great deal of hope; and (2) within general and specific spheres (Dufault, 1981). The view of hope being on a continuum is illustrated in this example.

> If it came to a point where I couldn't do it [being confined to a bed and having nothing left to try], I think I would give up hope.

For those individuals who view hope within general and specific spheres, there is a general sense of hope, even during times of great uncertainty.

> There must be something. Because there always is something that can help, I think, in any condition.

> Hope. I don't think it ["not knowing," the time period during which the diagnosis of bone metastases was suspected but not confirmed] affected my hope. It just, I don't know how to put it. See, I've never been of the opinion that I wasn't gonna get better no matter what came. So you couldn't say it affected your hope.

Regarding one's past experiences with hoping, the reaction to a given situation may be dependent upon two factors: (1) the individual's reactions to similar situations in the past and (2) life experiences.

> I had never been sick a day in my life.

> relationship between hope and] Enlightenment. You don't have to have schools for that. Very smart people who have no education, but they being smart, would correlate with whatever perception of hope they have or meaning of hope they have. I'm sure life experiences would also correlate with the degree of hopeness and what hope means. Someone who has never been sick before may react very violently to a chronic disease.

Consequences

The uncertainty of a situation may result in a number of shifts within the hoping network. There may be an impact on the hoping self, a shift in hoping objects, a reduction in hoping resources and an increase in hoping inhibitors. It is difficult to predict whether or not a shift in one component causes a subsequent shift in another. Thus, these changes are presented as covarying consequences.

Impact on the hoping self. The impact of the uncertainty of a situation upon the hoping self is dependent upon one's hope perspective. For those who view hope on a continuum, their hoping may be inversely related to their level of uncertainty. For example, during times of great uncertainty, they may have a very small hoping self. They may be unable to think about hope or they may see themselves as having little hope.

> I'm sure that the first month and a half, when I was on dialysis, there were moments when I started thinking how much hope I have. But then that whole period of a month or a month and a half, I don't think I was in my normal thinking process at all.....It was very difficult. I wasn't thinking about anything. I was just barely trying to make it.

> Q. How might you have rated yourself [with respect to hope] when you were first diagnosed with the polymyalgia rheumatica?
>
> A. You know, I couldn't even put a number on it because I was really floundering. I didn't know - I had never been sick a day in my life, you know - from digging coal in the coal mines, to swinging

> Q. What role do you think hope plays in your life?
>
> A.......Not much for myself. Well see, they can't operate. Basically what I've got is scar tissue which is the main concern......It's just an accumulation of these various accidents that have caused mine. So they can't operate on me. It won't do any good. Cause if they do it's just gonna leave more scar tissue......And so I myself am just looking forward to taking my medication.

These individuals may feel that their hopes are inhibited by the uncertainty of the situation and they may be more easily influenced externally by hoping resources and inhibitors.

> And I find that so many people with migraine headaches expect a doctor to do everything. And then if he doesn't do it, then they feel hopeless or very disappointed in him or they think they've reached the end of the line.

> Then I didn't know what was happening and the more they [the medical people] didn't know, of course, the more it made me worry what the heck is going on.

For those who view hope in terms of two spheres, general and specific, the hoping self is less dependent upon or influenced by external sources, such as uncertainty, hoping resources and hoping inhibitors. It may exist in isolation, with few or no hoping resources. However, it continues to retain a general sense of hope, "even at the lowest times" in life or "even when you're hurting." This is reflected in the comments of two of the participants.

> I'm very optimistic and even at the lowest point in my life, I feel optimistic. There is something.

> I've never felt where I was never gonna get well. I've always felt okay there's hope that I'm going to get well. Break an arm, maybe it doesn't heal quite as strong as it was before it was broken, but it's gonna heal so you can work it. And that's the way I look at things. If this is going to heal, so I'm going to work this leg, I'm going to be able to walk.

Impact on the hoping objects. For those who view hope in general and specific terms, there is an apparent shift in the hoping objects. During times of great uncertainty, the hoping self tends not to generate specific hopes, but is most likely to retain general hopes. Previous hoping objects may no longer be realistic or may be threatened. They may be redefined in very general terms, for example, just wanting to get well. This is similar to Dufault's (1981) concept of generalized hope.

> I think the only thing a person hopes for when they aren't well is to get well. That's the only thing. It's the same as if you're hungry, you hope to eat. When you're sick, you hope to get well. But as far as high hopes and building castles in the air, no. Life becomes much more realistic. These things are no longer important. You know, the fight for the dollar, the, who's got who thing or whatever's going on. It loses its importance and the things of feeling well, being happy become prime things.

Although there may be some degree of threat to their hopes, the hope is still greater than the threat.

> Q. Is there anything that's threatening your hope at this time?
>
> A......I don't say threatening cause the hope is more than the threat, but like, at this time, I can't have active treatment at the moment. So may be that will come up later. I don't know. I would be glad if it got to a point where I could.......So you have to sort if sit that spell out, if you know what I mean. But as far as permanent threat, no.

be related, in part, to the hoping resources' own internal struggles with the uncertainty of the situation. This particular quote refers the depletion of a hoping resource during a time of uncertainty (i.e. prior to the diagnosis of migraine).

> Also when initially as a child you had a flu, you went to the doctor, he told you to take aspirin, fluids, gave you an antibiotic if necessary and you got better. That was my experiences of a physician. This time I'd gone to the physician and he didn't fix me and he couldn't fix me. I was getting annoyed with him. And I thought he was hopeless you know. Why can't he fix this problem It's a simple problem. It's not - like I don't have cancer or something. It seemed to me - my experience of this was that it was a headache and surely to goodness you could fix a headache. So I was frustrated and angry as well.

Increase in hoping inhibitors. Hoping inhibitors may increase during times of uncertainty.

> What threatened my hope. Okay. Not having the support of a doctor as well, feeling alone, isolated and having the support of a doctor. And being condescended to by a doctor was really hard......I did at some time in my life not look on a physician as an equal, which I do now, but as an authority figure.

Major inhibitors such as permanent threats may be more prominent and may have a greater probability of occurrence.

"asking for help" or "willingness to risk."

> And you, like I say, well you got to turn things around.

Efforts by individuals other than the hoping self, for example, the discovery of a diagnosis by the medical profession, may also serve as a turning point.

Phase II: Strengthening the Hoping Self

("High Hopes" "Enhancing Hope")

Contingencies

In addition to the contingencies described under the nature of uncertainty, a number of other contingencies can be cited within specific contexts. Within the context of self, the hoping process may be affected by the individual's reaction to the uncertainty, which may range from rejection to acceptance. With respect to relationships, the degree of trust and confidence in others is an important factor in strengthening the hoping self. The duration of the uncertainty, within the context of problems, may also be an important issue. Finally, within the context of medicines, the length of the trial period, may impact upon the hoping process.

> Now if the doctor says you take this medication, I'll say okay, how long must I take it. Well, if they said, as long as you live, fine, if it is going to help me, I'll keep on taking this medication or I'll probably approach the doctor a year down the road and say, look like particularly this Gold, it is not helping me, is there any thing else?.......But I do like to know what is in it and what is the side effect. And if they say, well you know, you've got to take it for three years before you won't get any results, well, I'll take it for

Impact on the hoping self. For individuals, who see hope on a continuum, the size of the hoping self will increase as the level of uncertainty decreases. Others, who view hope in both general and specific terms, retain their general sense of hope, but give rise to a greater specificity of hope (i.e. development of particular hope objects).

Impact on hoping objects. Hoping objects, with a greater specificity than in phase I, are developed. Previous objects may be reinstated, as there may be a desire to return to the way things used to be. Hoping objects may be directed towards the future with an emphasis on simplicity or returning to a normal routine.

> Q. So what would you be hoping for [neck pain as a result of a car accident, followed by diagnosis of cancer of the uterus and cervix]?
>
> A. Relief of pain, so I could get back and live normally. I was given instructions not to raise my arms or my shoulders. Not to bend down. Don't do this. Don't do that. Dress down in button-down clothing. Little things that you normally wouldn't even notice......So, consequently, yes, I was looking for the time when I could get rid of these things. Just go for an afternoon tea or something without being in trouble.

> Q. At the time you were diagnosed initially with the polymyalgia rheumatica, what was your outlook for the future?
>
> A. Well, just to get rid of it and get on with my life. I continued to work under those terrible circumstances and I worked until I was forced to retire in 1988 in April. But it was very, very difficult to work under those circumstances, but I did.

> Q. During that time when things were "out of whack" even though you were trying to keep on track, what were you hoping for at that time?

> A. I think I just wanted not to have high blood sugars because I knew mine had been high forever and years. For years and years, I had high blood sugar. And I realized that the goal for diabetics is to have as close to normal blood sugars as possible. So if I am going to eat properly, I want my blood sugars to be in line with that. And when they weren't well, I just didn't know what to do.

Impact on hoping resources and inhibitors. Within this phase, there is a gradual shift within the hoping network between hoping resources and inhibitors. Hoping resources increase while inhibitors decrease. This is due, in part, to the strategies which are implemented within this phase.

Strategies. Within this phase, an attempt is made to develop or build upon hoping resources and to minimize hoping inhibitors. The strategies which are selected may also be dependent upon the relative weightings between the hoping inhibitor and the hoping object. As one participant described it, "the hope is more than the threat."

> I don't say threatening cause the hope is more than the threat, but like, at this time, I can't have active treatment at the moment . So maybe that will come up later, I don't know. I would be glad if it got to a point where I could.......that would probably help the game. So you have to sort of sit that spell out, if you know what I mean. But as far as permanent threat, no. I think we gotta go one step at a time.

A number of strategies may be implemented to assist in the hoping process, by bringing some certainty into one's life, without totally eliminating the uncertainty. These include strategies to develop hoping resources, to strengthen the hoping self and to minimize hoping inhibitors.

(1) Strategies to develop hoping resources. Attempts are made to access and/or develop specific hoping resources. Previous hoping resources may be relinquished and new ones developed. Strategies which may be helpful include learning about the illness and relationship building.

(a) Learning about the illness. The individual may try to learn about the illness through a variety of methods such as learning through observation; practical experience, for example, as in a diabetic teaching program; and reading and sharing information with others, for example within a support group. Some specific strategies for learning about the illness are described in two of the participants' comments.

> I read a lot in the area of mind over matter. I read everything that I can find on Japanese experiments, and cancer cures and everything that I can.....So I read everything in that field that I can find.

> The fourth thing was I had to read a lot and I had to join a [support] group in [a province]. I watched documentaries on TV.

> It's been very important to me to encourage me [reading about or understanding the illness]. And to feel that - I hate to feel that anybody, everybody else has control of me.......And to be honest, I feel that I'm more well informed than many doctors about my condition. And I just feel better about myself doing that.

(b) Relationship building (identification of qualities in others which are also found in self)

> And I really think finding a good doctor also is a major part of dealing with your disease, because I know that.....not many people are lucky to have doctors who are like that [accepting a "two-way process" in the relationship].

I had an indomitable spirit that I wanted to know what was going on and why couldn't I get better. And I kept struggling to find a good physician and I did. I found people who could support and help me and I found my family. All of those were missing and I had to find them.

And it was, I think, realizing - going into a support group and seeing that there were people from all walks of life who had this problem and you weren't alone. That's a very important thing......and that's where I say the support group comes in because you meet other normal people. You think you're abnormal. You think you're alone. Both of these are immediately quashed when you join a support group......One of the problems that we find in the support group is people not being satisfied with what's happening with their doctor. And when they do find a good physician that they can talk to it really lifts their spirits. It makes such a difference.

(2) Strategies to strengthen (enhance) and protect the hoping self.

These strategies include the following:

(a) **comparison of self with others,** for example, observing others who are hopeful or not hopeful;

(b) **drawing upon past experiences** and applying these experiences to the current situation;

(c) **introspection,** self-awareness;

(d) **self-discovery and education;**

I did it [finding support, reading about the illness] all really myself. I found everything myself.

(e) **helping others,** serving as a hoping resource for others.

I try and keep active. I am on three or four boards. I raised a half a million dollars for a school of business. I raised $20,000 for research into polymyalgia rheumatica right here. We just presented the cancer [hospital] and my doctor $4,000 to buy a new machine

> the cancer hospital] with televisions, Nintendo's and all of those games, so the kids could play while they are taking their chemo. Because it broke my heart, every time I was in there. The little kids broke my heart....So now I was there the other day and they are puking and singing but they are not screaming because they are playing that Nintendo game - so even five minutes does my heart good.

(3) Strategies to minimize hoping inhibitors ("Staying away from downers"). Any strategies which would reduce hoping inhibitors and thereby lower uncertainty, are implemented. Some examples include maintaining a positive attitude and avoiding people who "bring you down."

> Another thing too, you stay away from downers, people who are down in the mouth for no reason. Cut them off. Even if it means dissolving a friendship. Don't hang around people that bring you down. Be around people who give you a boost if anything. You're better off to come in here and have a laugh with somebody that you don't know as well, as to have a friend come in and sit and cry the blues. A good laugh is a lot better for you.

Phase III: Maintaining the Hoping Self
("Hoping as a way of life")
("Keeping the 'L-E-S-S' out of hope")

Conditions

The progressive and unpredictable nature of the illness continues. For some, a period of stabilization or a plateau may have been reached. For others, the uncertainty of the illness persists, but there is a greater acceptance of this situation.

Contingencies

Additional contingencies which must be considered in this phase can be described within the context of self. These include an awareness and acceptance of limitations; and a greater tolerance for or acceptance of uncertainty. One's perspective on hope and past experiences on hoping continues to be of importance.

Consequences

Impact on the hoping self. Within this phase, the hoping self is maintained and continues to flourish. The inner spirit of "not giving up" and "willingness to try" are maintained. There is a greater acceptance of one's limitations and a possible shift within one's belief system. The individual's view of life may change and take on new meaning. There may be a shift in values and priorities towards the enjoyment of simple pleasures and greater self-care. The individual's view of the illness may change with an emphasis on acceptance or tolerance. For example, there may be a change in view regarding finding a cure, as one participant stated, "You're never really gonna find a cure for epilepsy. Everybody's different. That's all there is to it."

Impact on hoping objects. A shift in hoping objects may occur. There is a process of "letting go" of old goals and resetting new goals which are more realistic.

> I decided to try them [non-medication forms of treatment] because I'm always looking. I used to always look for a 100% health. But I feel the balance has come into my life when I accepted 90% health or 85% health. And of some of the aggravation that I gave myself was looking for a 100% health. And you have to have a certain degree of acceptance I feel because at this present time, and I think so many of us in my support group feel the same way, that we can have a certain degree of health but we may not have 100%. As soon as you accept that you may not have a 100% then I think you're a bit more relaxed about it.

Hoping objects may be redefined in terms of some degree of uncertainty, for example, acceptance of 85% health; hope for 99.9% control; hope for survival, but not 100% health. There is an acceptance of some degree of uncertainty and a reluctance to make commitments too far in advance because "You never know."

> As far as medications are concerned, I believe that they will eventually find a drug or a derivative of a drug that will give them a 99.9% [control], you know you're safe if you're stable. You'd be all right for the rest of your life. But you can't be a hundred per cent cause you never know.

> A. I would probably rate myself way up near 8 or 9 [on a hope scale] - lots of hope. I don't think of the bad. I think there is always tomorrow and who knows what it will bring.
>
> Q. How about a year from now. Where might you place yourself on that scale?
>
> A. I don't know. A year from now is a year from now. How can one say? It is kind of up in the air. I don't think I will be that changed a person but you never know. Something could happen maybe not just to me but to someone else.

> At this point in time being in here [the hospital] if I didn't think that I had hope of getting better, not a 100%, but getting better, and getting better to a large extent, it would be very foolish for me to be here.......Like I say, not a 100% because as you get older you don't get better all the time. We're not wine and cheese. But better to an extent where you can at least enjoy life.

Impact on hoping resources and inhibitors. The uncertainty of the situation may continue to fluctuate and with it, so may the hoping inhibitors and resources. Some of the hoping resources may have also learned to tolerate the uncertainty of the situation and are more dependable during times of great uncertainty.

> And my children at one time were alarmed when I was in very severe pain. And I couldn't get out of bed and the doctor had to come and give me something in the house......But they have seen progress. They realize it's a condition that can be controlled......They're very understanding......And it's made my children very gentle and understanding of other people's illnesses, I think.

Not all hoping inhibitors can be minimized. The individual must learn to accept certain inhibitors, for example, the inevitability of renal failure.

Strategies. Strategies which strengthen the hoping self and encourage the development of hoping resources are maintained. Attempts to minimize hoping inhibitors continue, although there is a greater acceptance of the limitations of these strategies (i.e. not all hoping inhibitors can be eliminated).

Summary

The process of maintaining the hoping self is never-ending, requiring a lot of perseverance and faith. This comment by one of the participants captures the essence of the hoping process.

> The reason I'm here [in hospital] is I believe there's that - what should you say - rainbow out there. And if I take my medication, I do what I'm suppose to do, I try to get some exercise to get the muscles stronger in my legs and stuff again, and try to get some strength in my arms, or more strength so I can use the, so I can sit, and go through the process of sitting, standing, walking and that sort of thing - if I can go through that process and do that, and get well, which I think I will, fine. If I come in here with the idea, I've come in here to die, then why am I here? I come here with the idea of getting better, which I intend to do...........As I say, *you never give up that rainbow*. If you give up that then there's no point. You may as well stay home and take your pills or not take your pills at all, you know. The whole thing works together. You work at the whole thing together.

D. Phases of the Coping Process
("Learning to Live with Uncertainty")

The coping process has been described as a process of learning to live with uncertainty. The conceptualization of the chronic illness experience as a learning process is supported by some of the participants' comments.

> because I read. So from the first diagnosis of the first disease I would read about and the second one and so on......If every symptom that happens to me, I have to see the doctor, then I would have to see the doctor every day. But I've learned that these are simply the conditions of dialysis.....All of these things are just part and parcel of my condition.....and I don't jump to any conclusions until if they persist, if they become progressive......this is a situation that I would check with the doctor.

> But it's all a learning process. The self - the education process too - I had to self educate myself because there are good physicians out there. There are also very bad physicians who just, unfortunately I feel that women are often not taken seriously when they have headaches by some physicians.....A lot of people in my experience have had that type of a visit with a physician, where because they're a woman, because the majority of people in my group are women, have been patted on the head so to speak. Condescended to.

> I've learned to live with it [the hypertension].

The process of learning to live with uncertainty consists of three phases: (1) experiencing and assessing uncertainty; (2) reacting to the uncertainty (the transition or adjustment phase); and (3) mastering the life of uncertainty (learning to live with some degree of uncertainty; acceptance or tolerance phase).

The three phases are presented sequentially, in a linear fashion, implying a unidirectional movement from one phase to the next. However, the boundaries between Phases I and II are permeable, allowing for reciprocal movement between experiencing the uncertainty and reacting to it. The individual may oscillate between periods of uncertainty and periods of certainty. This is particularly true when a series of uncertain events develop over a short time period. Learning is occurring throughout the three phases of the coping process. The progression into Phase III, however, marks a significant shift in cognitive functioning. The phases of the coping process have been summarized in Table 6. The following is a review of these three phases.

Table 6

The Coping Process: Learning to Live with Uncertainty

Phase I: Experiencing and Assessing Uncertainty ("What's Happening?")

Conditions	Contexts/Contingencies	Covarying Consequences
Problems Undiagnosed symptoms Unpredictable course Uncontrollable symptoms Discovery of complications **Relationships** Change in or loss of relationships **Environment** Change in or loss of employment, social and/or financial status	**Self** Past experiences Tolerance for uncertainty Perspective on hope **Relationships** Influence of others Degree of change in relationships **Environment** Degree of change in routine **Problems** Rate of onset, intensity and progression Profile of the illness **Medicines** Effectiveness of treatment	**Impact on the self** Ranges from safety/connectedness to fear/isolation **Impact on the hoping network** Increase in hoping inhibitors Reduction in hoping resources Depletion of or minimal effect upon hoping self Development of generalized hoping objects or loss of previous hoping objects

Phase II: Reacting to the Uncertainty ("The Transition Period")

Conditions	Contexts/Contingencies	Covarying Consequences
Problems Undiagnosed symptoms Unpredictable course Uncontrollable symptoms Discovery of complications **Relationships** Change in or loss of relationships **Environment** Change in or loss of employment, social and/or financial status	**Self** Tolerance for uncertainty **Relationships** Degree of trust and confidence in others **Environment** **Problems** Duration of the conditions **Medicines** Length of trial period	**Impact on the Self** Ranges from resistance to change (rejection) to willingness to experiment (acceptance) **Impact on the Hoping Network** Strengthening of the hoping self Enhancement of hoping resources Minimization of hoping threats Redefinition of hoping objects with greater specificity or adoption of previous hoping objects **Strategies** Reduction of the uncertainty of the situation Enhancement of certainty in other aspects of one's life Protection of the self

Phase III: Mastering the Life of Uncertainty ("Coming to Terms")

Conditions	Contexts/Contingencies	Covarying Consequences
Problems Undiagnosed symptoms Unpredictable course Uncontrollable symptoms Discovery of complications **Relationships** Change in or loss of relationships **Environment** Change in or loss of employment, social and/or financial status	**Self** Awareness and acceptance of limitations Greater tolerance for or acceptance of uncertainty	**Impact on the Self** Redefinition of problem Shift within the belief system (eg. change in view of life, finding new meaning or purpose) **Impact on the Hoping Network** Further strengthening and maintenance of hoping self Enhancement of hoping resources Acceptance of some hoping inhibitors Redefinition of hoping objects in terms of uncertainty **Strategies** Less emphasis on minimizing uncertainty. Greater development of methods to tolerate the uncertainty and those hoping inhibitors which can't be changed Strategies to strengthen the hoping self and resources are developed further.

("What's Happening?" "The Turmoil Period" "Not Knowing")

The experience of uncertainty is highly individualistic. It is dependent upon the contexts, conditions and contingencies, which have been previously outlined under the nature of uncertainty. A specific event is assessed or appraised by the individual and placed along a continuum, ranging from minimal uncertainty to a great deal of uncertainty. This appraisal may also be viewed in terms of the degree of perceived threat, ranging from minimal threat to a great deal of threat.

Consequences

Impact on the self. The experience of uncertainty is based upon the individual's perception of the situation; and is reflected in the individual's initial feelings and reactions. These feelings and reactions may be placed on a continuum, ranging from confidence and connectedness to fear and isolation. This continuum corresponds with the continuums of uncertainty and perceived threat, as well as hoping inhibitors.

At one extreme of minimal uncertainty, the individual may feel relatively comfortable with the situation and accept it quite readily as a part of the whole process.

> I see that [my loss in organizational abilities] as a process that is going to happen and...if I can control it, I would have controlled it. In other words, I have to accept it. The fact that I am less organized, I must accept it.

At the other extreme of total uncertainty, there may be feelings of desperation. This may be related to a profound disruption in normal routine, in which the individual lacks a sense of direction and understanding of the situation. There may be a general feeling of being out of control.

> and strapping my legs and hammering them and kicking them and slapping them with boards and - because I didn't know what was happening to me because they were just hurting so bad......*Total uncertainty, total uncertainty*. Cancer I know all about. I often make a statement and I think it is a valid statement. I'm an Irish man. Irish men are not afraid of death. You give me something I can see and I can lick it. I could see cancer, I could feel it, I could push it, I could move it and I could lick it. But I can't see polymyalgia and I can't lick something I can't see. So now I am flying blind. I am running at every thing. Maybe this is it. Maybe it is endorphins, maybe this and I am running at everything.

> The first two months [of dialysis] I didn't think I would make it......I would get up and be very sore and somebody has to drive me, and go home and spend the four days between dialysis with severe back pain. That's how it affected me. The muscles in the back - he [the physician] gave me all kinds of muscle relaxants and so on, and at home I couldn't stand up. I was just lying on the couch and so on. It took about a month and a half, like that and then I got used to it. My body must have adapted to it.
>
> Q. What were you feelings during that time when you were adjusting to the dialysis?
>
> A. That's the time when I thought I may not - that the dialysis may not work.

Along this continuum, the individual may experience varying degrees of confusion, discomfort, isolation, depression and loss of control. This is supported by the comments of one of the participants.

> I guess I felt a sense of futility [prior to diagnosis of the illness] because nobody knew what the problem was and I felt that, I guess I felt that no one was giving me any help. That was what it was. I felt I was very much alone with this problem and nobody understood.

> I know that for some people, perhaps, and I know some people in our group, suicide is a thought in their mind and so on. Because it can really be excruciatingly painful. And if you don't know what's happening to you, really bewildering. But that really wasn't much of a thought in my mind. I was quite depressed though and weepy.

> Q. What was threatening your hope at that time (prior to diagnosis of the illness)?
>
> A. Well, I thought that number one, I was the only one. This is unrealistic but this is how you feel. I was the only one who was suffering this because I felt alone.

During this phase, the individual may experience a series of threats to the self, depending upon the degree of uncertainty. This may be viewed as a period of testing oneself.

Impact on the hoping network. Within this phase, the dynamics of the hoping network in Phase I of the hoping process are evident. There may be a series of threats to the hoping self, as well as to other parts of the hoping network. The hoping self may be depleted. Hoping resources may be reduced and inhibitors increased. Hoping objects may be redefined in general terms.

Phase II: Reacting to the Uncertainty
("The Transition Period" "Finding the Right Recipe" "Getting Used To")

This phase is characterized by attempts to regain control; and to return to a normal routine, based on the individual's previous definition of normal. The individual may try to gain a better understanding of the situation which initially resulted in the uncertainty. There may be some reductions in uncertainty, albeit temporarily. This phase may be viewed as a period of "transition" or "trial and error."

Contingencies

The reaction to the uncertainty is dependent upon the perceived degree and threat of uncertainty. This perception is partially dependent upon the duration of the uncertainty.

short-term, temporary periods to long-term, more enduring periods. Some participants viewed this time frame as a "slow-up period" and reinforced the importance of patience for waiting it out.

> I was quite annoyed when I found out about the spots on the bone because it was something that was kind of left high and dry. It wasn't anything that was nailed down to say 'yes, you have', well, they said, 'yes you have because they said you got spots in various places.' But there was a hangup there, before we got down to the nitty gritty to do cobalt.....til they were sure that it was cancer that they were finding in the bone and stuff. And like, at one point, I received a letter which said, like 'try not to worry'......'try not to worry but we're gonna have to wait another 2 or 3 months'......And it was hanging up and not knowing. Not knowing is the rough thing to go through. The knowing isn't near as bad as the guessing.

> I don't want to lie to you because I will tell you it [the pain, the illness] is wearing on you. Three years and ten months is wearing.

Consequences

Impact on the self. The reactions to the uncertainty vary along a continuum, ranging from acceptance to rejection. This reaction may also be viewed as a continuum of "wanting to know" to "not wanting to know."

Some of the participants accepted the situation quite readily.

> Q. Were there any feelings at that time [rejection of candidacy for renal transplant] about your hope or your future?
>
> A. Yes. I measured everything. In fact I read the statistics about being on dialysis and the statistics said that those who are diabetic on dialysis, 25% of them live more than 4 years. And I estimated, you know, then my life span is about 1 month to 4 years and if I'm lucky, maybe even more. And I accepted that very well. I even explained it to my wife. She didn't like to hear it......But I said look, this is it. And I better forget about it and live coping.

described this trial and error period as a process of "finding the right recipe" and emphasized the importance of patience.

> Absolute confidence in your doctor and openness with your doctor. Say okay, we're gonna try this particular chemical. We're gonna change this. The other one isn't working. Maybe this along with that one is the right recipe, if that's what you want to - I usually use that word - the right recipe for you. Cause they have to make all this up to suit the person. And it's very important that you have that confidence in your doctor.......And if you look at what they have to go through to match up your system with what they're giving you, you have to allow playing room or playing time for them to match the chemicals to your body. So therefore, you have to have patience for trial and error.

> But I think if you're in a state of illness, I think if you are feeling very badly, then it's not a problem for you to try something new because you have to look to trying to get better you know.

Others were less willing or likely to accept the situation. For these individuals, this phase may be characterized by a resistance to change, with attempts to maintain the status quo. The concept of "soldiering on" is descriptive of this resistance to accepting the situation.

> The longer you try and soldier on, the more likely you are of extending the pain, extending the migraine and just worsening your condition.......But everyone who has migraines.......tend to try and cope and go ahead as if they didn't have one.......Many people.....just don't accept it very well. And the sooner you learn to accept it the better.

It is important to note that, for most individuals, there is a fluctuation along the continuums of acceptance-rejection and "wanting or needing to know" versus "not wanting or needing to know." One participant described the need to know as a turning point.

> But at one point [prior to diagnosis of the illness], I felt extremely depressed. And that was like a turning point. It was at that point, my husband said, we'll have to do something about this and then we went to the doctor. It did come to a crisis point where I felt I couldn't cope with it anymore.......I remember we were at a convention in [a name of a city] and I had had a migraine the whole weekend. And that was the turning point. I can remember it clearly as being that incident that made me say something has to be done. These aren't just headaches.

Strategies. The strategies which are implemented are dependent upon the individual's position along the continuums of acceptance-rejection and "wanting to know"-"not wanting to know." These strategies may be categorized within one of three groups: (1) strategies to reduce the uncertainty of the situation; (2) strategies to increase the certainty in other areas of one's life; and (3) strategies to protect the self.

(1) Strategies to reduce the uncertainty. For those who perceive the uncertainty as a threat, an attempt is made to try to reduce the degree of uncertainty in one's life. Specific strategies to partially reduce the uncertainty of the situation might include searching for a diagnosis, a cause or a cure.

> I think in some ways I was driven because of perhaps being an A type personality that I was going to control this. I was going to find the cure. And so I kept searching.

Other strategies to reduce the uncertainty may include searching for the "proper medication" or a "good doctor." Strategies to control the symptoms may help reduce the uncertainty, although it may only be temporary.

> I have been working with [my psychologist] at the pain clinic at the [hospital] through [my physician] and she has taught me self-hypnosis which I use every day, all day. I can move blood around my body, I can move pain out of my body....I can move it right out my fingers and toes. I can light them up so that they are on fire with

Objectifying the situation through regular measuring and monitoring, may also be helpful in reducing some uncertainty.

> No, but that machine, I like having it. It's a stabilizer.......It's not a crux but it's a, let's see what does it tell me today, you know. It's like a horoscope........Well, before I must have been concerned, eh. That's why I was recording [my blood pressure every day]. Oh yeah, I kept records......See, especially if a person's trying out new drugs, eh. Was it doing anything for me? And I think that's when you see that the drug isn't, you know, performing, you start you get irritated and you know, you figure there's something that should be found than what they have today.......You know especially in the process of where you're trying to get it down and you say now well, what is it now. So you write it down. I used to take it two or three times a day........Maybe a person shouldn't be using the machine. But I still think it was the real thing for me. I knew where I stood and it made me feel better. Cause if you're walking around - now is it high or what you know.....I figured, you know, you like to face the facts that this is it. So you don't kid yourself. This is what it is and you start seeing that it's going up and you'll do something about it eh.

> Well I think that with me the machine would be, without it, I don't think I could - I sort of need it to know where I am at. Like I just can't, if I just went on by diet and diet and insulin, I would have no idea how I was doing....Plus you go in every three months and they take your hemoglobin A1C to see how your control is, but that is not going to tell me. Every three months is no good.

(2) Strategies to enhance the certainty in other aspects of one's life. Due to the relative uncertainty of a specific situation, there may be a need to bring greater certainty into other aspects of one's life, wherever possible. Specific strategies might include searching for and building "good" relationships. These are the same strategies which are used in Phase II of the hoping process to develop hoping resources and minimize hoping inhibitors. Strategies to ensure financial security may also be helpful in increasing the certainty in one's life.

> A good man, I think, has to know that if he is going [illegible] that what he has created is well looked after. And my family is well looked after [financially]......and that is a great relief to a sick person.

> I'm very lucky that I don't have to financially support a family......When I think about the things that I can do and the things that I can't do, I always end up counting my blessings. Because I think of the wonderful benefits of not having to support a family. Some people are single parents or they need the two incomes. We don't.

The ability to develop a normal routine, including continuing to work, if possible, may also be an effective strategy.

> I continued to work under those terrible circumstances and I worked until I was forced to retire in 1988 in April. But it was very, very difficult to work under those circumstances, but I did.

> I'm still working. I never stopped working [throughout the illnesses].

Finally, one's personal or spiritual beliefs may provide a source of some certainty. The individual's beliefs may be a representation of the driving force of the hoping self. The strategies which were useful in strengthening the hoping self in Phase II of the hoping process would be of benefit here.

(3) Strategies to protect the self. For those who reject the situation, denial may be adopted as a strategy. This strategy may be used in an attempt to artificially reduce the uncertainty to zero.

> I worried a bit about my wife and my son because you know, they also were blocking from their mind at that time [during dialysis]. I

> very trying period of learning about food for my wife and trying to help, even though I am very weak to stand up. And so on. But hope never really came up in my mind.

The strategy of denial may also be useful as a strategy to protect the self.

> Like I told [my physician] today, I said I'll be - I said give me a few weeks, I'll be scooting around in my walker, going up and down the elevator. Well, I know I'm lying. It'll be longer than two or three weeks, but it's fun to joke about it.

Turning Point

The degree of success with coping strategies in Phase II is variable. Attempts to reduce the uncertainty in one's life may be partially successful. For example, some strategies may help temporarily. Other strategies may be unsuccessful. In spite of all attempts to reduce the uncertainty, it still remains. The individual continues to experience a fluctuation in uncertainty ranging from minimal to a great deal of uncertainty. One participant described this process as a "rocking back and forth" between periods of uncertainty and periods of certainty. "One day you know what's happening, the next day you don't."

As a greater sense of certainty is developed within other areas of one's life, and as the hoping self is strengthened, the degree of uncertainty associated with a specific situation appears more manageable. At some point, there is an acknowledgement by the individual that there will always be some degree of uncertainty within one's life. There is a greater acceptance of the situation and of uncertainty. This shift marks the beginning of the third phase.

> director [of a support group], coming around and banging this, you know, into my head, to finally accept it. And I did....'cause some people see the light. Okay, maybe my mind went click and okay accept it. That's all there is to it. You're not gonna beat it. No way.

> That [getting hit by a vehicle while crossing the street on a red light] was just one of the minor things in the background before it got to the forefront. And I thought to myself, and my doctors telling me, hey you're committing suicide. One of these days, it's not gonna be a car. What's it gonna be?.........and it was slowly, slowly, slowly, it had already snowballed and it was going down the other side of the hill. And it was breaking up and getting smaller. My life was getting smaller and smaller and smaller because I was doing these things on a regular basis and I thought, oh well. Just before it came to the end, everything came to. I finally said, hey okay, stop hitting a cement wall with your head. This is the way reality is. You're gonna have to deal with it somehow yourself. And with the medication you can't take this and this and this.

> I felt that sometimes I was indispensable, which I now realize - no one is indispensable. But you learn that through an illness. You don't realize that at the beginning of the illness. You try and behave as a normal person without an illness. But then a certain degree of acceptance comes. And you realize that no one is indispensable.

Phase III: Mastering a Life of Uncertainty

("Coming to Terms")

("Uncertainty as a Way of Life" "Expecting the Unexpected")

This phase may be characterized by a greater feeling of contentment and satisfaction. The uncertainty remains and fluctuates, but the individual is better prepared to deal with the situations as they arise.

These include the acceptance of uncertainty in one's life and a shift in one's tolerance for uncertainty. The individual's perceptions of uncertainty as a threat may change.

Consequences

Impact on the self. Within this phase, the individual experiences a number of adjustments to a life in which uncertainty plays a role. This phase is characterized by a greater sense of direction and a feeling of being in control. The importance of regaining control is reflected in two of the participants' comments.

> [My psychologist] asked me one time who was in control of my health, the day she took me on as a patient and I said of course the medical people. She asked me a few months later and I said I'm in control.......I am a very stubborn Irish man, so I felt I had to control the cancer - the cancer couldn't control me. So I drove myself to my treatments. I took my treatments alone.

> It [the confrontation by the support group] just made me feel that.....I could cope with it better. That I was going to manage the headaches - they weren't going to manage me. That was like a role reversal. They were like monsters over me and now I was going to accept them and I was going to control them as best as I could.

There may be a greater awareness and acceptance of one's limitations, as well as a greater awareness of others.

> You become more aware of the world around you. You become more aware of the world around you and the people around you and what they're going through. And if you look you always find somebody worse off than you are. Which tells you to give yourself a kick and get going. So those are things you become very aware of. And it probably does help you with your patience.

> you're going to do. But you don't always fulfill those for various reasons. And that can be a disappointment. But, well, you just never know what's around the corner. And also you can make such a difference in small ways, so what's the big deal if you never did it in a big way. We can't all be Mother Theresa or whatever. So I just do what I can in small ways. I'm not really disappointed that I didn't make those big goals.

The individual has tried to come to terms with some of these limitations, for example, speaking about death, without giving up everything.

> It was at that time [rejection of candidacy for renal transplant] when I started thinking about death. When I really read the statistics. And I accepted it very much. I took out my will and I started, I said, gee, you know, while I am capable I should organize myself. Show everybody where the files are. If I want to update a will, I would do it. I've accepted the whole situation.

The components of the hoping network, specifically, the hoping self and hoping resources, assist in this process of "coming to terms."

> Q. How do the medications relate to your hope?
>
> A. Well, again, coping, I mean, how am I coping for example? Number one, with my psychological state of mind. Number two, my doctor and the treatments available to me. Number three, the medications I'm taking. So taking the medications - I'm still the same person I used to be - very meticulous, very organized and so on. It's part of the complex of coping. Medication, treatment, good doctor, good family support, good facility. And my psychological state of mind.

The individual may undergo a process of redefining the self. A new definition of normal may be devised, in which the illness is adopted as part of the self. The individual no longer sees him or herself as separate from the problem.

> without you, sort of thing. Yeah. It's like an extra member of the family to me.

> So all I have is migraine and really it's nothing in the whole scheme of things is it. Especially if it's fairly well under control.......It's just a part of your life.

> Q. How do you see yourself today with respect to hope?
>
> A. Oh much different today. I mean, I see, to me this blood pressure's stabilized, so what? I'm just along with everybody else.

Strategies. The strategies which are used in this phase place less emphasis on minimizing uncertainty and more on learning how to tolerate uncertainty. Strategies may be developed to manage the uncertainty of the situation and to deal with those hoping inhibitors which cannot be minimized. The individual continues to implement strategies from Phase II which were helpful. New strategies may be developed to maintain the hoping self and resources, by retaining some level of uncertainty. For example, goals (i.e. hoping objects) may be redefined in terms of some degree of uncertainty. There may be a reluctance to commit to specifics, as one participant stated, "Who knows what things will be like in a year from now?"

> Well, I guess you would be wrong not to realize that cancer is forever. I can go into remission which I am absolutely convinced I am going to go into. And it can come back or it can stay away and you can die of old age, shot by a jealous husband. Who knows? So I don't know what my hope will be [a year from now]. But I'm not - I don't want to lie to you because I will tell you it is wearing on you 3 years and 10 months is wearing. I hate, I hate having to go and lay down. I hate having to leave a party before everyone else does. I don't like being half a man. I like to be a full man and that's what I am shooting for. But who knows? Time will tell. A day at a time.

fatalist but I could walk out the door and [illegible] there and I could get shot. I don't think of myself of "I am going to die from diabetes."

HOPING AND COPING

A. Overview

As previously stated in Chapter V, the purpose of this study was to gain a greater understanding of the relationship between hope and medication compliance in chronically-ill individuals. This relationship is complex and difficult to study in isolation. The perplexity of this topic is reflected in one of the participant's comments.

> Q. How would you see the medications affecting your hope?
>
> A. How the medications affect my hope? That's kind of hard to answer.

Based on the data from this study, the relationship between hope and medication compliance is best understood within the complex coping process of learning to live with uncertainty. Thus, this relationship will be reviewed under the following topics: (1) the role of medications and compliance in chronic illness; and (2) the relationship between medication compliance, hoping, and uncertainty.

B. Medication Compliance in Chronic Illness: "Putting Things into Perspective"

Five contexts, within the chronic illness experience, were identified in this study. These included the self, relationships, the environment, medicines and problems. The contexts of medicines and problems are of greatest significance to the topic of medication the context of problems.

Within the context of medicines, many forms of treatment, which were of benefit to the chronically-ill individual, were identified. These treatments were both medical and nonmedical in nature. Medical forms of treatment are often coordinated and controlled by the medical environment. Some examples of medical treatments include medications, radiation therapy and physiotherapy. Nonmedical forms of treatment are more often adopted and controlled by the individual. Some of the nonmedical "medicines," which were used by the participants, included humor, meditation, work and "sound economics."

> Humor is the adrenaline of medicine - there is no question - humor is the adrenaline of medicine. If you get up in the morning [feeling] sick and you are not feeling well and something very, very funny happens, even if you are sick and you laugh, you feel better.

> Q. What kinds of things did you do to help you recover [from the mastectomy]?
>
> A.......Meditate. I meditate a lot. I try to eat reasonably well. I try to get a lot of exercise, as much as I can. Work, which I totally enjoyed until I was hurt and couldn't work over the past three years. But working is medicine to me.

> And I have had patients laying beside me [in hospital] dying. And I can guarantee you, if they had won the lottery, they would be alive today. The worry of that debt killed them. They had no fight left. What the hell would you fight for? So I am telling you, sound economics is a strong medicine.

Thus, the use of medications, as a form of medical treatment, may be viewed as one of many medicines.

nature, and others of which are not, for example, financial, social and work problems.

> I haven't been employed for ten years [since the diagnosis of epilepsy]. I mean this is it. I mean the volunteer work, that's it. And it does make it kind of tough at times......Once you haven't got the pay cheque, you're on the bread line and the bread line don't give you a hell of a lot.......I mean, what they pay me in a month, I used to make in a week.

The perspective on compliance may differ between the health professional and the chronically-ill individual. For the health professional, compliance is an important issue and may be cited as a major medical problem. In contrast, the chronically-ill individual may view medications and compliance as one of many problems; or they may not view it as a serious problem at all.

> I didn't find it that difficult to follow [my appointments for my medication, my medication schedule]......To me there it is.....Same as if you had to take an antibiotic for a cold. Same thing. One every so many hours you take one and say do your work little buddies and that's it.

> Q. How do you feel about taking your medications now?
>
> A. Doesn't bother me.

> I have never had a problem with the needle. I remember the first day they came in and they said, 'You have to take insulin,' because I had been really sick. And I said, 'Oh, okay.' And I put it in my leg and I had no problem.

> Q. How were you able to work that [taking two additional medications] into your routine, in addition to the insulin itself, when you were first diagnosed [with hypertension]?

Thus, one might conclude that medication compliance, although of great importance to the health care professional, may be of limited importance to the individual or may be a very small component of the whole chronic illness picture. Understanding where medications fit within the hoping process, as well as the process of learning to live with uncertainty, is of utmost importance in learning more about the area of compliance.

C. The Relationship Between Medication Compliance, Hope and Uncertainty

The Role of Uncertainty

The hoping and coping processes are linked together through the underlying theme of uncertainty. As mentioned previously, coping with a chronic illness is the process of learning to live with uncertainty. Hoping may be viewed as a process of bringing some certainty into one's life by maintaining the hoping self. The components of the hoping process, that is, the hoping self, hoping resources, hoping inhibitors and hoping objects, may covary with the level of uncertainty.

The underlying theme of uncertainty may serve as a link between medication compliance, hoping and coping. This may be explained from two perspectives: one, the interrelationship of medications, uncertainty and the hoping network and two, the inter-play between medication compliance, a coping strategy, and the hoping network. The role of medications within the hoping network is influenced by the degree of uncertainty associated with a given situation. Medications may influence the uncertainty by serving as hoping resources, objects or inhibitors. This interrelationship may, in turn, affect compliance. For example, if by taking the medication, the individual knows that the symptoms will be perceived as a hoping resource.

> I finally got help from various sources. Medication was one. And I find that the only medication that really works is prophylactic medication........You have a sense of apprehension because you know that the migraine is going to come and I'm sure that makes the migraine worse. But if you're on a prophylactic medication, you know the chances are that you can prevent the severity of it or perhaps you can prevent it all together. So you're a lot more relaxed about the situation.

If, on the other hand, an individual takes the medication and the situation does not improve or even worsens, then compliance may be lessened. This situation is supported by one of the participants, who became very frustrated when her blood sugars were out of control, in spite of taking the insulin and watching her diet. In this case, the medications may be viewed as a hoping inhibitor.

> I have them [insulin reactions] quite frequently. And, for a while.......I found it quite frustrating. I was trying to follow my diet perfectly, you know, exceptionally good. And I would have a reaction. You have a reaction, you treat it - rebound - your sugars go up, get them down again, and you have another. And I just seemed to be going up and down and up and down. And I got so frustrated, I said, 'Why bother?' Or I would follow my diet perfectly and I would have blood sugars of 20 or more and I go, 'Well, what am I doing wrong?'

An individual may be willing to put up with some degree of uncertainty for a specified time period, when taking medications. However, there comes a point when one's limits for tolerance are exceeded. It is at this point that the individual begins to ask questions or may become less compliant. This may be viewed as a potential turning point.

> I'll probably approach the doctor a year down the road and say, 'Look,' like particularly this Gold, 'it is not helping me. Is there any thing else?'.......But I do like to know what is in it and what is the side effect. And if they say, 'Well you know, you've got to take it for three years before you.....get any results,' well, I'll take it for three years. And at the end of three years, I'm going to start questioning it.

Medications and the Hoping Network

The relationship between medications and hoping can be described within the components of the hoping network. Medications, themselves, can serve as hoping resources, inhibitors or objects, based on the perceptions of the individual.

Medications as Hoping Resources

Medications can be categorized as hoping resources. These categorizations can be based on the functions provided by the medications. For example, they may provide a direct source of hope.

> So as soon as I got onto something [a prophylactic medication] that prevented them or prevented the severity of them [migraines], I felt a lot more hopeful.

> Q. How would the medication affect your hope?
>
> A. Well......say that a person didn't have the right medication or there's no medication and you knew that, you know, the old pump was just dying away. I think it would say, well any minute I'm gonna go. This way here, with the medication, you feel that you're as good as the fellow that doesn't take it. No problem. I think the medication.....proper medication.....gives a person more inspiration. You figure, I'll go through it and I'll last as long as the next guy.

> But you can't give in to it [the illness] and give up......With all the medications coming out, I don't know, they are there to help you, and if it doesn't well try something else.

a hope helper. The medications helped by bringing some stability to the situation.

> Q. How would you relate those medications today to hope? What hope do they give you or do they give you any hope?
>
> A. They don't give me any hope.......they are just a control.......they are just a control. They are not a cure. I'm not taking anything that will cure anything I have. I'm taking calcium to help build the bones, some of it, while the steroids eat it. But it is only a stop gap for it.

Another participant related the medications to hoping through the element of confidence. This relates to the concept of the confidence-connection which was discussed as a part of the hoping network in Chapter VI.

> Well, like they've [the medications] got to affect your hope because if you go back to the same, go back to step one again - the confidence in your doctor. Because if you didn't have confidence in your doctor you wouldn't have confidence in what he was giving you to make you well. It all ties in. It all ties in together.

By serving as hoping resources, the medications may assist in the coping process, by helping to control symptoms. As one participant described it, the medication "keeps me going."

> They put me on methotrexate. That to me, that was a hope, because it kept me out of hospital, keeps me going. I'm not.....I'm in pain, but not as severe as with the Gold.

of the medication and viewed this as a threat to hope.

> Q. During that time, when you were getting all those medications, was there anything that was threatening your hope?
>
> A. Well, I guess the only [threat] was when they tell you your heart won't take anymore. Or my bladder and my bowel stopped and I had to have tubes and take two liters of urine out of your body......Those kinds of things make you wonder......Are you going to die from that?......Because cancer spreads so fast, especially this type. Lymphoma is a bad cancer. There was a number of us in there and they're all gone.

> What scared me was......taking this medication, increase [the dose] and nothing doing [the blood pressure didn't come down]. Gee and God almighty.....a guy doesn't want to ruin his kidney taking a bunch of medication. You know it was a concern. It was, like I say, you don't know, you're only banking a few months ahead.

> The only thing that could be threatening hope to me is the danger of some medicines. You do know that some medications can really cause more serious problems than you have. And I keep always telling myself - I keep my fingers crossed that that doesn't happen to me.

Some hoping inhibitors, which relate to medications, may directly interfere with hoping objects. One participant described the fear of addiction to the medications as a type of hoping inhibitor. This inhibitor could potentially interfere with his hope for a remission of the illness.

> But I could take lots, I could get lots out of the pills because of the amount of pain I live with. But it doesn't take long, you know, until you are hooked on pills. And then when this disease goes away, I don't want to start having to come off of some - go to some drug

> worry, I still worry. And I guess I am the one that counts.

Medications may indirectly interfere with the hoping process, not as hoping inhibitors themselves, but by increasing the probabilities of occurrence of other hoping inhibitors. For example, the ineffectiveness of medications may enhance the possibility of developing other complications, which are perceived as hoping inhibitors or threats, such as a stroke.

> Q. When you were taking the medication that was not working well for you, did that affect your hope in any way?
>
> A. Well.....it did you know.......See a guy that's had a stroke, that could be me. It's no joke, you know. You have more negative feeling about it all. That could be me. Don't laugh.

Medications as Hoping Objects

Medications could also be classified as hoping objects. Some of the participants in this study identified a medication which would cure or control the symptoms of the illness as a hoping object.

> The medication of mine is to help me, may be it will cure me.

> I'm not looking for pity. If they're [hands] sore, they're sore. There's always hope that that pill is going to work and then maybe I'd be better.

> There might be something [medication] come along to some extent that will bring them [seizures] 99 point 9 percent under control......There's hope for a medication. I mean there's hope for

Others did not believe that a cure was possible. Their hopes centered around comfort or remission. Although medications are not directly mentioned, one might infer that they could play a role in achieving these hoping objects.

> So if you tell me you're very hopeful, I will tell you, 'Yes. Of course.' But hopeful for what? That the disease will go away? No. In fact, you could say, for example, that a cure for diabetes may happen in my lifetime. I don't even hang on that.......But with all the disease factors, my hope is that within the fact of that disease, I don't want to be a burden. I don't want to be depressed......I want to be as comfortable as can be.

> But I still believe that one day it [the polymyalgia rheumatica] will go.......It will be gone. [It] won't be cured, but it will go into remission.

The acceptance of having to take medications varied amongst the participants. Some individuals accepted the long-term need to take medications. Their hopes reflected this acceptance and were related to specifics regarding the medications, such as a simplification of the schedule, a reduction in side effects or control of symptoms.

> What I'd like is that I'd have one drug and hope it won't take this out of your system or that....If they could only come up with one medication and say, 'Well this is going to treat rheumatoid arthritis or this is going to treat heart problems or kidney problems, and not take this pill to help that one.' But I guess I'm dreaming.

> Q. Do you ever hope to be totally free of medications?
>
> A. I don't think so.......As far as I'm concerned, this medication, it's simple. And sure, if there's something that maybe completely eradicated your system, well I'd go for an experiment. But it isn't......such a hindrance to me taking this medication. I feel good. So what, eh?

> Q. How would you describe hope for yourself?
>
> A. Well, maybe one of these days I'll get weaned off my medication. And we'll see. That's about the only way that's gonna happen.

> I hate pills with a passion. When I am finished all this crap, if I see another pill.....

Medication Compliance and Hoping

Medication compliance may be conceptualized as a coping strategy. Using this perspective, it can be described in relationship to the components of the hoping network.

Compliance and the Hoping Self

The hoping self may be conceptualized as a driving force for behavior. When viewed from this perspective, one might hypothesize that the hoping self could influence medication compliance, which is a type of coping behavior. This is supported by one of the participants who described her "will to live," which one might infer as part of the hoping self, as her motivator for medication compliance.

> Q. When you were on the oral medication, how would you rate your compliance at that time, your ability to take your medications?
>
> A. Very easily. Medication's never been a problem for me.
>
> Q. Was there anything that motivated you to want to take your medications?
>
> A. The will to live. I'm not ready to go yet.

medication.

> Q. So you have some, what I'd say, confidence or trust in that the medication's going to work for you.
>
> A. Yes. Always. Always. Otherwise it'd be pointless to take it.

This same participant further described the importance of maintaining a positive attitude when taking medications.

> It'd be the same as you going to the doctor, if you had something wrong with you, and you said, 'Well, I'm gonna go to the doctor today, but he isn't gonna help me. The pills he gives me are not gonna help me.' Why bother going to the doctor? You're going in negative to start with. You go in there and say, 'Yes I'm gonna get some medicine from the doctor. In a few days, I'll be good.' So maybe you lie to yourself. But that's okay. It's okay to lie to yourself sometimes.

Compliance and Hoping Resources

Compliance may be described in relationship to hoping resources. In general, compliance may be used as a strategy to enhance hoping resources. However, it is equally important to note that hoping resources may enhance compliance. For example, if medications are perceived as hoping resources, then one might speculate that the individual would be more compliant. Hoping resources which are not directly related to medications may also be of significance. For example, confidence in one's physician, who is perceived as a hoping resource, may result in higher levels of compliance.

> over medicating myself too.......in fact many times I'm given a medicine and I don't take it [at] all, after I read about it, until I see my doctor the next time. Or I'll phone him.....So I am active in taking care of myself in terms of medication treatment.

Compliance and Hoping Inhibitors

A relationship also exists between compliance and hoping inhibitors. Hoping inhibitors can serve as a motivator for compliance. This is described by one of the participants who is a diabetic. She believed that the discovery of complications of hypertension and renal damage enhanced her compliance.

> Q. Do you think there was any change in your compliance or your ability to follow the schedule when you changed from the syringes to the pen [a special pen for injecting insulin]?
>
> A. I think compliance went more with 'Oops my kidneys aren't too hot and my blood pressure is up. I have to take care of myself. You better follow it.' It didn't have to do so much with the pen. The pen was maybe like a new toy at first and now it is just something that I can't do without......I know that you don't watch it then your kidneys are going to get worse and worse and worse and that will mean dialysis and more strict diets and things will get worse. And you won't always feel so good.

Medication compliance could also be viewed as a coping strategy to help minimize hoping inhibitors.

> Q. I am wondering if you see any relationship between your medications and your hope?
>
> A. I realize that if I didn't take them I would damage my - kidneys would be damaged a lot sooner than they are and so they sort of give me a temporary - I definitely see them helping me control, not just the hypertension, but control the damage. And help me, if I can keep on track a few more years, have a few more years of not having to

One might hypothesize that if medications are viewed as hoping inhibitors, then the individual is less likely to comply, in other words, noncompliance is used as a coping strategy to minimize the hoping inhibitor. This hypothesis may not always be valid, however. For example, in some cases, a specific hoping object may be of greater significance than the hoping inhibitor. Thus, compliance would be influenced by the hoping object rather than the inhibitor.

> Q. Would it [the threat of the danger of some medicines] affect your compliance do you think?
>
> A. No, not at all. I mean it affects me in the sense that I would discuss it with [my physician]. I was taking three pills for example, at one time, four pills of Basaljel. Now, I'm on only two. So with the two of us discussing it, we were able to reduce it to two. Things like that. But even if he said nothing, you can't - it has to be taken......And that's it. If we can reduce it, we reduce it. If we can't - what else can I do?

It is important to note that some hoping inhibitors can't be minimized. The individual must learn to accept or cope with the inhibitors.

> Of all the medications I'm on now, for example, I know that aluminum is not a good thing to take. But to survive I must take aluminum pills - The Basaljel that I take for my renal failure. See otherwise, the phosphorous would kill me.

Compliance and Hoping Objects

The relationship between compliance and hoping objects is variable. If following medications will assist in achieving the object, then the individual is more likely to comply. On the other hand, if the medications interfere with achieving the hoping object, then the object).

Summary

The variability in responses based on specific situations makes it difficult to predict compliant behaviors. Thus, all of these relationships must be viewed within the complete context of the interaction of the hoping self, hoping objects, resources and inhibitors within the hoping process. Further, this process is best understood within the process of learning to live with uncertainty.

A. Introduction

The concepts of hope and medication compliance, within the context of chronic illness, are complex. They are difficult to study in isolation and, based on the results from this study, can be integrated within a complex process of coping with the illness experience. The participants in this study represented a wide range of illness experiences. They have had to make many adjustments in their lives, not only within the medical realm of the illness process, but in other realms as well, such as social, financial and interpersonal. The strategies which they adopted to cope with the many changes varied considerably.

In spite of the diversity amongst the participants, a number of common themes emerged from the data. One of the most prominent themes was "learning to live with the uncertainty of the illness process," itself. Embedded within this process was a second process of maintaining the hoping self. Another theme which appeared to be influential within the coping process was the concept of the hoping network and the significance of relationships within this network.

This chapter will be limited to the discussion of two themes: (1) the interrelationship of the hoping and coping processes within the context of uncertainty and (2) the importance of the hoping network, particularly with respect to relationships. A third section, within this chapter, will outline the limitations of this study.

The results from this study suggest that the relationship between hope and compliance, in chronically-ill individuals, is best understood within a complex process of learning to live with uncertainty. This process is multifaceted, interactional and systemic in nature. Based on the findings in this study, a second concurrent process of maintaining the hoping self was identified. These two processes are linked together through the underlying theme of uncertainty.

The state of uncertainty is generally perceived as undesirable or threatening. Although the nature of life's experiences may be unpredictable or uncertain, most individuals prefer to have some form of predictability, stability or certainty within their lives. This view is exemplified by one of the participants in this study who expressed a desire or need "to be shown or proven things." It was only after something had been proven, that she would believe in it. This need for certainty was echoed in another participant's comments of needing to know, stating that "the knowing isn't near as bad as the guessing." Thus, one might hypothesize that most individuals, when confronted with uncertainty, would prefer to reduce the uncertainty in life. Research to support this hypothesis, however, is inconsistent (Berlyne, 1977; Lanzetta, 1971). Some researchers have even suggested that individuals may prefer to maintain some degree of uncertainty, since it facilitates hope (Folkman, Schaefer & Lazarus, 1979; Holmes & Houston, 1974).

Folkman et al. (1979) suggested that most information-processing theories focus on the reduction of uncertainty, while the issue of tolerating uncertainty is ignored. They indicated that a theoretical model which describes the processes to reduce uncertainty, as well as the processes to maintain uncertainty, was needed. Further, they suggested that the value of uncertainty should be addressed, particularly when it enables the individual to interpret events from a positive perspective.

The processes of hoping and coping, which were identified in this study, emphasize the importance of maintaining a balance in uncertainty within one's life. These processes, and their relationship to each other, can serve as a stepping stone to further research in this area.

To gain a greater understanding of the interrelationship between the hoping and coping processes, within the context of uncertainty, a secondary review of the literature was undertaken. This review will be limited to the following areas: the relationship between uncertainty and hope; the role of uncertainty in the illness process, highlighting the theory of uncertainty proposed by Mishel (1988); the relationship between hoping and coping; and the relationship between uncertainty and compliance.

The Relationship Between Uncertainty and Hope

The relationship between uncertainty and hope has been addressed in the literature. Uncertainty has been described in one of three ways: as a concomitant, an antecedent and an element of hope. Dufault (1981) refers to the relationship between hope and uncertainty in all three ways. Uncertainty was identified as one of eleven concomitants of hope. This type of relationship does not necessarily infer causality, but does confirm a link between these two concepts. She also alluded to the role of uncertainty as an antecedent of hope. Nine antecedents of hope, specifically, captivity, loss, stress, major decision making, hardship, suffering, life review, a threatening situation and challenges without certainty of outcome, were identified. A number of these antecedents may be associated with some degree of uncertainty. Similar to the concept of hope antecedents, Dufault and Martocchio (1985) make reference to uncertainty through the contextual dimension of hope. They suggest that the context can provide a milieu or opportunity for hoping. Stress, crisis and loss are contexts which may be associated with uncertainty. They further propose that the same life event can be an opportunity for hope, for hopelessness or for both.

The concept of uncertainty as an element of hope has been described by a number of individuals. Miller and Powers (1988) identified ten critical elements of hope, one of which was anticipation. Anticipation refers to a future orientation with positive outcome expectations, which necessitate trust and patience. There is some degree of uncertainty associated with anticipation, as the realization of one's expectations is not absolute. Similar to Miller and Powers, Stotland (1969) acknowledged the element of uncertainty within his definition of hope. He described hope in terms of probabilities of goal achievement. These probabilities are specified as greater than zero and less than 100%. This would correspond with the concept of uncertainty ranging from total certainty (0% uncertainty) to total uncertainty (100% uncertainty).

Menninger (1959), in his address on hope, to the American Psychiatric Association, highlighted the element of uncertainty within this concept. He suggested that the concept of hope is not the same as expectation, which implies a sense of certainty. He used a quote from St. Paul to illustrate his point. "We are saved by hope...but hope that is seen is not hope: for what a man seeth, why doth he yet hope for" (p.484)? He further went on to describe hope as a process, "an adventure, a going forward, a confident search" (p. 484). The view of hope as an adventure implies some degree of uncertainty.

The Role of Uncertainty in the Illness Process

The role of uncertainty in the illness process has been researched from a number of perspectives. Suls and Mullen (1981) investigated the role of uncertainty and perceived control in the occurrence of illness. Mishel (1984) explored the relationship between uncertainty and stress in illness. A theory of uncertainty (Mishel, 1988), as well as an instrument to measure this concept (Mishel, 1981), has been developed.

The relationship between uncertainty and hope has not been directly studied. However, Mishel's (1988) theory makes an indirect reference to the role of hope in the illness process. The following is an overview of Mishel's theory, followed by an application of this theory to the hoping and coping processes which emerged from this study.

Mishel's Theory of Uncertainty

Mishel (1988) proposed a theory of uncertainty in illness which helps explain how individuals construct meaning of illness events. Mishel defined uncertainty as "the inability of the individual to cognitively structure meaning of an event, due to the lack of sufficient cues." This theory can be described according to three components: the antecedents of uncertainty, the appraisal of uncertainty and the coping strategies which result in adaptation.

Antecedents of Uncertainty. Mishel (1988) identified three antecedent variables: "stimuli frame," "cognitive capacity" and "structure providers." These variables provide the information which is processed by the individual to assist in the appraisal of uncertainty. These antecedents could be conceptualized as the information-gathering phase of the uncertainty process.

Information is taken in by the individual through the stimuli frame. The appraisal of the uncertainty associated with this information is dependent upon the pattern of symptoms ("symptom pattern"), the individual's familiarity with the event ("event familiarity") and the degree of consistency between the expected and experienced illness event ("event congruence"). These components are inversely related to uncertainty, that is, the more erratic the symptoms, the less familiarity with the event and the greater the discrepancy between expected and experienced events, the greater the uncertainty.

The "cognitive capacity" and "structure providers" can influence the processing of information from the "stimuli frame." The "cognitive capacity" refers to the information-processing abilities of the individual. The individual is only able to absorb a limited amount of information at any given time. Thus, the perception of the uncertainty of a situation may be influenced by the amount of information received. "Structure providers" are those resources which assist the individual with the processing of information and help reduce the uncertainty. These include the individual's "educational level," "social supports" and "credible authority" (for example, physicians).

Appraisal. The experience of uncertainty is neutral until it is appraised by the individual. Uncertainty can be appraised as either a threat or an opportunity. The information from the "stimuli frame" is processed and appraised using one of two approaches, "inference" and "illusion." Inferences are based on the individual's personality, general experience, knowledge and contextual cues. In contrast, illusions are dependent on beliefs formed from the uncertainty, beliefs that have a positive outlook.

Strategies. The strategies which are implemented are dependent upon the appraisal of uncertainty. If uncertainty is appraised as a threat or danger, then coping strategies, which reduce the uncertainty or manage the emotions, are accessed. If uncertainty is appraised as an opportunity, then a possibility of a positive outcome is adopted, and coping strategies which buffer or maintain the uncertainty are implemented. With the appraisal of uncertainty as an opportunity, hope is possible and can be activated.

Uncertainty may be considered an opportunity when the alternative is negative certainty. The link between opportunity and hope is supported by the results of a study of family members of heart transplant patients (Mishel and Murdaugh, 1987). In this study, the family members perceived the uncertainty of the future as a second chance at life. This was in contrast to the certain death of their spouses had they not had a transplant. Hope maintenance methods were used to help cope with the threats of the situation.

Theory Application

Mishel's (1988) theory of uncertainty offers support for the conceptualization of the hoping process (the process of maintaining the hoping self) and the coping process (learning to live with uncertainty) existing concurrently. Mishel's conceptualization of the antecedents of hope (i.e. stimuli frame, cognitive capacity and structure providers) is similar to the conditions and contingencies of the hoping and coping processes, based on the five contexts of self, relationships, environment, medicines and problems. The structure providers, in Mishel's theory, are similar in function to the concept of hoping resources.

The appraisal of uncertainty as a danger or an opportunity would correspond with coping and hoping, respectively. If the event is perceived as threatening, then the strategies which are implemented are directed towards reducing the uncertainty (similar to the coping strategies within the coping process). If the events are perceived as an opportunity, then the strategies which maintain some degree of uncertainty are adopted. This is parallel to the strategies which are implemented to strengthen and maintain the hoping self within the hoping process, as well as the strategies which are developed to help tolerate or accept the uncertainty of the illness process.

The Relationship Between Hoping and Coping

The relationship between hoping and coping was discussed in Chapter II. Based on a review of the literature, the investigator identified three prominent perspectives regarding this relationship: (1) hope as an adaptive task; (2) hope as a coping strategy; and (3) hope as a prerequisite to coping. According to these perspectives, hoping is viewed as a part of the coping process.

In contrast, according to the results of this study, hoping and coping were identified as two separate, concurrent processes. Both of these processes could exist alone: that is, a person can have hope, but not necessarily within the context of coping. Similarly, an individual may be coping, in absence of the hoping process. It is the investigator's belief, however, that individuals who cope, without hoping, may not be coping in a way in which one would typically consider psychologically healthy. On the other hand, when these two processes do exist concurrently, one's ability to cope is more effective. Maintaining the hoping self gives the individual the strength, the courage and the patience to cope with a given situation.

Viewed from this perspective, hope does not readily fit into the three categories which were identified in the literature review in Chapter II. In some respect, the hoping process could be viewed as an adaptive task of coping. However, this would not explain how some individuals are able to hope seemingly independent of coping. The perspective of hoping as a coping strategy is not supported by the results. The strategies for hoping are different from the strategies for coping with the illness. Also, hoping strategies may exist independently of coping strategies. The coexistence of the hoping and coping processes does not necessarily support the view of hope as a prerequisite to coping. Rather than suggesting that hope is a prerequisite, one might view hoping as a corequisite to effective coping. This implies that the hoping process is dynamic and adapting throughout the coping process.

Partial support for the concurrent relationship between hoping and coping is offered by Weisman (1979). In reference to coping with cancer, Weisman suggested that the individual is confronted with many losses and situations which are irreversible. Effective coping with these losses may depend on the individual's ability to maintain hope. Hope may help the individual work through difficult, adverse situations. He further suggests that its presence may precede positive coping. This last statement was not necessarily supported by the results of this study, as it was difficult to discern whether or not the hoping was present before the coping. It is for this reason that a concurrent model of hoping and coping was selected. This is an area which would warrant further research.

Further support for the coexistence of hoping and coping is offered by Pruyser (1986). He suggested that patients who have been diagnosed with an incurable illness do not automatically make a decision regarding hoping. They go through phases which may be characterized by denial, anger, despair, flimsy illusions, rebelliousness, anxiousness or hope in various sequences. They may have to make choices between hoping and despairing, wishing and hoping; and may search for realistic hopes. Some individuals may fluctuate between different states, while others may follow a gradual, logical progression toward acceptance of their condition. These comments give further support to the dynamics of the hoping process.

The dynamics of the hoping process are characterized by changes which occur as the hoping self progresses through the three phases. The existence of the hoping self in isolation, which may occur in Phase I, may not be sufficient to sustain hope. The individual must learn to strengthen and maintain the hoping self, in Phases II and III, for example through building relationships, developing trust and introspection. The importance of strengthening and maintaining the hoping self is supported by Stotland (1969). He suggested that an individual's attitude was important in influencing the outcome of an event. However, he further proposed that being hopeful is not enough. The individual must build in "supports" or "buffers" to retain hope. This would correspond with Phases II and III of the hoping process.

The Relationship Between Uncertainty and Compliance

Based on the results from this study, it was hypothesized that medication compliance was related to the uncertainty of a situation. It was suggested that medications can increase, decrease or maintain a certain level of uncertainty. The decision regarding compliance is therefore affected by the effects of medication on uncertainty, as well as by the individual's desire to alter the uncertainty of a situation.

Research to support a relationship between uncertainty and compliance is limited and inconsistent. Support for a direct relationship between uncertainty and dietary compliance is provided by a study of chronic hemodialysis patients (Capritto, 1980). In this study, it was suggested that in progressive illnesses like chronic hemodialysis, the uncertainty regarding the outcome enhances compliance, as the individuals believe in the potential for recovery. In contrast, Given and Given (1989) proposed an inverse relationship between uncertainty and compliance, that is, the greater the uncertainty the lower the compliance. Based on the work by Mishel et al. (1984) on uncertainty, Given and Given suggested that the uncertainty regarding a diagnosis may reduce one's hope and positive beliefs about the effectiveness of therapy, thus resulting in lower levels of compliance. Other researchers have proposed that the relationship between uncertainty and compliance may be insignificant. In a study of compliance with three regimen requirements for cancer patients, Richardson et al. (1987) concluded that there was no significant relationship between uncertainty and compliance. This area would benefit from further research.

C. The Hoping Network

To answer the initial research questions, the components of the hoping process were identified and characterized. These components, which were represented within the framework of a hoping network, consisted of the hoping self, hoping resources, hoping inhibitors, and hoping objects.

The hoping network is a representation of the interactions amongst the components of the hoping process. This system is dynamic, undergoing many changes over time. This concept is in some ways similar to Dufault's (1981) concept of a hope profile. She described the hope profile as a construction of patterns of hope objects, sources and threats, at given times. Changes in these patterns can be monitored over time. Similar to the hope profile, the hoping network is dynamic. In contrast to this concept, the hoping network appears to be more interactional and process oriented. This is strengthened by the use of the word "hoping" as opposed to "hope." The second difference is that the conceptualization of the hoping self was not a part of Dufault's framework.

The Hoping Self

The hoping self has been difficult to elucidate although it appears to occupy the innermost core of the self. The concept of hope existing within the innermost core of the self is supported by Frankl's theoretical construct of the noetic realm (in Fabry, 1968). Frankl described the noetic realm as the "undiscovered" part of the unconscious which gives rise to individuality. He hypothesized that the noetic realm represents the innermost core of the self. Within this realm, a number of qualities exist, one of which is the capacity to hope. Other qualities include artistic inspiration, the sense of humor, religious faith and the need and direction for meaning in life. These additional qualities were not included as part of the hoping self, in this study, although the concept of religious faith or spiritual beliefs was integrated within the individual's belief system. There are many questions regarding the hoping self which remain unanswered and which could be considered for further research.

The elusiveness of the hoping self concept may be related to the symbolic nature of hope (Jevne, 1990). Schrag (1977) suggests that hope is first situated at the level of symbols and images, as opposed to the level of concepts. This is further supported by Lynch (1974) who described hope in terms of images and emphasized the importance of the imagination in hoping. He suggested that it is through imagination that one is able to hope. This idea is further supported by some of the participants who had difficulty explaining, in words, what hope meant to them. For example, one of the participants found it easier to describe hope metaphorically, in terms of a color.

The Importance of Relationships

One of the strengths of the hoping network is the interactional component of the hoping self with hoping resources. The themes of "working together" and the "confidence-connection" highlight this interactional system. Hoping resources can be defined within one of four contexts, specifically, relationships, medicines, problems and environment. Of these four contexts, the influence of relationships was a common theme for most of the participants.

The interrelational aspects of hope have been described in the literature. Miller and Powers (1988) identified the theme of "mutuality-affiliation" as one of ten critical elements of hope. Dufault (1981), in her model of hope, described six dimensions of hope, one of which was the affiliative dimension. In Lange's (1978) comparison of hope versus despair behaviors, she identified "moving toward people" as one of four behavioral themes of hope.

The importance of relationships, particularly with health care providers, has also been identified within the compliance literature. The facilitation of the communication process through the development of communication skills such as empathic understanding has been proposed as an essential element for the adherence to treatment regimens (Meichenbaum & Turk, 1987; Squier, 1990). As early as the time of Hippocrates, the significance of the patient-physician relationship, in recovery, was noted. "The patient, though conscious that his condition is perilous, may recover his health simply through his contentment with the goodness of the physician" (in Meichenbaum & Turk, 1987, p. 71).

It has further been suggested that part of the success in treatment and recovery is related to the physician's ability to influence patient compliance (DiMatteo & DiNicola,1982; Peck & King, 1985). This proposition is further supported by Berg (1987), who proposed that patient compliance is not solely dependent upon the technical expertise of the physician, but is also influenced by the physician's "psychological sensitivity" and the quality of the relationship between the physician and patient.

The affiliative component between hope and compliance has not been studied directly. However, it has been suggested that one's hope perspective can influence the hope perspective of others. Menninger (1959), in his address to the American Psychiatric Association, suggested that health care providers, and in particular physicians, may have a profound impact on a patient's level of hope.

> Sometimes they [the physicians] go too far, they presume, they expect or promise too much. More often, frustration, sad experience, or self-depreciation erodes the confidence required for persistent effort, and the *little candle of hope, which for awhile burned so brightly, weakens, sputters and goes out* [italics added]. We see the beginning of a repetition of scenes so common 25 years ago - hopeless physicians presiding, passively, over hopeless patients. (p. 482)

Menninger ([illegible] went on to suggest that a balance is required in inspiring the right amount of hope - so[illegible] but not too much. "Excess of hope is presumption and leads to disaster. Deficiency of hope is despair and leads to decay" (p. 482).

> And for our patients - miserable, apprehensive, discouraged and often desperate - what can we do better than that? What can we do better than to dispel their false expectations - good and bad - and then *light for them a candle of hope to show them possibilities that may become sound expectations* [italics added]. (p. 490)

Further, with respect to hope and compliance, Coleman (in Meichenbaum & Turk, 1987) proposed that the physician's own perspective of hope can influence patient compliance.

> Four major components are involved in physician behavior that may impact on patient compliance with treatment regimens: compassion, communication, activating patient self-motivation and shared responsibility with the patient. An attitude of concern coupled with hope and interest in the patient's future well-being affect compliance. (p. 71)

Although relationships serve as an important function within the process of hoping, coping and medication compliance, it is important to acknowledge the multidimensional aspects of this framework. Thus, the contexts of the self, the environment, problems and the medicines used to alleviate the problems must also be considered.

D. Limitations of the Study

The limitations of the study will be discussed according to the following categories: (1) the structure of the research questions; (2) the limitations of Dufault's (1981) model; (3) the interview guide; and (4) sampling.

The Research Questions

As mentioned in Chapter IV, the focus of the research questions shifted from an emphasis on content to process. The initial research questions, which were based on Dufault's (1981) conceptual framework of hope, included the following:

(1) How does the individual's perception of the chronic illness and medication experiences affect hope?
  (a) What are the individual's hope sources, objects or threats?
  (b) What contributes towards the individual's perception of medications as hope sources, objects or threats?
  (c) What factors contribute towards the individual's perception of the illness experience as hope sources, objects or threats?
(2) How does the individual's perception of the medication and illness experiences as hope sources, objects or threats affect compliance?

A number of difficulties were encountered with the structuring of the initial research questions. These difficulties included (1) the focus of the questions on content; and (2) the linear nature of the questions.

(1) The focus of the questions on content, in isolation of other variables. Initially, the intent of this study was to focus on the characteristics of hope objects, sources and threats within the context of the illness and medication experiences. Although the multidimensionality of hope was acknowledged, the behavioral dimension of hope, which would most closely relate to compliance, was isolated. During the data analysis process, however, it became apparent that the relationship between hope and compliance could not be viewed in isolation. The results from this study suggest that these two concepts are best understood within the complex process of learning to live with uncertainty. The multidimensional and interactional nature of this process makes it difficult to isolate specific variables or factors, as initially postulated. The process-oriented nature of the participants' experiences provided additional support for viewing these concepts within a systemic framework.

(2) The linear structure of the questions, implying a sense of causality. The representation of the initial research questions was based on linear models, that is, Leventhal's (1984) self-regulatory model and Herth's (1985) Coping Process Nursing Model. The research questions were structured in such a manner as to imply a sense of causality and a unidirectional view of hope affecting compliance. The questions were not initially designed to study the impact of compliance on hoping. Based on the results of this study, it appears that the relationship between hoping and compliance is multidimensional and systemic; and does not readily fit within a linear framework.

The Limitations of Dufault's Concepts

Dufault's (1981) model of hope was adopted as a framework for the initial research questions. Additional questions, which were proposed in Chapter II, were directed towards this model. The following additional questions were cited in this chapter:

(1) Is this conceptual framework unique to elderly cancer patients or can it be applied to any individual with chronic illness?

(2) Are the hope sources, objects and threats different for individuals with chronic illness than for cancer patients?

(3) Are the medication and illness experiences of the chronically ill different from those of elderly cancer patients?

These questions tend to focus on testing Dufault's (1981) model of hope, which was not the primary objective of this study. They may be better answered within a different methodological framework. Thus, it is the investigator's intent to address these questions in a general sense, rather than in specifics, by reviewing the limitations of Dufault's model within this study.

Dufault (1981) proposed that hope consisted of two spheres, generalized and particularized hopes, and six dimensions. She further developed the concept of a hope profile, consisting of hope objects, sources and threats. This model is one of the most comprehensive available to date and acknowledges the complexity and multidimensionality of the hope concept.

In spite of this complexity, based on the data collected from the eight coresearchers, a number of limitations in this model can be cited. Firstly, based on her concept of two hope spheres, Dufault suggests that hope fluctuates between two separate spheres, from general to specific hopes. Some of the individuals who were interviewed adopted this view. Others, however, viewed hope on a continuum, ranging from a great deal of hope to minimal or no hope. These individuals could give specific examples of when they might perceive a situation as hopeless or having no hope. This observation reinforces the importance of viewing hope from the individual's perspective, as opposed to forcing hope concepts within a specific model.

Dufault's (1981) concept of a hope profile, consisting of hope objects, sources and threats, was helpful as a foundation for the initial structuring of the interview process. However, it became apparent that these conceptualizations were not always personally meaningful to the coresearchers. Thus, these concepts were broadened and redefined, based on the individuals' experiences. The derivation of the terms hoping objects, hoping resources and hoping inhibitors, incorporated Dufault's concepts within a broader framework. The change in wording from "hope" to "hoping" reinforces the process - oriented nature of the data. In addition, the emergence of the concept of the hoping self wa not part of Dufault's conceptualization and added a new dimension to the hoping process, although the components of the hope profile may be related to the hoping self.

The Interview Guide

The interview guide was initially developed as a conceptual framework for use within the interview process. However, the complexity, structure and questioning style of this guide may have unintentionally introduced some bias into the study.

One of the difficulties with using this guide was that it incorporated a number of hypotheses within its structure. For example, the inclusion of the question regarding itemizing hope on a scale could be viewed as mixing quantitative elements within a qualitative study. An alternate view is that this question supported the perspective that hope can be viewed on a continuum, as opposed to Dufault's (1981) concept of hope spheres. A second example of incorporating a hypothesis within the framework of the guide is related to the questions regarding the influence of relationships, particularly patient-physician relationships, on compliance.

The second concern regarding the interview guide was the style of questioning which was used. Some of the concepts which were being studied such as hope or the hoping self were difficult to elucidate, partly due to their symbolic nature. Thus, questions which addressed the symbolic realm might have been more effective (for example, using metaphors), but were not incorporated within the initial format.

It is important to note that the interview guide was not followed consistently throughout the eight interviews. The change in focus and restructuring of the questions was related to the nature of the data which were being collected. However, one must consider the potential bias of a prestructured interview guide, such as the one used in this study, in future study designs.

Sampling

One of the issues regarding sampling was related to the principle of theoretical sampling. This was an effective process for the study design. However, the initial identification of potential participants was complex and time consuming.

A second issue regarding sampling is related to the type of individuals who consented to participate. Most individuals had come to terms with their illness and were willing to share their experiences, a large part of which was retrospective in nature. It would be interesting to interview individuals prospectively during specific phases of their illness process, for example, during times of uncertainty. However, these individuals may not be as willing or open to discuss their experiences during difficult times. This type of study would also have to be very sensitive to ethical concerns.

A third sampling issue is related to attrition. One of the participants died prior to the completion of this study. Thus, the number of participants who were available to review the results and the final report was reduced from eight to seven.

CHAPTER IX

CONCLUSIONS AND IMPLICATIONS

A. Conclusions

The results from this study have demonstrated that a relationship amongst hoping, coping and compliance does exist; and can be embedded within a multidimensional framework of the process of learning to live with uncertainty. These three concepts appear to be linked together through the underlying theme of uncertainty. The discovery of this common bond has helped to gain some understanding of these complex issues. However, the interactional, systemic nature of the process makes it difficult to isolate specific relationships or factors. There are still many questions which remain unanswered and many new questions which have arisen.

This study supports the view of researching these concepts holistically, within a specific context, as opposed to studying them in isolation. The qualitative paradigm assisted in the exploration of these concepts within the lived experiences of individuals with chronic illness.

Reflection on the Research Experience

Throughout this study, I have felt challenged by the difficulty of researching a topic which is complex, using an approach (i.e. the qualitative paradigm) which has not been universally accepted. My frustrations and difficulties have been transformed into a personally meaningful and valued learning experience, which has resulted in some of my own internal shifts in thinking. The following is a summary of some of my valued learning experiences.

With respect to the qualitative research paradigm, I have grown to appreciate the richness and diversity of the kinds of data which can be collected. I have also learned to recognize the values of patience, organization, tolerance for ambiguity and focusing on a specific topic. The data, although rich, can be muddied with extraneous information. The process for teasing out the core, essential, common patterns is tedious, yet rewarding. It is my firm belief that the qualitative method has much to offer the research field, and complements the rigors and objectification of the quantitative approach. My own background in and bias towards quantitative perspectives has been enriched by the differing, yet broadening elements of the qualitative design.

Differing views, which are characteristic of the qualitative-quantitative debate, are also evident within the realm of the qualitative paradigm. My experience throughout this study, in talking with a number of people involved in qualitative research, strengthens my belief that there is no one way, right way, proper way to do qualitative research. Biases which exist between the quantitative-qualitative debate also exist between camps within the qualitative research field. My own quandaries with respect to the specificity of the research question, the selection of the sample and the process for analysis were echoed by many who reviewed my study proposal. The confidence which I have gained within this study is that, regardless of the outset, the final results have been grounded in the data and are truly reflective of the experiences of my eight coresearchers. It is reassuring to know that the data are always there. One must develop a level of trust that something will always come out of the data. I felt less of a need to prove a particular viewpoint or theory, and more of a sense of gaining a greater understanding of a very complex phenomenon.

As I progressed through the data collection and analysis phases of this study, I became more aware of my own personal biases which were contributing towards a coloring of the results. Some examples of my biases included adopting the perspective of a health professional, as opposed to that of the coresearchers; inclusion of a question which supports the view of hope as being on a continuum; wanting to force the data into specific categories (eg. hope objects, sources, threats); viewing the research questions and model as being linear, implying some degree of causality; and the analysis of categories initially as a taxonomy (content), as opposed to a process.

A number of shifts occurred within myself, throughout the study: (1) a change in focus from the view of the health professional to that of the individual; (2) letting go of theoretical concepts and working from the data to the theory; (3) a change in focus of the research questions; (4) a change in analysis from content to process; (5) a change in style of questioning, although I still feel this area needs improvement (integration of hope and medications much earlier in the interview process); and (6) a re-analysis of the initial research questions and questioning, "What is the real problem?" As I progressed, I also developed a greater understanding of the qualitative research design, particularly with respect to data analysis.

One of the most significant revelations of this experience was the wealth of information which I gained from my coresearchers. I have grown to appreciate the complexity of coping with a chronic illness; and the difficulty in trying to understand two very complex issues of compliance and hope. Although medication compliance is of significance within the chronic illness experience, it may comprise a very small part of the coping process. My understanding of the concept of hope began with my own personal awareness and understanding of what hope means to me. It coincides with a firm belief that to serve as a hope model for others, one must begin with understanding one's own process of hoping.

B. Implications for Practice

Who Needs to be Educated?

The training of health professionals is primarily based upon the scientific method, with an emphasis being placed on the preciseness and exactness of science. To be effective, health professionals need this scientific base.

However, the health professional field is changing. There is a shift occurring in which the scientific elements are being challenged by the human element, in which a need is being expressed for greater patient-oriented approaches. There is a need to strike a balance between the rigor of "science" and the compassion of "art," within medicine. Although most health professionals acknowledge this need, many lack the knowledge and skill to deal with the human or artistic element of medicine.

Health professionals have been primarily trained to problem-solve, for example, through diagnosis and treatment. There is an over-riding expectation within the health profession, as well as the public, to be able to heal, to cure, "to fix." The degree of one's success may be tied into these unrealistic expectations of healing. Cases which present with a great deal of uncertainty, not only within the patient, but also within the medical field, may be very frustrating. These cases which are difficult to treat or are incurable, as with chronic and terminal illnesses, may be viewed as unsuccessful. One might hypothesize that health professionals have a low tolerance for uncertainty, due to their scientific training and personal and public expectations for healing.

The question of "Who needs to be educated?" emerged during the data analysis of this study. Compliance has been cited as a major problem for health professionals. The results from this study suggest that, for some individuals, compliance was not a problem or was only one of many problems associated with the illness experience. These results emphasize the importance of understanding the illness experience from the individual's frame of reference. A number of questions which have arisen and could be considered for further research include the following: Is compliance the real problem? Do health professionals need to become more realistic in their expectations? How can a balance be achieved between the science and art of medicine? Who needs to be educated?

Strategies for Enhancing Hoping, Coping and Compliance

A number of strategies which health professionals may use to assist the individual with the complex process of hoping, coping and compliance, have been identified, based on the results of this study. They include the following:

(1) **Serving as a hoping resource.** This may include adopting the role of a hope model; providing help and support through information sharing; the development of common goals (hoping objects); evaluation of progress and re-definition of goals, if necessary; and building trust and confidence, using basic counselling skills such as active listening and empathic understanding.

(2) **Understanding the illness process from the individual's perspective.** This can be achieved through a variety of methods: attending to the individual's language; identification of the components of the individual's hoping network; acknowledging the uniqueness of experiences; allowing for increased flexibility or control by the patient, if so desired (i.e. openness to individual needs); acknowledgement of the patient's diversity in "medicines," which include but are not limited to medications; viewing medications and compliance as just one of many problems (putting things into perspective).

(3) **Adopting a systemic, multidimensional approach toward compliance, hoping and coping.** This may include adopting a team approach to health care and actively involving the chronically-ill individual, as well as significant others.

(4) **Increasing self-awareness regarding one's own hoping process.** This may include identifying personal hoping resources, inhibitors and objects, as well as gaining a greater awareness of the qualities of the hoping self.

(5) **Acknowledging the important role of "art" in medicine.** This may include the development of effective communication skills.

C. Implications for Further Research

Throughout this study, the investigator encountered a number of terms which were ambiguous. For example, in the description of hope, the terms "adaptive task," "prerequisite to coping" and "coping strategy" are differentiated by some individuals, whereas others use these terms interchangeably. As a second example, concepts within Glaser's (1978) theoretical coding family, the "six C's", have been interpreted in different ways in the literature. The ambiguity associated with these terms reinforces the need for further research.

Further research is required in a number of areas. These include the significance of uncertainty within the realms of hoping, coping and compliance; the concurrent processes of hoping and coping; the elaboration of the hoping self in relation to other components of the hoping network; and the importance of relationships.

A number of questions, relating to uncertainty, emerged from the data. These need to be researched further:

(1) What is the relationship between hope and uncertainty?

(2) How does one's tolerance for uncertainty affect coping?

(3) What is the relationship between uncertainty and medication compliance?

The nature of the hoping and coping processes require further research. The conceptualization of these two processes as separate, yet concurrent, needs to be explored. An elaboration of the process, within each of the phases, would be helpful. For example, one could focus on the specifics of the strategies which are used within each process. One might ask the questions, "What types of strategies are employed? How does the individual develop effective strategies?".

The nature of the hoping self remains elusive. A number of questions remain unanswered. Some of the questions may be answered through the identification of additional semantic relationships.

(1) What are the components of the hoping self?

(2) What is the relationship between beliefs and the hoping self? Are beliefs a part of the inner core?

(3) What is the relationship between the hoping self and other parts of the self? Can other parts of the self be described as hoping resources?

(4) How does the hoping self differ from hoping resources?

The interactions within the hoping network could be explored further. The use of symbolic questioning would be helpful. For example, using the metaphor of a football game, the following questions might be posed: What type of game are you playing? How do you play the game? What are the objectives? Who's winning? How do you get on the winning team? Who's the quarterback?

The significance of relationships or "people" was a prominent theme within this study. The data appeared to be weighted towards the importance of the physician-patient relationship. This area warrants further research. Relationships, with other health professionals, family and friends, as well as nonhuman relationships, such as with pets, could provide additional research topics. One potential area for research is related to the attitudes of health care professionals. One might ask, "What is the relationship between the health professionals' personal hoping process and the nature of hope-enhancing strategies which they use with patients?" A second issue which could be further explored relates to the importance of language. For example, "How does the health professional's use of language enhance or inhibit hoping and coping?"

C. Closure

This study is only a beginning. It has lightly touched upon the intricacies of hoping and medication compliance within the complex process of coping with a chronic illness. There is still much to be learned.

Our greatest teachers are those individuals who have been there themselves, the chronically ill. They are the only ones who really know what it is like to have a chronic illness. As a result of their experiences, they have developed special skills for dealing with a very complex, uncertain, and at times, frustrating process. Thus, they are the best models for others who have been recently afflicted with an illness and for those in the health care field who want to help, but are unsure of where to begin. Let us begin by listening to those who are most knowledgeable in this area, the chronically ill.

> Q. Is there anything that you would like to add that you think would be important for me to know?
>
> A. For anybody who's on medication, terminal illness, that sort of thing? Just never give up hope. Just - I'm trying to think of a good word for it, how to put it. I guess that's as simple as you can say it. There's no such thing as giving up hope. There's no such thing as no hope. There's no such thing as no hope unless you want to make it that way.

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APPENDIX A

Research Design Summary

Project Title: **Coping with Chronic Illness: The Relationship Between Hope and Medication Compliance**

Investigator: **Cheryl Nekolaichuk**
Phone: 430-7943 (residence)
492-5245 (Ed. Psy. General Office)

I am a student in the Master's program in the Department of Educational Psychology at the University of Alberta. As a former hospital pharmacist, I have a special interest in the health care area, particularly with respect to the medication treatment process. As part of the requirements for the completion of the Master's program, I am conducting a research study which would explore the relationship between hope and medication compliance in persons with chronic illness. The purpose of this study is to determine how an individual's views of illness and medication relate to hope and medication compliance. By gaining a greater understanding of the hope-compliance relationship, effective strategies for the use of hope in enhancing medication compliance could be devised.

The design for this study is qualitative, requiring in-depth, semistructured interviews with approximately six to ten individuals. It is important that the subjects selected for this study be articulate and willing to discuss the research topics, and are representative of the broad range of experiences (i.e. ranging from high to low levels of compliance and hope). The criteria for subject selection include the following: (1) English-speaking; (2) twenty-one years or older; (3) having a diagnosis of chronic illness; and (4) receiving physician-prescribed medication for treatment of the illness. The data collected from the interview process will be analyzed for common themes. Participation in this study is voluntary and all information will be kept confidential. A research proposal will be submitted to the Ethics Review Committee within the Department of Educational Psychology for ethical approval prior to initiation of this study.

Your assistance in the identification of potential subjects for this study would be appreciated. Once a potential subject is identified, I will contact the individual by phone, or in person, to explain the study; to obtain consent to participate; and to schedule an interview appointment. Should you have any further questions or concerns regarding the research design, please do not hesitate to contact me.

APPENDIX B

Research Study

Request for Participation

Project Title: **Coping with Chronic Illness**

Investigator: **Cheryl Nekolaichuk, Master's Student**
Department of Educational Psychology

The purpose of this study is to increase our understanding about the use of medications by persons with chronic illness. There is no judgment about how you should or should not be taking your medications. Our purpose is to gain a greater understanding of this complicated process.

You are being asked to participate in an interview of approximately one hour. During the interview, you will be asked about your illness, medications and feelings, particularly hope. You will be free to deny any answer to specific questions. If necessary, a second interview may be scheduled to clarify some topics.

The interview will be audio-recorded and then transcribed into a written format. You may be asked to review the transcription for accuracy. If there are any topics which you may wish to elaborate upon, then an additional interview will be arranged.

All information will be kept confidential. At the end of the research, the tapes will be erased. The information from this study may be published, but your name will not be associated with the research.

To participate in this study, you must be English-speaking; twenty-one years of age or older; diagnosed as having a chronic illness; and receiving a minimum of one medication prescribed by your doctor. If you are interested in participating in or learning more about this study, please contact me at the following number: 430-7943.

APPENDIX C

The Interview Guide

The Illness Experience

Individual Perspective

"A lot is known about .... (insert specific illness of the participant) from a medical perspective, but little is known about the individual experience of living with a chronic illness. Tell me what it has been like for you."

How do you view your illness? What do you think is the cause?

Change/Coping

What is different in your life since you were diagnosed with .... (insert specific illness)?

What ways have you used to cope with your illness? How well do you think you are coping with your illness?

Patient-Physician Relationship

What has been your doctor's role in your illness? How often do you ask your doctor for advice about what to do concerning your illness? How often does your doctor consult you about your illness? How helpful has your doctor been?

Future Orientation

What do you think the future holds for you? Is your view of the future any different now?

Relationship with Hope

What role do you feel hope has played in your life?

Has the experience of having a chronic illness affected your hope? If yes, what influence do you sense your illness has on your hopes? and on your being a hopeful person?

What effect, if any, do your hopes have on your illness?

Medication Experience

Individual Perspective

"A lot is known about the use of medications in .... (insert specific illness of the participant) from a medical perspective, but little is known about the individual experience of taking medications on a long-term, regular basis. Tell me what it has been like for you."

Change

What is different in your life since you were started on medications for the treatment of .... (insert specific illness)?

What specific results are expected from the medications, according to your doctor? What do you think they will do for you?
What do you see as the benefits of taking your medications? What do you see as the risks involved?

How are the medications affecting you? Are they helping you? interfering with your day-to-day activities? If so, how?

How do you feel when you start a new medication? What are your thoughts?

Coping/Compliance

How have you approached the task of taking medications on a regular basis? How well do you think you are managing your medications?

Do you have any difficulties taking your medications as prescribed? If yes, what are they? What factors make it difficult for you to follow these recommendations?

Are there things that you do to help you to take your medications as prescribed? If so, what are they? How do they help?

Do you need any help in taking your medications? If yes, is anyone helping you? How can others help you?

What do you know about your medications? How much information have you received about your medications? From whom? How has this information helped you? affected your level of hope? How well-informed regarding your medications do you feel?

How much are you involved in decisions regarding your medication treatment? How much do you want to be actively involved?

How important is it for you to take your medications as prescribed?

Have you ever rejected a therapy that your physician has made available or encouraged you to take? If yes, what was the nature of and reasons for the rejection?

How often are you unable to take your medications as prescribed?

Thinking about the degree of compliance that you have, on a scale of 1 to 10, where 1 is zero compliance and 10 is 100% compliance, tell me the number that would best describe you. How would someone who knows you well answer the same question? How do you explain the differences or similarities in responses?

Are you taking any medications/treatments which have not been prescribed by your doctor? If yes, what types? How are these medications/treatments helping you?

Past Experiences

How have your past experiences with medications affected how you feel about taking medications today?

Relationship with Hope

What influence do you sense your medications have on your hopes? and on your sense of being a hopeful person?

What effect, if any, do your hopes have on your use of medications?

Hope

General Assessment and Views

Generally, how hopeful a person are you?

How would you describe what hope is for you?

How important is it for you to have hope?

Thinking about the degree of hope that you have (apart from specific hopes), using a scale of 0 to 10, where 0 is no hope and 10 is a great deal of hope, tell me the number that would best describe your hope now.

What would your score have been 6 months ago? What do you anticipate your score might be in one year? How do you explain the differences or similarities?

How has having hope been a help to you? Has it been a hindrance in any way?

Are there things that you do to help assure that you attain your hopes? Are these strategies successful? If not, how do you deal with the lack of success?

Hope Objects

What are your hopes now? Tell me about your hopes. What do you look forward to?

What were your hopes prior to your illness? Have they changed? If so, how have they changed?

How might your hopes change with time?

How does what you hope for relate to your medication or illness experiences?

Hope Threats

What or who might be a threat to your hope? If you were to lose hope, what might be the cause?

What or who has the most influence in diminishing your hope?

Do you have any special beliefs about life that interfere with you being hopeful?

How might your illness experiences be a threat to your hope? How might your medication experiences be a threat to your hope?

Hope Sources

What kinds of things make you feel hopeful?

What or who has the most influence in strengthening your hope?
What helps you hold on to your hope the most? How does it help you?
Who helps give you hope? In what ways do they help?

Do you have any special beliefs about life that have helped you to be hopeful?

How might your illness experiences give you hope? How might your medication experiences give you hope?

Concluding Questions

Is there anything else you would like to add?

Are there any questions you wish to ask of the interviewer?

What was it like for you to participate in this interview? Were there any questions which you felt were too personal or painful to answer?

APPENDIX D

Review of the Interview Guide

Project Title:	**Coping with Chronic Illness: The Relationship Between Hope and Medication Compliance**
Investigator:	**Cheryl Nekolaichuk** **Master's Student** **Department of Educational Psychology, U of A** **Phone: 492-5245 (Ed. Psy. General Office)** **430-7943 (Residence)**

As part of the requirements for the completion of the Master's program, I am proposing to conduct a research study which would explore the relationship between hope and medication compliance in persons with chronic illness. The purpose of this study is to determine how an individual's constructions of the illness and medication experiences, in relationship to hope, might affect compliance.

The design for this study is qualitative, requiring in-depth semistructured interviews with approximately six to ten individuals. I have attached a copy of the interview guide which will serve as a conceptual framework within the interview process. Depending on the subjects' responses, the sequencing and number of questions asked may vary from one subject to the next.

I would appreciate your comments regarding each question within this guide from the following points of view: (1) relevance to the research question; and (2) clarity. Based on these criteria, please indicate if each question should be included as is, deleted or revised. You may indicate your preferences by placing a check mark in the appropriate columns, on the right-hand side of each page, for each question, using the following key: y = yes; n = no; inc = include; del = delete; rev = revise. I would also appreciate any suggestions which you may have regarding rewording of questions or inclusion of additional questions. Please feel free to write your comments directly on the guide.

Should you have any further questions or concerns, please do not hesitate to contact me.

APPENDIX E

Biographical Data

Code Number: ____________________

Age: ______

Sex: ______

Marital Status: _____________

Ethnic Background: _____________

Level of Education: _____________

Type of Chronic Illness: _____________________

Onset of Illness: _______________

Duration: _______________

Severity/Stage: _____________________

Current Medication Regimen: _____________________

____

____

____

____

____

Source of data: ________________

Completion of form by: ________________ (print name & title) _______ (date)

APPENDIX F

Consent Form

Project Title: **Coping with Chronic Illness**

Investigator: **Cheryl Nekolaichuk, Master's Student**
Department of Educational Psychology, U of A

The purpose of this study is to increase our understanding about the use of medications by persons with chronic illness. There is no judgment about how you should or should not be taking your medications. Our purpose is to gain a greater understanding of this complicated process. You are being asked to participate in an interview of approximately one hour. The interview will be audio-recorded. If necessary, a second interview may need to be scheduled to clarify some topics. During the interview, you will be asked about your illness, medications, and feelings, particularly hope. All information will be kept confidential.

THIS IS TO CERTIFY THAT I, ______________________________
(print name)

HEREBY agree to participate as a volunteer in the above named project.

I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that, at the completion of this research, the tapes will be erased. I understand that the information may be published, but that my name will not be associated with the research.

I understand that I am free to deny any answer to specific questions. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

________________	________________	________________
(Participant)	(Witness)	(Researcher)
________________		
________________		________________
________________		(Date)
(Address)		

(Adapted from Field and Morse, 1985)

APPENDIX G

Field Notes Worksheet

Code Number: ________ Date of Interview: ____________ Starting Time: _______ Ending Time: _______

Content (e.g., topics, focus, exact words, what stands out)	**Non-Verbal** (e.g., tone of voice, facial, body posture, tone of interview, hand gestures, eye movement)	**Investigator's Impressions** (e.g., emotional responses, discomfort with certain topics, sense of the person, personal thoughts)	**Analytical Processes** (e.g., questions, hypotheses, inferences, patterns or themes, interpretations)

(Adapted from Dufault, 1981)

APPENDIX H

Summary Profiles

Anne

Anne is a 51 year old female who was diagnosed with rheumatoid arthritis 14 years ago. She is currently married and has three children, two boys who are married and a 9 year old daughter at home. At the time of her diagnosis, Anne was a single mother of two boys and was practising dentistry. Her view of the illness was just one of many challenges in life, "a block that blocked my wheel." Her reaction was that of being tested, "Can I cope with it? Can I go on or will I give up?"

Anne had spent a lot of time searching for the cause of her illness. She has a number of theories, including having large babies, food allergies, fractured bones related to a fall and having a hysterectomy at an early age. She interviewed family members, but could not find a genetic link. She also spent time in hospital undergoing many tests, where they suggested that she had juvenile arthritis. Her conclusion from all of this searching was that even the doctors were unsure as to what starts off rheumatoid arthritis. Her attitude toward the illness is one of acceptance "I don't question, why me Lord. I figure it was meant to be, it was meant to be. I take it with a grain of salt."

Since the onset of her illness, Anne has received many different treatments, including both medications and surgery. She is currently receiving 11 different medications and was scheduled for further reconstructive surgery at the time of the interview. Her past experiences with medications have given her a healthy respect for them. She is willing to try, to experiment, but with a certain cautiousness. Before she tries any new medication, it is important for her to understand how the medication works and what are its side effects. She is willing to try medications providing that she, as well as her doctor, believes that they will be helpful. She describes herself as "not one to take pills." She follows the doctor's orders and does not believe in self-medication.

She describes her relationships with her physicians as collaborative and information-sharing. It is important that her physicians be honest, realistic and caring, without giving false hopes ("gives you hope, but not lie to you"). She emphasizes the importance of a reciprocal relationship based on trust. "It's got to do with the patient and the doctor. If the patient doesn't have confidence in the doctor, well, they haven't got confidence in theirselfs and they're just going to give up."

Since the onset of her illness, Anne has had to give up many things. Shortly after her diagnosis, she was forced to give up dentistry. Due to physical restrictions as a direct result of the illness, she has had to give up many sports which she had enjoyed. Although she has many physical limitations, she describes herself as a "fighter," a common theme for her being "not giving up."

One of her major forms of coping is to keep busy, to distract her from the pain. A common example of this is moving furniture in her home. She admits that by keeping busy, it distracts her from the pain during the day, but then the nights are difficult as she may have "overdone it."

She describes her life as one of many "challenges" and "hurts;" and that she came up the hard way. Her willingness to risk, to "try," to "fight," "to not give up" were a part of her even before the onset of her illness. A skill which she has developed as a result of the illness is resourcefulness, always thinking of ways to get around obstacles or "blocks."

With respect to hope, Anne sees herself as being very hopeful. She has a positive outlook for the future, "You got to look, tomorrow is another day. Tomorrow you might have hope." Other things which add to her own hopefulness include family and friends, "good doctors," "good science," success with her current medications and past success with surgery. Her hopes for the future include the safety and success of her family; a cure for herself as well as others; a greater understanding of the cause of the illness; a single medication which reduces the pain without side effects; and "good doctors." The one thing which would cause Anne to give up hope would be if she were confined to a bed. "If I was ever confined to a bed that......I'd give up hope then. Because I wouldn't be able to do what I've always done."

Brian

Brian is a 35 year old male who was diagnosed with epilepsy 10 years ago. He is single and lives on his own. Most of his family live in a different province. Brian experienced his first seizure or "accident" while at work 17 years ago. Initially, he did not know that he had epilepsy. He stated, "I kept ending up in the emergency ward. What am I doing here again?" It wasn't until his parents confronted his physician that Brian found out he had epilepsy.

His initial reaction to the diagnosis was one of misunderstanding and confusion. He described it as "a pretty heavy thing to all of a sudden find out and have happen to you." This situation was intensified by Brian's recurrent, unexplained admissions to a psychiatric ward and his neurologist's reluctance to openly discuss the disorder with Brian. He described the neurologist's response in the following manner: "You wouldn't understand and it's too many words for me to tell you."

Brian described the next four years as his "transition period," when he was not accepting the disorder. He described this period as being a "great time to party," being the basic "rebel" and saying "Ah, It'll go away." During this time, he was abusing alcohol and his prescribed medications. His view of this time period was a "one way crusade to massacre myself." "It had already snowballed and it was going down the other side of the hill and it was breaking up and getting smaller. My life was getting smaller and smaller."

He described a turning point of acceptance, when he was admitted to a psychiatric ward and his family, doctors and the executive director of the epilepsy support group confronted him. Everything came to the forefront. "My mind went click and okay accept it. That's all there is to it. You're not gonna beat it. No way."

Brian has speculated on a number of causes of the disorder. He described himself as a "rambunctious kid" who was always falling on his head. "You name it, I've done it to my head." He suggested that he did "major damage" when he was three. In addition to the head injuries, he also referred to the possibility of his lifestyle, misusing drugs and the move to a new city as contributing factors.

Since the onset of the epilepsy, Brian has received a variety of different combinations of medications. For the last three years, he is on a stabilized regimen of two medications and describes it at "the best one we've come up with." His current view of taking medications is "No problem. Doesn't bother me." "I know what I've got. It works. It's good. Hey, I'm a lucky dog." Brian is not a candidate for surgery, as the cause of his epilepsy is related to scar tissue from previous head injuries.

Although he has had unpleasant relationships with physicians in the past, he is more satisfied with his current relationships, particularly with his neurologist. "We see eye to eye. He's got a sense of humor and I can bounce things - bounce things off him and he throws them back to me. And there's no problem there." He is not as open with his "GP," his general practitioner; and is currently in disagreement with him regarding an application for funding from AISH (Assured Income for Severely Handicapped).

The greatest impact of this illness has been on Brian's financial and social status. He has been unemployed for ten years, as a direct result of the seizures and the reluctance of employers to hire a person with epilepsy. He feels discriminated against and has taken "steps lower in society." He has had to limit his spending and adjust his "basic living conditions," including food rationing. He has not received any support from the government, other than welfare, and feels that he is "basically fighting everyday."

Brian has managed to cope with his situation by remaining active, including involvement in an epilepsy support group. He describes himself as a "volunteer professional leisure counsellor." If he is able, then he would like to get back to some form of work someday. However, he is aware of his limitations, particularly with respect to stress and work.

His view of life, at this time, is one of acceptance of his situation, with awareness of limited options. "This is it. That's all there is to it." He currently sees his illness as a "friend," a "companion," an "extra member of the family."

His hopes regarding his illness are realistic. He does not hope for a cure for his condition, as it is not operable. His greatest hope is for "99.9% control" of the disorder with medications. "If you're stable you'd be all right for the rest of your life. But you can't be a hundred per cent cause you never know." He sees himself as hopeful, particularly with respect to control. Things which add to his hope include previous success with medications, present control of seizures and recent medical advances. The primary threat to his hope is the uncertainty and unpredictability of seizure control.

Catherine

Catherine is a 39 year old female who was diagnosed with having migraine headaches approximately eight years ago. She is currently married and has two daughters, aged 10 and 16. Catherine's headaches started when she was a child and around puberty. At that time, she would have the occasional "sick headache" which she would "sleep off." After her last child was born, which was approximately 10 years ago, she began to have monthly premenstrual migraines, as well as during the month. The "headache pills" which she was taking were not helping her and the headaches were getting worse. She didn't know what was wrong with her and described this time period, prior to the diagnosis, as being very "difficult." "I felt a sense of futility because nobody knew what the problem was and I felt that, I guess I felt that no one was giving me any help. That was what it was. I felt I was very much alone with this problem and nobody understood." The headaches were very "disruptive" in Catherine's life. She was losing weight because she couldn't eat and took about three days to recover from each headache. This recovery time made her feel unreliable as a prospective employee, which was very frustrating to her.

She described an incident in which she had had a headache for a whole weekend as a "turning point" or "crisis point." She felt extremely depressed and that she "couldn't cope with it anymore." It was at this time that she and her husband went to see a doctor to discuss her problem and to impress upon him the seriousness of this situation.

After having had the problem diagnosed, there was a period of time during which she did not accept it and tried to "soldier on." "I felt that sometimes I was indispensable, which I now realize is--no one is indispensable, but you learn that through an illness. You don't realize that at the beginning of the illness. You try and behave as a normal person without an illness. But then a certain degree of acceptance comes." She described two factors which were instrumental in accepting her situation. One was the availability of prophylactic medication which reduced the severity and apprehension of having a migraine. The second was the confrontation by members in a support group regarding her anger towards herself. It was at this time that she realized she was totally blameless. "It was like a light going on."

Catherine was much more relieved when a biological cause for her headaches (i.e. "hormonally-related") was identified. She stated that "the hormonally-related headaches are toughest to cure......and so I've just accepted my condition now."

She has undergone many forms of treatment for her migraines. She was initially taking painkillers which were not that helpful and produced side effects. After a trial of a number of medications, she is satisfied with her current regimen, consisting of four medications, one of which is a prophylactic medication. She has also tried a number of treatments other than medications, such as transcendental meditation (TM), biofeedback, relaxation therapies, and hypnotherapy, which have not been that successful. She is presently using homeopathic remedies, in combination with her medications, which seems to have helped. Catherine described one unfortunate incident in which she had tried a form of back manipulation, as a treatment, which resulted in a back injury. Since that time, she is still willing to try new treatments, but is adamant about knowing what is involved in any treatment process. "It's my body and I want to know what drugs are going in to it and what the side effects will be. And I feel much better knowing that. And then I can make an educated decision on whether or not I want to try something." Although she is always searching for something new, she admits that she has probably "tried everything."

She described her previous conception of physicians as authority figures. She was frustrated and angry when she initially sought help for what she thought was a "simple problem" and the physician was unable to "fix it." She felt that the physician was nonsupportive and patronizing. She "struggled" to find a "good physician" and describes her current relationship as being reciprocal and collaborative. There is honesty, trust, information-sharing and active listening. She has learned about her condition on her own and feels that she is more well-informed than many doctors.

Since the onset of her illness, Catherine has had to give up certain things, such as a career. She spoke of a certain amount of "resentment" which goes along with that. However, she stated that she is over all of that now and has grown to appreciate the positive aspects of having migraines. She has accepted her limitations in life and describes her life as being "enriched," having a greater "realization of simple pleasures." Her view of life has changed from being a "Mother Theresa" to achieving goals in "very small quiet way, on a one-to-one basis." She has also grown to value her health and to put herself first. She stated that a "balance came into her life" when she changed her goals from "100% health" to "85% health." Her view of her illness, at this time, is "a small cross to bear," "nothing in the whole scheme of things."

Catherine has managed to cope with her situation primarily through her own inner strength and spiritual beliefs. She describes herself as having "a spirit inside me that nobody could flatten. And nobody has. I've always been extremely optimistic. And it's just a gift I guess." She emphasized that she has had to learn about her condition by her self, "I had to self-educate myself," and reinforced the need for greater "recognition of this as being an illness or a condition." Her family and church have been major sources of support.

She describes herself as being very "optimistic" and "hopeful," even during low times in her life. "I never really give up on anything. I'm very optimistic and even at the lowest point in my life I feel optimistic. There is something." Other factors which add to her own hopefulness include her family, the church, her support group, a good relationship with her physician, prophylactic medications, reasonable control of her migraines and recent advances in medical science. Her hopes for the future include hope for something to treat or cure the problem; possible career plans; and an enjoyable retirement.

David

David is a 65 year old retired, railroad superintendent who was first diagnosed with hypertension 27 years ago. He is married and his children are no longer living at home. The hypertension was first discovered during a routine check-up. When it was first diagnosed, David did not see it as a serious problem and did not always take his medications regularly. "I used it off and on."

It was not until approximately seven to eight years later that his doctor became quite concerned about his blood pressure readings and admitted him to hospital to help stabilize it. During this hospital stay, David stated that he had the unpleasant experience of having his roommate "pass away on me." He also met different people with more problems than what he had. He always thought that he would make it, but this experience reinforced his desire to get well and to take his medications regularly.

David stated that the doctor's term for his illness is "essential hypertension," meaning that there is no known cause. Some of his own personal theories included eating block salt as a kid; the possibility of it being hereditary as his mother had high blood pressure; or being "keyed up."

Since the onset of his illness, David has received a number of different medications. He is currently receiving two medications. There was a period of time, when David's blood pressure was out of control, and the medications were not helping. He described himself as being "somewhat in a panic." "Well, I don't know. I've just had the feeling, God, you know, is this the best they can do? Isn't there something else you can do better than that you know?" He also described an incident where he became anxious about receiving a medication which was helping, but which caused a lot of side effects. " Well, I thought if it would arrest it fine. But I came to the conclusion then that I was..... too much medication...... I was starting to get scared of, you know." "A guy doesn't want to ruin his kidney taking a bunch of medication." His general view of medication was that it was "something that you could keep away from." The medication which he is currently taking for his hypertension has been very effective without any major side effects. His view of medication today is that it is "simple," "a necessity of life." "It's sort of a habit with me......I have no problem at all [remembering to take the medication]." He is willing to experiment with new medications although he admits that things are well under control now.

David has a trusting relationship with his physicians. "I always left it in the hands of the doctors - especially if you go to the cardiologist." He has a blood pressure machine at home which he uses to monitor his readings. He sees the doctor as a source of confirmation for his readings at home. He described the machine as a "horoscope," which he used to measure and record his blood pressure on a daily basis. Now that his blood pressure is more stabilized, he measures it less frequently (eg. once a week).

Since the onset of the illness, David has made some changes in his life. He stated that he always was "health conscious," but that he has altered his diet and quit smoking. One of his primary coping strategies is to remain active. His view of his illness has changed from not being serious, when it was initially diagnosed, to being serious and not to be taken lightly. He has accepted his illness, particularly now that it is well-controlled.

"So many people have it, you know. Why shouldn't it be me? So what. No big deal. It's not - especially if you have the proper medication." He describes his illness as being "secondary" and is more concerned about other illnesses to which he may be susceptible, due to his age, such as cancer. However, he does state that he is always on the "defensive."

His view of life is "survival of the fittest," and he sees himself as being "strong," "tough." He also is realistic regarding life experiences. "Face the facts." "Don't kid yourself."

His outlook for the future is positive. "I'll get by. I know I'm gonna make it." A number of factors contribute towards his hopefulness, including his mother who had hypertension and lived to the age of 93; other family members who lived long, healthy lives; other people who are worse off than he is; trust in his physicians; the "proper" medication; the ability to monitor blood pressure on a daily basis in the home; and the present control of his blood pressure. His hopes for the future include a hope for a cure, "something which completely eradicates the system;" for a medication which can be taken less frequently, although he admits his present schedule is "simple;" and "to live to a ripe, old age, but you can never tell." A number of things which may interfere with his future hopes include his fear of a stroke; the fact that his father died of a heart attack; and fear of developing another illness such as cancer, due to his age. "Anything could happen anytime. I don't trust anything."

Eric

Eric is a 55 year old male who was diagnosed with diabetes 29 years ago. Nineteen years ago, it was discovered that he had developed hypertension, as a complication of the diabetes. The progressive nature of this illness resulted in chronic renal insufficiency one year ago, necessitating regular dialysis treatments. Eric is married and has one son who is living at home.

When Eric was first diagnosed with diabetes, he was a single, graduate student who did a lot of travelling related to his studies. His view of the illness, at that time, was that it was "not serious, not made to me serious, when it was first diagnosed." The illness did not interfere with his lifestyle and his compliance was variable, especially with respect to his diet. "My compliance was as much as I could, without sacrificing the lifestyle that I had to live." He was started on the diabetic pill, but was switched to insulin shortly after.

Nine years after he was first diagnosed, Eric was referred to a specialist to handle his diabetes. He was still "active" and had just recently married. At this time, he attended a diabetic teaching program and stated that from then on, he was much more careful, especially with medications. His lifestyle changed in that he was more settled, had more of a regular routine and did not travel as much.

A year later, he was diagnosed with having hypertension. During the next 4 to 5 years, he was put on a number of different combinations of new medications. He described himself as being "very adaptable, very compliant." "I just take what comes and cope with it." His reaction to his illnesses was one of acceptance. "And I lived with it. It's just a part of my, an extra part of my routine."

He gradually began to develop a number of other complications related to the diabetes, including neuropathy and retinopathy. At this point, he still saw the disease as "a problem that has to be coped with." "But it did not really show that this problem was serious. That if you slack a little bit it could be dangerous later on."

A few years later, his kidney function began to decline, as a result of both the diabetes and the hypertension. His reaction was as follows: "I accepted it as part of the complications.....I never thought that, gee, that means it could be in my lifetime, that my kidney could fail completely.....I blocked out of my mind the seriousness of the kidney situation because I thought always that I'm in control."

About four years ago, Eric began experiencing further complications of his decreased renal function. It was at this time that he realized his kidney was going to fail and he accepted it. "I just gave in. My kidney is going to fail.....Accepted it right away a started reading about dialysis." The intensity of the complications increased to the po where he was working at "20%" of his energy. His hemoglobin began to drop and h experienced extreme fatigue.

Approximately one year ago, he became very ill, was admitted to the hospital was started on dialysis the next day. The first two months of dialysis were very diffi didn't think I would make it." "That's the time when I thought I may not - that the di may not work." He described this time as a "turmoil period," a "very trying period," tried to adjust to the dialysis and his new renal diet. Once he began to adjust, he rega some energy. He was checked for the transplant program but after reading about it a statistics for survival, he decided to reject the possibility of a transplant and remain o dialysis.

Since the onset of the diabetes, Eric has received a variety of medications. H initially on a diabetic pill and then switched to insulin. He was taking insulin alone f approximately ten years, at which time he was started on the antihypertensive medic He is currently receiving 9 different medications, in addition to his renal dialysis trea which alternate between two and three times per week. His view of medications is th are a "necessity" and he has readily accepted them. However he stated that "I don't t medications just like that....I feel that I have control over medicating myself too." H always reads about and discusses his medication with his physician before he decide take it.

Eric describes his relationship with his physician as a "two-way process." "I share and he does his share of treating me." He has taken an active role in the decisio making regarding his illness and treatments. He was appreciative of his doctor's gra step-wise approach regarding the complications of his illness, which he described as cultural part of medicine," having an "emotional touch." He also acknowledged the c role which the physician plays in coping with an illness. "I really think finding a goo doctor also is a major part of dealing with your disease, because I know that not.....m people are lucky to have doctors who are like that [allowing the patient a certain degre control and independence]."

Since the onset of the diabetes, Eric has had to make certain adjustments in his Initially, his lifestyle was not adversely affected. As the complications worsened, hov and he became weaker, he had to limit his travelling and adjust his work schedule. Th thing which he has not had to give up was his ability to work.

His primary method of coping has been his philosophical approach to life of "acceptance." In all aspects of his life, he has always been aware of his limitations an worked within them. If something was beyond his control, then he would automatica accept it, rather than try to reject or deny it.

Eric viewed hope as a part of the coping process. "Hope really is a state of mi which through influence, through religion, through beliefs, through whatever, keeps person going, with although he has a detrimental condition.......Hope to me is the cc process.....The reason I cope easier is because I have hope." He describes his major source of hope as coming from within. His model of hope is derived from historical religious leaders. "It impresses me that people could live comfortably even suffering.....History to me shows that hope can work." Other factors which help wi "complex of coping," in addition to his psychological state of mind, include a "gooc doctor," the "treatments available," the "medications," "good family support" and a facility." His hopes for the future include "not to be a burden;" "not to be depressed; for "comfort;" hope for "acceptance and stabilization of the condition;" hope to be at cope; hope to make things easier for his family; and a hope to work as long as possi The major threat to his hopes, at this time, is the possibility of complications from tl medications.

Faye

Faye is a 58 year old female who was diagnosed with two different types of cancer: cancer of the uterus and cervix, 24 years ago; and breast cancer, 13 years ago. At the time of this interview, Faye was married and had one son who no longer lived at home.

She was informed of her first diagnosis, by her physician, over the phone. She stated that she took it "quite calmly," although "the rest of the family didn't." Her philosophy was not to overreact until all the facts were available. "You don't put the horse before the cart. And until you go and have the surgery done or whatever is done - there's no use putting a cap on it and saying one way or the other." The cancer was removed surgically and she "wasn't troubled for several years later." Her sense of hope, at that time, was for "100% hope of survival." "I never gave it a thought that I wouldn't survive." Her family and caring for her child, who was 5 years old at the time, helped her maintain her hope and gave her the "courage to go on." Her situation was complicated by the fact that she had been in a car accident one year prior to the cancer diagnosis and was receiving treatment for chronic neck pain. Her hope for the future was to return back to a simpler way of life. "I was looking for the time when I could get rid of these things. Just go for an afternoon tea or something without being in trouble." Her major concern, at that time, was that there wouldn't be a "permanent injury."

Faye had no more signs of cancer until 12 years later when a lump was discovered in her breast and she had a mastectomy. "There was a good spell in there where I had no problems." Her initial reaction to the diagnosis was anger and disappointment, a "ticked off feeling," as she saw it as another "interruption" in her life. Her reaction to the surgery was to "go ahead and do it." "You don't duck the issue. You never duck the issue." She had quickly resolved, in her own mind, any grief over the loss of her breast, even before the mastectomy. "In my own mind that night [prior to surgery] the mastectomy was done mentally.....I don't need a breast to eat with. I don't need it to think with. I don't need it

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She saw her medications as "helping the cause," and was disappointed when a treatment was postponed. She stated that her motivation for taking her medications was the "will to live. I'm not ready to go yet." She also recognized the importance of being patient while her doctors were trying to find the right combination of medications, the "right recipe." She did not believe in taking medications which were not prescribed by a physician, for example health food store products. She is currently receiving ten medications while in hospital.

She described her relationship with her physician as being "open." She had a lot of trust in this relationship. She did not acknowledge any negotiation in this relationship and saw herself and her physician in two distinctive roles of "patient" and "doctor." However, she did suggest that if there were problems with side effects with medications, then she would discuss this. She stated that she had a lot of "faith" in her doctors, but that they had to have faith too. "You don't give up on hope......and if the doctor gives up hope, find a new doctor. I'll go so far as that. If the doctor gives up then find a new doctor. Cause you don't want him on your team. If he's out there telling you you're not gonna win the game, you don't want him on your team."

Faye's primary coping strategy was maintaining a positive attitude, "even when you're hurting." Work and humor were two "medicines" which she found very helpful. Her view of life had changed with her illness, as she stated, "Life becomes more realistic." She saw life at the "top end of the thing." "Just plain living is you're at the top end of the scale. If you aren't, you should be working to get there." One skill which she had developed as a result of her illness was "patience." "You have to be patient. You can't rush things. It's not like taking a pill and the headache goes away. I mean when you have something like this you take a lot of pills and you have the headache for a lot of days and maybe eventually it'll go away if you keep working on it."

Faye described hope as a hope for living. She saw it as being "bright," "fun." "It's a lifter. It's not a downer." Her own positive attitude was her greatest asset. "By and large, I think there's always a solution to everything.....I believe there's that, what should you say, rainbow out there.....You never give up that rainbow." Other things which added to her hopefulness included the support of her family and friends; faith and confidence in her physician and herself; confidence in her medications; and medical advances. Her hopes for the immediate future related to her mobility and independence, for example, to be able to get out of bed on her own. Her long-term hope was for active treatment with medications and getting better to enjoy life. Things which she saw not as threats, but as delays, towards her future hopes included not being able to have active treatment and physical complications related to the cancer. She also emphasized the importance of finding a new doctor, "if your doctor gives up hope," as well as staying away from people who are "downners." "You don't want anybody hanging onto you that brings you down. You fight to stay up and they bring you down. Where are you?"

Gordon

Gordon is a 58 year old male who developed four different chronic illnesses over a four-year time frame. Initially, Gordon was diagnosed with polymyalgia rheumatica. One year later he developed rheumatoid arthritis, followed closely by osteoporosis. Then, two years ago, he was diagnosed with cancer, specifically Hodgkin's lymphoma. He is married, has three married daughters and four grandchildren.

He described the onset of his first illness as coming on "instantly." "It hit me on July 4th, at 7:30 in the morning, with massive body pain." It was not diagnosed as polymyalgia rheumatica until two weeks later. He described his reaction during those two weeks as being confused, anxious and painful. "The pain was so excruciating..... the pain was so vicious." He had never been sick a day in his life prior to this event and felt he was really "floundering." He was unable to describe his sense of hope at that time. "I couldn't even put a number on it [hope] because I was really floundering .... hope......it never entered my mind." He was prescribed some medication to help relieve the pain and was told that there was no cure.

He continued on his medications and developed rheumatoid arthritis, followed by osteoporosis, approximately one year later. The osteoporosis was a direct result of his medications for the polymyalgia rheumatica.

Then, a year later, he was diagnosed with cancer, Hodgkin's lymphoma, which he himself discovered. The initial reaction by the surgeon was that the tumor was inoperable and that treatment was not indicated. Gordon responded by taking the initiative. He found himself the best "cancer doctor" and began treatments the day of surgery.

Gordon received a vast amount of medications. He described himself as being on "buckets of pills." He was given a "sledgehammer treatment" of chemotherapy, followed by radiation treatments. He describes the time period when he was receiving chemotherapy as being "tough." "It is the worst thing you could ever go through. I wouldn't wish it on my worst enemy if I had an enemy." He refused to have any help and drove himself to all of his treatments. "I had to control the cancer. The cancer couldn't control me." He experienced many side effects while on the chemotherapy,"With me everything went wrong." Yet he continued to take his medications, without saying anything. "No, I wouldn't [say anything].....because they would stop the treatments and I would be dead. So I just kept on taking it.....Every minute of every day, I was first in line." Today, he views his medications as "poison" and he sees himself as a "junkie." He is afraid of becoming an addict and so is reluctant to take a lot of pain killers. He views his medication as a "control;" they are not a cure.

He values his relationships with his physicians and sees them as being the "best." He takes an active role in reading about his illness but is dependent upon his physician, particularly with respect to medications. "[Medications] That's the one area where a layman has to totally depend on the medical profession."

He describes "massive changes" in his lifestyle since he became ill. He had to give up work, which he thoroughly enjoyed. He had a very high profile in the community and has had a change in financial status. He describes himself as a "workaholic" and finds it very difficult to have to rest. He sees himself as "half a man," because of his limitations. "I don't like being half a man. I like to be a full man and that's what I am shooting for." His primary method of coping has been his "fighting attitude." He uses a number of self-healing practices such as self-hypnosis and reading. His family provides him with continual support. He mentioned that "sound economics" and "humor" are important medicines. "Humor is the adrenaline of medicine."

Gordon describes hope as the "art of living." "I can continue to fight and hope means the art of living. I can continue to live, I can continue to do.....work towards a normal life which I hope to have one day soon." His hopes for the future include a remission of the polymyalgia rheumatica; to"get rid of the cancer;" "to work towards a normal life;" and to teach his grandchildren the "importance of financial sound structure," and to see them graduate. Factors which contribute to his own hopefulness include his "love of family," his friends, his doctors, his psychologist and the "best cancer treatment [facility] in the world." Things which may interfere with his future hopes is the fear of addiction to medications; and the length and severity of the pain. "I can tell you there is times when my patience runs a little thin. I mean three years and ten months is a long time to suffer pain. It's a long time to suffer pain."

Heather

Heather is a 25 year old laboratory technician who was diagnosed with diabetes 18 years ago. Approximately two and a half years ago, she developed a complication of hypertension, accompanied with some renal involvement. She is presently single and lives at home with her mother and her 16 year old brother.

Heather was eight years old when she was first diagnosed with diabetes and was started on insulin. Her mother took responsibility for looking after her insulin until Heather was old enough to do it on her own. She remembers her first reaction to getting the needle. "I must be weird or something but I have never had a problem with the needle. I remember the first day they came in and they said you have to take insulin because I had been really sick. And I said, oh, okay, and I put it in my leg and I had no problem. The second day maybe I remember crying."

She recalled her experiences of being an adolescent and having diabetes. She had a poor relationship with her physician, whom she thought never understood her. "You [in reference to her physician] don't know what it is like. You don't understand what it is like to take a needle and what it is like to measure and what is it like - you just don't know what it is like." She also described her compliance as variable. "I would take my shots but I never cared what I ate, to a certain degree."

For the first 14 years of her illness, she was being monitored by her family physician, as opposed to a specialist. When she was 21 years old, her sugars became more difficult to control. Everything was "out of whack." She described her frustration and anger with the situation because she had been trying so hard to be "perfect" or "good," yet things were still out of control. She was forwarded to a specialist who sent her through a diabetic teaching program. He also changed her insulin, as it was no longer effective. She stated that she had forgotten "how to be a diabetic."

Approximately two and a half years ago, Heather was diagnosed with hypertension, which involved some renal damage. It was at this time that she became more careful with her medications and her compliance. She stated that she regretted not having taken better care of herself when she was younger.

Heather has been taking insulin ever since she was diagnosed with the diabetes. Her insulins have been changed over the years. She is currently receiving two types of insulin and two medications for her hypertension. She doesn't feel that she has any problem taking her medications. "You know, taking a pill to me is nothing. It's not something I have to think too hard about." She states that she is "not an exceptionally compliant patient," particularly with respect to her diet.

Her previous relationship with her physician was not good, due to a lack of understanding. She is more satisfied with her current relationship, and sees her physician as her "watch dog." She stated that she needs someone to keep "close tabs" on her, to encourage and remind her regarding her care. She sees this role being fulfilled by her physician.

She doesn't feel that she has had to change much of her lifestyle to accommodate her illness, although she did admit that there are certain "limitations" and that "it makes life a little more complicated." To Heather it is "normal" to be a diabetic. "I don't think of myself as any different from anyone else, like that doesn't stop me from doing what I want to do." She did mention that she has had to become more organized and plan ahead, particularly when travelling. She is not able to be as spontaneous.

Her major form of coping comes from within herself. She has tried to maintain a positive attitude regarding her illness. "If you don't dwell on what is wrong or what is going to happen, then you lead a basically normal life." She has also been able to see a positive side to her illness of being able to help new diabetics. "Well you know, you can maybe help someone else deal with something they are going through. By saying that you are not limited by.....diabetes. Like you don't have to lock yourself away and not do anything and not dream of being a mountain climber or whatever you want to do. If you want to and have the drive to do it you can really." Her spiritual beliefs are also of importance. Her family provides a form of support, but she is directly and solely responsible for caring for herself. "My family is very - we're very close. But when it comes to worrying about my diabetes I think it is more my own. I have to do it on my own."

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APPENDIX I

Project Work Plan

Project Title: **Learning to Live with Uncertainty: The Role of Hope and Medication Compliance in Chronic Illness.**

Investigator:
Cheryl Nekolaichuk
Master's Student
Department of Educational Psychology

Phase I: Development of Proposal

Time Period	Activities	Rationale
Aug - Oct, 1989	Development of research question	
	Review of literature	
	Development of Interview Guide	
	Review of interview guide by panel consisting of two physicians, one nurse, two psychologists and one patient; as well as from pilot sample data	Credibility

Phase II: Obtaining Ethical Clearance

Time Period	Activities	Rationale
Nov, 1989 - Jan, 1990	Submission to Ethics Review Committee Department of Educational Psychology (approved Oct 30, 1989)	
	Submission to Ethics Review Committee Edmonton General Hospital (approved Jan 11, 1990)	
	Submission to Ethics Review Committee Cross Cancer Institute (submission withdrawn)	
	Contacting family physician, private practice	

	Contacting support groups (i.e. Alberta Migraine Assistance Assoc, Edmonton Epilepsy Assoc, Arthritis Society, Parkinson's Disease Society)	
	Contacting Northern Alberta Cardiac Rehabilitation Unit, Royal Alexandra Hospital	

Phase III. Identification of Potential Participants

Time Period	Activities	Rationale
Nov, 1989 - Mar, 1990	Contacting institution/physician/nurse/support group to identify potential participants	
	Contacting participant by phone to explain study, obtain verbal consent to participate and arrange interview time	

Phase IV. Data Collection

Time Period	Activities	Rationale
Nov, 1989 - Mar, 1990	Completion of biographical data sheet by investigator/nurse/physician/participant prior to interview	Fittingness (Data Triangulation)
	Conducting interview(s) with participant incorporating elements of a "good interview." Interviews to be audio-recorded.	Credibility
	Completion of field notes by investigator within 24 hours of interview	Auditability
	Translation of audio recordings into written transcripts	Credibility
	Comparison of transcript with audio recording by investigator	Credibility
	Review of transcript by participant and discussion with investigator	Credibility
	Review of interviewing style by thesis supervisor	Credibility

Phase V: Data Analysis

Time Period	Activities	Rationale
Nov, 1989 - June, 1990	Coding of transcript by investigator and thesis supervisor	Fittingness (Investigator Triangulation)
	Organization of codes using computer program "Factfinder"	
	Comparison of codes from one interview to the next	
	Detailed documentation of coding procedures, coding comparisons, memoes, field notes	Auditability
	Based on coding comparisons, selection of next participant	
	Development of emerging codes, patterns, themes (i.e. findings)	
	Review of transcripts by secondary coders	Auditability and Fittingness (Investigator Triangulation)
	Review of model, prior to final report, by participant, investigator's supervisor and family physician	Fittingness (Investigator Triangulation)

Phase VI: Review of Findings and Preparation of Final Report

Time Period	Activities	Rationale
May - June, 1990	Preparation of final report with detailed documentation of development of research question, sample selection, data collection and analysis	Auditability
	Comparison of study findings with findings in the literature	Fittingness (Theoretical Triangulation)
	Review of study findings by two chronically-ill individuals who were not participants in the study, as well as by a family physician	Fittingness

APPENDIX J

Review of Model and Research Findings

Review of Model (Figure 2)

All three reviewers, that is, the investigator's thesis supervisor, the physician, and one of the participants from the study, agreed with most aspects of this model. The study participant strongly identified with the word "uncertainty," stating that it was an "excellent" word. He further went on to describe the continual fluctuations which he experiences between periods of uncertainty and certainty, like "a rocking back and forth."

To strengthen the fittingness of the model, a number of suggestions which were offered by the reviewers were incorporated:

(1) Initially, the hoping network was represented independently of the uncertainty of the illness process. This was changed to an integrated figure which represents the interconnectedness of this network with the uncertainty of the situation.

(2) The three phases of the hoping and coping processes tend to overlap. Therefore, double arrows, indicating a reciprocal process were added.

(3) Some of the terminology was too "academic," according to one of the reviewers. A number of changes in terms were implemented.

(a) the term "people" was added (as opposed to "relationships")

(b) with respect to goals or hoping objects, the term "hope for" was removed (eg. "hope for a cure" became "a cure"; "hope for a remission" became "remission")

(c) "environment" was changed to "living environment"

(d) Phase III was renamed "Mastering the Life of Uncertainty," as opposed to "Learning to Live with Uncertainty"

(e) suggestions for the term "problems" included "disease," "sickness," "life vs. death," "limitations," "crippledness." Although the investigator chose not to change this term, she did acknowledge that it was not descriptive enough. The use of language which is meaningful to the chronically-ill individual is an area for further research, as discussed in Chapter IX.

(4) Regarding the "hoping self," one of the questions which was raised was "Where do you find the "hopeless self" in this diagram?" The interrelationship of the hoping self with other aspects of the self requires further research, as discussed in Chapter IX.

Review of Findings

All three reviewers, that is, the family physician and the two women with breast cancer could relate to most aspects of the research findings. The family physician stated that he was not surprised by the comments of the participants. He believed that this study emphasized the importance of the patient's role in health care. He suggested that physicians should encourage patients to become more active and provide a role as the patient's advocate. He also agreed that if a patient has faith and confidence in the physician, then he or she is more likely to comply with medications. This relates to the concept of the physician as a hoping resource. He mentioned that the family physician has a special role to play in this area due to the continuity of care and relationship building which evolves over time with many patients. This may be of significance when patients are involved in varying levels of care within the health care system (for example, the involvement of both the family physician and the specialist in the terminal care of a patient). However, he did suggest that the physician may not be a hoping resource for everyone, in that some people are "easier to connect with than others." In general, he believed that this study would be beneficial for general practitioners to read, to increase their awareness of and sensitivity to patients' reactions regarding health-related issues.

In general, the two women with breast cancer suggested that they could relate to most of the quotes by the participants regarding personal health experiences and subsequent reactions. One of the women stated that she identified most strongly with the concept of the hoping network, particularly the two components of the hoping self and hoping resources.

The second reviewer identified a number of key issues: (1) the importance of the active involvement of the patient in health care; (2) the concept of the hoping self; (3) the significance of the physician-patient relationship; (4) the concept of the illness as a learning experience; (5) the value of normalization within support groups; (6) the importance of friendships with positive people; (7) the initial experience of confusion, isolation and loss of control when first being diagnosed with the illness (i.e. Phase I of the Coping Process); (8) the relevance of the term "uncertainty"; and (9) an increased awareness of the world and others who are worse off than oneself. Her concluding comments were that this study "helped put into perspective all the fears, doubts and uncertainties during the past years."

APPENDIX K

Oath of Confidentiality

Project Title: **Coping with Chronic Illness: The Relationship Between Hope and Medication Compliance**

Investigator: **Cheryl Nekolaichuk**
Department of Educational Psychology, U of A

All persons associated with the Coping with Chronic Illness Study, which is being conducted with individuals with chronic illness, are asked to sign an Oath of Confidentiality. Such oaths are rather common place in many government offices. However, because this project involves health-related, confidential information, the need for strict adherence in this matter is to be taken very seriously. You and the principal investigator could be held legally responsible for any damages resulting from breach of confidentiality. Therefore, I would ask that the signing of this oath be an indication of your commitment to the personal nature of all data gathered in this project.

I, ____________________________, swear (or solemnly affirm) that I
(print name)

will diligently, faithfully and to the best of my ability, execute according to law the duties required of me as an associate of the project known as **Coping with Chronic Illness: The Relationship Between Hope and Medication Compliance.** I will not, without undue authorization, disclose or make known any matter or thing which comes to my knowledge by reasons of my involvement in the service of this project.

____
(Signature)

Taken and subscribed before me at ______________________________

this ________ day of ____________, A.D. ________.

____
(Witness)