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A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCE OF HOPE IN FAMILIES WITH CHRONICALLY ILL CHILD

By

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ABSTRACT

A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCE OF HOPE IN FAMILIES WITH CHRONICALLY ILL CHILD

By

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The purpose of this study was to generate a structural description of the phenomenon of hope as experienced by families with a chronically ill child. The Giorgi modification was chosen as the phenomenological method for this study, since it is directed toward uncovering the meaning of a phenomenon as humanly lived. A small sample of two families with a chronically ill child, responded to an interrogatory statement. Descriptions of the experience of hope were sought from each family member and then analyzed to uncover the meaning of hope for each family.

It was found from this investigation that hope was a process of creating anew that became known as the individual anticipated the future. Hope was a uniquely lived process, heralded by a changing view of the situation which acted as an anchor for the individual.

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CHAPTER I

Introduction

Hope is a phenomenon, common to the human experience, that has intrigued many people. Philosophers, theologians, psychologists, scientists and nurses, all have shown interest in studying hope and in understanding this powerful dimension of the human experience. The importance of hope in man's experience has long been known to laymen and professionals, and it is widely accepted that with hope, people act, move, and achieve (Stotland, 1969). The concept of hope has been referred to as an emotion, an expectation, an illusion, or a disposition. According to Miller (1983), hope is the intrinsic component of life that nurtures a person's transition from being weak, vulnerable or dispairing, to living life as fully as possible. Hope is an energizing element that propels a person in transcendence toward the not yet.

Hope has been noted to be an important part of the healing process; in nursing, hope has been identified as being both a curative and carative factor (Watson, 1979). Korner (1970) saw hope as the source of

strength in all healing processes. For Lange (1970) hope was the motivational force which maintained an individual's energy and was essential to mobilizing forces toward health. In addition, Hickey (1986) saw hope as the necessary element in the life of an individual because it enabled one to either continue living or to die better.

Traditionally then, the role of the nurse regarding hope was to enable or instill hope within the patient and family unit (Hickey, 1986; Hinds, 1984; Korner, 1970; Stanely, 1978; Travelbee, 1971; Vaillot, 1970). According to Vaillot (1970), this inspiring of hope within the client by the nurse, enabled the individual to choose his/her own health state. However, there has been one nursing researcher, Magan (1986), whose results indicate a different focus for nurses. Magan (1986) conducted a phenomenological study of the lived experience of hopefulness/hopelessness, and found hopefulness not to be an element or trait, but rather a process. From Magan's (1986) study, hopefulness was the extended imagining spurred by resolute choosing that culminates in creating a new context. Since this new context is unique to each individual, nurses would not instill a universal trait or element but rather facilitate the individual's living the phenomenon, or process of hope.

Hope then, has been shown to be a phenomenon common to the human experience, and to understand its nuances and common elements, one must study hope as humanly lived. The unique nature of the human experience as it is lived, is its expression in relationship with others, in situation (Dilthey, 1961; Merleau-Ponty, 1974; Parse, 1981). It is in this interrelationship with others, in situation that the individual not only lives the experience, but also comes to know the experience (Parse, 1981). Thus an individual's expression of knowing a phenomenon, such as hope, can be illuminated through that individual's interrelationships in situation.

Rossi (1983) agrees that hope's focus is indeed communal -- that is, it is not just of oneself but of each other. Rossi (1983) states, "Hope arises with the acknowledgement of human likeness. . . . hope is the expectation that from the acknowledgement of our likeness, we can then act in ways that enable us to go on" (p. 75). It is in this recognition of human communality that hope is aroused (Rossi, 1983).

A primary community, sharing in likeness, is the family. Through the interrelationships within the family, the knowing of the experience of hope emerges. Important to this concept of knowing is also situation. Marcel (1951) defines situation as "something in which

I find myself involved. . . I can not place myself outside it or before it. . . I am engaged in it." Thus, the situation is the context which cocreates the hope experience.

A situation some families are engaged in, which cocreates the hope experience, is that of having a child with a medical diagnosis of a chronic illness. Traditionally, chronic illness was believed to have an impact on the family in many dimensions of life's situations (Strauss, 1974). Sabbeth (1984) states that even the family's myths, which include attitude toward birth, growth, happiness, hope, despair, sickness, and death, shape and are shaped by the serious illness of a child in the family. However, according to Parse (1981), consistent with Marcel (1951), it's the meanings that the family assigns to the situation that create the reality for that family and thus the knowing of hope that the family experiences. The focus of this study is to investigate the meaning of the lived experience of hope for subjects experiencing a family situation in which one child has a chronic illness.

Research Question

This present study was undertaken to answer the following research question: What is the structural

description of the lived experience of hope for families with a chronically ill child?

Purpose

The purpose of this study is to generate a structural description of the phenomenon of hope as it is experienced in families with a chronically ill child. The structural description is synthesized from the essences of the phenomenon as described by the subjects. The rationale for choosing the phenomenological method for this study is that this method is directed toward uncovering the meaning of a phenomenon as humanly lived. The aim of this research is to shed light on the meaning of hope as humanly lived. The phenomenological method seeks descriptions from subjects who actually live the experiences. These descriptions are analyzed to uncover the meaning and create the structural description.

Phenomenon

Hope has been described as the most general name which can be given to the way people have access to the reality of a world of what ought to be. Hope is paradoxical. It is neither passive nor is it an unrealistic forcing of circumstances that cannot occur. Hope is the empowerment of imagination. In imagination, hope provides access for thinking and practice. Hope's

origin is in freedom, and hope engendered by that freedom shapes one's expectations of the future (Rossi, 1983). Lynch (1965) and Callieri and Frighi (1968) claim that hope is basic to the human experience and hope is at the center and heart of being human.

Eric Fromm (1968) states that hope is a decisive element in any attempt to bring about change in the direction of greater aliveness, awareness, and reason. In describing what it is to hope, From relates that hope is not solely to have desires and wishes. Fromm calls that passive hope -- the waiting for something to happen in the next moment and nothing expected in the now. Fromm sees passive hope as a disguised form of hopelessness. Rather, hope means "to be ready at every moment for that which is not yet born, and yet not become desperate if there is no birth in our life time" (Fromm, 1968). Fromm sees hope as dynamic and paradoxical. Hope is the intrinsic element of the dynamic nature of an individual's spirit. Hope is moving in the direction of transcending (Fromm, 1968).

Marcel, a contemporary existential philosopher, has written extensive phenomenological-oriented descriptions of hope. According to Marcel (1951), hope is also viewed as a process and psychic activity that is impossible to separate from the situation of which

it is a part. Hope is not a desire, nor is it optimism, but rather hope springs from the depths of one's being. Marcel (1951) emphasized the relation of hope to the experience of intra-subjectivity and "otherness." It is through this experience of communion with others, that one opens oneself to hope. Marcel (1951) attempted a definition of hope:

> We might say that hope is essentially the ability of a soul which has entered intimately enough into the experience of communion to accomplish in the teeth of will and knowledge the transcendent act -- the act establishing the vital regeneration of which this experience affords both the pledge and the first-fruits (p. 60).

For Vaillot (1970), hope involves reaching out beyond oneself. Hope does not stop at things -- it reaches out to "being." Vaillot (1970) bases the description of man's "being" upon Marcel's philosophy. Mankind achieves the perfection of its own being by participating as fully as possible toward a transcendent being. The way individuals reach toward the transcendent or fuller being is in connection with others. Vaillot (1970) implies that since hope is the reaching out to "more-being," or the transcending being, hope is uniquely lived by the individual while simultaneously connecting with others.

Dufault and Martoccio (1985) describe hope, as analyzed from their study, as a multidimensional

dynamic life force. Hope is characterized by a confident, yet uncertain, expectation in achieving a future good, which is realistically possible and personally significant. Hope is a complexity of many thoughts, feelings, and actions that change with time. Hope is process oriented; it is not unidimensional or trait oriented (Dufault & Martoccio, 1985). Stanely (1978) postulates from a phenomenological study of hope in healthy, young adults, that the

> lived experience of hope is a confident expectation of a significant future outcome accompanied by comfortable and uncomfortable feelings, characterized by a quality of transcendence and interpersonal relatedness and which action to effect the outcome is initiated (p. 165).

In summary, the lived experience of hope is synthesized from the literature as a multidimensional life force which is central to being. Hope is characterized by the paradoxical rhythm of uncertainty-certainty in the process of transcendence. Hope is spurred by resolute choosing and culminates in creating a new context.

Assumptions

This study is based upon the following assumptions.

1. The family is an interrelated living unit who is co-existing while co-constituting rhythmical patterns with the environment.

2. The family is an open system, who freely chooses meaning in situation.

3. The family, in its interrelatedness, co-creates the health of its individual members.

4. The experience of hope is a common human experience.

5. Human experiences are expressed in connectedness with others in situation.

6. Common human experiences have like elements.

7. Like elements are expressed under the same label.

Limitations

The limitations of this study are as follows:

1. The sample consists of two families, each of whom have a chronically ill child. The hope definition is derived from each family member's transcription. Thus the definition is only generalizable to those two families.

2. In this phenomenological research study, the lived experience of hope is sought from the subjects and analyzed by the researcher. Although the researcher makes his/her perspective explicit, the results of this study must be viewed from that perspective. Other researcher's could analyze the data differently. However it is hoped that other researchers

will understand the results in light of the researcher's stated perspective.

3. In phenomenological research theory is generated. Specifically using the Giorgi methodology a hypothesis regarding hope will be generated. This hypothesis will then need to be further examined using other subjects.

4. In phenomenological research, the quality of the data depends on the subject's verbal or written skills. In addition, the validity and reliability of a phenomenological study rests on the trusting relationships with the subjects by the researcher; the remembered accounts of hope are assumed to be valid and reliable for each subject.

Overview of Chapters

This study is presented in six chapters. In Chapter II, the pertinent literature relating to the research question will be reviewed. In Chapter III, the researcher's perspective, which is the researcher's beliefs about the phenomenon of hope, is made explicit. It is here that the researcher describes the meaning of the phenomenon of hope in the form of a propositional statement and includes beliefs from a theoretical frame of reference. In Chapter IV, the phenomenological

methodology and research design as well as the rationale for data analysis will be explained. In Chapter V, the data and the results of the data analysis will be presented. Finally study findings, conclusions, recommendations, and nursing implications for research, practice, and education will be included in Chapter VI.

CHAPTER II

Review of the Literature

Introduction

The focus of this chapter is on the research and significant literature of the phenomenon of hope. The purpose of this study is to generate a structural description of the phenomenon of hope as it is experienced in families with a chronically ill child. At present, there have been relatively few research studies conducted to uncover the experience of hope. However, there are numerous theoretical analyses, descriptions and conceptualizations from varying disciplinary perspectives which include: philosophy, theology, psychology, psychiatry, and nursing. These theoretical perspectives as well as related supportive literature, and research dealing with the phenomenon of hope will be presented.

The literature review will be divided into three sections which are related to the three emerging perspectives of hope. Section one deals with hope as a motivational construct, that ranges from drive theory to mastery or effective motivation. From this perspective hope is a determinant of human behavior which

motivates an individual to act. Section two deals with enabling hope in others, and section three deals with hope from an existential perspective. Each section will focus on both the theoretical and empirical literature concerning the phenomenon of hope.

Theoretical Perspectives Relating to Hope

There appears to be three perspectives emerging within the literature regarding hope. Within each perspective there is both a theoretical as well as an empirical basis. The first perspective posits that hope is a determinant of human behavior, a phenomenon that motivates the individual to act (Bernard, 1977 (p. 15); Breznitz, 1986 (p. 26); Erickson, Post & Paige, 1975; Harter, 1981; Korner, 1970; Lynch, 1965 (p. 21); Menninger, 1959; Mowrer, 1960; Mowrer & Gottshcalk, 1974 (p. 19); Stotland, 1969). The second perspective sees hope as being able to be manipulated by other people, or instilled in others. This perspective have been common to the helping services, especially the: nursing literature (Buehler, 1975; Dufault & Martocchio, 1985; Hickey, 1986; Hinds, 1984; Kubler-Ross, 1974; Lange, 1978; Miller, 1983; Stoner & Keampfer, 1985; and Vaillot, 1970). The third perspective emerges from a existential stance. Within this framework hope is viewed as both mystery and process.

This perspective values such concepts as struggle, the courage to be, mystery, and transcendence (Fromm, 1968; Magan, 1986; Marcel, 1951; Mermall, 1970; and Stanely, 1978).

Hope as a Motivational Construct

According to Harter (1981), motivational constructs have traditionally been at the very center in theorizing about human behavior. There appears to be three general approaches in regard to motivation. The first approach is behavioristic and is known as Drive theory. From this perspective an individual's instincts or drives force one to act in a certain manner or behavior. There is no choice on the part of the individual but rather reflex-like behaviors.

The second approach to motivation is from a cognitive perspective, and is known as the attributional model. From this perspective, there is believed to be a relationship between extrinsic rewards and intrinsic motivation. Finally, it is from this approach known as intrinsic motivation that the third approach has emerged and is called effectance or mastery motivation. Originally proposed by White (1959), effectance motivation impelled an individual toward competent performance and was satisfied by a feeling of efficacy. White considered this need to deal effectively with the

environment as intrinsic. When this need was satisfied, it produced inherent pleasures.

One of the earliest writings in regard to hope as a motivational construct was written by Menninger (1959). Menninger (1959), a psychiatrist, described hope as "the dim awareness of unconscious wishes which, like dreams, tend to come true" (p. 484). Hope is a creative drive that struggles with destructiveness and ultimate dissolution. For Menninger hope is active; there is no such thing as "idle hope", for a person's thoughts, hopes and wishes are already correlated with a plan of action and subsequent behavior. Thus hoping is intimately connected to purposing, intending and attempting.

Another behavioristic approach in the study of hope was used by Mowrer (1960). Hope was viewed as positive expectancy. Mowrer (1960) proposed that emotions are connected to instigating, guiding, and directing behavior. He classified the emotions of fear, anger, sorrow, and hope. Hope was seen as the prospect of the situation getting better whereas fear was the prospect of the situation getting worse. Anger was the possibility that something hoped for may be lost, and sorrow was that something hoped for <u>was</u> lost. Thus hope and fear were viewed as mirror images of the same phenomenon and dynamically intertwined.

However, unlike Menninger (1959), Mowrer (1960), did not view hope as a drive, with hopelessness meaning an individual was driveless or unmotivated. Rather Mowrer (1960) stated this:

> primary (biologically given) drives do not directly motivate behavior at all -- their chief function is to provide the basis for the conditioning of hopes and fears to independent or response dependent stimuli, whereas the hopes and fears thus acquired have a double function -- they motivate (direct) behavior also providing the basis for further (high-order) conditioning (p. 474).

Thus Mowrer (1960) saw the emotions of hope, fear, anger, and sorrow as the true motivations of human behavior. These emotions controlled, organized and directed behavior. Primary drives were important as reinforcers of that behavior since they provided the basis for the acquisition of fears and hopes.

Stotland (1969), another behaviorist, made a major contribution regarding both theoretical and empirical literature on hope. Stotland (1969) conceptualized hope as a sense of goal attainment. He concluded that achievement, accomplishment or attainment of future goals were not possible without hope. Hope was considered necessary for motivation and action, and the mediating process used to connect antecedent and consequent events. Stotland (1969) developed a theory of hopefulness and applied this theory to a number of different

clinical and research data in order to demonstrate the relationship between levels of expectation and goal achievement. According to Stotland (1969), there must be a sense of the possible regarding the attainment of future goals. He found after applying his theory to the data from other studies related to hope, that when the perceived probability of attaining the goal is high, the effective commitment and motivation for attaining the goals is also increased. Stotland (1969) proposed that the two determinants of motivation, the importance of the goal and the expectation of achieving it, would lead to 1) overt action toward the goal, 2) covert symbolic action toward the goal, and 3) selective attention to those aspects which are relevant to attaining the goal. Thus Stotland concluded that without hope, achievement of future goals would not be possible. However, Stotland (1969) did indicate limitations related to his measurement of hope since only in a few studies were direct measures utilized to study the level of expectation of goal achievement. Thus Stotland (1969) emphasized the need for an improved technique of measurement related to hope.

Although Stotland's (1969) theoretical constructs regarding hope and motivation and goal attainment were considered promising, his strategy for theory construction was criticized by Erickson, Post and Paige (1974).

Stotland's work was based on after-the-fact interpretations of previous studies rather than original research. As a result, Erickson, Post and Paige (1974) designed a study to empirically test those aspects of Stotland's theory related to hopefulness and an individual's psychiatric status.

A hope scale was developed consisting of a list of twenty future goals "common to our society" (p. 324). The hope scale was designed to measure both perceived importance (I) as well as perceived probability of attaining desirable goals (P). The hope scale was administered to several undergraduate classes at the University of Washington, and to hospitalized psychiatric patients at Seattle's VA Hospital (N=225). Preliminary reliability and validity data for the scale were presented with a test-retest reliability of .793 and I and .787 for P (p less than .001, two-tailed). Specific validity data were not presented.

The results showed support for Stotland's theory related to hope. Specifically support was substantiated for these three propositions: 1) An organism's motivation to achieve a goal is, in part, a positive function of perceived probability of attaining the goal and the perceived importance of the goal; 2) The higher an organism's perceived probability of attaining a goal and the greater the importance of that goal, the

greater will be the positive affect experienced by the organism; 3) That psychopathology is associated with lower estimates of perceived probability of goal attainment. The results also provided evidence for the reliability and validity of the Hope Scale as a measure of Stotland's construct of hopefulness. Thus Erickson, Post and Paige (1974) provide evidence that hope is a part of goal attainment and is necessary for motivation and action. In addition, this evidence is consistent with Stotland's theory of hopefulness.

Gottschalk (1974) also attempted to measure hope through the creation of the Gottschalk Hope Scale. Gottschalk (1974) defined hope as a measure of optimism that a favorable outcome is likely to occur in a person's earthly activities as well as spiritual or imaginary events. Gottschalk's (1974) Hope Scale demonstrated a method of measuring hope through content analysis of verbal behaviors. The sample consisted of groups: 1) 91 employed, medically healthy white men and women between the ages of 20 and 50; 2) 109 white male and female children from first through twelfth grades; 3) a group of medical patients with terminal cancer; 4) a group of psychiatric patients coming to a mental health clinic; 5) a group of male prisoners who were incarcerated in Maryland; and 6) a group of 23 diagnosed acute schizophrenic patients.

Five minute speech samples were elicited from the subjects in response to standardized instructions. The standardized instructions were:

> This is a study of speaking and conversational habits. I would like you to speak into the microphone of this tape recorder for five minutes about any interesting or dramatic personal life experiences you have ever had. While you are talking I prefer not to reply to any questions you have until the five minutes have elapsed. Do you have any questions now? If you have no more questions you may start speaking now (p. 799).

The instructions were designed to elicit speech behaviors likened to free association and, at the same time, to minimize the influence of the interviewer's behavior, both verbal and nonverbal, in determining the content of the speech. Subjects were asked to speak into a tape recorder about any interesting or dramatic personal life experience.

The transcripts were then scored by trained technicians familiar with the seven content categories on the Hope Scale (Interrater reliability = .85). The hope scores were found to be capable of predicting: 1) favorable outcome among patients in a Mental Health Crisis Clinic. 2) survival time in patients with terminal cancer, 3) patients likely to follow treatment recommendations, and 4) improvement in the depression factor in acute schizophrenic patients after a single dose of thioridazine. While the hope scores were found

capable of predicting outcomes for a variety of patients, the validation of the Gottschalk Hope Scale presented a problem since there were no measures for the psychological state of hope (Gottschalk, 1974). The results for Gottschalk's (1974) study do support the perspective that hope is part of an individual's motivation to achieve a future goal.

The foregoing analysis regarding hope literature related to the motivation of an individual has thus far reflected a behavioristic perspective. However, there are other approaches which also need to be highlighted.

Bernard (1977) suggested that hope is both genetic as well as environmentally linked. Bernard (1977) stated that "because physical health, perceptual capacities, and intelligence are in part inherited, it is likely that these, as factors in personality orientation, do predispose one to hope or hopelessness" (p. 285). Children though, according to Bernard (1977), learn about hope from their family environment generated by the patient-child interactions. In addition, Bernard also contended that personal choice and responsibility were important aspects of hope, since individuals are in part dynamic creations of their own life patterns.

Hope has also been viewed as a method of coping (Korner, 1970; Meissner, 1973; Breznitz, 1986). From

this perspective hope is seen as a positive phenomenon and its primary purpose is the avoidance of despair and its secondary function is to allow an individual to psychologically bypass ongoing or unpleasant situations. Breznitz (1986) in a discussion regarding the effect of hope on coping and stress makes the distinction between hope and the work of hoping. Hope according to Breznitz (1986), relates to a description of a cognitive state, whereas hoping implies an ongoing process. In order for hoping to impact an individual's adjustment to stress as well as health status, hope must consist of a process that is persistently intense enough to stimulate the physiological changes that account for its effect. Thus the work of hoping is an active, time consuming investment in cognitive work. That work or process often occurs at the point of helplessness and despair (Breznitz, 1986) and provides an individual with the motivation to act or cope.

In summary, the perspective of hope as a motivational construct, has been approached both behaviorally and cognitively. While there have been a few studies conducted related to the behavioral aspect of the motivational perspective of hope (Erickson, Post & Paige, 1975; Gottschalk, 1974; and Stotland, 1969) none have been conducted to study the cognitive approaches -- specifically, the effect of hope on coping with stress.

Furthermore, the studies which have been completed have only measured hope in relationship to perceived goal attainment with motivation thought to be related to goal attainment. Thus only one possible outcome of hope has been measured (with relatively poor validity data), and the process of hope has been totally ignored.

Enabling Hope in Others

The basic premise inherent within the second perspective, involves the manipulation of hope in order to enable or inspire hope within another individual. It is this perspective about the phenomenon of hope that appears to be the theme of most of the literature within nursing. The fact that hope is of importance to nursing has been well documented with the majority of the writings stemming from a clinical observational stance (Buehler, 1975; Dufault & Martocchio, 1985; Hickey, 1986; Hinds, 1984; Isoni, 1963; Lange, 1978; Miller, 1983; and Stoner & Keampfer, 1985). The salient points of those authors dealing with hope from the observational stance shall be discussed first, and the empirical studies discussed last.

According to Vaillot (1970), hope is part of the restoration of being. Through a clinical illustration, Vaillot (1970) demonstrated how a nurse's consistent

faith that a terminally ill woman could indeed be restored to a fuller being, was the element that "triggered hope in the family" who had "given up".

Vaillot went on to describe how the awakening of hope by the nurse in the family resulted in regained hope in the ill person. Thus, for Vaillot, the primary aim of nursing is to help clients to live as fully as possible. Nurses do this by facilitating clients to reach out to a fuller being or in other words, inspiring hope (Vaillot, 1970).

Similarly, Travelbee (1971) and Miller (1985), also saw the role of the nurse as assisting the ill person to maintain or regain hope, and avoid hopelessness. For Travelbee (1971), hope was defined as a mental state characterized by the desire to gain an end or accomplish a goal with some degree of expectation that the goal or end was attainable. She identified six characteristics of hope based on a experiential frame of reference: 1) hope is strongly related to dependence on others; 2) hope is future-oriented; 3) hope is related to choice; 4) hope is related to wishing; 5) hope is clearly related to trust and perseverance; and 6) hope is related to courage. Miller (1983) on the other hand, stated that she viewed hope as springing from several different sources for each person. Miller saw hope arising from an individual's faith, communion

with another, feeling needed, and from having something to accomplish. It was those sources that she thought provided a framework for nurses to select hope-inspiring strategies. The hope-inspiring strategies included: 1) emphasizing sustaining relaticnships; 2) telling the patient that the loss of control is temporary; 3) "radiating hope"; 4) expanding the patient's coping repertoire; 5) teaching reality surveillance; 7) helping the patient renew his/her spiritual self (Miller, 1983).

According to Lange (1978), the Hope Continuum was an explanatory model introduced to help nurses identify both hope and despair behaviors. For Lange (1978), hope and despair were at opposite ends of a continuum. Hope was comprised of four different behaviors: 1) Activation - feeling vibrant, interest and involvement; 2) Comfort - feeling free of conflict, feeling safe, that life is worth living; 3) Moving toward people - having an intense positive relationship with another, reaching out, wanting to touch, hold and be close; and 4) competence - feeling strong inside, being motivated, self efficacy. In addition, hope had both affective comments and cognitive functions.

The affective components of hope within the faith-doubt continuum includes elements of faith (a positive belief that unknown forces can be relied on), trust,

confidence in self and others, and fortitude. These are shown in attitudes and behaviors recognized as determination, motivation, inspiration, and encouragement. According to Lange (1978) when faith weakens, the person experiences doubt which can lead to despair. Despair is a complex concept consisting of attitudes and feelings which include hopelessness, helplessness, sadness, depression, and grief.

The cognitive component of hope as defined by Lange (1978) is the way one perceives and processes reality. The cognitive component protects the affective piece from threatening reality facts. The cognitive component is made up of selected information which will support the desired hope. Thus Lange (1978) states that if a person becomes overwhelmed by contradictory facts, denial or an increased faith may be utilized as a defense mechanism or the person may retreat from future oriented thinking, and concentrate only on the present. Lastly, Lange (1978) sees hope as a motivational force which maintains energy and is essential to mobilizing forces toward health. Nurses must provide an atmosphere of hope in order to maintain or restore hope by first exploring one's views of the meaning of life, illness, and death, and secondly, giving encouragement, and thirdly providing a clearer picture of the reality of the situation. In completing

the three hoping tasks, the nurse is better able to assist the client in coping, for hope helps to sustain a person's use of coping skills and prevent the individual from despairing (Lange, 1978).

Buehler (1975) studied the factors that contribute to hope in cancer patients by interviewing twenty-four clients who were receiving radiation therapy, as well as eight staff members from a urban medical center. From her interviews Buehler found one of the elements that instilled hope in the clients, was the expectation by the staff that the patients would be involved actively in their own care. Buehler posited that the reason this element was the main factor for instilling hope was due to a strong hope ideology which was manifested by the staff's interactions with their clients.

Hickey (1986) also explored the concept of hope as it applied to patients with cancer and their families. Hickey saw hope as an essential element in the lives of those experiencing cancer, because it "enables the living to continue on and the dying to die better" (p. 133). According to Hickey (1986) hope is an active behavior that can be enabled by nurses through five approaches. These approaches facilitate a realistic hope rather than a false hope in clients and include: 1) the use of active listening. Active listening helps the nurse skillfully guide a client's expression of

thoughts and feelings; 2) identifying a reason for living; 3) establishing support systems; 4) incorporating religion (as individually needed); and 5) setting realistic goals (Hickey, 1986).

The preceding literature provides nursing with insights regarding the healing aspects of hope, its connection to health, and the need for this element in order to give life meaning and direction. These theoretical pieces are not based upon empirical data. There have, however, been a few scientific investigations to uncover the meaning of hope, or the relationship of hope to health. Those empirical studies which are a part of the enabling hope perspective shall now be discussed.

Hinds (1984) attempted to induce a definition of hope through the use of Strauss' grounded theory methodology. In this study, 25 adolescents, ranging in age from 13 to 17 years old, served as the informants. Two populations were represented in this study. One group was considered "well". These "well" subjects were obtained from an alternative learning center for secondary education. The other group was considered "patient", and those subjects were obtained from an inpatient adolescent treatment unit for substance abuse.

Hinds (1984) translated the why, what, when, where, and how aspects of the conceptualization of hope

into eight questions. The data obtained was compared within and across each adolescent group from the two samples and categorized according to a certain shared similarity or underlying uniformity. Hinds was able to synthesize a construct definition of hope for both groups which comprised four categories, and formed a continuum of the degree of hope. The synthesized construct definition of hope found in this study was:

> the degree to which an adolescent believes that a personal tomorrow exists; this belief spans four hierarchical levels proceeding from lower to higher levels of believing.
>
> 1. Forced effort: the degree to which an adolescent tries to artificially take on a more positive view.
>
> 2. Personal possibilities: the extent to which an adolescent believes that second chances for self may exist.
>
> 3. Expectation of a better tomorrow: the degree to which an adolescent has a positive though non-specific future orientation.
>
> 4. Anticipation of a personal future: the extent to which an adolescent identifies specific and positive personal future possibilities (p. 360).

In another qualitative study, by Dufault and Martocchio (1985), a construct definition of hope was obtained. Dufault and Martocchio collected data over a two year period on 35 elderly cancer patients. Those subjects were 65 years or older. Then, to confirm the analysis and to further generalize the results, another

two year longitudinal study was conducted on 47 terminally ill persons with varied diagnosis who were 14 years and older. All data were collected through participant observation in multiple settings which included the acute care hospital and the subject's homes. From the analysis of the data of both longitudinal studies, Dufault and Martocchio (1985) found that:

> hope is a multidimensional life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically and personally significant. Hope has implications for action and for interpersonal relatedness. Hoping is not a single act but a complex of many thoughts, feelings, and actions that change with time. Hope is. . . process-oriented. . . and is conceptualized as being composed of two spheres and having six common dimensions (p. 380).

Dufault and Martocchio (1985) describe the two spheres of hope as generalized and particularized hope. Generalized hope is more intangible, broad in scope, and is a sense of some future beneficial developments. Particularized hope is concerned with a hope object of particularized valued outcome, good, or state of being. The six dimensions of hope identified were affective, cognitive, behavioral, affiliative, temporal, and contextual. Dufault and Martocchio (1985) then took the construct definition of hope and developed a framework to depict that construct definition. This framework of

hope can thus assist nurses in designing interventions to help individuals achieve or maintain hope by facilitating the nurse's knowledge of the nature of hope and manifestations of hope. Awareness of hope as a multidimensional life force can guide the nurse's listening, observing and interacting with the client in order to detect the presence or absence of each dimension and determine ways in which each dimension is present and can be further enabled.

Stoner and Keampfer (1985) conducted a quantitative study in which the relationship between hope and recalled life expectancy information was addressed. This study used a cross-sectional survey design in which data was collected by interview, at one point in time. Fifty-five subjects were interviewed using the Stoner Hope Scale (1982) and an interview guide. The interview guide elicited demographic, illness, and life expectancy information. The Stoner Hope Scale was used to measure the patient's hope level. Hope as defined by Stoner and Keampfer (1984), as a subtle, if not unconscious expectation regarding an abstract but positive aspect of the future.

The Stoner Hope Scale was based upon Stotland's (1969) theory of hopefulness and Erickson, Post, and Paige's (1975) tool to measure hope. Stotland's (1969)

conceptualization of hope as the importance and probability of attaining future goals was retained, but the tool also tried to incorporate the theoretical framework of both Lynch (1965) and Marcel (1951). Lynch (1965) and Marcel (1951) recognized the interior sense of hope which requires interaction with external resources.

Thirty goals which represented three spheres of hope were identified, tested, and used. Those spheres included: 1) intrapersonal hope (the interior domain of hope) i.e.: "to see the end to the threat of nuclear war"; and 3) global hope which goes beyond the person. The hope score then equaled perceived importance times the probability products summed. Thus the nursing applications derived from this study focus on determining the what, how much, when and how to communicate life expectancy information to patients who have cancer or other life threatening illnesses. In addition, giving too much information regarding the client's prognosis, according to this study, would not inspire or enable hope but rather foster hopelessness.

In summary, hope from the perspective most common to nursing, known as enabling hope, has viewed hope as a necessary and vital element in healing, health and life. Most nursing authors indicate that nurses should and do inspire, instill or enable hope in others. Some

of the authors even state strategies to instill hope in others. One strategy common to all the authors relates to reality surveillance or facilitating a realistic hope. However in the one quantitative study regarding communication of information and hopelessness just the opposite was found -- a person had a higher hope level when that individual could not recall information regarding life expectancy. Although one study does not provide conclusive evidence, it does indicate the need for more additional testing of the concept of hope.

In the few qualitative studies that have been completed common findings were revealed. Hope was found to contain aspects of a positive oriented outcome (Dufault & Martocchio, 1985; Hinds, 1984). Hope was characterized by interpersonal relatedness, action, and transcendence (Dufault & Martocchio, 1985). In addition, these qualitative studies provided nursing implications to enable hope or instill hope in others.

Existential Perspective

The last perspective which appears to be emerging in the literature is based in part on existential philosophy. Within this framework hope is viewed both as mystery and process. Concepts such as struggle, the courage to be, mystery, and transcendence are valued (Fromm, 1968; Mermall, 1970; Magan, 1986; Marcel, 1951;

and Stanely, 1978). At present there are both theoretical and empirical writings concerning hope from this perspective. The major writings from this perspective, both theoretical and empirical, shall be addressed.

One of the most significant existential-phenomenological descriptions of hope was written by Marcel (1951). Marcel (1951) viewed hope as a process and psychic activity which is impossible to separate from the situation of which it is a part. Marcel situated hope within the framework of captivity with the nature of that captivity being the human condition. Marcel saw the individual as constrained externally where the freedom to act is very constricted. The situation might seem impossible to the individual, and he/she might be tempted to despair. But hope is the act by which this despair or captivity is overcome. Marcel saw this overcoming as an "interior" overcoming which means the individual accepts the captivity as a necessary part of the self, rather than overcoming the external situation itself.

Hope for Marcel includes liberation as well as an element of despair. The situation seems impossible to control. However to hope means that "man must live in hope. . . ." rather than concentrate attention on encounters which cause no respite, fear and ruin (Marcel, 1951; p. 61). According to Marcel (1951) when

one is living hope, that individual makes him/herself available to accomplish "the transcendent act" which means the act that establishes one "as before, but differently and better than before" (p. 67).

Another significant description of hope was written by Pedro Lain Entralgo and translated and explicated my Mermall in 1970. Mermall (1970) referred to Lain Entralgo as Spain's philosopher of hope. Lain Entralgo's theory related the concepts of expectation, belief, hope, temporality and transcendence. Expectation was defined by Lain Entralgo, as interpreted by Mermall (1970), as the primary disposition of a "future oriented being." Expectation "consisted of inquiry and planning based on a set of beliefs that is articulated through creativity" (Mermall, 1970,p. 108). Inherent in this philosophy then is trust. One's trusts are based on how reality is perceived and trust according to Lain Entralgo is articulated by an individual's creativity. This creativity is an activity directed toward the enrichment of being and actualizing the possible (transcendence). How this creativity is acted out determines the degree of engagement which then in turn affects ones expectation. Hope, according to Lain Entralgo as interpreted by Mermall (1970), is trustful expectation in the possibilities of "being" -- the

hopeful person trusts that his creation "will be" (Mermall, 1970).

There have been a few empirical studies consistent with Marcel and Lain Entralgo's view of hope, and based upon existential phenomenology. Stanely (1978) used a phenomenological approach to study the everyday lived experience of hope in healthy young adults, ages 19 to 24. In this qualitative study, Stanely (1978) collected 100 responses to the research question: what are the common elements in the lived experience of hope? Stanely's aim was to unfold a structure of hope through a process of isolating the themes or experienced moments common to the individual experience of hope. Stanely (1978) used the specific methodology of Van Kaam, a contemporary phenomenologist. Subjects were asked to describe a situation in which hope was experienced and to describe their feelings just as they were when they experienced the situation.

Stanely (1978) was able to isolate seven common elements from the descriptions of the lived experiences of hope. The seven common elements were: expectation of a significant future outcome; the feeling of confidence of an outcome; the quality of transcendence; interpersonal relatedness; experiencing comfortable feelings; experiencing uncomfortable feelings; and

action or effort to effect outcome. These common elements were synthesized into a general structure of hope. Based on the research findings, Stanely (1978) formulated the structural definition of hope as a "confident expectation of a significant future outcome, accompanied by comfortable and uncomfortable feelings, characterized by a quality of transcendence and interpersonal relatedness and in which action to effect the outcome is initiated" (p. 165). Thus the existential view of struggle (hope was accompanied by uncomfortable and comfortable feelings), and transcendence were evident from this study.

Another qualitative study related to hope, sought to uncover the lived experience of hopefulness and hopelessness, (Magan, 1986). Magan (1986) based her study on both an existential perspective as well as Parse's (1981) Man-Living-Health Nursing Theory. To more fully understand the nursing perspective of this study, Parse's Nursing Theory, Man-Living-Health and its major concepts and principles shall now be discussed. The importance of this discussion relates not only to the understanding of Magan's (1986) phenomenological study, but Parse's (1981) Man-Living-Health theory of Nursing provided the perspective from which this present study was undertaken.

According to Parse (1981) Man is a synergistic being, more than and different from the sum of the parts. Man is recognized through patterns of relating. Man is an open being who coexists with the universe and whose negentropic unfolding is in a mutual and simultaneous interrelationship with the environment. Man is free to choose in situations and is transcending multidimensionally with the possibles.

Health is an open process of becoming uniquely lived by the individual. Health is the rhythmically coconstituting process of the man-environment interrelationship, and the intersubjective process of transcending with the possibles or man's struggle with the familiar toward the not yet (Parse, 1981). Thus, "man living health is structuring meaning multidimensionally in cocreating rhythmical patterns of relating while cotranscending with the possibles" (Parse, 1981).

According to Parse (1981), "structuring meaning multidimensionally," refers to the infinite number of universes that exist simultaneously for each person, and is the way that person cocreates reality with the world. Reality then is the harmony of those universes made concrete through a person's choosings. When a person makes choices, a world view and personal reality are created while giving meaning to unique experiences.

Thus Man living health is continually cocreating reality by assigning meaning to multidimensional experiences.

The ways to structure meaning multidimensionally, according to Parse (1981), is through languaging of valuing and imaging. Imaging is a process of shaping personal knowledge, or knowing, explicitly and tacitly all at once. This explicit and tacit knowing evolves simultaneously and is how Man gives meaning to experience. When imaging happens, the meaning given to the multidimensional experiences is made concrete.

Valuing as described by Parse (1981), is the way individuals confirm their cherished beliefs, and reflects a world view. Valuing occurs when a person chooses from the imaged options and owns these choices. As a person chooses and then acts on these values, meaning is sought. Thus, meaning-making and valuing are both aspects of the same reality.

Languaging, according to Parse (1981), involves speaking and moving, and is the expression of the valued images. Inherent in languaging is a person's interrelatedness with others. Through languaging, a person symbolizes unique realities with others, and thus meaning is shared with others.

Furthermore, Man living health is structuring meaning multidimensionally in cocreating rhythmical

patterns of relating (Parse, 1981). The rhythmical patterns of relating are how a person constitutes a way being in the world. These ways of being are rhythmical and are cocreated with others. Opposite rhythmic patterns are present simultaneously as a person relates to another. Cocreating these rhythmical patterns of relation happens in living the paradoxical unity of revealing-concealing, enabling-limiting, while connecting-separating.

Revealing-concealing according to Parse (1981), is the simultaneous disclosing of some aspects of self, while hiding other aspects. A person cannot disclose all that he/she is to another, so in choosing the ways of being to another, there will be present those things that are also concealed.

Enabling-limiting is a rhythm of relating that happens when a person chooses to be in a situation (Parse, 1981). In choosing, a person enables movement in one direction, while simultaneously limiting movement in another direction. A basic principle inherent in this rhythm is that an individual cannot be all possibilities at one time.

Connecting-separating can be recognized as a person is connecting with one phenomenon while simultaneously separating from another. This is the rhythm of communion and aloneness. This process of connecting-

separating is the main thrust of human development and a source of humanness unfolding. In separating from one phenomenon and dwelling with another, a person can integrate thought, become more complex, and will seek new unions (Parse, 1981).

Lastly, Man living health is structuring meaning multidimensionally in cocreating rhythmical patterns of relating, while cotranscending with the possibles (Parse, 1981). Cotranscending with the possibles is Man reaching toward the future to make possibles actuals, or going beyond toward the not yet. Cotranscendence is related to an individual's freedom in a situation. When a person transcends a given situation, alternatives or possibles open up and decisions are necessary to make these possibles actuals. Cotranscending with the possibles is the way Man with the environment reaches beyond the propels into the future. Cotranscending with the possibles is powering unique ways of originating in the process of transforming (Parse, 1981).

Powering according to Parse (1981) is a process that is a part of change and transformation. It is the pushing-resisting rhythm that happens when a person turns toward the future. Powering is the force of human existence and it underpins the courage to be. Powering is recognized in the continuous offering of

self in light of the possibility of non-being or loss of self. Powering unfolds itself in Man's interrelatedness with the world and is incarnated in man's intentions and actions in moving toward possibles.

Originating is a process of creating ourselves and is coconstituted in the interrelationships of others (Parse, 1981). Originating happens when one transcends the paradoxes inherent in this process, and thus new possibles of the self can be imaged. In originating, Man uniquely lives the paradoxical unity of conformity-nonconformity and certainty-uncertainty, simultaneously. These patterns of originating are languaged through one's ways of relating (Parse, 1981).

Transforming is the process of changes: a deliberate shift in the way one views the familiar (Parse, 1981). In struggling to integrate the familiar with the unfamiliar, unique possibilities emerge for the self in the person-world interrelationship. In transforming, one coconstitutes anew in a deliberate way. The individual is open to discovery, and the phenomenon is open to be discovered (Parse, 1981).

Parse (1981) states "Man-Living-Health, Man becoming, is the day to day creating of reality through languaging of valuing and imaging. Languaging reflects the rhythms of revealing-concealing, enabling-limiting,

and connecting-separating as people live powering as a way of originating transforming" (p. 67).

This discussion briefly outlined Parse's main theoretical concepts and principles inherent in her Theory of Nursing. From there principles and concepts Magan (1986) derived her researcher's perspective.

Magan (1986) saw hopefulness as the:

> intentional expectant anticipation of the future that is marked by gracefully giving oneself over to the flow of events that appears to be constricting and limiting, while being aware of that which threatens an individual's anticipation.

For Magan (1986) hopefulness is grounded in the view that hopelessness and hopefulness are complimentary and exist as a unity. "Hopefulness serves as a ground for hopelessness. When one of these experiences is focal, the other lies quiesent, so that each experience powers and transforms the other."

This view of hopefulness-hopelessness is consistent with Parse's Theory of Nursing, Man-Living-Health. Magan (1986) derived the following theoretical structure from the three principles of Parse's Theory of Nursing, and states that it is related to the lived experience of hopefulness-hopelessness. That theoretical structure is as follows:

> Transforming occurs in the rhythmical process of enabling-limiting while imaging. This means that individuals experience changing views of self while imaging. These specific

> characteristics about their goals that limit their movements and those that mobilize them in preferred directions. Hopefulness-Hopelessness as a lived experience is a manifestation of a rhythmical pattern of moving beyond certain situations by anticipating the newness of change and transformation through imaging the future.

After making explicit the researcher's perspective, that perspective was put aside or bracketed while the researcher analyzed the data. Data were collected from three male subjects. Each subject was asked to describe into a tape recorder a situation in which they experienced a feeling of hopefulness, and then an experience of hopelessness. The audio tapes were transcribed and then analyzed using the Giorgi methodology of phenomenological research.

The final level of analysis known as the general structural description of hope was derived by Magan (1986) and is as follows: "Hopefulness is the extended imagining spurred by resolute choosing that culminates in creating a new context."

In Magan's (1986) discussion of results she states that her findings include a moment of resolute choosing by the individual, the turning point in creating a new context or motivating action. However that moment of decision was not a part of her researcher's perspective. While her theoretical structure as stated was confirmed, it did not explicitly include the moment of

resolute choosing. Thus a hypothesis was generated for further research. That hypothesis is known as this study's general structural description of hopefulness (see preceding paragraph).

The nursing implications from Magan's (1986) study of hopefulness provide a new focus for nurses. Hope or hopefulness can not be instilled or enabled by nurses but rather the process of hoping can be facilitated by nurses. From Magan's (1986) study, hope is an active process of an individual creating anew. That work of creation must be done by the individual and has meaning as the individual chooses from options in situation, thus moving in a chosen direction. The direction is uniquely chosen by the individual and is uniquely lived by the individual. Thus nurses provide support, illuminate the health patterns for the individual and facilitate the hope process which produces action.

As was discussed, Magan's (1986) study is consistent with the existential perspective that values process, choice, struggle and mystery and transcendence. Mystery is evidenced by the individual choosing an uncertain direction of the future; struggle relates to the process of hope which is marked by periods of hopefulness and hopelessness. Finally transcendence occurs as the individual lives through the process of hope, moving in a uniquely chosen direction.

Summary

The review of literature was divided into three sections which are related to the three emerging perspectives of hope. Section one dealt with the literature on hope as a motivational construct, Section two dealt with the hope literature especially common to Nursing that believes hope can be enabled or instilled in others. Finally Section three discussed hope as it related to the existential perspective.

In Chapter III, the researcher's own beliefs about the phenomenon of hope from a theoretical framework shall be outlined and discussed. Furthermore, a theoretical proposition shall be posited that is consistent with Parse's (1981) Theory of Nursing, Man-Living-Health.

CHAPTER III

Researcher's Perspective

In a phenomenological study, the researcher's beliefs about the research phenomenon are made explicit and are known as the researcher's perspective. The purpose of this chapter is to describe the researcher's personal meanings of the phenomenon of hope from a theoretical frame of reference. From the personal meanings, a propositional statement based on theory is set forth. The propositional statement makes explicit the view of the phenomenon of hope from the researcher's perspective.

From this researcher's perspective, hope is the process of originating or creating anew. Parse (1985) describes originating as choosing a particular way of self emergence through inventing unique ways of living. Originating is a process of creating self and is co-constituted in interrelationships with others. This is congruent with Van Kaam's view of the whole of human development. Van Kaam (1974) states, "as man I am both 'potentiality' and 'emergency'. . . I experience my

potentiality as a dynamic tendency toward self emergency. . . I am 'becoming.' I am the potentiality of dying to my life at any moment and being born to what I am not yet. . ." (p. 109-110). Thus, originating is the process of self emergence, and hope is that force within originating. With originating, one transcends paradoxes inherent in this process, and images new possibles of the self. Inherent in the force within originating are two paradoxical essences.

Parse (1981) describes these paradoxes of originating as the paradoxical unity of living conformity-nonconformity and certainty-uncertainty all at once. Conformity-nonconformity surfaces in human encounters as individuals seek to be like others (sameness) and yet, simultaneously, not like others (differentness). Through living this paradox, sameness and uniqueness are confirmed. The paradox of certainty-uncertainty also surfaces in human encounters as individuals make concrete, clear choices <u>in situation</u> and yet, simultaneously, live the ambiguity of the unknown outcomes. In transcending these paradoxes man images new possibles, seeking a vision of the whole structure (Parse, 1981).

Imaging, according to Parse (1981), is a process of shaping personal knowledge. Coming to know, explicitly and tacitly all at once, is man's way of giving

significance to experiences as personal reality. Polanyi (1969), consistent with Parse, states that "the process of coming to know is through indwelling as man integrates the subsidiary awareness of particulars with the focal awareness of wholes, thus unfolding the meanings of experiences" (p. 134). In addition, Schutz (1967) states that the meaning of an experience is what constitutes reality. Thus imaging reality is making concrete the meaning of experiences and incarnates personal knowing (Dilthey, 1961; Parse, 1981).

In the process of imaging a way of being, man makes reality by choosing from options within multidimensional experiences. Merleau-Ponty (1974) states, one can not be all possibilities at once. In choosing, one is both enabled and limited (Parse, 1981). Thus, the enabling-limiting rhythm is evident as possibilities unfold and there is movement toward creating anew. In choosing a particular direction one is enabled and limited both by the chosen direction and the direction not chosen. According to Parse (1981), enabling-limiting happens as a person chooses in situation. It is a rhythm that incarnates the imaged reality making explicit the significance of the situation. The enabling-limiting rhythm surfaces in opportunities and limitations as the imaged possibles cocreates new ways of being. Hope is the force within this process.

Summary

From this researcher's perspective, hope is the process of originating or creating anew. Originating is described as man's choosing a particular way of self emergence through inventing unique ways of living. Man's choosing is made concrete in transcending the paradoxical unity of conformity-nonconformity, and certainty-uncertainty. In transcending these paradoxes, Man seeks a vision of the whole structure by imaging new possibles. Imaging shapes the process of originating through making concrete the meaning of experiences and incarnating personal knowing. In the process of imaging, choices are made which are enabling-limiting. Enabling-limiting is evident as possibilities unfold and there is movement toward creating anew in a particular direction.

From this theoretical frame of reference, which is the researcher's beliefs about the phenomenon of hope, the propositional statement which directs this study is synthesized as: hope is originating the enabling-limiting of imaging. This means that hope is creating the not yet through choosing opportunities and limitations incarnating the significance of an event.

CHAPTER IV

Methodology

Introduction

The research design, which unfolds a structure of hope through the process of isolating the themes or common experience moments, is the topic of this chapter. Included in this section are: 1) the description of the research design; 2) the criteria for selection of subjects; 3) procedure for data gathering; 4) procedure for protection of rights of human subjects; and 5) the procedures for data analysis.

Research Design

A phenomenological approach was employed to uncover the meaning of hope for families with a chronically ill child. The specific methodology adopted for this study is that of Giorgi (1970, 1975). The phenomenological method seeks to uncover the meaning of the phenomena as humanly experienced through the analysis of subjects' descriptions. This method explicitly takes into account an individual's participation within a situation by using the subject's oral or written description as the raw data (Parse, 1985). For this

study oral descriptions from each family member describing a hope experience were used, through the use of audiotaping and then transcribing, and became the raw data for analysis. It is through the analysis of that raw data describing hope that the nature and meaning cf hope were revealed and understood for each subject.

Study Sample

In phenomenological research, the sample is drawn from a population living the experience of the phenomenon. Adequacy of the sample is reached when the researcher experiences redundancy in the descriptions. In using the Giorgi methods, a small sample size (2-10 subjects) is considered adequate. The Giorgi method focuses on uncovering the meaning of the lived experience through an in-depth study of the subject's description (Parse, 1985).

For this phenomenological study, the sample contained two families. Each family consisted of two parents and a child between the ages of 6 and 11 who had a medical diagnosis of a chronic illness. For the purpose of this study the sample also included the siblings or other extended family members living with the

parents and the chronically ill child. The descriptions of the concepts central to the sample in this study are as follows:

1. Family: A bonded unit of interacting and interdependent persons who have some common goals and resources, and for part of their life cycle, at least share living space. . . families with different configurations of age, sex, marital status and role patterns which can be delineated (Andrews et al., 1980, p. 32).

2. Childhood: Those persons, male or female, who are between the ages of 6 and 11.

3. Chronic Illness: A medical diagnosis of a sickness or a disease of long duration (Osol, 1973).

The criteria for selecting the sample for this study were based on certain abilities of the subjects, as well as the previously stated assumption that the experience of hope is a common human experience. The criteria are as follows:

1. The ability to express one's self verbally with relative ease in the English language.

2. The ability to recall a situation of an experience of hope.

3. The ability to reflect upon and to describe the experience as well as the feelings that accompanied it.

4. An interest and willingness to participate in this study.

The criteria were broad in order to allow a variety of possible subjects (families) who could verbalize their experiences of hope. A pediatric clinical nurse specialty in the Lansing area was contacted to help identify possible families meeting these criteria for this study.

Data Gathering

After the pediatric clinical nurse specialist identified several potential families who met the criteria for this study, initial contact was made by the pediatric clinical nurse specialist to elicit their willingness to participate in the study. Each family was then contacted by the researcher by telephone, confirming their consent to participate in the study. Since the phenomenological method involves retrospective descriptions of lived experiences, an interrogatory statement which lead the subjects to reflect on and describe a situation in which the experience occurred, was asked of each subject. The interrogatory statement constructed for this study was:

> Describe a situation in which you experienced hope. Share all the thoughts, perceptions,

and feelings that you can recall until you have no more to say about the situation.

During the initial phone contact, an explanation regarding the study and the protection of human subject rights was verbalized to each family. The interrogatory statement described above was also included in the phone contact by the researcher. Once the families agreed to participate, an interview was scheduled with each family. After signing the consent form, the interview took place in the homes of each family in order to provide a relaxed atmosphere to enable the subject to describe freely the situation in which they experienced hope. A time was scheduled when all family members were present.

Approximately 20-30 minutes were used at the start of the interview to establish rapport with each of the subjects. This time was especially necessary for the children to enable them to become more relaxed around the researcher, and familiar with the audiotaping equipment. Once all family members acknowledged verbally that they felt ready to begin, the data gathering processes were initiated.

Each family member was asked to describe individually into a tape recorder, a situation unique to him/her in which they experienced hope. There were no other questions or comments directed to the subjects by

the researcher other than the previously stated interrogatory statement during this interview. This was to ensure that there were no attempts made by the researcher to influence the type of situation each subject described, thus each description would clearly be the subject's perspective of the phenomenon. In gathering data from the children of the family, the researcher needed to deviate from the usual data gathering procedure used with the adults, and used more exploratory questions. Common exploratory probes used with the children were: 1) "Tell me more about. . ."; 2) "You just said _____, tell me more about that"; or 3) "You said _____, tell me more what you were feeling at that time." The exploratory probes were necessary to elicit more detailed responses regarding their recalled hope situations.

In addition, each set of parents were asked to share with their child the meaning of the concept of hope as they believed it. The parents were also asked to discuss the interrogatory statement of the study with each child in order to facilitate the child's recollection of a situation, and familiarization with the concept of hope. This discussion was to take place before the researcher conducted the interviews. The parents verbal report was elicited regarding this discussion with the children and was considered evidence

that the discussion had been previously ensued. This information was probed (before the data gathering procedure was initiated) for an initial 30 minutes with each family. All interviews were audiotaped and subsequently transcribed. Further data was gathered from each family member for an elaborated description of the phenomenon after the researcher had begun the analysis of data.

The researcher, after initially dwelling with the data through the process of analyzing, intuiting, and describing, identified ambiguous areas from the transcriptions. The researcher then returned to the subjects for these clarifications. The initial descriptions and the clarifications became the new data known as the elaborated descriptions. A more detailed discussion regarding the elaborated descriptions will follow in a later section.

As already stated, the specific methodology adopted for this study is that of Giorgi (1970, 1975). Giorgi (1975) described eight characteristics which are essential to a phenomenological approach for the human sciences. A summary of Giorgi's characteristics are as follows:

1. Fidelity to the phenomenon as it is lived. This means that those aspects selected for study are perceived and understood by the person living through

the situation. This is known as the "lived context" of the phenomenon. In addition, those same aspects are also to be perceived and understood by the researcher. This does not mean that every conceivable aspect of the phenomenon will be unfolded, but rather those aspects as identified by the subjects. Anything that the subject feels is worth mentioning is registered as data. For this study, the subjects described a situation in which they experienced hope. In the process of describing this situation, the subjects presented their understanding and perceptions of the concept of hope. All data were recorded with the use of a tape recorder and no data were omitted -- only full transcriptions were considered raw data for this study.

2. Primacy of the life-world. What is meant by "life-world" is the everyday world as it is lived by everyone. This "life-world" then becomes the ground for all science and systematic knowledge. Giorgi states that the scientific expressions of a discipline must remain in a constant dialogue with the ordinary expressions of the life-world. It is those ordinary expressions of the life-world which supply researchers with an inexhaustible source of all data, thus facilitating studies of the unique domain of the human experience. The life-world is the everyday world the subjects live, and were described to the researcher, and

audiotaped. Those descriptions of the subject's hope situation became the ground for the data analysis. This was the lived context of the concept of hope for each individual.

3. Descriptive approach. Description is the usual technique of phenomonology because of the inherent power of communication through language. By circumscribing attitudes, delineating aims, and providing adequate contexts for all descriptions, a more rigorous approach is applied to basic communication patterns. For this study, the descriptive approach was evident in the data gathering procedure in that the subjects were asked to describe a situation in which they experienced hope.

4. Expression of situation from viewpoint of subject. In phenomenological research, the data collected must include the subject's context as well as the subject's specific expressions. It is the subject's viewpoint of the situation that provides the data for the study. During the data gathering process, for this study, only the subjects' verbal expressions were recorded as data. The researcher, in the initial data gathering process, directed no other questions to the subjects, thus ensuring that the subjects' viewpoints of the concept of hope were recorded. Although this

procedure was deviated from in regard to the data gathering process for the children, the probes used only lead the children to further discuss, or explicate what they had already stated. The probes used were nondirectional, thus the children's own viewpoints of the concept of hope were elicited and recorded.

5. Situation as unit of research implies structural approach. The basic unit of phenomenological research is the "lived situation." This means that the primary variables are the meanings attributed in that situation by the subject and the researcher. Inherent in the research situation is the interpersonal nature of the dialectical exchange between researcher and subject. It is from this exchange that the lived meanings can be made explicit and amenable to interpretive procedures. The subjects in this study, described a situation in which they personally experienced hope. The situation was told as a story. The subjects were asked not to analyze or interpret the situation, but rather to share the details of the situation and all their thoughts, feelings and perceptions until they had no more to say. The researcher concluded the data gathering process after each subject reported that they had no more to say.

6. Biographical emphasis. The key themes formulated using a phenomenological approach will be

identified after dwelling with the data and not before. This means that the initial data will be biographical and personal since human phenomena are temporal, historical, and personal. Since all subjects had to recall, and describe a situation in which they experienced hope individually, the data collected was temporal, historical, personal.

7. Engaged researcher. In phenomenological research, the researcher is engaged and active in the co-constitution of the actual data for study. The researcher's perspective is made explicit in regard to the phenomencn being studied. There is an evolving transformation of the descriptions given by the subject through the interpersonal exchanges between researcher and subject. These transformations are directed toward the intentions and aims of the experimenter's research.

In the data gathering process, the researcher was present for the interviews and played an active though non-directive role for the subjects in the constitution of the data for this study. Initially, the researcher elicited descriptions from each subject regarding a remembered experience of hope. The researcher then dwelled with the data, identified areas of ambiguity, returned to the subjects for clarification. After the elaborated descriptions were completed, the researcher had no further contact with the subjects. The

researcher then proceeded with the process of data analysis.

8. Search for meaning. Giorgi (1975) states that scientific measurement can be a significant route to meaning. In a phenomenological approach, the "meaning is in the measurement." The meaning of the phenomenon is uncovered through use of a method that systematically explores meaning directly.

Inherent in this study, the method of data gathering was an approach that systematically explored meaning directly by having the subjects describe the hope situation and their thoughts, feelings and expressions. Using the descriptions provided by each subject, the researcher was able to uncover the meaning of hope for each family. The results generated which are the family's definition of hope become the hypothesis for further study. In addition, the results which were analyzed in light of the researcher's perspective and the existing literature, either support or not support existing theory. Thus this methodology is theory generating.

Protection of Human Rights

In accordance with Michigan State University College of Nursing requirements, application was made to the University Committee on Research Involving Human

Subjects for permission to conduct this research. Permission was granted and all possible efforts were made to ensure protection of the participants' human rights. A consent form which identified the researcher; briefly explained the nature of the study, and also explained that consent was being given to allow the researcher to audiotape the responses to an interrogatory statement was presented for signature to each subject. Confidentiality, anonymity, as well as the family's right to withdraw from the study were assured (Appendix A).

The points made in the consent form were initially explained during the telephone contact. An opportunity to ask questions was also provided at that time. Respondents were made aware of the only foreseeable risk to participation, that is, their becoming more aware of, and possibly concerned by, any old or new issues raised by describing the situation of hope. The participants were urged to discuss their concerns with possible supportive persons or their health care provider. In addition, the researcher also made herself available for discussing any concerns engendered by the retrospective descriptions.

In order to ensure confidentiality, each subject was assigned an identification number and only the researcher was able to associate the names with the identification numbers. All transcribed audiotapes

used identification numbers in connection with the descriptions. Fictitious names were used in reporting the data. The transcriptions of the data obtained from the interviews were placed in the researcher's private file to prevent public access. The audiotapes were then erased after transcription.

Procedure for Data Analysis

Giorgi (1975) has identified seven steps in the data analysis process of phenomenological research. A summary of Giorgi's processes which were followed in this study are as follows:

1. Dwelling with the phenomenon. Parse (1985) best explains this initial process of Giorgi. Parse states that dwelling with the phenomenon is "the undistracted reading and rereading of the descriptions with the intent to uncover the meaning of the lived experience for the subject. This contemplative dwelling frees the researcher to be open to both the tacit and explicit messages in the data" (p. 19).

In dwelling with the phenomenon, the processes of analyzing, intuiting, and describing were used. Intuiting is a demanding activity requiring much concentration. It is to grasp the uniqueness of the phenomenon by openly looking, listening and feeling with each transcription. Intuiting is the "coming to know" the

phenomenon as described by the subject. Each transcription was read in a quiet setting with minimal distraction to allow the researcher an atmosphere conductive to reflection and intuiting.

Analyzing is the intentional tracing of the elements and structure of the phenomenon that was revealed from intuiting. Each of the elements related to the phenomenon of hope were traced for the subjects by underlining those key aspects found in the transcriptions while intuiting the data. Analyzing is the general examination of the structure of the phenomenon.

Describing is a process which is really part of intuiting and analyzing. Describing affirms the connection between the phenomenon and all denotations and connotations found in the transcriptions. In describing, the essences of the scenes, themes, and focal meanings were selected and set forth to provide the meaning of the lived experience of hope for the subjects.

2. Returning to the subject for elaboration on ambiguous areas of description. After initially dwelling with the data, the researcher identifies areas of ambiguity and questions which might enable clarification of any of the present descriptions. The

researcher then returns to the subjects for those clarifications. The subjects were shown the transcriptions and asked to read the transcriptions one section at a time. The areas of ambiguity were pointed out, and each subject was asked to clarify what they had stated. Only one type of probe was utilized to elicit those clarifications and was "You said. . ., tell me more about that." This probe was used for both parents and children within the family. If the children were unable to read their own transcriptions, then the researcher read the transcriptions to them aloud, and followed by asking the previously stated probed. This new data obtained is known as the elaborated descriptions. The elaborated descriptions for this study were also audiotaped and then transcribed. The clarifications were then placed on the appropriate line in the original transcriptions and made easily identifiable in the data by using parenthesis and paragraph indents to enclose the clarifications.

3. Identifying natural meaning units. After dwelling with the elaborated data, the researcher looked for those units which are the beginning and ending of a thought. Those natural meaning units might be compared to the scenes of a play. To identify those natural meaning units, the researcher looked for the

shifts in the thoughts patterns within the transcriptions. The natural meaning units, also known as scenes, are then set apart from the elaborated descriptions and further analyzed by the researcher.

4. Identifying themes. The scenes identified were then examined by the researcher for emerging themes. The themes were identified in the words of the subject and are the central elements of the scenes (Parse, 1985). The themes are listed beneath each corresponding scene (see Table I). The themes are then examined and crystallized on a higher level of abstraction in the language of the researcher.

5. Identifying focal meanings. The focal meanings developed for this study were based upon this researcher's background and frame of reference with Parse's (1985) Theory of Nursing. Thus within the focal meanings there is a shift in discourse to a higher level of abstraction. In doing so, the "ground" as described by the subject recedes, and only the abstract language of the researcher (based upon the theme) is seen. Each focal meaning was then listed below the corresponding theme (see Table I).

6. Synthesizing the situated structural descriptions. The focal meanings are then synthesized by the researcher and become the situated structural descriptions. These descriptions specify the meaning of the

phenomenon from the perspective of each subject (Parse, 1985). In the synthesis of the focal meanings, the "ground" is now brought back into the analysis. Thus the "story" of hope was retold using the researcher's language (the focal meanings) and the subject's description of the situation (also known as the ground to the story).

7. Synthesizing a general structural description. The situated structures for all subjects were then synthesized together into a general structural description of the phenomenon. This general structural description becomes the meaning of the lived experience of the phenomenon as studied from the perspective of the subjects (Parse, 1985). A general structural description was developed for each family. The researcher through the process of dwelling with the data, synthesized the situated structural descriptions of the members of each family, to derive the general structural description for that family. The general structural description is at an even higher level of abstraction, but as inherent in the focal meanings, the ground is lost with respect to each individual.

For the data analysis, a researcher who is doctorally prepared and an expert in qualitative methodologies was consulted. This ensured that the data

analysis was thorough, and complete with a consistent level of discourse within each level of analysis.

Summary

In Chapter IV, this study's design, data gathering and data analysis procedures were described. The study's sample and setting were also described. In addition those concepts central to the description of the sample were defined. This study used the Giorgi (1975) modification for phenomenological research.

In Chapter V, the data and the results of the data analysis will be presented. The discussion of findings which normally appears in Chapter V, will be presented in Chapter VI.

CHAPTER V

Data Presentation and Analysis

Overview

A phenomenological study was conducted to generate a structural description of the phenomenon of hope as it is experienced in families with a chronically ill child. The aim of this research was to uncover the meaning of hope as humanly lived. A sample consisting of two families who each had a child between the ages of six and eleven with a medical diagnosis of a chronic illness was asked to respond verbally to an interrogatory statement (see Appendix B). Each family member was asked to describe individually a situation unique to him/her in which they experienced a feeling of hope. Although descriptions were elicited from every family member, only the parents' descriptions were used for data analysis. The parents' transcriptions were the only transcriptions that were clear, and of enough substance to be analyzed. In addition, the children's data were contaminated since the use of leading probes became necessary to elicit more than a two sentence description of hope. Since the children's data were

both contaminated and of minimal length for analysis, only the parents' transcriptions were used as data.

The data which provided a general structural description of hope for each family shall now be presented. The families shall be labeled Family A or Family B, with each parent as either subject #1 or subject #2.

Data Analysis - Family A

Subject #1

After dwelling with the elaborated data (see Appendix C) of subject #1 from Family A, the natural meaning units were identified. These natural meaning units, also known as the scenes were the beginning and ending of a thought. There were six scenes identified from subject's #1 transcription. As this researcher dwelled with each scene, the theme that was inherent in each scene was described in the language of the subject, and was listed below the corresponding scene

The six themes of subject #1 were then further analyzed and crystalized on a higher level of abstraction in the language of this researcher. These crystalizations are called the focal meaning and are listed below its corresponding theme. The six focal meanings were then synthesized by this researcher and became the situated structural description of subject #1 of Family

A. This description specifies the meaning of the phenomenon from the perspective of the subject. In the synthesis of the focal meanings the "ground" was now brought back into analysis. Thus the story of hope for subject #1 was retold in the language of the researcher.

The data for subject #1 are now presented. (See Appendix C for complete elaborated transcriptions.)

Scene #1. It was in summer of 82 I think. To set the scene, I was going to college living in family housing with my two boys. I was single parent at that time. And my ex had just given up on seeing or supporting the kids, so I was all alone.

> (Well, I didn't have anyone to share responsibilities with, was the big thing. I was the only one responsible for their upbringing. As far as how it felt, I would say it was a little overwhelming at times. It wasn't a whole lot different than the way it was before. It was good and bad. I didn't have anyone to share the responsibility with, but then he wasn't always there anyway. It was kind of a relief I didn't have to be responsible for him anymore. So as far as that, I didn't mind the responsibility I guess. I was all alone. It might sound like a complaint, but it really wasn't. I didn't mind being alone. I was able to handle that.)

Theme #1. Though the subject felt overwhelmed at times while being a single parent and sole supporter of two children, she was also relieved at not having the added responsibility of a marital relationship, since she could handle being alone.

Focal Meaning #1. In the struggle of parenting alone, the subject experienced living the paradoxical feelings of being overwhelmed, and yet relieved.

Scene #2. I was on ADC, which I hated. I hated being on it. It's a lot of work to keep them happy and to do all the form work and all that kind of stuff, and it went against the grain. I didn't want to have to be on it, but it was a means to an end. To get where I wanted to go.

> (It's like taking a hand out. Somebody else supporting you. You're not self-sufficient. You've got my feelings are that everybody should be able to take care of themselves. And you have a vision of what people are that are on ADC. You think about them as a lowlife that doesn't want to get off their butt and do something for themselves. That was my picture of somebody on ADC. And here I was on it, and I didn't picture myself as being that type of a person. I didn't like being on it because of that. And when you go in there you sit with these people, and you'd look around, and you're like I don't belong here. I don't want to be doing this.)

> (It's very embarrassing to go to the store and use food stamps. I felt like people were looking at me and going "What's the matter with you?" And then I felt like everything we bought was being scrutinized because you're using food stamps. The food stamps is the worst because that's the thing that everybody sees. When you get your ADC check you put it in the bank and nobody sees it. But the food stamps are a constant reminder that you're being helped by the state. And I just didn't like the feeling that I couldn't do what I wanted without people looking at me. Because in reality, everybody's paying your way. Your taxes. I see people on ADC and you're supporting them with your taxes. And so I'm thinking, they're looking at me like I'm looking at everybody else and scrutinizing. So it gave me a feeling of what

> they would feel. But I really kind of watched what I was doing.)

Theme #2. The subject felt embarrassed using the support of social agencies as a means to an end, since she viewed herself as self sufficient.

Focal Meaning #2. In the process of reaching for a goal, the subject experienced uncomfortable feelings as her view of self was shaken by her experiences of reality.

Scene #3. I had just met Bob that summer, and we were getting along real well.

> (I was happy. I shouldn't say it like I hadn't been happy before. But it was a whole different kind of feeling. I felt loved and I was loving him. Not at first. It was just the new love. And the new love is something else anyway. And a new beginning, looking forward to something. So that was a feeling as far as him. We were both on ADC and we both hated it. But I guess it (hope)(fit in because we both had the same goal to get off ADC. And we were both trying to make a life, both trying to better our lives. That's why we were in school and going through everything. Although he was also getting VA benefits. Things looked a lot brighter. It looked like there was more of a future I could grasp than just a door at the end of a tunnel. It looked like I could see what was out at the end. It wasn't like I was going out blindly. Which was what I was looking at before he came alone. I was going to graduate and I was going to start a new life, but I didn't know what. I had no idea. Whereas he gave me something more to look forward to. More concrete.)

And I got a notice from ADC that they were cutting me off because I didn't file my form in time. And I

was just devastated, and I remember crying and just thinking what can come next because it was just something hitting.

> (This happened about in early August. Hope felt pretty hopeless. It just wasn't (hope), it was like somebody pulled the rug out from under your feet. You're moving along and it's like you take a step back and fall back. Or take one step forward and you go back two. You're trying to get somewhere and then they do something like that and it all seems to unreasonable. For what reasons? I felt like I wasn't a person at that time. I wasn't being treated like a person. I was just being treated like something on a piece of paper. They would take my life and turn it upside down just over paperwork was unbelievable to me. And that just reinforced the feeling that I want it off and I don't want to handle this kind of crap. I was just really upset with it.)

And it was at that time when things were going well with Bob, I was thinking once I get off ADC things are going to be a lot better. I haven't got that much more to go.

> (I was happy that I had someone to share it with, and that I wasn't alone. That was a lot easier on me. Somebody else that knew how I would be feeling, could understand it.)

Theme #3. During the time of a new relationship the subject anticipated a positive future amidst the hard times, since both parties were struggling to better their lives.

Focal Meaning #3. The subject's anticipation of new possibles emerged through a shared struggle.

Scene #4. I was graduating that December. So I was hoping at that time that things were really going to turn around once I graduated and got off ADC,

because it just seemed like that was the real blow. I didn't want to be there and I was there and they were giving me a hard time. It wasn't easy going. So the main feeling of hope was that once I got off that my life would straighten around and I wouldn't be dependent on anybody else and I would have control over my life again. And that was the big part, just being able to have control. I wanted control, so that I think everything else would then fall into place.

> (Being in control, to be able to be responsible for my own mistakes. And that I've paid for my own mistakes on my terms and not somebody else's terms. That I'm not following somebody else's rule book. I've got my own rule book as to what is accepted and what isn't accepted. I feel everybody should be allowed to screw up, and on ADC you aren't allowed to screw up. You have to pay for it, I mean literally. Moneywise you pay. I didn't want every mistake to cost me money. Not when you're struggling just to survive. To have control over, like when you're on ADC you can't have a car with car payments. You're not allowed to have assets, because then you're not eligible. Being in control is not always good. There are scary feelings with it too. I am in control and that's why I'm responsible. But I still think of them as good feelings. Being in control, coming and going and doing what I want and not having anybody. I'm just trying to think of this in relation with ADC. If I get too broad. I'm trying to think of all the regulations and such that they had on me. Daycare, the expenses, and what they would allow you. And they changed while I was on it, different rules. I guess that bothered me too. Every year you didn't know what to expect. They changed the rules and what was going to apply. It's just like doing your taxes now. You can't declare that anymore. That doesn't work. So it was the same thing I guess. You exchange one for another. I've learned that. That it's not all that I thought it was going to be. I do have control, but.)

Theme #4. The subject looked forward to no longer receiving assistance--a time when she would be in control of her life and responsible for her own mistakes, yet at the same time she feared the control and responsibility.

Focal Meaning #4. In imagining the future, the subject experienced both a longing for, and a fear of, her independence.

Scene #5. And that was the one thing I keyed in on, was the ADC because that seemed to be the one thing holding me back from attaining other goals. And that was the feeling of hope.

> (Frustrating. (The feeling of hope.) The goals I had in mind was to have a career and support my family. And my goal was to get an education so I could get a better job and support my family. Because I had tried it before, that's why I went back to school. I had tried with no degree, and I couldn't demand the money. I thought with an education I would be able to demand a higher income and therefore support my family, because I wasn't getting any help from anybody. And I knew it had to be me that did it. I wasn't receiving any help from my ex at that time. And my family didn't give me a lot of money. I wasn't one of those fortunate people that mom and dad helped support you. So I just wanted to live. I'd grown in a comfortable environment, and I wanted to be able to have that kind of environment for my family, for my two boys and me. That was my goal. To be able to be comfortable and live within what I wanted and plus have a job that I liked and that I felt would compensate me for what I was doing. With those goals in mind, it was a real blow against my ego. I wanted to attain so much more than what I would think the normal person on ADC would

> have in store for them. It was just a stepping stone to me. And it was just frustrating, it was disheartening, embarrassing. The whole thing. I just wasn't where I wanted to be. And it was like fighting to get out of a paper bag. You have to be there for so long, and you can't just say ok, I quit. I'm off it. You can't do that. You have to bite the bullet and stick with it.)

Theme #5. The subject experienced frustration in the daily struggle to attain a comfortable environment, and was disheartened as she fought to change her situation.

Focal Meaning #5. While persisting in an effort to change the situation, the subject experienced feelings of discouragement and frustration.

Scene #6. Now as far as the result of it, it was like a weight. The feeling of being under. Receiving ADC was like a weight on my shoulders. A responsibility that I didn't want. I was responsible for my actions to somebody else, instead of just me, and I didn't like that feeling at all. So I felt that it would just take a big load, that physical weight which I've experienced. When I got my divorce I felt that weight coming off my shoulders. And this was just another one that was heaved right back on. I thought I've felt that relief before, so I was just going to look forward to just having that pulled off and it did. Once I was off ADC I felt I'm on my own. So that's it.

> (I was fairly accepting of it. I think I am fairly logical, and I knew that it was coming to an end. And I was well it's just a little big longer. Anticipation of being off it. I'm coming up blank. I think it was a little bit almost regret too. Thinking about going off. Well this is pretty easy money. It's like, you're not going to have that anymore. I was looking forward to getting rid of the paperwork, the food stamps, which are an

> embarrassment. But it was a little scary that I've got to some up with the funds that are going to support. So I think there was a little bit of worry that I was going to be able to do it. But then you don't go off ADC until you're making money. So I thought it's going to come out ok. It'll even out.

Theme #6. The subject looked forward to feeling relieved from the burden of being assisted by social agencies, yet felt regret as she worried about her ability to be the sole provider for her family.

Focal Meaning #6. The subject's anticipation of relief occurred in the midst of an uncertain struggle for independence.

Situated Structural Description of Subject #1. The subject experienced a feeling of hope during the time she was a student, a single parent and sole supporter of her two children. She experienced the paradoxical feelings of being overwhelmed and yet relieved in the struggle of parenting alone. Furthermore, the subject experienced uncomfortable feelings in the process of reaching for a goal as her view of self was shaken by her experience of reality. The subject's anticipation of new possibles emerged through a shared struggle in a new relationship. Over time, as the subject lived this struggle she experienced both a longing

for and a fear of achieving her independence. In addition, feelings of discouragement and frustration surfaced as the subject continued to persist in the effort to change her situation. The anticipation of relief occurs in the midst of an uncertain struggle for independence.

Subject #2

The researcher then dwelled with the elaborated data of subject #2 of Family A. Again the natural meaning units, or scenes, were identified. The scenes represented shifts in thought patterns by the subject. There were four scenes found in subject #2 of Family A.

As each scene was further analyzed, the theme or central element of each scene was identified by the researcher. The theme was listed below its corresponding scene. The four themes of subject #2 were then further analyzed and crystalized on a higher level of abstraction in the language of the researcher. These crystalizations were the focal meanings of the scenes and were listed below the corresponding theme.

The four focal meanings were then synthesized together to formulate the situated structural description of hope. As was stated before the situated structural description of hope is the distilled story of

hope of subject #2, retold in the language of the researcher.

The data for subject #2, Family A, are now presented.

Scene #1. Describe a time or experience when I felt hope. I'm of such a nature that I feel hope every day. It starts in the morning and will end at night for each day.

> (That's because I leave my nights, my sleeping time for a fantasy. I see hope as something really concrete. Hope itself is pretty nebulous. But I put it all into something that's concrete. It's easier for me to handle. Even emotions. I try to put it in terms of something concrete that I can deal with. My hope starts in the morning and ends at night because those are my concrete times. And that something I can see, I can hear it. I can touch it. So as far as it starts in the morning, that's because I wake up and I'm thoroughly conscious. And then it ends at night when I go to bed or go to sleep. It feels exciting to have hope every day, something new. But yet something you can depend on. I can depend on every day being new, and hope for a better day than what I've had previous. Excitement, less worry. Something that will straighten out, something that will pull together.)

I'm in sales, so a good portion of my time is spent in hope, hope that I'll make a sale, hope of this or hope of that. But I do feel hope every day.

Theme #1. The subject experiences the excitement of hope each day as he anticipates a positive, yet uncertain future outcome.

Focal Meaning #1. The subject was swept up in the excitement of imagining new possibles as each day unfolded.

Scene #2. For me to sit back and pull one day out of the 365 that come in a year would be extremely difficult. The nearest one would be yesterday. And again going back to my sales, a feeling I experienced hope. I had a promotion going on at the Water's Edge in Toledo. And I worked extremely hard to pull this all together, getting bands, getting food, getting staging, getting music, getting give-aways, getting wine coolers. Just getting everything for putting a promotion together. My experience of hope, I woke up just anticipating.

> (Woke up in the morning that day and it was rainy, it was overcast, and we were supposed to have a luau outdoors. We had a best tan line contest, a hula-a-hoop contest, best flowered shirt contest. All of these outdoorsy type of contests. And it was windy, it was cold and it was rainy. And for hope I had hope that it was going to clear up and be warm at least, even if it was still a little cloudy. To bring more people there. We got there and it was lousy. The weather just stayed lousy and I had to run around and get all the sound equipment in the morning. Get leis, we were giving away leis. And I had to pick up all the little bits and pieces. Records we are going to give away, the hats we were going to give away. Making sure my itinerary was all straight. What we wanted to do at what time. What bands were going to be playing and when. Just making sure that was all still running, even though it was so lousy and the weather was lousy. It must have been around 1:00 and it was still really lousy out. And I had all my people there. There were jocks and other people from the radio station there. So I took them down and I fed them a lunch. We got done with lunch and we got up there and everything should have been rolling for a half hour, and there was no one there. There was absolutely no one there. And it was terrible. I was burning out. Just feeling really lousy, like

> this is just really a failure. So at that time I started looking for excuses or reasons as to why, other than the weather. I felt it was something other than the weather. Even though the weather was bad, there was enough going on. As the day progressed, it just stayed that lousy, never improved. We had bands and tents and food and wine coolers, and the radio station was there. And albums to give away. We had 500 leis to give away. We had 16 people come through the door for the whole afternoon. That was 3 hours and 16 people showed up. So it was just worse than a total disaster as far as a promotion, a far as all the work I put into it. That was the way the whole day went. Then to top it off, the person that ran the Water's Edge and the restaurant that got the bands, wanted me to foot half the bill for his bands and his expenses, whereas I had already put out close to $2,000 worth of stuff from the radio station, let alone all my time and extra time I put into it. So I had hoped for something a whole lot more than what we had gotten. But it just never improved all day long.)

Theme #2. The subject anticipated a positive future outcome amidst struggles and failures.

Focal Meaning #2. The subject's anticipation of new possibles emerged through struggles.

Scene #3. It was the excitement of I guess the unknown. Maybe that's what hope is to me, the unknown. And just everything leading up to the day.

> (To hope during this time wasn't really hope as I see hope. Hope is something nice to have. This was almost I was begging. Oh please, please I hope it gets better. That type. I can't think of the word I want to use right now other than begging. That's the only word I can think of right now. That's now exactly what I mean, but I can't think of the word I want to use to describe other than a begging, pleading type of hope. For my

> life, for my security, for my business, for my radio station, for everything.)

And when I woke up it was rainy, it was cloudy and overcast. Just a real lousy day, but I still had hope for a big turnout.

> (I was not really anticipating a bad day. I was still hoping for a good one. But knowing that this would really bomb out because of all the factors that were involved that were out of my control.

Theme #3. Striving for success amidst failures, the subject found himself pleading for a positive outcome.

Focal Meaning #3. In the struggle to find meaning amidst failure, the subject found his sense of hope changing.

> Scene #4. So by the next day, I did everything that I could possibly do for it. I felt bad that it didn't come off and that it didn't work, but yet I didn't feel that anxiety because it didn't. Because I had done everything I could do and the radio station had. So I had hope that maybe my client at that time wouldn't try to say hey, it was you at the radio station, because you didn't handle something correctly. That wasn't so. My hope was let's move on to the next one. That's done. That's completed. Let's learn from it and move on. I was back then saying at this particular time it wasn't right for whatever reason.)

For that promotion to be a big turnout would be the same as making a big sale, or the same as having another good day within my family life, or the same type of hope that I would feel if they found a cure for CF. Hope is that we would have just a huge turnout at this luau. I was excited, I was a little bit nervous,

and I was worried. But I believe that's everything that goes with the word hope.

Theme #4. Although many alternatives were tried in order to create a successful event, and each alternative failed, the subject recalled past successes and began to anticipate other positive future outcomes rather than becoming despondent.

Focal Meaning #4. The subject anchored self in remembered and anticipated successes, fostering his perseverance in hardship.

Situated Structural Description of Subject #2. The subject experiences hope each day and is swept up in the excitement of imaging new possibles. The subject recalled the time of a business promotional event when the anticipation of new possibles emerged through many struggles. In striving for success amidst the failures of the promotional event, the subject found himself struggling to find meaning in those failures. In doing so, he found his own perspective changing. As the day unfolded many alternatives were tried by the subject to create a successful event. As each alternative failed, the subject did not experience despondency but anchored self in remembered and anticipated successes, fostering his perseverance in hardship.

General Structural Description of Hope - Family A

The situated structures for both subject #1 and subject #2 of Family A were then synthesized together into a general description of hope for that family. The general structural description becomes the meaning of the lived experience for hope as it was studied from the perspective of the subjects of Family A. The general structural description is at an even higher level of abstraction, thus loosing the ground inherent in the situated structural description.

The general structural description of hope as lived by Family A is as follows.

General Structural Description of Hope - Family A. Hope is the process that becomes known as one anticipates a future outcome. It arises from a struggle with the paradoxical nature of day to day experiences. It is in living these paradoxes that choices surface which lead the individual to choose a different view of the situation. That view then becomes the anchor for the individual and fosters movement, which both enables and limits the individual, in creating a new context of the situation.

Data Analysis - Family B

Subject #1

This researcher dwelled with the elaborated data of Subject #1 of Family B and identified four natural meaning units or scenes from the transcriptions. As was previously stated the scenes are shifts in thought patterns, much like scenes in a play. The researcher then dwelled with each scene to identify the inherent theme or central element of that scene. The theme was described in the language of the subject and is listed below its corresponding scene.

The four themes of subject #1 of Family B were then further analyzed individually and crystalized on a higher level of abstraction by the researcher. As previously stated, these crystalizations are known as the focal meanings of the scenes and are listed below the corresponding theme.

The four focal meanings were synthesized together by the researcher and became the situated structural description of subject #1, Family B. This description specifies the meaning of the phenomenon from the perspective of the subject. In the synthesis of the focal meanings, some of the ground is brought back into analysis. Thus the story of hope for subject #1 was retold in the language of the researcher.

The data for subject #1, Family B, are now presented (see Appendix C for Family B's complete elaborated transcriptions).

Scene #1. Well, the circumstance or situation that I thought back on was one that my idea of hope, or that was over a long period of time. Because there's been many times in our lives that, even day to day, you have hopeful situations. But this one was actually when I was pregnant for James. Because of health problems that I have being diabetic and different things, the doctors had warned about all the different things that could go wrong. All the things that could go wrong. I was so excited because we wanted children and all that, yet in the back of my mind there was this, is it going to be something I can cope with.

What if my child has an illness? What if I lost this child? And all those type of things.

And that's where the hope for a good easy pregnancy, the hope for a healthy child, came in. And also the hope that no matter what happened, I could cope with it. That I could handle it.

> (As I said I was very excited because children were something that I had always wanted, so there was this job. But because of my health problems there was always this nagging feeling that are you going to have a healthy baby. Are you going to be able to carry it full time? And of course the doctors had outlined many things that could happen. Many things that did happen as a result of it. Mainly there was a fear there. I don't think it was an ungrounded one. Just a fear that possibly this thing I wanted so badly was just going to escape me somehow. Those times that I felt like that were very short though. I get the feeling that way and then I'd start thinking now that's dumb, because I knew that whatever would be the outcome that it would be for my best. And that somehow I would be able to get through it. That I had the hope which is very much in my life the same as the faith in God that he would see me through each thing. And even if something tragic did occur, there was a reasoning behind that. So

> I suppose that my one fear though was that would I be able to cope and handle whatever would happen. If there was a tragic ending or a happy one like there was. And just be able to come through it without just falling to pieces or losing that faith that I had.)

Theme #1. During the pregnancy of her first child, the subject joyfully anticipated the upcoming birth and yet feared possible tragedy because of her health situation.

Focal Meaning #1. In preparing for birthing, the subject experienced joy and fear, as she imaged the future.

Scene #2. Throughout the time, there would be days that everything would go right, and you wouldn't worry or anything. But during the worrying times, that's when you had to have something to cling to. To think I'm going to get through this.

> (I remember back specifically one day I had been to the clinic, where I went every two weeks. And the ladies, we were sitting, all talking. And most of us were diabetic. And one was telling how many still born children she had lost. And one other lady I know had a baby that was born perfectly and just died in delivery. And I think those were the days when I really needed something to cling to. That this isn't going to happen to me. That day I remember going home and still feeling down about it. Feeling, is this in my mind, just something I'm dreaming is going to happen. And I think those were the times when I did actually have to cling to something. Not just in my mind think this is going to be fine. But actually even possibly go to the Bible and read some of the promises there. Sometimes I remember going to someone that had the same feelings I did, the same beliefs, and talking to them and getting that

> extra, just knowing that they would be there. That they understood, that they were concerned about it too. And throughout it all though, I have to go back to what I said before, it's really just believing that God had it in control. And the days that I would start worrying are the days that I would try to take everything upon myself, and figure how am I going to work this out. And then I'd just keep going down and down because I knew myself I couldn't do much. And I was in this circumstance and I just had to wait to see it through. I couldn't do anything right now to assure a positive outcome.)

Sometimes hope felt far away. Sometimes it seemed like, this is almost going to sound like I've lost my faith in the Lord, but it wasn't that. It just seemed like is this just something that's superficial, and not real. I remember just a few times feeling like that. Is it just ridiculous to believe in this. Yet then as soon as I'd almost have those thoughts I'd say no it's not. In the past the many things that I've gotten through and the Lord's helped me through. And he's the same today, yesterday, and forever. And I know that. And so I think it was more when that hope seemed far away, it was almost like it was myself doubting. And that it needed to be reestablished by going to maybe the Bible, or going to someone that was strong and could reinforce my prior beliefs. I can't say I ever lost that belief or that hope, but sometimes circumstances might push it in the background for a little bit and it had to be remembered and brought out.

Theme #2. The subject experienced times when she worried about future outcomes and yet struggled through those fears by talking to others and clinging to a deep felt faith in God.

Focal Meaning #2. The subject transcended fear through sharing struggles and reaffirming beliefs.

Scene #3. At the end I was in the hospital two months before James was born. So two months in the

hospital is a long time to just sit and think. But I guess my hope is almost synonymous with my faith, because we do believe in God, believe that he is all knowing, that you can just trust him, you can put your faith and hope in him. And I'd have to say that's what my hope was all this time, is that God knew the situation. God was going to take care of it.

> (It was getting closer to seeing the final result. And I think that really the hope was almost the same as it had been all along except that it had to be stronger at this time because there were problems developing with the pregnancy. They had put me in the hospital because of toxemia. And every day the doctor would come into the room and say these tests don't look good but we're going to keep you here. I was on total bed rest at that time. And so I needed something much more than must, it had to become a very real thing, the hope then. At home, or when you're busy you can forget about bad situations. But when you're placed in a hospital, when it's continuously on your mind, and you're not able to get up or do your housework to take your mind off it. It's something that became a very present thing. A very continuing thing. You couldn't get away from it. And I think in that respect, I needed that hope much more. I had to be a continuous attitude. And I think that's where when I talked about God and my faith in him being my hope, that that's what really got me through that time. Because that was not something that's a shaky situation. It's there. It's there all the time, and all I had to do was to look to that. And then I'd see that I'd have that positive hope again for the future. I can't say, I really can't say all that time I can't say that I ever became without hope. Sometimes it would just be not as clear in mind if a whole bunch of bad situations came along. It would have to be reinforced again. But it was always there. And probably just the idea of being continuously reminded of the situation called for a creative measure.)

And whatever was the outcome, it was going to be for my good. And so, through this time it really built

up that faith and that hope. So that the next situation you went on to, you could say he got me through that. I can get through this next one. And there were times when James was born, he went immediately to the ICU nursery. He had apnea, so he would turn blue and all this. So I don't think that my fears at that time were unfounded. It wasn't I was a hypochondriac and thinking this was just going to happen. But through it all I never really got in despair or anything like that, because I just kept hoping and knowing that things were going to work out.

> (I felt very fortunate in this circumstance and in other ones afterward, that I had a hope and a belief to cling to. When James was diagnosed with CF, there other parents there at the same time going through the same things, and some of them would just deny that my son couldn't have that. I was very glad that I was in a position because of that hope to say I can deal with reality, no matter what happens. And I can not just completely fall apart. That there's something there. And many of these people that I had met they don't seem to have anything, a solid hope there. And when they are told some bad news or a bad situation comes, and they can't rely on any strength in themselves, they do fall into despair. And so I've never been in that situation. I've never been to the place where there's just nothing to get me back up. Because there's always, it's almost like I just have to turn back to look at that faith and that hope again to bring me up.)

Theme #3. During the first months of pregnancy the subject in confinement was able to anticipate a positive outcome amidst the darkness and hard times by remembering how her faith had seen her through past hardships.

Focal Meaning #3. The subject rose above bleakness by remembering past transformations within struggles.

Scene #4. Sometimes though they work out in ways that maybe you haven't hoped for exactly that situation. But then again, you have the courage, the strength to deal with that certain situation and then go on from there. I think that probably the hardest time through it all are the times that you almost would lose hope, when everything would just come crashing down. And I just thought I can't handle this, I can't do it. But I guess in the back of the mind you have the hope. You keep coming through. You think well, I've just got to do it and there's got to be an outcome to it if I just wait patiently, which I don't always do that patiently. But just wait and see what happens.

> (And those are the times when I would almost lose hope in the fact that I wasn't focusing in on it, and saying hey, it's there. God is still here. He's not changed. The same hope for tomorrow is still there, even if things do happen here on earth, my eternity is going to be in heaven. And those are the things that in a sense the feelings of hope were the same, I just had to grab hold of them and focus back in on them. And straighten my thinking toward them.
>
> But as I said finishing up, I came to the conclusion that I just had to wait, and I had to accept what happened, and I'd have to just focus in on that hope again, that faith that things in the future would word out, and that things in the future would be for my best no matter what they turned out to be, which sometimes can be a very difficult thing too.)

Theme #4. The subject was able to draw upon faith and courage during the difficult waiting times of despair by focusing her thoughts upon positive future possibilities.

Focal Meaning #4. While waiting, the subject anchored self within uplifting imaginings and felt both faith and courage emerging.

Situated Structural Description of Subject #1. The subject experienced a feeling of hope during the pregnancy of her first child. In preparing for the birthing, the subject experienced both joy and fear since she joyfully anticipated the birth, yet feared tragedy related to her health situation. Yet by clinging to her deep faith in God, and sharing the struggle, the subject was able to transcend her fear and reaffirm her beliefs. During the last months of pregnancy while the subject was in confinement she transcended the bleakness of the situation by remembering other past transformations within struggles. The subject found both faith and courage emerging as she anchored herself within uplifting imaginings.

Subject #2

The researcher then dwelled with the elaborated data of subject #2 of Family B. Again the natural meaning units or scenes which are shifts in thought patterns were identified. There were three scenes found in subject #2, Family B, transcriptions (see Appendix for complete elaborated transcriptions).

As each scene was individually analyzed, the central element or theme was identified by the researcher. The theme was listed below its corresponding scene. The three themes were then further individually analyzed and crystalized on a higher level of abstraction in the language of the researcher. These crystalizations were the focal meaning of the scenes and were listed below its corresponding theme.

The three focal meanings were then synthesized together to formulate the situated structural description of hope. As was previously stated, the situated structural description of hope is the distilled story of hope, of subject #2, retold in the language of the researcher.

The data for subject #2, Family B, are now presented.

Scene #1. Well, for myself, I've never had a personal time when I was sort of been in real trouble. I've never been in the hospital for anything that you could call major. I've never been in any work situation or school situation that looked beyond hope. That looked like there was no end to it. So in a way, it's kind of difficult for me to understand the word hope itself. So that's why the definition I go by is the biblical definition, because that's the only one that I can sort of latch on to, or make any sense of. In the time that I was almost slinging onto hope was when James got so sick when he was like four months old. It was hot weather, unusually hot for that time of the year. And he was virtually getting sicker and we were told that there was nothing really the matter with him.

(We were taking him to the baby clinic every week like everybody else did. And then I

suppose about the second or third week they noticed that something was the matter with him. And of course the first thing they latched onto was that the mother was doing something wrong or wasn't doing something right. something was amiss, but they couldn't put their finger on it. And this went on for several weeks. They tried several things to do to get him around and find what the problem was. And then they sent up to the doctor. And we'd been there ourselves before I think a few months earlier because of something else. But I think all these things in the end were related. But the doctors kept saying there's nothing the matter with him. He's so happy, he wouldn't be happy if he was sick. Well, they kept telling us all these things, and the problem was that we had no other babies around that we knew to just sit him beside to see that there's such a difference. Looking back at some of the photographs now that were taken once he came out of the sickness, he still looked so bad. Looking back at them now, he must have been horrible right at the depths of this. But the feeling right in the middle of this, if I can remember this accurately, was just plain frustration. We knew there was something the matter with him, but yet, the doctors said there was nothing the matter with him. It's your imagination. There was just a sort of blank space where minds didn't meet. I don't know why. Looking back now it was there seemed no logical explanation for it all. Because everything was there for anybody to see that something was wrong. And then we went to the doctor. They sent us to the doctor on a Friday and sent us around to the x-ray place. And we got the x-ray and took him back home. The doctor looked at him and said pneumonia. And somehow he sent us home and he was still bad, wouldn't feed, all these sorts of things. Nothing had changed for the better. Just going downhill continually. And the doctor, while he'd been our friend and doctor for a long time, I'm sure he knew there was something terrible going on. I got the feeling he didn't sleep that night because the next morning he phoned us before we were out of bed. He phoned us to see how James was doing. He was sick still

and getting worse. And he said just to get him into the hospital.)

And so toward the end of that particular month when he was so bad, I could see myself one Saturday morning when the....that if we didn't get it fixed within the week that was going to be the end of it. So...hospital and I started working on him. And right on the day they transferred him to another hospital where there was a pediatrician close by who had first hand of this type of illness. And they started doing extra treatments. Then that night when I got home, I was so sad in my soul. I don't really remember any other time in my life when I was so out of it because someone was sick or something of that nature. Probably because I didn't understand what was the matter with him, although we could see that it was something terrible. And the doctors didn't yet know for sure what was going on. So that night there was only me in the big old cold bedroom, and I was sort of thinking to myself, what have I done. That was the only, that seemed to be the only way I could get an understanding of the thing, was to examine what I had contributed if it was anything, still not understanding the full story of his illness. Or not wanting to understand it. Just sort of wanting to blame myself, and hope this thing will just go away if that was possible.

Theme #1. The subject experienced frustration during the first months of his child's life, as he watched his child becoming sicker and weaker, yet was told that his child was normal by health care professionals.

Focal Meaning #1. Feelings of helplessness emerged as the subject felt trapped by the persisting view of the health care professionals toward his son's health.

Scene #2. (Well, this is one of those times when hope had sort of run off and left me.

> At least that what it seemed to be. There are times when I get so tired and mountains of things are piling up against me. I sort of I guess emotionally collapse. Like someone dropped a whole house full of stuff right on top of me. That was the end of me, flat. Never to come up again. But once I had a good night's sleep and things were rational and logical and plain again, I was better able to understand what they'd been telling us and what we'd seen happen to him. And then not that faith came back, but I cam back to faith. I have a hard time just telling the difference between faith and hope and all these things. Somehow they're all the same. I'm not an intellectual you see. Faith and hope, they're always there. Initially you either have them or you don't. And to my way of thinking, if you have the, the Christian hope or faith, you can not lose it. The only way that you can get away from it is if you depart from it yourself, because faith and hope are based on trust in the Lord to take care of our needs. And he is always there, never changing.)

Theme #2. The subject experienced a brief loss of hope as he struggled, while exhausted, to understand his son's health situation. However, his situation began to look clearer after a period of restoration when the subject could remember his ever present faith and hope in God.

Focal Meaning #2. Amidst the struggle with despair, the subject began to understand his situation; feelings of lightness emerged after letting go of exhausted struggling and anchoring self within the familiar.

Scene #3. Then, they transferred him to. . . State Hospital. . . to really work at getting him out of the sickness. . . six weeks I think. And so I kind of knew that he couldn't get any worse. They were getting his lungs cleaned out and giving enzymes so his food would be digested. . . so he ought to be coming up again. And this is where hope comes in because there was a different point where our own abilities just come to an end. That's as far as we can go. Someone else is going to take over. That's the end of the line for us in a sense. . . And whether he survives it or not is up to the Lord. He has everything in control.

> (I started praying to Lord Jesus that James would come out of this. And that I would uphill through this. . . And I guess everybody else in the family too. It sort of had hit all of us. . . only months before my grandfather had died, and there was certain feelings around all that that sort of clouded everything. Everybody was in a muddle. But, once I got everything into perspective, I discovered that hope was still there. There was hope for the future, that James was either going to come out of this okay, or if this took his life he was going to be in a better place. He was going to be in heaven. So he was going to be okay.

Theme #3. The subject anticipated a positive future outcome after everyone involved in this situation had tried all possibilities, and the subject placed complete trust in his faith in God.

Focal Meaning #3. The subject's anticipation of a positive future emerged over time as he was able to anchor self in his trust in God.

Situated Structural Description of Subject #2. The subject experienced a feeling of hope during the

difficult first months of his son's life as he watched his child becoming sicker and weaker. After several weeks, feelings of helplessness emerged as the subject felt trapped by the persisting view of the health care professionals that his child was normal. In the subject's exhausting struggle for an answer, he experienced a brief sense of hopelessness. Letting go of the struggle, a sense of lightness emerged for the subject as he remembers his ever present faith and hope in God, thus anchoring himself in the familiar. Over time the subject is able to anticipate a positive future by continuing to anchor himself in his trust in God.

General Structural Description of Hope - Family B

As was the same for Family A, Family B's situated structural descriptions for both subject #1 and subject #2 were synthesized together into a general description of hope for that family. The general structural description becomes the meaning of the lived experience of hope as it was studied from the perspective of the subjects. The general structural description is at an even higher level of abstraction, thus loosing the ground which was inherent in the situated structural description.

The general structural description of hope as lived by Family B is as follows.

General Structural Description of Hope - Family B. Hope is the process that becomes known as one anticipates a future outcome. It arises from a struggle with the paradoxical nature of day to day experiences. It is in living these paradoxes that choices surface which lead the individual to choose a different view of the situation. That view then becomes the anchor for the individual and fosters movement, which both enables and limits the individual, in creating a new context of the situation.

Summary

Data analysis revealed a general structural description of hope that was the same for both Family A and Family B. While the meaning of the lived experience of hope was the same for each family, the process or experience of hope was uniquely lived by each individual. This was evidenced by four different recalled experiences of hope. A more detailed and complete discussion of results, as well as conclusions and implications will be presented in Chapter VI.

CHAPTER VI

Interpretation, Conclusions and Implications of the Study

Overview

A phenomenological study was conducted to generate a structural description of the phenomenon of hope as it is experienced in families with a chronically ill child. The aim of this research was to uncover the meaning of hope as humanly lived. The research question formulated for this study was: What is the structural description of the lived experience of hope for families with a chronically ill child.

As in accordance with phenomenological research, the researcher's beliefs regarding the phenomenon of hope were made explicit and a propositional statement set forth. From this researcher's perspective, hope is the process of originating or creating anew. Originating is man's choosing a particular way of self emergence through inventing unique ways of living. These choices are made concrete in transcending the paradoxical unity of certainty -- uncertainty as man makes concrete, clear choices in situation and yet,

simultaneously, lives the ambiguity of the unknown outcomes. In transcending the paradox of certainty -- uncertainty, a vision of the whole structure is sought by imaging new possibles. Imaging then shapes the process of originating as choices are made which are enabling and limiting all at once. Thus, movement in creating anew is in a particular direction.

The propositional statement synthesized from the researcher's beliefs regarding the phenomenon of hope is posited as: Hope is originating the enabling -- limiting of imaging. This means that hope is creating anew through living the opportunities and limitations of pictured possibles.

Methodology

A sample consisting of two families who each had a child between the ages of six and eleven with a medical diagnosis of a chronic illness were asked to respond verbally to an interrogatory statement (see Appendix B). Each family member was asked to describe individually into a tape recorder, a situation unique to him/her in which he/she experienced a feeling of hope. There were no other questions or comments directed to the subjects by the researcher at this time. All

audiotapes were transcribed and those data were initially examined by the researcher to discover areas of the description that were unclear.

The researcher then returned to the subjects for verbal clarifications (audiotaped) of the ambiguous areas found in the transcriptions. The audiotapes of the clarifications were then transcribed and placed within the original text at the appropriate line. This new complete data were known as the elaborated descriptions and became the raw data for analysis (see Appendix B for each subject's elaborated descriptions).

Study Sample

Although descriptions were elicited from every member of each of the two families, only the parents' descriptions were complete and clear enough to use for data analysis. In obtaining the descriptions from the children of the families, the data were contaminated through the use of leading probes. In every attempt to follow the methodology of this study, the children would respond in one or two sentences, and were unable to elaborate their responses. Thus the actual study sample consisted of, two parents from each of two families.

Findings

The General Structural Description of Hope

The data analysis provided a general structural description of the phenomenon of hope for each family. That structural description which was common to both families was: Hope is the process that becomes known as one anticipates a future outcome. It arises from a struggle with the paradoxical nature of day to day experiences. It is in living these paradoxes that choices surface which lead the individual to choose a different view of the situation. That view then becomes the anchor for the individual and fosters movement, which both enables and limits the individual, in creating a new context of the situation.

Discussion and Interpretation of Findings

In the next section, the findings which emerged from this phenomenological study will be discussed in relation to the data of each subject and family, the researcher's perspective of the phenomenon of hope and the three major perspectives of hope found in the literature.

Family A - Subject #1. For subject #1 (mother of Family A, a feeling of hope was experienced during the time when she was a student, single parent and sole

supporter of her children. She described that experience initially, as feeling both frustrated at being the sole supporter for her family and yet relieved at no longer having to care for the added responsibility of her husband. In addition the subject was receiving ADC which was "a means to an end" but nonetheless brought about confusion, doubt and fear for the subject. Those feelings surfaced as her view of herself, and her future were shaken. The subject didn't see herself as the type of person she imaged as receiving ADC assistance. In imaging her future while receiving ADC, doubt and fear arose, yet the subject continued to go to school, and to follow the path of her original goal (to finish college, and to be self supporting).

Furthermore, the subject had met her future husband during that same period of time. He too was on ADC and also disliked using the program. However being able to share this struggle with a new friend brought the subject to a place where she had to decide how she saw her future. She stated it "was a new beginning", and that she was "looking forward to something anyway".

From this point on in her transcription, although the subject described other times when "hope felt pretty hopeless", she continued to anchor herself in both her relationship and her choice for the future. It was as if after choosing her image of the future,

the subject grounded herself or anchored herself in that view and persevered through the rough times. And yet one serves a relief that occurs in light of the choice.

This subject did reach her goal -- she graduated from college and no longer needed the assistance from ADC. Hope had helped her carve out her goals, and persevere in achieving them. From this description, the hope experience emerged as a process, arising out of doubt and fear of an anticipated future. Hope lead to a changing view of the future. The subject anchored herself with that vision in order to persevere and continue in movement toward her goal.

Family A - Subject #2. Subject #2 (father) described his hope experience as occurring during the time of a business promotional event. He recalled that day as beginning with just a feeling of anticipation. The subject had spent much time and energy organizing and getting ready for the "big day". The event was to be an outdoor promotional for the radio station complete with leis, booths, and food and drink. But on this particular day the weather was rainy, cloudy and overcast.

The subject began to feel the beginnings of despair and many doubts as he feared failure. However,

he continued to work toward achieving his goal of a great promotional event. Then at the end of the day in the midst of the many struggles to achieve his goal, the subject had to make a decision regarding his view of the situation: he chose the view that he had done all that was possible to create the event. The subject stated, "So by the next day I did everything that I could possibly do for it (the event). I felt bad that it didn't come off and that it didn't work, but yet I didn't feel the anxiety because it didn't". Furthermore, a sense of relief emerged after he chose a different view of the situation. Again, it was the chosen image that became the anchor for this subject, and fostered perseverence and movement in a new direction.

For Subject #2, hope was the process that began as he saw an anticipated future outcome in the midst of fear and doubt. Hope lead the subject to decide on a different view of the situation, and in that imaging grounded himself in order to persevere against struggles, creating a new context. He stated "my hope was, let's move on to the next one. That's done. That's completed. . . So I wasn't despondent. I didn't feel bad. I was back then saying at this particular time it wasn't right for whatever particular reason."

For both subjects of Family A, hope was described as a process of creating anew. The reader felt the

struggle inherent in the hoping process and yet also the relief that occurred after a decision is made by the subjects regarding their changed views of the situation. Once that decision is made it's as if the subjects could "grind their heels into the sand" and stand up in the struggle moving along a chosen path, thus creating a new context of the situation.

Family B - Subject #1. For Subject #1 (mother) of Family B, hope was described as occurring over a long period of time. Specifically the subject recalled the time when she was pregnant with her first born son. Because the subject had diabetes and other health problems, the doctors and others had warned the subject about all the difficulties that could occur during the pregnancy and birth. Thus, although the subject was excited about the birthing, she also experienced many fears and doubts as she imaged the future happenings.

Throughout the pregnancy though, the subject described the reoccurrence of many doubts, and fears. Each time the fears arose, the subject tried to find something to cling to. Again, as with the other subjects, the subject made a decision as to how she was going to view the situation. For this particular subject, that decision seemed to reoccur many times. In choosing, the subject anchored herself in that view or

image of her future. Those anchorings became the somethings the subject "needed to cling to".

The subject stated, ". . . and so I needed something much more than just, it had to become a very real thing, the hope then. . . when you're at home and busy you can forget about bad situations, but in the hospital (the subject was hospitalized for 2 months before the birth), you couldn't get away from it. . . .(it was) a very continuous thing. . . . in that respect I needed that hope much more. It had to be a continuous attitude."

The reader sensed a relief that occurred after the subject was able to anchor herself in those imaginings. For this subject, being able to transcend those fears and choose her images for the future occurred through sharing struggles with others and reaffirming her belief in God. Once again, in making the decision, or a different view of the situation, the subject created a new context. The subject's last remarks describing her hope situation were, ". . . and I'd have to just focus in on that hope again, that faith that things in the future would work out, that faith that things in the future would work out, and that the things in the future would be for my best no matter what happened. . . I just had to grab hold of them, and focus back in on them. And straighten my thinking toward them. . ."

Subject #2 - Family B. For Subject #2 (father), a feeling of hope was experienced during the difficult first months of his son's life. During this time, the subject saw his son becoming sicker and weaker and yet the health care professionals found nothing physically wrong with the baby. Eventually, feelings of helplessness emerged, as the subject felt trapped by the persisting view of the health care professionals that his son was normal. The subject stated, "the feeling right in the middle of this, if I can remember accurately, was plain frustration. We knew there was something the matter with him, but yet, the doctors said there was nothing the matter with him. It's your imagination. There was just a sort of blank space where minds didn't meet."

As the child neared death, the subject took his son to the hospital again for more medical treatment. He stated, "I could see if we (hospital and father) didn't get it fixed within the week that was going to be the end of it." While the physicians continued to work with his son, the subject returned home and tried to understand all that had taken place.

It was during this night that the subject recalled experiencing despair, "when hope had sort of run off and left me." The subject struggled that night to the

point of exhaustion to understand the "full story of his son's illness." This struggle for understanding by the subject seemed very intense since his view of the situation was not matched by the health care profession.

Finally after giving up the struggle and getting a full night's sleep, the subject was able to choose a different view of this situation. The subject chose to remember his deep faith and trust in God. In so doing the subject was "better able to understand what they'd been telling us and what we had seen happen to him. And not that faith came back, but I came back to faith."

From this point on in the description, the subject continued to anchor himself in the familiar, which for this subject, was to trust in God. This anchoring allowed the subject to persevere through the hard times. A lightness was sensed in light of the choice by the subject. In the end, the subject anticipated a positive future as he continued to anchor himself in his trust in God.

For both subjects of Family B, hope was described as a process of creating anew. One is able to feel both the inherent struggle in that process and yet the relief that occurs after a decision is made by the subjects regarding their view of the situation. Again, as

for Family A, in light of that decision, the subjects persevered through hardships since the view provided an anchoring for their process of hope. Furthermore, as the subjects continued to move along a chosen imaged path, a new context was created of the situation. Thus the hoping process for Family A and B, although lived uniquely by each individual has been shown to have similar characteristics within the process. In the next section, the findings of this study will be examined in light of the researcher's perspective.

Discussion/Interpretation of Findings as Related to the Researcher's Perspective. The findings of this study will now be examined in light of the researcher's perspective for this study. In Chapter III the researcher's perspective regarding hope was made explicit. The purpose of that chapter was to describe the researcher's personal meanings of the phenomenon of hope from a theoretical perspective before the data were analyzed to make clear the "bracketed" view. In addition a propositional statement was set forth. In this section that propositional statement as well as this researcher's beliefs regarding the phenomenon of hope is compared and examined with the study's findings.

From this researcher's perspective, hope is a process of originating or creating anew. In originating, an individual chooses a particular way of self emergence and does that by inventing unique ways of living. Originating then is a process of creating the self and is coconstituted in interrelationships with others. Furthermore, hope is the force within originating.

In the process of originating or creating anew, there are paradoxes that the individual transcends thus creating new possibles or images of the self. One part of originating, is the paradox of certainty-uncertainty. This paradox surfaces in human encounters as individuals make concrete choices <u>in situation</u> and yet, simultaneously live the ambiguity of the unknown outcomes. It is in transcending this paradox by the individual that new possibles are imaged and a vision of the whole structure is sought. Imaging then is a part of the process of originating as well as part of transcending the paradoxical unity of certainty-uncertainty.

Imaging is the process of shaping personal knowledge. It is the coming to know both explicitly and tacitly all at once, and is the individual's way of giving significance, or meaning, to experiences as personal reality. For the meaning of an experience is

what constitutes reality for an individual. Thus imaging reality is making concrete the meaning of experiences and incarnating personal knowing.

In the process of imaging, an individual makes his/her reality by choosing from options within multidimensional experiences. In choosing, the individual is both enabled and limited by his/her choice. This, the enabling -- limiting rhythm, is lived simultaneously and is evident as possibilities unfold and the individual chooses. These choices propel movement in a particular direction. This movement is the individual's creating anew.

Hope then is the process of originating or creating anew. Originating is described as man's choosing a particular way of self emergence through inventing unique ways of living. Man's choosing is made concrete in transcending the paradoxical unity of certainty-uncertainty. In transcending these paradoxes, Man seeks a vision of the whole structure by imaging new possibles. Imaging shapes the process of originating through making concrete the meaning of experiences and incarnating personal knowing. In the process of imaging, choices are made which are both enabling and limiting. The enabling-limiting rhythm is evident as possibilities unfold and there is movement toward creating anew in a particular direction. In addition, the

propositional statement synthesized from the researcher's perspective, will also be examined in light of the findings of this study. The propositional statement for this study was: Hope is originating the enabling-limiting of imaging.

From these concepts, which were part of the researcher's perspective, a schematic presentation was derived and is illustrated by Figure 1. This schematic presentation is a nondirectional framework which depicts the linkage of the concepts: imaging, enabling-limiting, and originating. Furthermore, it is posited that there are no causal relationships among these concepts, but rather a connectedness among concepts.

The findings of this study reveal that hope is a process that becomes known as one anticipates a future. Hope arises from a struggle with the paradoxical nature of day to day experiences. It is in living these paradoxes that choices surface which lead the individual to choose a different view of the situation. That view then becomes the anchor for the individual and fosters movement, which both enables and limits the individual, and creates a new context of the situation.

All of the researcher's beliefs concerning hope were confirmed by the findings of this study. This is evident in that hope was found to be a process that

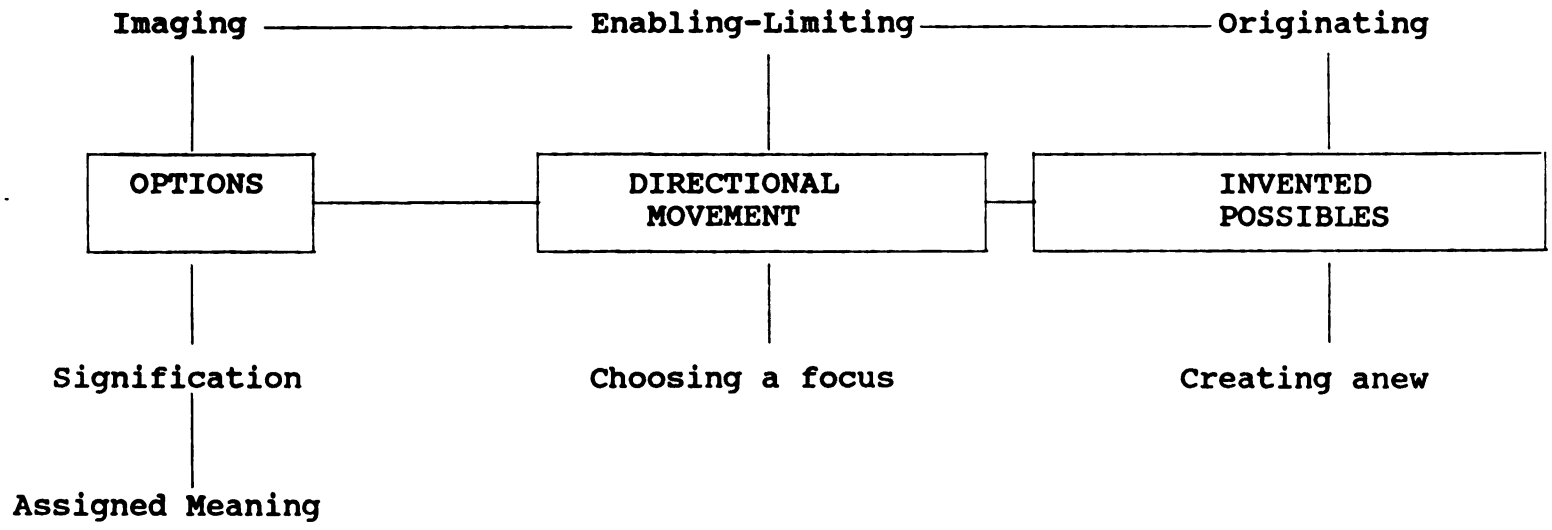

Figure 1. Logical Mapping of Concepts of Researcher's Perspective

included living the paradoxes of a certain and yet uncertain outcome. Hope involved choosing a view of the situation, which anchored the individual in that process. Finally, hope is a part of movement. It is created by the individual through choices in situation and is ever changing.

There were a few findings from this study which were not explicitly a part of the researcher's perspective. These new findings were incorporated into a new logical mapping of the Researcher's perspective. The new logical mapping of concepts included the specific constructs found in the general structural description of hope for Family A and Family B (see Figure 2).

Specifically, the new logical mapping indicated that in the process of hope, the chosen view made by the individual became the individual's anchor which facilitated perseverence in hardship. Furthermore, the anchoring by the individual often was the rememberances of past successes or familiar beliefs. Thus a person's past and belief system became intimately linked with his/her imaged present and future. This new finding provides insights not only in the specific processes of imaging and originating (creating anew) but also of hope. In the next section, the findings of this study will be discussed in relationship to the three major perspectives of hope that were found in the literature.

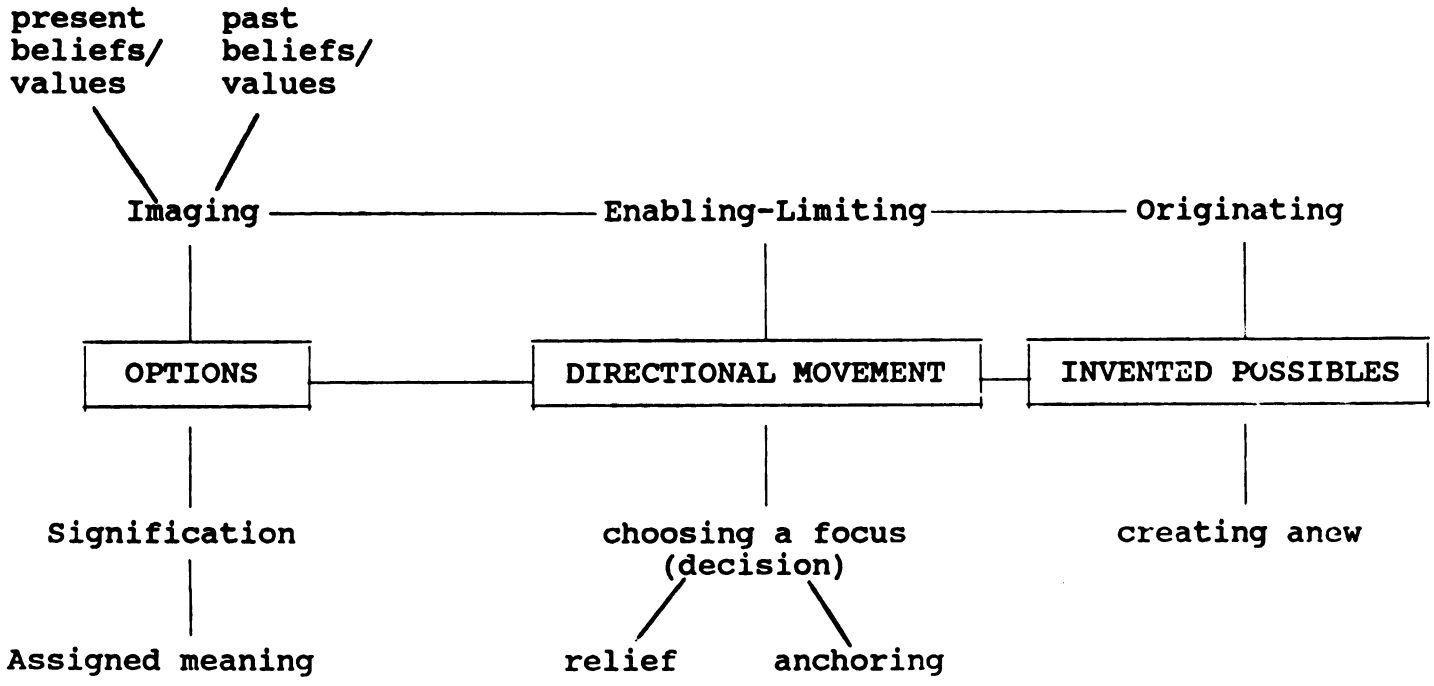

Figure 2. New Logical Mapping of Concepts of Researcher's Perspective.

Discussion of Methods

The phenomenological method seeks to uncover the meaning of phenomena as experienced by individuals through analysis of the subjects' descriptions. The phenomenological method explicitly accounts for an individual's participation with a situation by using the subjects written or oral retrospective descriptions as raw data. It is in analyzing those descriptions that the nature of the phenomenon is revealed and the meaning of the experience for the subject understood (Cohen, 1987; Parse, 1985).

The method used in this present study was the Giorgi modification of phenomenology. This method seeks to uncover the meaning of lived experiences through indepth analysis of subjects' descriptions. Each family member was asked to describe individually a situation unique to him/her in which a feeling of hope was experienced. The researcher examined the descriptions for areas which were unclear. The researcher then returned to the subjects for verbal clarifications. The clarifications and the original descriptions were the raw data for analysis and were known as the elaborated data.

The parents of the families had no difficulty describing a retrospective description of a experience

of hope. Each parent was able to articulate their experience which included their feelings, and thoughts surrounding the experience of hope. In addition the parents were able to elaborate the unclear or ambiguous areas of their descriptions. Thus the parents data were complete and able to be analyzed to reveal the meaning of hope as lived by each subject.

The children of each family had great difficulty describing a retrospective experience of hope. Although the children usually were able to describe a remembered future oriented event as in describing a time in which they wished for something, they were unable to elaborate for more than two sentences without prompting by the researcher. The younger children (ages 6-7) were unable to remember a future oriented event, and could only describe a present hoping experience (hoping for a bike for a birthday). Thus the children's descriptions could not be analyzed using the Giorgi modification of phenomenology.

Since the children had such difficulty describing retrospective descriptions of an experience, the Giorgi method of phenomenology is not appropriate for qualitative research using children as subjects. What would be appropriate is a methodology in which the researcher could lead the children to discuss their present feelings and thoughts regarding a phenomenon. Thus by

using such a methodology, a child's perspective or meaning assigned to that experience could emerge. This finding is congruent with Bernheimer's (1986) recommendation regarding the use of qualitative methods in child health research. Bernheimer found the method most applicable to research using children as subjects was the structured open-ended interview format. This format, which is the methodology used in a descriptive/case study qualitative approach, provided the most insight regarding a child's perspective.

Discussion/Interpretation of Findings Related to the Theoretical Literature of Hope. In the literature concerning hope, there appear to be three emerging perspectives. The first perspective which is incongruent with the findings of this present study posited that hope is a phenomenon that motivates an individual to act, and this is a determinant of human behavior. Furthermore, within this motivational perspective there appear three general approaches. The first approach is known as Drive Theory and from this perspective it is believed that an individual's instincts or drives force one to act in a certain manner or behavior.

The second approach to motivation is the attributional model. From this perspective, it is believed that there is a relationship between extrinsic rewards

and intrinsic motivation. Thus if an individual is rewarded positively, he/she will be motivated to act in a manner which will continue the reward pattern.

The third approach is actually an offspring of the attributional model and is known as mastery motivation (Harter, 1981). Originally proposed by White (1959), mastery motivation impelled an individual toward competent performance and was satisfied by a feeling of efficacy. Thus from this perspective an individual's need to deal effectively with his/her own environment was considered intrinsic, and that when satisfied, produced inherent pleasures.

The theorists that considered hope a motivational construct (Bernard, 1977; Breznitz, 1986; Menninger, 1959; Mowrer, 1960; Stotland, 1969; Erickson, Post & Paige, 1974; Gottschalk, 1974; Korner, 1970; & Meissner, 1973) used either a psychoanalytic or cognitive-behavioral approach. However, with either approach, hope was considered the trait or force that impelled an individual to act. Furthermore hope was measured in relationship to perceived goal attainment. From the psychoanalytic perspective, hope is examined in relation to drives. For Menninger (1959) hope was a creative drive that struggled with destructiveness and ultimate dissolution. Hope was active and correlated with a plan of action and subsequent behavior. Mowrer

did not view hope as a drive. He believed that true drives do not motivate behavior, but rather provide reinforcement for behavior. Hope and fear were true motivations and were acquired by the individual.

Stotland (1969) conceptualized hope from a cognitive-behavioral perspective, as the sense of goal attainment. He concluded that hope was necessary for motivation and action, and that the achievement, accomplishment or attainment of future goals were not possible without hope. Thus hope could be measured in regard to an individual's goal attainment.

Other researchers (Erickson, Post, & Paige, 1974; Gottschalk, 1974) who share the cognitive-behavioral perspective of hope have also measured hope in relationship to perceived goal attainment. All have found that hope is part of an individual's motivation to achieve a goal and that hope is a positive function of the perceived importance of the goal.

The findings of this study do not concur that hope is a determinant of human behavior which can be measured. Specifically, since hope was found to be originating or creating anew, then the findings of this study suggest that hope is a process rather than a trait or a drive or an attribute. Furthermore the concept of process as viewed by this researcher, consistent with the simultaneity paradox, is not one created

of steps to produce an effect i.e. A + B -> C but rather is based in the belief that people are open beings who coexist with the universe and whose negen tropic unfoldings are in mutual and simultaneous inter-relationships with the environment (Parse, 1981). The perspective of hope as a motivational element also does not take into account the individual's point of decision regarding imaged choices. Rather, hope from this perspective is choice-less, and only either inherent as a drive or acquired as a attribute.

The second perspective of hope found in the literature is common to most of the nursing literature. The basic premise of this perspective involved the manipulation of hope in order to enable or inspire hope within another individual. Hope was viewed as a necessary element in healing, health and life.

According to Vaillot (1970), hope is part of the restoration of being. Through a clinical illustration, Vaillot (1970) demonstrated how a nurse's consistent faith that a terminally ill woman could be indeed restored to a fuller being, was <u>the</u> element that "triggered hope in the family" who had "given up". For Vaillot then, the primary aim of nursing is to help clients to live as fully as possible. Nurses do this by facilitating clients to reach out to a fuller being or in other words, inspiring hope (Vaillot, 1970).

Similarly, Travelbee (1971) and Miller (1985) also saw the role of the nurse as assisting the ill person to maintain or regain hope, and avoid hopelessness. For Travelbee (1971), hope was defined as a mental state characterized by the desire to gain an end or accomplish a goal with some degree of expectation that the goal or end was attainable. She believed hope to be strongly related to: dependence on others; further-orientation; choice; wishing; trust and perseverence; and courage. Miller (1985) on the other hand, stated that she viewed hope as springing from several different sources for each person. Miller saw hope arising from an individual's faith, communion with another, feeling needed, and having something to accomplish.

According to Lange (1978), the Hope Continuum was an explanatory model introduced to help nurses identify both hope and despair behaviors. For Lange (1978), hope and despair were at opposite ends of a continuum. In addition, hope had both affective components and cognitive functions. The affective components of hope of the faith-doubt continuum included elements of faith (a positive belief that unknown forces can be relied on), trust, confidence in self and others, and fortitude.

The cognitive component of hope as defined by Lange (1978) is the way one perceives and processes

reality. The cognitive component protects the affective piece from threatening reality facts. The cognitive component is made up of selected information which will support the desired hope. Lastly, Lange (1978) saw hope as a motivational force which maintains energy and is essential to mobilizing forces toward health.

Buehler (1975) and Hickey (1986) studied the factors that contribute to hope in cancer patients. Buehler (1975) found one of the elements that instilled hope in the clients, was the expectation by the staff that the patients would be involved actively in their own care. Buehler posited that the reason this element was the main factor for instilling hope was due to a strong hope ideology which was manifested by the staff's interactions with their clients.

Hickey (1986) found hope to be an active behavior that can be enabled by nurses through five approaches. Hickey saw hope as an essential element in the lives of those experiencing cancer, because it "enables the living to continue on and the dying to die better" (p. 133). Hickey (1986) developed approaches which facilitate a realistic hope rather than a false hope in clients. These approaches include: 1) developing an awareness of life through the use of active listening, 2) identifying a reason for living; 3) establishing

support systems; 4) incorporating religion (as individually needed); and 5) setting realistic goals (Hickey, 1986).

Other nursing researchers who have influenced this perspective on hope have completed both quantitative as well as qualitative research. The qualitative studies were completed to develop a construct definition of hope in order to understand the meaning of hope and thus indicate implications for practice and further research.

Hinds (1984) attempted to induce a definition of hope through the use of Strauss' grounded theory methodology. Hinds (1984) synthesized construct definition of hope found from her study was:

> the degree to which an adolescent believes that a personal tomorrow exists; this belief spans four hierarchial levels proceeding from lower to higher levels of believing.
>
> 1. Forced effort: the degree to which an adolescent tries to artificially take on a more positive view.
> 2. Personal possibilities: the extent to which an adolescent believes that second chances for self may exist.
> 3. Expectation of a better tomorrow: the degree to which an adolescent has a positive though non-specific future orientation.
> 4. Anticipation of a personal future: the extent to which an adolescent identifies specific and positive personal future possibilities (p. 360).

In another qualitative study, by Dufault and Martocchio (1985), a construct definition of hope was

obtained. From the analysis of the data of longitudinal studies, Dufault and Martocchio (1985) found that:

> . . . hope is a multidimensional life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically and personally significant. Hope has implications for action and for interpersonal relatedness. Hoping is not a single act but a complex of many thoughts, feelings, and actions that change with time. Hope is. . . process-oriented. . . and is conceptualized as being composed of two spheres and having six common dimensions (p. 380).

Dufault and Martocchio (1985) describe the two spheres of hope as being generalized and particularized hope. Generalized hope is more intangible, and broad in scope. Particularized hope is concerned with a hope object or particularized valued outcome, good, or state of being. The six dimensions of hope identified were affective, cognitive, behavioral, affiliative, temporal, and contextual. This framework of hope assists nurses in designing interventions to help individuals achieve or maintain hope by facilitating the nurses knowledge of the nature of hope and manifestations of hope. Awareness of hope as a multidimensional life force can guide the nurses' listening, observing and interacting with the client in order to detect the presence or absence of each dimension and determine ways in which each dimension is present and can be further enabled.

In summary, hope from the perspective most common to nursing known as enabling hope, has viewed hope as a necessary and vital element in healing, health and life. Most nursing authors indicated that nurses should and do inspire, instill or enable hope in others.

The findings of this present study indicate that hope is a common lived experience, and in that sense is related to health. However, hope as described in this present study is incongruent with Dufault and Martocchio's (1985) interpretation of their construct definition of hope. Certain aspects of the definition seem congruent. For example, Dufault and Martocchio (1985) state that "hope is characterized by a confident yet uncertain expectation of achieving a future good." This finding correlates well with the present study's findings, that an individual's hoping process is part of originating or creating anew since certainty and uncertainty are transcended in originating.

Dufault and Martocchio (1985) also state that "hope has implications for actions and for interpersonal relatedness." This corresponds to the present findings that state that hope enables movement thus creating a new context for the individual. Furthermore, Dufault and Martocchio (1985) state that "hope is process oriented it is not a single act but a complex

of many thoughts, feelings, and actions that change with time." This also corresponds to the present findings in that hope was also found to be a process that changed over time.

However, Dufault and Martocchio (1985) also found that hope was composed of two spheres and six dimensions as was previously discussed. The findings from this present study do not support their results. Nevertheless, it must be stated that it was not the intention of this research to study the process of hoping, but rather describe the experience of hope as lived by the subjects.

In addition, the findings of this present study do not support many of the earlier perspectives of hope found in the nursing literature. Specifically since hope was found to be process oriented, and chosen by the individual, then hope by its very nature can not be instilled, given or enabled by another person. Rather hope can be supported by the nurse as each person chooses in his/her own hoping process.

The last perspective which appears to be emerging in the literature is based, in part, on existential philosophy. Within this framework hope is viewed both as mystery and process, and concepts such as struggle, the courage to be, mystery, and transcendence as valued (Fromm, 1968; Mermall, 1970; Magan, 1986; Marcel, 1951;

and Stanely, 1978). At present there are both theoretical and empirical writings concerning hope from this perspective.

Marcel (1951) viewed hope as a process and psychic activity which is impossible to separate from the situation of which it is a part. Marcel situated hope within the framework of captivity, with the nature of that captivity being the human condition. The situation might seem impossible to the individual, and he/she might be tempted to despair. But hope is the act by which this despair to captivity is overcome.

Hope for Marcel includes liberation as well as an element of despair. The situation seems impossible to control. However to hope means that "man must live in hope. . ." rather than concentrate attention on encounters which cause no respite, fear or ruin (Marcel, 1951; p. 61). According to Marcel (1951) when one is living hope, that individual makes him/herself available to accomplish "the transcendent act" which means the act that establishes one "as before, but differently and better than before" (p. 67).

Another significant description of hope was written by Padro Lain Entralgo and translated and explicated by Mermall in 1970. Mermall (1970) referred to Lain Entralgo as Spain's philosopher of hope. Lain Entralgo's theory related the concepts of expectation,

belief, hope, temporality and transcendence. Hope according to Lain Entralgo as interpreted by Mermall (1970), is trustful expectation in the possibilities of "being" -- the hopeful person trusts that his creation "will be" (Mermall, 1970).

Stanely (1978) found seven common elements from the descriptions of the lived experiences of hope. From her study those elements were: 1) expectation of a significant future outcome; 2) the feeling of confidence of an outcome; 3) the quality of transcendence; 4) interpersonal relatedness; 5) experiencing comfortable feelings; 6) experiencing uncomfortable feelings; and 7) action or effort to effect outcome. These common elements were then synthesized into a general structure of hope. Stanely (1978) formulated the structural definition of hope as a "confident expectation of a significant future outcome, accompanied by comfortable and uncomfortable feelings, characterized by a quality of transcendence and interpersonal relatedness and in which action to effect the outcome is initiated" (p. 165).

Another qualitative study related to hope, sought to uncover the lived experience of hopefulness and hopelessness, (Magan, 1986). Magan (1986) based her study on both an existential perspective as well as Parse's (1981) Man-Living-Health Nursing Theory. For

Magan (1986) hopefulness is grounded in the view that hopelessness and hopefulness are complimentary and exist as a unity. "Hopefulness serves as a ground for hopelessness. When one of these experiences is focal, the other lies quiesent, so that each experience powers and transforms the other." From Magan's (1986) study the derived definition of hopefulness is as follows: "Hopefulness is the extended imagining spurred by resolute choosing that culminates in creating a new context." From Magan's (1986) study, hope is an active process of an individual creating anew. That work of creation must be done by the individual and has meaning as the individual chooses from options in situations, thus moving in a chosen direction. The direction is uniquely chosen by the individual and is uniquely lived by the individual.

This present study is mostly consistent with the existential framework that values process, choice, struggle, mystery, and transcendence. Mystery is evidenced by the individual choosing an uncertain direction of the future; struggle relates to the process of hope which is marked by periods of uncomfortable feelings, uncertainty and despair. Transcendence occurs as the individual lives the process of hope, moving in uniquely chosen directions, thus creating anew.

A nursing theory consistent with the existential framework is Parse's (1981) theory of nursing, Man-Living-Health. The findings of this present study do support Parse's three principles inherent within her theory. Specifically, the concepts of originating, enabling-limiting, and imaging as related to the lived experience of hope are supported by the research findings.

Nursing Implications

In this last section of Chapter VI, the nursing implications and recommendations for research, practice and education shall be discussed. Specifically those three areas will be addressed as it relates to this present study, advanced nursing practice, and primary care.

Research. This researcher used a phenomenological qualitative methodology by Giorgi. While the lived experience of hope was elicited from four subjects, and is considered an in-depth analysis of their descriptions, the results are only generalizable to those families. Thus it is recommended that larger populations be utilized, using the Van Kam methodology of phenomenology, to study the lived experience of hope.

The purpose of phenomenology is to study a phenomenon as uniquely lived by the subjects and generate

theory. For this study, the theory generated was in the form of a propositional statement. That statement was based on Parse's (1981) Man-Living-Health Theory of Nursing. The results were consistent with that framework and hope was understood from three principles of Parse's theory. Further research is indicated using other principles from Parse's theory to study the phenomenon of hope in order to generate a conceptual framework that will look at all the nuances of hope.

Because this researcher attempted to describe a family definition of hope, and used the parent's descriptions of hope for analysis -- other studies need to be conducted to understand the lived experience of hope from the child's perspective. Phenomenology uses retrospective descriptions for data, and the children were unable to recall a hope experience, thus a different methodology needs to be used to understand their perspective. A descriptive qualitative methodology is recommended since a series of open ended questions could be asked of each child. The results would allow researchers to describe the meaning of hope for these children.

Assuming that the process of hope would be confirmed in other studies, that process could then be further studied from a qualitative ethnographic approach. This would allow the researcher to

understand all the phases of the hope process from many cultural contexts. Large numbers or repeated research studies would need to be completed to generate a full understanding. In order to describe the meaning of hope for large populations, a qualitative descriptive study could be completed. The descriptive study uses a conceptual framework to guide open ended interviews. The data would then be analyzed in light of the framework to generate more theory. As stated previously, the theory supported would then provide implications for practice, education and further research.

Each of these proposed methodologies would generate more theory regarding the phenomenon of hope from the perspective of Man-Living-Health framework. Furthermore, if hope is truly a phenomenon common to the human experience then other populations would also need to be sampled to better understand how hope is lived for other populations in other situations.

It is the belief of this researcher that a phenomenon does not have to be quantified to test the theory generated. This is based on the belief that the methods used to study a phenomena, or concept must be true ontologically with that theory in order to test or support the theory. If the methods are inconsistent with the theory, the results then cannot be linked to that theory.

The results of this present study support Parse's (1981) Man-Living-Health Theory of Nursing, thus this theory guides the implications for further research, practice and education. In the next section, Nursing practice recommendations shall be discussed.

Practice. The results of this study indicate that hope is a process uniquely lived by the individual heralded by a changing view of the situation which acts as an anchor for the individual. Hope is accompanied by uncomfortable feelings of uncertainty but when transcended, by the chosen perspective of the individual, movement occurs and the situation is created anew. Thus practice implications shall be derived for the Clinical Nurse Specialist (CNS) in Primary Care and will be process oriented. For it is the theory which was supported by these findings that directs practice.

Since hope was found to be a process rather than a drive, or a trait, the CNS will need to support the individual's process of hoping. Although it has been thought that hope can be instilled, this study's findings indicate that hope is not a trait which can be instilled but rather a series of movements which could be facilitated. Specifically, the CNS would "be with" the person through illuminating meaning, synchronizing rhythm, and mobilizing transcendence. More plainly

stated, the CNS would have the person describe the meaning of the situation, the important persons involved and their dreams and hopes in the situation.

The individual's past, and belief system, influence the process of hope, and thus the CNS would need to have the individual describe their belief or value system/ their past rememberances of hope; their perceptions of the future; and finally how other times of hopelessness/despair were lived by the individual. This information would provide the CNS with a basis in regards to the individual's health patterns and also allow the CNS to better understand how hope was lived in past situations by the individual.

The individual's process of imaging could be supported by the CNS thru illuminating with the individual the new imaged options, alternatives or possibilities. As these new possibilities emerged, support could be given to the individual in order to facilitate the individual's resolute choosing regarding the situation. Once the view is chosen by the individual, that viewpoint must be supported by the CNS. The CNs would need to realize that all views or images will continue to shape and change, and that with time, those images will shape a person's actions. Thus hope is not instilled by the CNS but illuminated with the individual from his/her perspective.

As a client advocate, the CNS would support the hope process as chosen by the individual and assist that person in the process. Specifically in this role, true mutuality is established with the individual. Furthermore, the control lies with the individual, and the CNS is often the follower, and learner in the situation. Together the CNS and the individual discover the process of hope as the CNS "is with" the individual.

Realizing that the hoping process cannot be removed from situation, the CNS would need to involve the individual's family in the hoping process. Since the individual's past family history influences his/her imaging, which in turn affects the resolute choosing in the hoping process, the CNS could share with the family and elicit their perceptions of remembered hopes. This would illuminate each member's hope process. As each member participated in his/her hope process, new possibles could emerge for the client as well as the family. IN this way the CNS would act as the client/family advocate of hope.

Education. Nursing implications for education can be derived from this current research study for both the CNS, and bachelor prepared nurse in learning and teaching roles. Clinical Nurse Specialists, student

nurses, and nurses in practices, can learn research based nursing interventions and can in turn teach others what they have learned.

Traditionally, the nurses' role in regard to hope has been to enable individuals by instilling hope or fostering hope for the individual when he/she could not do so individually, thus preventing despair or hopelessness. This study's findings indicate that hope doesn't become known until that person is tempted with despair and hopelessness. Thus despair and hopelessness, as well as other uncomfortable feelings are a part of the hoping process.

In order to address these new results, both baccalaureate and graduate nursing curricula needs to include both content regarding process oriented nursing interventions as well as process oriented nursing theories. Taking results of a study with a process ontological basis and then manipulating the findings to fit a causal nursing model, invalidate the findings and the research methodology as well as generate inconsistent frameworks. Thus nurses need to be taught frameworks which value process in order to integrate the findings into practice. Nurses then would practice research theory based nursing.

Specifically, nurse educators would teach nurses the basis regarding process oriented theory and

research. From such preparation, a baccalaureate nurse could assess an individual's imaging process and facilitate the process by providing support to the individual. Advanced practice nurses in primary care would have an education of more breadth and depth regarding theory, research, and practice. Thus the CNS in primary care could support, guide an individual's and family's hoping process, from their perspective.

Since most continuing education programs for baccalaureate nurses often deal with concrete interventions strategies that help restore an individual's health, programs would need to be developed by advanced practice nurses which would sensitize practice settings to soft research and the importance of that research to practice. Thus qualitative research inservices with relevance to practice need to be conducted.

Advanced practice nurses could also be instrumental in developing learning experiences for the general public. The public health CNS could provide seminars and group self help seminars to help individuals learn more about hope. If hope is necessary for health, then educating the general public in regard to this process would help meet the national health goals.

Lastly, practicing nurses (both baccalaureate and graduate), student nurses and other health care professionals should be taught to incorporate the study

results into their practice. To do this nurses need to understand Parse's (1981) Man-Living-Health Theory of Nursing for this theory that dictates practice concerning the hoping process as studied by this researcher. The goal of such education would be to teach nursing students that the goal of nursing is the quality of life as viewed by the person.

Summary

In Chapter VI an overview of the research was presented. In addition the findings were discussed and analyzed in regard to the subject's transcriptions, the researcher's perspective and the three emerging perspectives of hope found in the literature. Finally, the significance of this study in regard to nursing research, practice and education were discussed.

Appendices

Appendix A

Consent Form

CONSENT FORM

The study in which I am asking you to participate is designed to learn more about the experience of hope in families. You and your family will be interviewed in your home at two different times. Each member will be individually asked to describe a time in which you experienced a feeling of hope. You may choose to write your descriptions or verbalize your descriptions into a tape recorder. Each family session will take approximately one to one and one-half hours. If you agree to participate, please sign the following statement.

1. I have freely consented to take part in a study of the experience of hope in families conducted by a graduate student of the College of Nursing at Michigan State University.

2. The study has been described and explained to me and I understand what my participation will involve.

3. I understand that participating in this study is voluntary and I can withdraw from participating at any time. I understand that my decision of whether or not to participate will in no way affect the care that I or my family are receiving.

4. I understand that no immediate benefits will result from taking part in this study, but am aware that my responses may add to the understanding of health care professionals of the lived experience of hope in families.

5. I understand that all descriptions will be treated with strict confidence and that I and my family will remain anonymous.

I, _____, state that I understand
(print name)

what is required of me as a participant and agree to take part in this study. I agree that my child(s), _____, may also participate in this research study, if he/she is willing.

Signed_____
(Signature of participant/parent or legal guardian)

Date_____

Appendix B

Interrogatory Statement

Appendix B

Interrogatory Statement

Describe a situation in which you experienced a feeling of hope. Share all your thoughts, perceptions, and feelings that you can recall until you have no more to say about the situation.

Appendix C

Elaborated Descriptions of Family A and Family B

Appendix C

Family A - Subject #1 - Mother

It was in summer of 82 I think. To set the scene, I was going to college living in family housing with my two boys. I was single parent at that time. And my ex had just given up on seeing or supporting the kids, so I was all alone.

> (Well, I didn't have anyone to share responsibilities with, was the big thing. I was the only one responsible for their upbringing. As far as how it felt, I would say it was a little overwhelming at times. It wasn't a whole lot different than the way it was before. It was good and bad. I didn't have anyone to share the responsibility with, but then he wasn't always there anyway. It was kind of a relief I didn't have to be responsible for him anymore. So as far as that, I didn't mind the responsibility I guess. I was all alone. It might sound like a complaint, but it really wasn't. I didn't mind being alone. I was able to handle that.)

I was on ADC, which I hated. I hated being on it. It's a lot of work to keep them happy and to do all the form work and all that kind of stuff, and it went against the grain. I didn't want to have to be on it, but it was a means to an end. To get where I wanted to go.

> (It's like taking a hand out. Somebody else supporting you. You're not self-sufficient. You've got my feelings are that everybody should be able to take care of themselves. And you have a vision of what people are that are on ADC. You think about them as a lowlife that doesn't want to get off their butt and do something for themselves. That was my picture of somebody on ADC. And here I was on it, and I didn't picture myself as being that type of a person. I didn't like being on it because of that. And when you go in there you sit with these people, and you'd

look around, and you're like I don't belong here. I don't want to be doing this.)

(It's very embarrassing to go to the store and use food stamps. I felt like people were looking at me and going "What's the matter with you?" And then I felt like everything we bought was being scrutinized because you're using food stamps. The food stamps is the worst because that's the thing that everybody sees. When you get your ADC check you put it in the bank and nobody sees it. But the food stamps are a constant reminder that you're being helped by the state. And I just didn't like the feeling that I couldn't do what I wanted without people looking at me. Because in reality, everybody's paying your way. Your taxes. I see people on ADC and you're supporting them with your taxes. And so I'm thinking, they're looking at me like I'm looking at everybody else and scrutinizing. So it gave me a feeling of what they would feel. But I really kind of watched what I was doing.)

I had just met Bob that summer, and we were getting along real well.

(I was happy. I shouldn't say it like I hadn't been happy before. But it was a whole different kind of feeling. I felt loved and I was loving him. Not at first. It was just the new love. And the new love is something else anyway. And a new beginning, looking forward to something. So that was a feeling as far as him. We were both on ADC and we both hated it. But I guess it (hope) fit in because we both had the same goal to get off ADC. And we were both trying to make a life, both trying to better our lives. That's why we were in school and going through everything. Although he was also getting VA benefits. Things looked a lot brighter. It looked like there was more of a future I could grasp than just a door at the end of a tunnel. It looked like I could see what was out at the end. It wasn't like I was going out blindly. Which was what I was looking at before he came along. I was going to graduate and I was going to start a new life, but I didn't know what. I had no idea. Whereas

> he gave me something more to look forward to. More concrete.)

And I got a notice from ADC that they were cutting me off because I didn't file my form in time. And I was just devastated, and I remember crying and just thinking what can come next because it was just something hitting.

> (This happened about in early August. Hope felt pretty hopeless. It just wasn't (hope), it was like somebody pulled the rug out from under your feet. You're moving along and it's like you take a step back and fall back. Or take one step forward and you go back two. You're trying to get somewhere and then they do something like that and it all seems to unreasonable. For what reason? I felt like I wasn't a person at that time. I wasn't being treated like a person. I was just being treated like something on a piece of paper. They would take my life and turn it upside down just over paperwork was unbelievable to me. And that just reinforced the feeling that I want it off and I don't want to handle this kind of crap. I was just really upset with it.)

And it was at that time when things were going well with Bob, I was thinking once I get off ADC things are going to be a lot better. I haven't got that much more to go.

> (I was happy that I had someone to share it with, and that I wasn't alone. That was a lot easier on me. Somebody else that knew how I would be feeling, could understand it.)

I was graduating that December. So I was hoping at that time that things were really going to turn around once I graduated and got off ADC, because it just seemed like that was the real blow. I didn't want to be there and I was there and they were giving me a hard time. It wasn't easy going. So the main feeling of hope was that once I got off that my life would straighten around and I wouldn't be dependent on anybody else and I would have control over my life again. And that was the big part, just being able to have control. I wanted control, so that I think everything else would then fall into place.

(Being in control, to be able to be responsible for my own mistakes. And that I've paid for my own mistakes on my terms and not somebody else's terms. That I'm not following somebody else's rule book. I've got my own rule book as to what is accepted and what isn't accepted. I feel everybody should be allowed to screw up, and on ADC you aren't allowed to screw up. You have to pay for it, I mean literally. Moneywise you pay. I didn't want every mistake to cost me money. Not when you're struggling just to survive. To have control over, like when you're on ADC you can't have a car with car payments. You're not allowed to have assets, because then you're not eligible. Being in control is not always good. There are scary feelings with it too. I am in control and that's why I'm responsible. But I still think of them as good feelings. Being in control, coming and going and doing what I want and not having anybody. I'm just trying to think of this in relation with ADC. If I get too broad. I'm trying to think of all the regulations and such that they had on me. Daycare, the expenses, and what they would allow you. And they changed while I was on it, different rules. I guess that bothered me too. Every year you didn't know what to expect. They changed the rules and what was going to apply. It's just like doing your taxes now. You can't declare that anymore. That doesn't work. So it was the same thing I guess. You exchange one for another. I've learned that. That it's not all that I thought it was going to be. I do have control, but.)

And that was the one thing I keyed in on, was the ADC because that seemed to be the one thing holding me back from attaining other goals. And that was the feeling of hope.

(Frustrating. (The feeling of hope.) The goals I had in mind was to have a career and support my family. And my goal was to get an education so I could get a better job and support my family. Because I had tried it before, that's why I went back to school. I had tried with no degree, and I couldn't

> demand the money. I thought with an education I would be able to demand a higher income and therefore support my family, because I wasn't getting any help from anybody. And I knew it had to be me that did it. I wasn't receiving any help from my ex at that time. And my family didn't give me a lot of money. I wasn't one of those fortunate people that mom and dad helped support you. So I just wanted to live. I'd grown in a comfortable environment, and I wanted to be able to have that kind of environment for my family, for my two boys and me. That was my goal. To be able to be comfortable and live within what I wanted and plus have a job that I liked and that I felt would compensate me for what I was doing. With those goals in mind, it was a real blow against my ego. I wanted to attain so much more than what I would think the normal person on ADC would have in store for them. It was just a stepping stone to me. And it was just frustrating, it was disheartening, embarrassing. The whole thing. I just wasn't where I wanted to be. And it was like fighting to get out of a paper bag. You have to be there for so long, and you can't just say ok, I quit. I'm off it. You can't do that. You have to big the bullet and stick with it.)

Now as far as the result of it, it was like a weight. The feeling of being under. Receiving ADC was like a weight on my shoulders. A responsibility that I didn't want. I was responsible for my actions to somebody else, instead of just me, and I didn't like that feeling at all. So I felt that it would just take a big load, that physical weight which I've experienced. When I got my divorce I felt that weight coming off my shoulders. And this was just another one that was heaved right back on. I thought I've felt that relief before, so I was just going to look forward to just having that pulled off and it did. Once I was off ADC I felt I'm on my own. So that's it.

> (I was fairly accepting of it. I think I am fairly logical, and I knew that it was coming to an end. And I was well it's just a little bit longer. Anticipation of being off it. I'm coming up blank. I think it was a little bit almost regret too. Thinking about going off. Well this is pretty easy money. It

like, you're not going to have that anymore. I was looking forward to getting rid of the paperwork, the food stamps, which are an embarrassment. But it was a little scary that I've got to come up with the funds that are going to support. So I think there was a little bit of worry that I was going to be able to do it. But then you don't go off ADC until you're making money. So I thought it's going to come out ok. It'll even out.

Family A - Subject 2 - Father

Describe a time or experience when I felt hope. I'm of such a nature that I feel hope every day. It starts in the morning and will end at night for each day.

> (That's because I leave my nights, my sleeping time for a fantasy. I see hope as something really concrete. Hope itself is pretty nebulous. But I put it all into something that's concrete. It's easier for me to handle. Even emotions. I try to put it in terms of something concrete that I can deal with. My hope starts in the morning and ends at night because those are my concrete times. And that something I can see, I can hear it. I can touch it. So as far as it starts in the morning, that's because I wake up and I'm thoroughly conscious. And then it ends at night when I go to bed or go to sleep. It feels exciting to have hope every day, something new. But yet something you can depend on. I can depend on every day being new, and hope for a better day than what I've had previous. Excitement, less worry. Something that will straighten out, something that will pull together.)

I'm in sales, so a good portion of my time is spent in hope, hope that I'll make a sale, hope of this or hope of that. But I do feel hope every day. For me to sit back and pull one day out of the 365 that come in a year would be extremely difficult. The nearest one would be yesterday. And again going back to my sales, a feeling I experienced hope. I had a promotion going on at the Water's Edge in Toledo. And I worked extremely hard to pull this all together, getting bands, getting food, getting staging, getting music, getting give-aways, getting wine coolers. Just getting everything for putting a promotion together. My experience of hope, I woke up just anticipating.

> (Woke up in the morning that day and it was rainy, it was overcast, and we were supposed to have a luau outdoors. We had a best tan line contest, a hula-a-hoop contest, best

flowered shirt contest. All of these outdoorsy type of contests. And it was windy, it was cold and it was rainy. And for hope I had hope that it was going to clear up and be warm at least, even if it was still a little cloudy. To bring more people there. We got there and it was lousy. The weather just stayed lousy and I had to run around and get all the sound equipment in the morning. Get leis, we were giving away leis. And I had to pick up all the little bits and pieces. Records we are going to give away, the hats we were going to give away. Making sure my itinerary was all straight. What we wanted to do at what time. What bands were going to be playing and when. Just making sure that was all still running, even though it was so lousy and the weather was lousy. It must have been around 1:00 and it was still really lousy out. And I had all my people there. There were jocks and other people from the radio station there. So I took them down and I fed them a lunch. We got done with lunch and we got up there and everything should have been rolling for a half hour, and there was no one there. There was absolutely no one there. And it was terrible. I was bumming out. Just feeling really lousy, like this is just really a failure. So at that time I started looking for excuses or reasons as to why, other than the weather. I felt it was something other than the weather. Even though the weather was bad, there was enough going on. As the day progressed, it just stayed that lousy, never improved. We had bands and tents and food and wine coolers, and the radio station was there. And albums to give away. We had 500 leis to give away. We had 16 people come through the door for the whole afternoon. That was 3 hours and 16 people showed up. So it was just worse than a total disaster as far as a promotion, as far as all the work I put into it. That was the way the whole day went. Then to top it off, the person that ran the Water's Edge and the restaurant that got the bands, wanted me to foot half the bill for his bands and his expenses, whereas I had already put out close to $2,000 worth of stuff from the radio station, let alone all my time and extra time I put into it. So I had hoped for something a

> whole lot more than what we had gotten. But it just never improved all day long.)

It was the excitement of I guess the unknown. Maybe that's what hope is to me, the unknown. And just everything leading up to the day.

> (To hope hope during this time wasn't really hope as I see hope. Hope is something nice to have. This was almost I was begging. Oh please, please I hope it gets better. That type. I can't think of the word I want to use right now other than begging. That's the only word I can think of right now. That's not exactly what I mean, but I can't think of the word I want to use to describe other than a begging, pleading type of hope. For my life, for my security, for my business, for my radio station, for everything.)

And when I woke up it was rainy, it was cloudy and overcast. Just a real lousy day, but I still had hope for a big turnout.

> (I was not really anticipating a bad day. I was still hoping for a good one. But knowing that this could really bomb out because of all the factors that were involved that were out of my control. So by the next day, I did everything that I would possibly do for it. I felt bad that it didn't come off and that it didn't work, but yet I didn't feel the anxiety because it didn't. Because I had done everything I could do and the radio station had. So I had hope that maybe my client at that time wouldn't try to say hey, it was you at the radio station, because you didn't handle something correctly. That wasn't so. My hope was let's move on to the next one. That's done. That's completed. Let's learn from it and move on. So I wasn't despondent. I didn't feel bad. I was back then saying at this particular time it wasn't right for whatever reason.)

For that promotion to be a big turnout would be the same as making a big sale, or the same as having another good day within my family life, or the same type of hope that I would feel if they found a cure for CF. Hope is that we would have just a huge turnout at this luau. I was excited, I was a little bit nervous,

and I was worried. But I believe that's everything that goes with the word hope.

Family B - Subject #1 - Mother

Well, the circumstance or situation that I thought back on was one that my idea of hope, or that was over a long period of time. Because there's been many times in our lives that, even day to day, you have hopeful situations. But this one was actually when I was pregnant for James. Because of health problems that I have being diabetic and different things, the doctors had warned about all the different things that could go wrong. All the things that could go wrong. I was so excited because we wanted children and all that, yet in the back of my mind there was this, is it going to be something I can cope with.

What if my child has an illness? What if I lost this child? And all those type of things.

And that's where the hope for a good easy pregnancy, the hope for a healthy child, came in. And also the hope that no matter what happened, I could cope with it. That I could handle it.

> (As I said I was very excited because children were something that I had always wanted, so there was this job. But because of my health problems there was always this nagging feeling that are you going to have a healthy baby. Are you going to be able to carry it full time? And of course the doctors had outlined many things that could happen. Many things that did happen as a result of it. Mainly there was a fear there. I don't think it was an ungrounded one. Just a fear that possibly this thing I wanted so badly was just going to escape me somehow. Those times that I felt like that were very short though. I get the feeling that way and then I'd start thinking now that's dumb, because I knew that whatever would be the outcome that it would be for my best. And that somehow I would be able to get through it. That I had the hope which is very much in my life the same as the faith in God that he would see me through each thing. And even if something tragic did occur, there was a reasoning behind that. So

> I suppose that my one fear though was that would I be able to cope and handle whatever would happen. If there was a tragic ending or a happy one like there was. And just be able to come through it without just falling to pieces or losing that faith that I had.)

Throughout the time, there would be days that everything would go right, and you wouldn't worry or anything. But during the worrying times, that's when you had to have something to cling to. To think I'm going to get through this.

> (I remember back specifically one day I had been to the clinic, where I went every two weeks. And the ladies, we were sitting, all talking. And most of us were diabetic. And one was telling how many still born children she had lost. And one other lady I know had a baby that was born perfectly and just died in delivery. And I think those were the days when I really needed something to cling to. That this isn't going to happen to me. That day I remember going home and still feeling down about it. Feeling, is this in my mind, just something I'm dreaming is going to happen. And I think those were the times when I did actually have to cling to something. Not just in my mind think this is going to be fine. But actually even possibly go to the Bible and read some of the promises there. Sometimes I remember going to someone that had the same feelings I did, the same beliefs, and talking to them and getting that extra, just knowing that they would be there. That they understood, that they were concerned about it too. And throughout it all though, I have to go back to what I said before, it's really just believing that God had it in control. And the days that I would start worrying are the days that I would try to take everything upon myself, and figure how am I going to work this out. And then I's just keep going down and down because I knew myself I couldn't do much. And I was in this circumstance and I just had to wait to see it through. I couldn't do anything right now to assure a positive outcome.)

Sometimes hope felt far away. Sometimes it seemed like, this is almost going to sound like I've lost my

faith in the Lord, but it wasn't that. It just seemed like is this just something that's superficial, and not real. I remember just a few times feeling like that. Is it just ridiculous to believe in this. Yet then as soon as I'd almost have those thoughts I'd say no it's not. In the past the many things that I've gotten through and the Lord's helped me through. And he's the same today, yesterday, and forever. And I know that. And so I think it was more when that hope seemed far away, it was almost like it was myself doubting. And that it needed to be reestablished by going to maybe the Bible, or going to someone that was strong and could reinforce my prior beliefs. I can't say I ever lost that belief or that hope, but sometimes circumstances might push it in the background for a little bit and it had to be remembered and brought out.

At the end I was in the hospital two months before James was born. So two months in the hospital is a long time to just sit and think. But I guess my hope is almost synonymous with my faith, because we do believe in God, believe that he is all knowing, that you can just trust him, you can put your faith and hope in him. And I'd have to say that's what my hope was all this time, is that God knew the situation. God was going to take care of it.

> (It was getting closer to seeing the final result. And I think that really the hope was almost the same as it had been all along except that it had to be stronger at this time because there were problems developing with the pregnancy. They had put me in the hospital because of toxemia. And every day the doctor would come into the room and say these tests don't look good but we're going to keep you here. I was on total bed rest at that time. And so I needed something much more than just, it had to become a very real thing, the hope then. At home, or when you're busy you can forget about bad situations. But when you're placed in a hospital, when it's continuously on your mind, and you're not able to get up or do your housework to take your mind off it. It's something that became a very present thing. A very continuing thing. You couldn't get away from it. And I think in that respect, I needed that hope much more. I had to be a continuous attitude. And I think that's where when I talked about God and my faith in

> him being my hope, that that's what really got me through that time. Because that was not something that's a shaky situation. It's there. It's there all the time, and all I had to do was to look to that. And then I'd see that I'd have that positive hope again for the future. I can't say, I really can't say all that time I can't say that I ever became without hope. Sometimes it would just be not as clear in mind if a whole bunch of bad situations came along. It would have to be reinforced again. But it was always there. And probably just the idea of being continuously reminded of the situation called for a creative measure.)

And whatever was the outcome, it was going to be for my good. And so, through this time it really built up that faith and that hope. So that the next situation you went on to, you could say he got me through that. I can get through this next one. And there were times when James was born, he went immediately to the ICU nursery. He had apnea, so he would turn blue and all this. So I don't think that my fears at that time were unfounded. It wasn't I was a hypochondriac and thinking this was just going to happen. But through it all I never really got in despair or anything like that, because I just kept hoping and knowing that things were going to work out.

> (I felt very fortunate in this circumstance and in other ones afterward, that I had a hope and a belief to cling to. When James was diagnosed with CF, there other parents there at the same time going through the same things, and some of them would just deny that my son couldn't have that. I was very glad that I was in a position because of that hope to say I can deal with reality, no matter what happens. And I can not just completely fall apart. That there's something there. And many of these people that I had met they don't seem to have anything, a solid hope there. And when they are told some bad news or a bad situation comes, and they can't rely on any strength in themselves, they do fall into despair. And so I've never been in that situation. I've never been to the place where there's just nothing to get me back up. Because there's always, it's almost like I

just have to turn back to look at that faith and that hope again to bring me up.)

Sometimes though they work out in ways that maybe you haven't hoped for exactly that situation. But then again, you have the courage, the strength to deal with that certain situation and then go on from there. I think that probably the hardest time through it all are the times that you almost would lose hope, when everything would just come crashing down. And I just thought I can't handle this, I can't do it. But I guess in the back of the mind you have the hope. You keep coming through. You think well, I've just got to do it and there's got to be an outcome to it if I just wait patiently, which I don't always do that patiently. But just wait and see what happens.

(And those are the times when I would almost lose hope in the fact that I wasn't focusing in on it, and saying hey, it's there. God is still here. He's not changed. The same hope for tomorrow is still th ere, even if things do happen here on earth, my eternity is going to be in heaven. And those are the things that in a sense the feelings of hope were the same, I just had to grab hold of the them and focus back in on them. And straighten my thinking toward them.

But as I said finishing up, I came to the conclusion that I just had to wait, and I had to accept what happened, and I'd have to just focus in on that hope again, that faith that things in the future would work out, and that things in the future would be for my best no matter what they turned out to be, which sometimes can be a very difficult thing too.)

Family B - Subject 2 - Father

Well, for myself, I've never had a personal time when I was sort of been in real trouble. I've never been in the hospital for anything that you could call major. I've never been in any work situation or school situation that looked beyond hope. That looked like there was no end to it. So in a way, it's kind of difficult for me to understand the word hope itself. So that's why the definition I go by is the biblical definition, because that's the only one that I can sort of latch on to, or make any sense of. In the time that I was almost clinging onto hope was when James got so sick when he was like four months old. It was hot weather, unusually hot for that time of the year. And he was virtually getting sicker and we were told that there was nothing really the matter with him.

> (We were taking him to the baby clinic every week like everybody else did. And then I suppose about the second or third week they noticed that something was the matter with him. And of course the first thing they latched onto was that the mother was doing something wrong or wasn't doing something right. Something was amiss, but they couldn't put their finger on it. And this went on for several weeks. They tried several things to do to get him around and find what the problem was. And then they sent up to the doctor. And we'd been there ourselves before I think a few months earlier because of something else. But I think all these things in the end were related. But the doctors kept saying there's nothing the matter with him. He's so happy, he wouldn't be happy if he was sick. Well, they kept telling us all these things, and the problem was that we had no other babies around that we knew to just sit him beside to see that there's such a difference. Looking back at some of the photographs now that were taken once he came out of the sickness, he still looked so bad. Looking back at them now, he must have been horrible right at the depths of this. But the feeling right in the middle

> of this, if I can remember this accurately, was just plain frustration. We knew there was something the matter with him, but yet, the doctors said there was nothing the matter with him. It's your imagination. There was just a sort of blank space where minds didn't meet. I don't know why. Looking back now it was there seemed no logical explanation for it all. Because everything was there for anybody to see that something was wrong. And then we went to the doctor. They sent us to the doctor on a Friday and sent us around to the x-ray place. And we got the x-ray and took him back home. The doctor looked at him and said pneumonia. And somehow he sent us home and he was still bad, wouldn't feed, all these sorts of things. Nothing had changed for the better. Just going downhill continually. And the doctor, while he'd been our friend and doctor for a long time, I'm sure he knew there was something terrible going on. I got the feeling he didn't sleep that night because the next morning he phoned us before we were out of bed. He phoned us to see how James was doing. He was sick still and getting worse. And he said just to get him into the hospital.)

And so toward the end of that particular month when he was so bad, I could see myself one Saturday morning when the....that if we didn't get it fixed within the week that was going to be the end of it. So...hospital and I started working on him. And right on the day they transferred him to another hospital where there was a pediatrician close by who had first hand of this type of illness. And they started doing extra treatments. Then that night when I got home, I was so sad in my soul. I don't really remember any other time in my life when I was so out of it because someone was sick or something of that nature. Probably because I didn't understand what was the matter with him, although we could see that it was something terrible. And the doctors didn't yet know for sure what was going on. So that night there was only me in the big old cold bedroom, and I was sort of thinking to myself, what have I done. That was the only, that seemed to be the only way I could get an understanding of the thing, was to examine what I had contributed if it was anything, still not understanding the full story of his illness. Or not wanting to understand it. Just sort

of wanting to blame myself, and hope this thing will just go away if that was possible.

> (Well, this is one of those times when hope had sort of run off and left me. At least that what it seemed to be. There are times when I get so tired and mountains of things are piling up against me. I sort of I guess emotionally collapse. Like someone dropped a whole house full of stuff right on top of me. That was the end of me, flat. Never to come up again. But once I had a good night's sleep and things were rational and logical and plain again, I was better able to understand what they'd been telling us and what we'd seen happen to him. And then not that faith came back, but I came back to faith. I have a hard time just telling the difference between faith and hope and all these things. Somehow they're all the same. I'm not an intellectual you see. Faith and hope, they're always there. Initially you either have them or you don't. And to my way of thinking, if you have the, the Christian hope or faith, you can not lose it. The only way that you can get away from it is if you depart from it yourself, because faith and hope are based on trust in the Lord to take care of our needs. And he is always there, never changing.)

Then, they transferred him to. . . State Hospital. . . to really work at getting him out of the sickness. . . six weeks I think. And so I kind of knew that he couldn't get any worse. They were getting his lungs cleaned out and giving enzymes so his food would be digested. . . so he ought to be coming up again. And this is where hope comes in because there was a different point where our own abilities just come to an end. That's as far as we can go. Someone else is going to take over. That's the end of the line for us in a sense. . . And whether he survives it or not is up to the Lord. He has everything in control.

> (I started praying to Lord Jesus that James would come out of this. And that I would uphill through this. . . And I guess everybody else in the family too. It sort of had hit all of us. . . only months before my grandfather had died, and there was certain feelings around all that that sort of clouded

everything. Everybody was in a muddle. But, once I got everything into perspective, I discovered that hope was still there. There was hope for the future, that James was either going to come out of this okay, or if this took his life he was going to be in a better place. He was going to be in heaven. So he was going to be okay.

Appendix D

Human Subjects Letter of Approval for Research

Appendix D

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
238 ADMINISTRATION BUILDING
(517) 355-2186

EAST LANSING • MICHIGAN • 48824-1046

July 8, 1986

Ms. Cynthia Brunsman
College of Nursing
A230 Life Sciences Building

Dear Ms. Brunsman:

Subject: Proposal Entitled, "The Lived Experience of Hope in Families with a Chronically Ill Child"

UCRIHS' review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on July 7, 1986.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to July 7, 1987.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

Henry E. Bredeck
Chairman, UCRIHS

HEB/jms

cc: Dr. Barbara Given

Appendix E

Risk/Benefit Ratio

Appendix E

Explanation of Risk/Benefit Ratio

The potential risks to the subjects of this investigation were psychological in nature. For example, in describing a hope situation, painful memories may be recalled. Therefore to minimize this potential negative effect from participating in this research, the researcher was present during all data gathering procedures. Using professional judgment, the researcher would abandon the data gathering if the subjects experienced considerable discomfort in describing their situation and seemed unable to continue. The researcher would also be available at this time to provide any supportive counseling or community referrals that seemed necessary.

In addition, the subjects were given a choice in the data gathering process. If the subjects believed that they were better able to express themselves with ease through writing, then written descriptions of the experience of hope were obtained. If the subjects preferred to verbally describe their experience of hope, then audiotapes were used to record such descriptions.

All written and oral descriptions were edited for names to provide subjects with anonymity. All audio tapes were erased after the transcription of data. The data obtained were locked in the researcher's private file. Only code numbers were used for each subject/ family. Each family was informed of these procedures before data gathering. If the families requested the results to this study, a copy was sent via the mail.

There are no immediate benefits for the subjects in participating in this research except a new awareness of an experience of hope. Nevertheless, this study hoped to broaden theory based nursing practice to better illuminate, mobilize, and synchronize a family's health process in light of the phenomenon of hope.

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