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INTEGRATING CHRONIC ILLNESS INTO ONE'S LIFE:
A PHENOMENOLOGICAL INQUIRY

by

Susan Rush Michael, MS, RN

A dissertation presented to the
FACULTY OF THE PHILIP Y. HAHN SCHOOL OF NURSING
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requirement for the degree
DOCTOR OF NURSING SCIENCE

August, 1994

Abstract

Integrating Chronic Illness into One's Life:

A Phenomenological Inquiry

Chronic illness is currently the number one health problem facing the United States; however, little is known about the experience of making chronic illness a part of one's life, particularly from the perspective of the chronically ill person. If nurses are to assist people in living with chronic illness, then an understanding of this experience is essential. Therefore, the purpose of this phenomenological inquiry was to explore how chronically ill adults integrate chronic illness into their lives.

Seventeen chronically ill adults were interviewed by the researcher, and asked to describe how they integrated chronic illness into their lives. Each interview was audio taped and transcribed. Utilizing Colaizzi's method of data analysis, significant statements were extracted from each interview and then collated and analyzed for formulated meanings. The four major themes that emerged from this analysis were: confronting loss, riding a roller coaster of emotions, making changes, and gaining control of an altered life direction.

Some of the major recommendations and implications for practice centered around a need for health care providers to recognize and assess factors important in integrating chronic illness into one's life. These major factors

included: loss as a ongoing and unending experience, and how this loss may influence participants' willingness and ability to implement changes; emotional drain of living with chronic illness; dilemmas that arise between implementing treatment plans and participating in valued activities; and support of friends and family as valuable, but not always available. Further research is needed to address how these factors can be incorporated into the care of the chronically ill and the influence these might ultimately have on the course of the illness and quality of life.

August , 1994 Susan Rush Michael

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DEDICATION

This dissertation is dedicated to my dad, who taught me so many important lessons about life, including anything that is worthwhile or worth having can only be achieved through hard work, determination and faith accompanied with an attitude of never, never give up. Dad, this one's for you.

ACKNOWLEDGEMENTS

Completing a doctoral dissertation is no easy task and certainly one that is not done alone. There are numerous people that I am indebted to who made this dissertation possible. First, I would like to acknowledge the participants whom I interviewed. Their openness and willingness to share their stories touched me deeply. I would also like to acknowledge my committee members, Dr. Jan Harrison and Dr. Evelyn Anderson for all their time and effort in assisting me towards this endeavor. I would particularly like to thank my chairperson, Dr. Patricia Roth for her guidance, numerous suggestions, patience and encouragement. To my children, Julia, Rebecca and Eric, I thank you for your understanding, your love and your nightly prayers. To Grace, who took care of the children and daily details of the household for so many years, thank you for everything. Lastly, to my husband Paul, there is no way to adequately express my feelings of gratitude to you for all you have done in making this dissertation a reality. Only you know what a sacrifice it has been for me, you and the family. Thank you for all your love, for your shoulder to lean on, for listening to my thoughts and feelings, and for your encouragement. Each time I said "I can't do it anymore", you gently said "yes you can" knowing it meant hours and hours away from you and the family.

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CHAPTER 1

The Problem

Chronic illness is currently the leading health problem facing the United States (Lubkin, 1990). Approximately 110 million people in the United States are affected by one or more chronic illnesses (Bureau of Census, 1986). As the population becomes older, and prevalent disease patterns shift from an acute orientation to a chronic one, it becomes quite clear that chronic illness will become an even more significant problem in the future.

With the escalating numbers of chronically ill people, there has been an increasing interest in understanding how chronically ill people come to live with their illness (Johnson & Morse, 1990; Kazak, 1989; Larsen, 1990; Pollack, Christian & Sands, 1990; Radley, 1989). However, despite this increasing interest, little is known about the experience of making chronic illness a part of one's life, particularly from the individual's perspective. Four significant factors contribute to this lack of understanding.

First, much of the literature dealing with chronic illness has focused on the impact of the illness and not on the day-to-day experience of living with the illness (Gregg, Robertus & Stone, 1989; Miller, 1992; Packard, Haberman,

Woods & Yates, 1991). While much has been learned concerning what the chronically ill are faced with, these studies do not illuminate what people do, or how they make the illness a part of their lives.

Second, the literature that is concerned with living with chronic illness has focused predominantly on psychological adaptation to chronic illness and not on the entire experience (Bohachick & Anton, 1990; Dakof & Mendelson, 1989; Felton, Revenson, & Hinrichsen, 1984). As Pollack (1987) noted in a review of literature concerning adaptation to chronic illness, most of the articles investigated some aspect of psychological adaptation such as quality of life or life satisfaction. Living with chronic illness involves more than psychological adaptation. Pollack, Christian and Sands (1990) addressed this apparent deficit in the literature through a research study focusing on psychological and physiological adaptation of 240 chronically ill people. However, this focus is still limited as other realms were not addressed (social, spiritual, and cultural).

Third, within the literature concerning psychological adaptation to chronic illness, studies have primarily dealt with interventions that facilitate, predict or measure adaptation without a clear conceptualization of adaptation. (Long & Sangster, 1993; White, Richter & Fry, 1992). Some studies do not define what is meant by adaptation, (Livneh &

Jones, 1984; Matson & Brooks, 1977) and others commonly define adaptation by interchanging with terms such as adjustment, coming to terms, and acceptance (Craig & Edwards, 1983; Pollack, Christian & Sands, 1990). Those authors that do define adaptation do so differently, which makes comparison of the studies difficult, even though they are looking at the same process. Duffy (1987) examined the concept of adaptation and concluded that not only is there a lack of clear conceptual definition, but there is also the limitation of its use as a measure of health in nursing research. Clearly, an understanding of how people make illness a part of their lives is indicated before intervention studies are conducted to assist this process.

Lastly, although models have been proposed to explain adaptation to chronic illness, few are based on the actual experiences of how people make chronic illness a part of their lives. Most of the models have their basis in the theoretical literature, particularly theories of grief concerning death and dying. This approach assumes that the experience of living with chronic illness is the same or similar to the dying experience. The obvious difference is that one focuses on adapting to living with loss, while the other focuses on adapting to dying. Also, these models are based in theory and not in the experience of individuals with chronic illness. In addition, those models that have been proposed concerning adaptation commonly discuss the

role of acceptance within adaptation in significantly different ways (Chapman, 1984; Livneh & Jones, 1984; Kerr & Thompson, 1972; Vash, 1975). While acceptance has been seen as a critical event in adaptation to chronic illness by some authors (Dembo, Leviton & Wright, 1956; Kerr & Thompson, 1972; Lewis, 1985), others do not include acceptance in their theoretical models (Craig & Edwards, 1983; Lawrence & Lawrence, 1979; Pollack, 1986). In several studies, adjustment to chronic illness is seen as a response to loss where acceptance is the final stage, (Chapman, 1984; Livneh & Jones, 1984). Other studies cite acceptance as an initial critical event in the process of adaptation (Vash, 1975) and some studies describe acceptance as an ongoing process, achieved little by little over time (Kerr & Thompson, 1972).

Not only is the role of acceptance seen differently, but there is no consensus as to the definition of acceptance. Edelwich and Brodsky (1986) state that acceptance does not mean resignation, but a realistic adaptation to a specific illness. Lewis (1985) states that acceptance means keeping a firm grip on oneself and working toward safeguarding individual's integrity. Dush (1986) sees acceptance as simply an accurate understanding of the illness.

Statement of Problem

A lack of understanding of the process of how people make chronic illness a part of their lives, and confusion as

to the definition and role acceptance plays in this process, leads to the emergent problem of a lack of understanding of the experience of integrating chronic illness into one's life. Therefore, the purpose of this study is to describe the lived experience of integrating chronic illness into one's life. Specifically, this study sought to explore:

1. What is the experience of integrating chronic illness into one's life?

The following definition of terms is utilized for the purpose of this study:

Definition of Terms

- Adaptation - Process of adjusting to a chronic illness where the focus is on the chronic illness and what the individual must do to fit their lifestyle to the needs of the illness.
- Acceptance - Acknowledging and possessing an accurate understanding of chronic illness in one's life (Dush, 1986).
- Integration - Process of making chronic illness a part of one's life and one's self where the focus is on the individual and not on the illness.

Chronic Illness - Chronic illness is the irreversible presence, accumulation of latency disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function and prevention of further disability (Lubkin, 1990).

Assumptions

The researcher has certain assumptions about the experience of integrating chronic illness that must be stated and put aside in order to gain an understanding of the individual's experience of this phenomenon. By setting aside assumptions one can become aware of one's own beliefs and then wonder how it is for others. This setting aside of assumptions is referred to as bracketing and is an essential component of phenomenology (Munhall, 1994). These assumptions are:

1. Integration of chronic illness into one's life is dependent upon acceptance.
2. Medical diagnosis is not a significant factor in determining the life experience of chronic illness.

Significance to Nursing

Nurses are faced with the challenge of caring for the chronically ill and the number of people with chronic illness is increasing dramatically (Lubkin, 1990). During

the next two decades, between 1990 and 2010, it is estimated the number of people over the age of 85 will increase by 100% or more in fifteen states and by 150% or more in the five states of Alaska, Arizona, Florida, Hawaii and Nevada (Kovar & Feinlab, 1991). With this increase in the number of older people, the correspondent rise in chronic illness is predictable.

People with chronic illness require health care and health care is expensive. According to the Congressional Budget Office and the Office of Management and Budget, the U.S. spent 650 billion dollars or 12% of the gross national product on health care in 1990. It is estimated by the year 2000 health care costs will increase to 17% of the gross national product and by the year 2030 will be 37% of the gross national product (American Family, 1990). It is believed a large portion of this cost is related to chronic illness.

With increasing numbers of chronically ill and increasing costs to care for this population, it is essential that nurses understand how persons integrate the experience of chronic illness into their lives and how this affects the course of their disease. Knowing what chronically ill people are experiencing provides nurses with a greater depth of insight which could positively influence their nursing care and expectations of the individual. This could ultimately lead to interventions that assist the

chronically ill to live life optimally.

How people live with their chronic illness may affect variations in the disease course as well as in treatment outcomes (Lazarus & Folkman, 1984). For example, it has been suggested that psychosocial and demographic factors may contribute 25-50% of the variance in diabetes control (Wise et. al., 1986). The Diabetes Control and Complications Trial (1993) has provided evidence to show that good control of diabetes translates to less complications and that means decrease in cost. Providing information and health care therapies to assist people in controlling their disease process is not sufficient (Lambert & Lambert, 1987). Chronic illness requires a total readjustment of the individual's life, not simply information about the disease. This adjustment needs to be understood by health care professionals in order to provide care that positively influences the course of the illness and enhances the quality of peoples' lives.

This study provides a description of the lived experience of integrating chronic illness into one's life and contributes to the knowledge base concerning chronic illness. This description provides the beginning to understanding how people make chronic illness a part of their lives.

CHAPTER 2

Literature Review

The literature review discusses theoretical perspectives of chronic illness including definition, trajectory and impact. These aspects of chronic illness serve as the foundation for exploring how people integrate chronic illness into their lives. Literature concerning adaptation and adjustment is presented and analyzed for what is already known about the experience of integrating chronic illness. Proposed models concerning adaptation and adjustment are presented and limitations of these models are discussed. Lastly, a review of how acceptance appears in the literature is examined including the utilization and exploration of acceptance from a nursing perspective.

Disease, Illness, Disability, and Sickness

The last forty years have given rise to numerous definitions of chronic illness as well as its interchange with terms such as chronic disease, disability and less frequently chronic sickness. However, these terms are significantly different, and it is important to not only identify the differences, but to come to some understanding about what are the meaning of these terms in this study.

First, disease is considered to be a biological and objective phenomenon. Diamond and Jones (1983) state that

disease signifies a state of non-health where the body is malfunctioning. Disease involves an entity that is biological and physiological in nature and encompasses the disciplines of biology and medicine where diagnosis of a disease is based on biological principles.

Illness, however, refers to the subjective phenomena that the person is experiencing. When a person is talking about the symptoms of the disease, he is explaining his feelings of illness (Diamond & Jones, 1983). Therefore, illness is more than a disease state. Viewing illness as an abstraction widens the perspective of what is meant by illness and can include a variety of experiences (Wu, 1973). Kane (1991), a physician, suggests that the personal subjective experience of disease, which is illness, is immeasurable. Yet, this experience is so real that it deserves the attention of physicians who often are concerned only with disease because physicians have lacked sufficient interest in the subjective methods for addressing illness. Kane continues by saying " the distinction between disease and illness is the most important idea in this book" (Kane, 1991, p. 14).

Disability is defined as "a functional limitation" (Fraley, 1992, p. 4). Fraley does not differentiate between chronic illness and disability and interchanges these words throughout her book; however there is a distinction. Disability, as defined by Fraley, only includes the

biological aspect of limitation regardless of the cause. For example, a limitation can result from an accident or congenital anomaly as well as a disease. Chronic illness, on the other hand, includes functional limitation, but also the subjective experience of having a disease.

Another distinction between chronic illness and disability is the connotation of the word disability. Disability emphasizes the negative or the inability to do something. Although chronic illness may bring to mind a negative picture, it is much more a neutral word than disability.

Sickness denotes a personal event when it becomes a social phenomenon (Diamond & Jones, 1983). Usually sickness defines a role for the individual and much has been written about the sick role. Sickness is different from disease in that there needs to be no underlying disease or objective phenomena for its presence. Sickness is also different from illness in that it is a subjective experience that is communicated or shared with others. Even though sickness is introduced here, it is not as frequently interchanged with chronic disease. Therefore, the preferred word is chronic illness as it encompasses not only an objective but subjective phenomena as well.

One of the earliest definitions of chronic illness comes from the National Commission on Chronic Illness (1956, p. 1). The Commission stated that,

chronic illness is concerned with all impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration; require special training of the patient for rehabilitation and/or may be expected to require a long period of supervision, observation or care.

Although this definition is comprehensive, it is also complex and medically orientated. Lubkin (1990) reviewed eight definitions of chronic illness and then created a definition that is comprehensive, flexible, and with a nursing perspective. She states "Chronic illness is the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function and prevention of further disability." (Lubkin, 1990, p. 6). Although there is no mention of individual growth that can occur with chronic illness, this definition is clear, concise, and can be the guidepost for further discussion of what is meant by a chronic illness. Also note that the terms "disease" and "disability" are included within this definition showing that the term "illness" is broader and encompasses the words disease and disability.

Trajectory of Chronic Illness

The course of a chronic illness varies greatly with remissions and exacerbations which can leave residual effects. The trajectory of a chronic illness is much more than the course of the illness. Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek and Wiener (1984)

identify that an illness trajectory is not only the physiological unfolding of the illness, but the total organization of work done (i.e. all the work that the chronically ill need to do in order to control and manage their illness) plus the impact of those involved in the work and organization. Therefore, the chronic illness trajectory is influenced not only by the disease process itself, but by the medical plan, the individuals involved and what they bring to the situation, complications of the illness, and even current technological developments (Lubkin, 1990). Because of these factors, each person's trajectory is unique to that individual and his or her illness. The importance of this illness trajectory is that health professionals may focus primarily on the physiological aspects while the patient may focus more on the symptoms, anxiety over treatment, or a sense of uncertainty.

It is also known that each trajectory occurs over time and moves in some direction. Acute illnesses, because of their short duration, are fairly predictable. However, in chronic illness, the duration is one where individuals and their significant others must cope with the illness for the rest of their lives; therefore some trajectories go straight down, some vacillate and others reach a plateau and then move quickly in one direction or another. It becomes evident that chronic illness is neither a stable event nor something that ever goes away completely, but requires

ongoing work which is influenced both by the course of the illness and also by the work of those involved with the illness. This illness trajectory is then an important consideration when discussing adjustment, integration, or acceptance. As things change and the shape and direction of the illness trajectory changes, so does the person who must adjust and accept these changes with integration into his or her life-style. Strauss et al state, "the illness trajectory has importance in the psychological acceptance of the new level of normality." (1984, p. 86).

Impact of Chronic Illness

Integration and acceptance of chronic illness are not fully appreciated unless one acquires an understanding of what the chronically ill individual is adjusting to and accepting in their life. The impact of chronic illness is tremendous not only on the individual, but also on significant others and society at large.

Chronic illness can significantly influence and alter individuals' lives in a dramatic way. First, people who are chronically ill must modify their view of themselves in order to integrate the evolving identity of who they are. (Gregg, Robertus & Stone, 1989). Not only does self concept alter, but so does perception of mortality, which may be significant for young people who typically see themselves as immortal. Because illness affects how one feels about the self, this in turn will affect how one interacts with family

and friends. People may become withdrawn and isolated which can ultimately lead to depression. One's occupation is also often affected where long range goals and pre-retirement plans must change.

Strauss and his co-authors (1984) developed a framework for the physical, social and psychological problems that are faced by the chronically ill population. The framework incorporates eight key problems: prevention of medical crises, control of symptoms, prevention or living with social isolation, adjustment to the changes in the course of the disease, attempts at normalizing interaction with others and with their own life, funding of the illness, and lastly, confronting the psychological, marital and familial problems. The impact of chronic illness goes far beyond the medical management of controlling the symptoms and extends into all areas of a person's life.

Miller (1992) discusses the impact of chronic illness in terms of the coping tasks with which the individual is faced. Her findings confirmed some of Strauss's work but adds many tasks for the chronically ill. These tasks include: 1) grieving over losses associated with the chronic illness (particularly such things as losing physical abilities, status, roles and dignity, and gaining roles such as dependent help seeker), 2) modifying daily routine, 3) obtaining new knowledge and skills, 4) adjusting to altered social relationships, 5) dealing with role changes, 6)

handling physical discomforts, 7) complying with prescribed regimen, 8) confronting one's own death, 9) dealing with social stigma, 10) maintaining a feeling of being in control, and 11) developing a sense of hope.

Not only is there a tremendous impact on the chronically ill individual and those significant others who surround that person, but society is impacted as well, primarily in terms of social burden of financial cost. As the number of elderly people continue to increase so will the number of people with chronic conditions. Davis (1986) cites that people with arthritis will increase from 11 million in 1979 to 14 million in the year 2000; those with hypertension will increase from 10 to 13 million, and those with hearing impairments will go from 7 to 9 million in that same time period. Multiply these by the numerous chronic conditions that exist, and it becomes apparent that people requiring medical care, in their homes as well as in hospitals and physicians' offices, increases costs tremendously. In financial terms this means that health expenditures as a percent of the Gross National Product are predicted to increase from 5.3 percent in 1960 to 15 percent in the year 2000 (Davis, 1986).

Adaptation and Adjustment

In order to lessen this impact and help people better manage their chronic illness, researchers have investigated the process of adapting and adjusting to chronic illness.

Pollack (1987) reviewed the nursing literature on chronic illness from the years 1980 to 1986 and found 54 studies that dealt with adaptation to illness. Many of these studies dealt with interventions that promoted or factors that influenced adaptation rather than a description of the process. Since that time, numerous studies have begun to appear in the literature concerning the process of making chronic illness a part of one's life. Many of these studies have focused on psychological adaptation, not the entire process, and have utilized the concepts of adaptation and adjustment without clear definition. A presentation of some of these studies is important in gaining an understanding of at least part of this process of living with chronic illness.

Northouse (1989) found that patients with breast cancer experienced difficulties in psychosocial adjustment not only in the early phases of the illness, but over time. In her study with 43 patients she assessed adjustment at 3 days, 30 days and 18 months post mastectomy by measuring level of distress. The less distress experienced by patients, the more adjusted they were to their breast cancer. She found no significant decrease in distress levels at each of the designated time periods indicating that psychological adjustment had not occurred for her patient population.

Another study that addressed adjustment to chronic illness with a breast cancer population was that of Taylor

(1983). In her qualitative study she interviewed 78 women with breast cancer, and concluded that the adjustment process centered around three themes: a search for meaning in the experience, an attempt to regain mastery over the event and over one's life, and an effort to restore self esteem. Taylor felt this represented a theory of cognitive adaptation such that when people are faced with threatening events they respond with cognitively adaptive efforts. This study did not discuss acceptance as part of this process.

Cognitive strategies were identified by Felton, Revenson and Hinrichsen (1984) and found to play a significant role in affecting self esteem and adjustment to illness. In a study of 170 chronically ill middle-aged adults, they found that information seeking as a cognitive strategy positively influenced self esteem and adjustment to the illness, while emotional strategies like avoidance, blame and emotional ventilation contributed to a lowered self esteem and poorer adjustment.

Adjustment was seen as a 'winning position' in a qualitative study by Forsyth, Delaney and Gresham (1984) where making the illness a part of one's life was also seen as a cognitive process. They interviewed 50 chronically ill hospitalized patients about their attitude toward their illness and the hospitalization. Central to their organizing concept of a winning position was the cognitive work that patients felt they had to do. Patients explained

that there was a redefinition of themselves and what they could do. For example, one patient with multiple sclerosis (MS) explained it took her all afternoon to fix a meal. Rather than being frustrated with a seemingly intolerable situation, she redefined it so that she was pleased just to be able to do the task and not frustrated with the length of time that it took. Forsyth et al. (1984) also found from their qualitative data that patients spoke concretely about limitations they must accept in order to live. These patients did not view their limitations in a negative way, but employed a strategy of what the authors called "comparative optimizing". In other words, patients described their condition in terms of other patients in greater pain, or patients with a more severe disease form. This is similar to Dembo, Leviton and Wright's (1956) original work regarding lost values as asset values rather than comparative values (seeing ones own state as a worthy one). Therefore these researchers found redefinition of the self and abilities were vital to having what they called 'a winning position'.

While there have been numerous studies looking at the process of living with chronic illness, the work of Strauss and his co-authors has been most widely referenced. They first described this process in terms of how people manage their illnesses through redesigning their lifestyle utilizing grounded theory and from the perspective of a

sociologist (Strauss et al., 1984). Corbin and Strauss (1988) have continued to investigate the phenomenon by refining and expanding these ideas through in-depth interviews of couples in which one of the spouses was experiencing a chronic illness. In this work the term "accommodation" is introduced and is defined as the day-to-day struggle that occurs as couples try to live their lives while managing their chronic illness. While this study further elaborates on his model of chronic illness, it does not address the areas of acceptance and integration, but adds another term, accommodation, to the arena of concepts describing living with chronic illness.

Proposed Models of and Theories of Adaptation

Several models and theories have been proposed to describe the process of making chronic illness part of one's life. Most of these models and theories have utilized the word 'adaptation' to describe the process; however even within the models there is frequent interchange between adaptation, adjustment and acceptance. Because this process has been regarded as a reaction to loss, grief theories have been utilized to understand the process of adjustment to chronic illness as a response to loss. Werner-Beland (1980) noted that most of what is inferred about grief in illness and disability has been derived from knowledge gained in grief responses to the terminally ill. Specifically, Engel's (1964) grief theory and Kubler-Ross's (1969) death

and dying concepts have been utilized to explain adjustment to chronic illness.

Engel (1964) states that the grief process involves five stages; shock and disbelief, developing awareness, restitution, resolution of the loss, and idealization. Crate (1965) then applies these same stages to chronic illness and states further that successful adaptation will occur when the chronically ill individual can live comfortably or resignedly with himself as a person with a specific condition. Although Engel (1964) discusses acceptance occurring within the stage of resolution, Crate (1965) discusses acceptance throughout the model.

In the first stage, shock and disbelief, Crate (1965) states that a person may seem to accept the diagnosis but shows inappropriate reaction. As the patient reaches developing awareness, acceptance of care and dependence on others occurs. During this stage anger is often expressed. In reorganization the patient moves further toward adaptation and is able to accept the increased dependence as well as reorganizing relationships which accommodate the chronic illness. Lastly, in resolution and identity change the patient begins to acknowledge the changes in himself and begins to identify with others who have the same condition; these events help the person toward acceptance of himself with a specific illness.

When the final stage is reached, a person can

acknowledge the presence of the illness and the limitations it imposes. This does not mean that the person has adjusted to or accepted the illness or doesn't mind being ill. It is unclear as to what Crate means by this in light of the fact that she has used the term acceptance throughout the model. Crate does identify that successful adaptation is reached when the person with a chronic illness can "live comfortably or resignedly with himself as a person who has a specific condition" (1965, p. 72).

Crate's model of adaptation to chronic illness was modified by Lawrence and Lawrence (1979) condensing it into three stages: shock and disbelief, developing awareness, and resolution of the loss. These authors also define adaptation differently and state that true adaptation occurs when a higher form of human functioning occurs than existed prior to the illness. This model is a more condensed version of Crate's model and indicates there is no termination or complete resolution of any stage since this would make the illness strictly a negative event and would not provide the opportunity for positive growth. Although the authors do not clearly explain how complete resolution would make the illness a negative event, it is implied that in each of these stages, the emotions that occur provide an impetus for growth and change.

Another grief theory is that of Kubler-Ross (1969). Her work is a classic in the grief literature and formed a

framework for research on grief, not only with death, but with other types of loss. Her theory lists five stages in the process of grief which are denial, anger, bargaining, depression and acceptance. Chapman (1984) utilized Kubler-Ross's stages of grieving and applied them to the psychological adjustment of the chronically ill. She surveyed 53 chronically ill people and asked them to rate four statements which identified the experience of acceptance. The statements looked at indicators of acceptance as being positive and realistic about the illness, as well as being able to cope with their medical condition and go on with their life. Chapman found that 80% of the people did experience acceptance as she perceived acceptance in chronic illness. Note that this was Chapman's interpretation of what is meant by acceptance. This is because Kubler-Ross never explicitly defined acceptance but only suggested some aspects of it. She implied acceptance as not just adjustment to death, but a resolution of tension with a feeling of peace and tranquility. She later differentiated between the concepts of resignation and acceptance (Kubler-Ross, 1974). People in the stage of acceptance show feelings of equanimity and peace, while those who resign themselves to their death are often bitter, indignant and full of anger. Therefore, while Chapman's work seems to justify the existence of acceptance, it is her interpretation of what is meant by chronic illness

acceptance and does not confirm Kubler-Ross's idea of equanimity and peace.

Craig and Edwards (1983) proposed a model of adaptation to chronic illness and utilized Lazarus' model of appraisal as the basis for their model rather than a grief theory. Lazarus (1966) conceptualized individual's response to stress as a process where the individual appraises significance of a situation in terms of potential outcome and available coping behaviors. Craig and Edwards (1983) utilized this conceptualization to propose that adjustment does not occur through a stage process, but by a continual appraisal and reappraisal of the changing situation of chronic illness. While this model brings in the perspective of the illness trajectory, it does not give much attention to the fact that there are a multitude of losses that occur with chronic illness over time and sometimes simultaneously. Although the authors do acknowledge that the person will experience loss, the model does not address how the chronically ill appraise each of these losses to initiate coping behaviors. The authors define adaptation as a coming to terms with chronic illness as a state of being where false hope is discouraged and a restructuring of the environment occurs. The authors infer that adaptation means that the individual reorganizes and accepts self so that meaning and purpose to live transcends limitations implied by illness. Key factors of adaptation are identified as

hopeful perspective, maintenance of self esteem, personal worth, and redefinition of roles which other authors have identified as components of acceptance (Dembo, Leviton & Wright, 1956; Lewis, 1985).

Perspectives of Acceptance

Gaining a perspective of the concept of acceptance is important in understanding the process of integrating chronic illness into one's life since acceptance is frequently addressed in the literature concerning adaptation and adjustment. Hoover (1979) noted that acceptance, as defined by the dictionary, means to receive gladly or willingly. From this definition one has difficulty applying acceptance to chronic illness, but Hoover makes no attempt to clarify what acceptance means in terms of chronic illness. She does state that any education program directed at individuals with diabetes will be wasted if they have not accepted their illness. This demonstrates both the contradiction and dilemma of not clearly defining what chronic illness acceptance is, yet stating it is an essential experience in learning to live with the illness. Acceptance of a chronic illness is more complex than a simple dictionary definition. The concept of acceptance has been addressed by a number of disciplines and has been found to be a multifaceted phenomenon (Benner & Wrubel, 1989; Bostos, 1983; Dembo, Leviton & Wright, 1956).

Historically, acceptance of disability did not come

into existence as a concept of interest until World War II. The War produced a large number of injured men and women faced with a life-long disability. The emergence of this population precipitated the investigation by psychologists, sociologists, and health care providers of the social-psychological rehabilitation of the physically disabled. Dembo (1956) interviewed 177 injured persons, many of them being servicemen or veterans of World War II and 65 non-injured people in regard to their feelings toward the injured men. Ages ranged from 19 to 58 years with the duration of their disabilities from two months to 33 years. More than half had suffered amputation and almost one fourth had facial disfigurements.

The conclusion from Dembo's qualitative research was that acceptance of disability involved a change in a person's value system. This value change involved two factors. First, change centers on enlarging the scope of the person's values (realizing the existence of other values). For example, the person must see that a loss of a limb or changed appearance is not the only factor that determines who they are but the person must value other abilities that remain. The individual must see himself as a valuable person despite the changed appearance. Second, the person must regard lost values as asset values rather than comparative values (seeing one's own state as a worthy one, freeing the person of devaluating). For example, the person

learns to live within the limitations of the disability and sets goals that are within his or her grasp.

This research was significant in that researchers then began to label the phenomenon under study as "disability acceptance" or "acceptance of loss". In an additional study Wright (1960) further defined acceptance by extrapolating two additional components from Dembo's work that he believed essential if acceptance was to occur. First, physical appearance or ability must diminish in importance (subordinating physique) in a person's life. Second, disability effects must be contained. Containing disability effects is best illustrated when considering the person who speaks loudly to a blind person. The disability of blindness has expanded so that one also perceives the person as being deaf.

Linkowski (1971) developed an instrument which measured acceptance of disability based on the work of Dembo (1956) and Wright (1960). The instrument is a 50 item questionnaire with a demonstrated reliability of .93 (Linkowski, 1971). This instrument has been used almost exclusively when attempting to measure acceptance of a condition. Trainor (1982) adapted the instrument to measure acceptance of ostomies and Wingate (1986) adapted the instrument to measure acceptance of pacemakers. It has not been utilized or adapted to measure chronic illness acceptance primarily because the instrument is based on

qualitative work that was done with a predominantly male population who had physical impairments. This would make the instrument inappropriate for females with chronic illness as well as any chronic illness that did not have an associated physical disability connected with it. The instrument was developed from data obtained from those physically disabled in World War II. This population was different and younger than the current chronically ill population limiting the use of the instrument.

Bostros (1983) differentiated general life attitude acceptance from acceptance of a particular event. According to Bostros, in order for an event to be accepted it must first be irreversible or inevitable. Secondly, the event must not be immediately under the individual's control, and lastly, when acceptance is reached, energy is released so that acceptance is associated with activity rather than passivity.

Self, peer, and social acceptance is addressed in the literature; however, of these three, self-acceptance appears to be the most applicable when discussing acceptance of an event such as a chronic illness. Linkowski and Dunn (1974) found that how people view their disability relates to how they view themselves as well as how they view their relationships with others. Brillhart (1986) examined self-acceptance in disabled adults and found that a positive attitude toward self was indicative of acceptance of self

and disability. They did this by comparing self esteem and satisfaction with social relationships to disability acceptance (measured by Linkowski's (1971) disability acceptance scale). These researchers found significant correlations between disability acceptance and self esteem ($r = .52, p < .01$) and between disability acceptance and satisfaction with social relationships ($r = .34, p < .05$). In other words, people who have positive self attitudes and experience well-being with their social relationships demonstrate disability acceptance.

The literature discussing acceptance as it specifically relates to chronic illness is fairly limited with much being written in terms of personal accounts or literature for the lay person (Lewis, 1985; Pitzele, 1985). However, several studies illuminate what is currently understood concerning acceptance and it's role in the process of making chronic illness part of one's life.

Benner and Wrubel (1989) discussed coping with chronic illness from a phenomenological perspective. They state that medical researchers tend to view acceptance as something that can occur in totality in response to a diagnosis of an illness. However, this perspective is based on the premise that the future of the illness is known at a single point in time. This perspective is limiting, as all illnesses have multiple courses and unfold over time. At best the individual can cope with the present and only the

near future. Benner and Wrubel (1989, p. 135) state that accepting a diagnosis means:

that the person becomes constituted in a new way with his or her illness. This new constitution permits the patient to redefine meaning for the self in the situation and the situation allows the possibility of new ways of expressing old concerns.

This definition is far more than simply gaining a mental grasp of information or as a process to regulate the flow of information. It involves finding a connectedness to the world in terms of what possibilities are available in the present situation.

Acceptance has been viewed as a stage in the process of adapting to chronic illness. Edelwich and Brodosky (1986) discussed stages of adaptation to diabetes and proposed acceptance as one of these stages. They conceptualized acceptance as a realistic adaptation to diabetes and not a resignation or a dwelling on what has been. This means exerting as much control on one's life as possible and not passively reacting to it.

Speelman (1988) stated that acceptance is marked by the diabetic patient's acknowledgement of his or her responsibility for management of his or her condition. She also put adjustment or adaptation in parentheses after acceptance, suggesting that they are synonymous. While this definition adds a dimension to chronic illness acceptance, it also contributes further confusion by implying a synonymous interchange between adjustment and adaptation.

Although some of the literature equated adjustment with acceptance, Vash (1975) and Russell (1981) stated that acceptance is separate and essential to the outcome of psychological adjustment. Wright (1960) suggested that if one accepts a disability then one is on the way to being adjusted to it. Although they are not the same concepts, it seems that acceptance may be part of psychological adjustment. Kinley (1980), a nurse with multiple sclerosis, supported this perspective through her own personal experience with her illness and felt that she had accepted the illness by literally shifting her life into a lower gear. That is to say, there was a redefinition of her life. She concluded that an optimistic outlook on life constituted her acceptance and subsequent positive adjustment. Lastly, she commented how thankful she was to be alive, suggesting that she felt her life was still worthy despite having a chronic illness.

Acceptance of chronic illness has also been conceptualized in terms of non-acceptance. Werner-Beland (1980) stated that acceptance means "to keep a firm grip on oneself and to work toward safeguarding one's integrity (p. 176)." There is an inherent refusal on the part of the chronically ill to give up and become a useless person; this involves a non-acceptance of all the restrictions that the illness entails as well as those restrictions which the health providers are apt to place on the individual.

Together, acceptance of the problem and non-acceptance of the restrictions comprise hope.

Analysis and Critique

The literature review addresses what is known concerning how the chronically ill make illness a part of their lives. Numerous studies have looked at adjustment and adaptation, however many have focused on only a psychological adaptation which limits understanding the entire experience. Several of the studies looked at very specific populations which limits their generalizability. Northouse (1989) and Taylor (1983) both looked at women with breast cancer. Although information concerning adjustment and adaptation to chronic illness is significant, conclusions from these studies would have to be applied cautiously to populations of men as well as other chronic illnesses. The study of Forsyth, Delaney and Gresham (1984) represented numerous chronic illnesses as well as an evenly distributed sample of men and women, however their conclusions were based on interviews from a hospitalized population. Again caution would be needed in generalizing the results of their study to the chronically ill population as a whole because these researchers interviewed these people during a medical crisis that had resulted in hospitalization. What people consider as positive adjustment in the hospital may be an entirely different experience from the day-to-day adjustment when at home.

Another difficulty in making generalizations concerning the studies on adjustment and adaptation is that each one defines the terms of adjustment and adaptation differently or simply fail to define their terms at all. Taylor implies that adaptation occurs when chronically ill people "return to or exceed their previous level of psychological functioning" (1983, p. 1170). Northouse (1989) does not explicitly provide a definition of adaptation, but utilized three different instruments to measure adjustment. The instruments measured mood, symptom distress and role functioning. These two studies only demonstrate the tip of the iceberg in terms of the number of studies that give no explicit definition of adaptation and adjustment or utilize the terms so differently, that comparing studies to come to some generalizations and conclusions is almost impossible. In fact, Duffy (1987) concluded after an in-depth examination of the concept of adaptation, that the nursing literature lacks clear conceptual definitions of adaptation. The studies cited reflect this lack of clarity.

Models and theories of adjustment and adaptation to chronic illness have been proposed, but most are not grounded in the experiences of the chronically ill. This limits their ability to guide nursing interventions as they may not represent a true reflection of what the chronically ill are experiencing. Specifically, Crate's model (1965) is based on Engel's (1964) grief theory. Note that the

literature of the 1960's interchanged the terms models and theories whereas today it is generally accepted that theories are derived from models. Both Engel and Crate based their theoretical ideas on the experience of individual's grieving the loss of a significant other and not on the experience of the chronically ill. While these early types of conceptualizations were helpful in providing a beginning in understanding the chronically ill's experience in reacting to the losses of chronic illness, they assume that the reaction to the losses of chronic illness and loss of significant other are the same. These conceptualizations also do not provide any understanding of the entire experience of making chronic illness a part of one's life.

Other author's refined some of these early models in an attempt to clarify the process of making chronic illness part of one's life. Lawrence and Lawrence (1979) utilized Crate's (1965) model and condensed it into three stages. However, in the process they also defined adaptation differently. While Crate stated adaptation occurred when an individual could live comfortably or resignedly with his or her illness, Lawrence and Lawrence state that true adaptation occurs when a level of human functioning is obtained that is higher than existed previously to the illness. Further, this behavior is identified as self-dependency. The limitation of this study is that once again

it is not grounded in the experience of the chronically ill, and in addition does not confirm previous definitions of adaptation, but adds another definition which further obscures what is meant when authors and researchers are discussing adaptation.

Chapman (1984) utilized the grief theory of Kubler-Ross (1969) and concluded that the grief experienced in one's death is similar to the grief experienced in chronic illness. Chapman's study had several limitations. First although she was utilizing Kubler-Ross's theory, she conceptualized acceptance differently. While Kubler-Ross (1974) defined acceptance as showing feelings of equanimity and peace, Chapman identified indicators of acceptance as being positive and realistic about the illness as well as being able to cope with the medical condition and go on with life. Also Chapman's study utilized a self-administered questionnaire with several open-ended questions. She did not establish any statistical validity and reliability of the questionnaire and did not clearly delineate how she analyzed the responses to the open-ended questions. Both of these factors weaken her conclusions considerably.

While some authors utilized grief theories to conceptualize the process of making chronic illness part of one's life, others utilized ideas from psychologists' writings of stress. Craig and Edwards (1983) utilized Lazarus' conceptualization of appraisal of stress. Again

this model provided a beginning understanding of the psychological processes of adapting to stress, but does not provide any clarity to the entire experience of adapting to chronic illness. In addition, another definition of adaptation is proposed in this study which is different from every other definition utilized in studies cited in the literature review. Crate and Edwards proposed that adaptation was a "coming to terms with the reality of chronic illness as state of being, discarding false hope and destructive hopelessness and restructuring the environment in which one now functions" (1983, p. 399). These multiple definitions not only add to the confusion of what is meant by adaptation but comprises the ability to compare studies and draw any general conclusions.

The literature review concerning the concept of acceptance produced some excellent studies; however, these studies have dealt with either specialized populations (ie. male veterans or diabetic clients) or have dealt with acceptance of a condition other than chronic illness (i.e., physical disability or terminal illness). Although inferences can be made from these studies to chronic illness, these studies do not represent the experience of the chronically ill individual. While the literature supports that acceptance is a necessary experience for the chronically ill, there is no clear conceptualization of this phenomenon.

It becomes evident that there is a limited understanding of how people integrate chronic illness into their lives and this is further complicated by a lack of consensus as to the description of chronic illness adjustment, adaptation and acceptance. The present phenomenological investigation concerning the experience of chronic illness integration attempts to illuminate this phenomenon and add to the body of nursing knowledge.

CHAPTER 3

Methodology

The purpose of this study was to describe the lived experience of how people integrate chronic illness. Phenomenology is a qualitative method that is uniquely appropriate to this purpose because it is utilized to understand the experience of an individual. Phenomenology is the suggested method when there is little known about the investigated phenomenon or when present knowledge or theories appear in conflict or inadequate (Field & Morse, 1985). The literature review indicates that the experience of integrating chronic illness is not really addressed from the perspective of the individual. While models of adaptation and adjustment have been proposed, many have not been grounded in people's lived experience.

Phenomenology

Phenomenology is a philosophy, an approach, or perspective to living, learning and doing research (Munhall, 1994). It is an inductive, descriptive research method that is based in the naturalistic paradigm. This paradigm is concerned with understanding by discovering meaning. Within this paradigm there are several assumptions that exist. First, reality is dynamic and multiple, which means that numerous meanings can be obtained from similar

experiences and these meanings can change over time. Another assumption is that the phenomena under study must be studied in context or studied so that the researcher does not manipulate or control variables to obtain data. Lastly, the researcher is an integral part of the research process (Haase & Meyers, 1988).

The goal of phenomenology is to investigate and accurately describe the phenomenon as it is experienced and exists in the consciousness of the individual. Phenomenology utilizes a holistic approach to questions recognizing that human realities are complex. The focus is on the human experience, ordinary daily human experiences where attention is turned toward the subjective experience of people to discover meaning (Munhall, 1994). Meaning is discovered by gaining access to the outer world from inside the human experience. This is accomplished through reflection of peoples' disclosed perceptions of the lived experience. Because of this perspective, not only the phenomenon must be accounted for, but the relation of the phenomenon to the experiencing person.

Perception is an important aspect of phenomenology. Munhall and Boyd (1993, p. 103) state "perception is original awareness of the appearances of phenomena in experience." Perception gives the individual the ability to access the experience of the world as it is without prior analysis of it. The reality of this experience cannot be

separated from a person's experience and interpretation of it. Therefore there is no objective reality in phenomenology (Smith, 1991), only reality as it is constructed by the person.

Phenomenology does not produce theories or models or develop general explanations. A prerequisite for phenomenology to occur is that the investigator has no preconceived expectations and is not validating any theoretical framework, but is seeking to understand the phenomena under study from the perspective of the participants in the experience (Omery, 1983). That is why bracketing or the setting aside of assumptions is an essential component in understanding the experience of the participant.

The methodology utilized for this study was phenomenology as described by Munhall & Boyd (1993). The specific approach of Colaizzi (1978) was utilized to collect and analyze data. Colaizzi was an empirical phenomenologist and educated at Duquesne School. The phenomenologists from this school were descriptive in nature and based their work on Husserl's philosophy (Beck, 1994).

Data Collection

Selection Criteria

Selection criteria for this study assured that participants had a chronic illness and were willing to verbalize how they lived with their chronic illness. It is

important to obtain the most insightful data by selecting key informants with a thorough knowledge of the topic being investigated (Morse, 1986).

Studies show that the process of adaptation to chronic illness is essentially independent across diagnostic categories (Cassileth et al., 1984; Pollock, Christian & Sands, 1990). Therefore, the specific medical diagnosis was not the primary consideration for patient selection and no attempt was made to have specific chronic illnesses represented but a variety of sources were utilized to obtain participants. Participants were obtained through referrals from the local chapter of the American Association of Diabetes Educators, volunteers from the Arthritis Foundation's support group and volunteers from the Better Breather's Club of the American Lung Association. Other potential participants were referred by colleagues. Additional requirements for participation in the study were that the person be at least 21 years of age, speak English and be able to verbalize about their illness.

Sample

A total of seventeen people comprised the sample. Six people were obtained from referrals from the local chapter of the American Association of Diabetes Educators, one person from the Arthritis Foundation, six from the Better Breather's Club, and four people from colleagues who personally knew someone with a chronic illness who would be

willing to talk about the experience of integrating chronic illness into their lives. Data collection stopped at seventeen when the data was becoming redundant. Lincoln and Guba (1985) suggest sample size be determined by redundancy or saturation of data.

The age range of the sample was from 21 to 75 years, all Caucasian, three men and fourteen women. The duration of illness was from five years to forty eight years and the severity of illness as perceived by the participants was from very severe to not severe at all. This information was obtained by asking participants at the beginning of each interview. Participants fulfilled Colaizzi's criteria of being in this study by having a chronic illness and being able to verbalize about it. A brief description of each participant is included in Appendix A.

Interview Process

Each participant was contacted by telephone and received a brief explanation of the purpose of the study and were told that the research interview would take approximately one to two hours. After the individual agreed to participate, a mutually agreed upon time and place was set for the interview. At this time, each individual was also told that they may be asked to do a second interview at a later date for additional information.

The interviews took place in a variety of settings. Fifteen of the interviews took place in the participants'

homes. One of the remaining interviews took place at this researcher's office and the other interview took place in a private lounge area of a local YMCA.

At the beginning of each interview participants were informed of the purpose of the study, potential risks and benefits, and how confidentiality would be maintained during the study. Participants were also informed that they could withdraw at anytime during the study and that they could turn off the tape recorder at any time during the interview. Several people did turn the tape recorder off when they became emotional. These interviews occurred between August of 1992 and December of 1993.

The consent form was verbally reviewed with each participant and all questions were answered before the consent form was signed. A copy of the consent form was given to each participant to keep and the other was kept on file at the researcher's office. The Consent form can be found in Appendix B.

The interviews were semi-structured. This technique allowed a free flow of information without forced replies or biased responses (Waltz & Bausell, 1981). A sample of the questions that were utilized during the interview can be found in the Thematic Interview Guide in Appendix C. The Thematic Interview Guide was initially created based on the researcher's clinical practice and pilot study (Michael, 1988) then evolved as participants shared their experiences.

Interviews continued until both the participant and researcher felt everything was said about the phenomenon of integrating chronic illness. Each interview ended by asking the participant if there was anything else they wanted to say that was important in the experience of how they lived with their chronic illness.

All interviews were audio tape recorded and later transcribed by a professional transcriptionist. Each interview lasted anywhere from 45 minutes to 2 hours. Although not in the initial plan, each respondent was telephoned within one week of the interview to ask if they had any additional information or wished to clarify what they had said. This was done initially because the first participant had become tearful during the interview. This reaction was unexpected. Talking with the participant several days was necessary to determine if further intervention was needed. This contact also provided the opportunity to ask any questions or obtain clarification on what was said during the interview and to establish credibility of the research. These telephone follow up interviews lasted from 10 to 30 minutes. These interviews were not audio taped, but written notes were taken.

A final aspect of the interview process involved presenting the findings to 5 of the 17 respondents in order to validate the findings with these participants' experiences. Five participants were selected because it was

felt these participants' experiences were sufficiently different and would expose any discrepancies that existed between the author's findings and the participant's experiences. These interviews occurred between March 1994 and June 1994.

Ethical Considerations

The study proposal was approved by the Committee for the Protection of Human Subjects at the University of San Diego before data collection was begun. Approval for this study can be found in Appendix D.

One potential risk for subjects in this study was the discomfort of talking about their illness. For one participant this did occur, and she was referred to a mental health nurse consultant. Although the consultant called her, the participant later decided not to use the consultant services. It was made clear to the participant that there was no charge for the mental health consultants services. There were no immediate benefits for the participants, but many felt that they might be helping others to understand their experience. All data were coded and first names only were used in the transcription. All interview materials were kept locked in the researcher's desk at her work place during the study period. All audio tapes, as well as the list of names of participants, will be destroyed when the study is completed.

Journal

A journal was kept by the researcher that included initial impressions of interviews, hunches about meanings, methodological notes, and a comparison of what was found in previous interviews to the present interview. Sometimes the journal was kept by tape recorded notes after the interviews and other times they were hand written notes that were jotted in a notebook. The journal was utilized to gain a perspective of what was emerging as themes, as well as a guide to the method of the interview. It was a useful tool in improving the interviewing skill of the author. A record of feelings and impressions helped guide the author in the analysis of data. Reflecting on why some interviews were particularly emotionally draining provided insight into the meaning of participants' experiences.

Data Analysis

Data analysis was conducted utilizing the method described by Colaizzi (1978). There are seven steps in Colaizzi's method. Colaizzi states that his procedure of analysis should be

viewed only as typical and by no means definitive: furthermore, they (the steps) usually develop with much overlapping among them, so that both listed procedures and their sequences should be viewed flexibly and freely by each researcher so that depending upon his approach and his phenomenon, he can modify them in whatever way seems appropriate (1978, p. 59).

Therefore the seven steps were used as a guide and the researcher modified the analysis procedure where it seemed

appropriate to the phenomenon.

The first step was to read through the subject's entire description for a sense of the whole. This was done by first listening to the tape recording of the interview and then listening again to the tape with the transcription in hand so that it could be corrected, clarified with non-verbal information, and an overall sense of the interaction could be obtained.

The second step was to extract statements from each participant's description which were significant to the experience being studied. Once a sense of the whole was obtained, the transcription was read again and statements that were found to be significant in how people lived with chronic illness were highlighted.

The third step in Colaizzi's method was to determine meanings for each of the significant statements. At this point in the analysis, Colaizzi suggested that the researcher must use creative insight and "leap from what his subjects say to what they mean." He noted that it is important to go beyond what is stated in the data in order to illuminate meanings, but at the same time to stay with the data. Possible meanings were proposed for each of the identified significant statements.

The fourth step was to repeat each of the first three steps for each interview and organize the formulated meanings into clusters of themes. Within this step it is

important to validate the cluster of themes by referring back to the original subject's statements. This will control for any omission or addition of data. Each of the above steps was repeated for each subject's interview. At this point prior to clustering themes, each significant statement was placed on a 3 by 5 index card for each of the interviews. The cards were then placed into stacks that seemed to go together. Once they were in these stacks, the statements were read and the researcher became immersed in the data. Statements were then moved to stacks that seemed to contain the same meaning. This process was one in which the researcher became absorbed with the data, and themes emerged from the groupings. This was done to ensure that the meanings derived did come from participants' statements.

The fifth step was to develop an exhaustive description of the themes. The researcher developed an exhaustive description and then listened to the tape of each participant for a third time. This was done to validate that the themes reflected the participants' experience.

The sixth step was to formulate a statement of identification of the fundamental structure of the investigated phenomenon. This was accomplished creatively with a poem that exemplified the fundamental structure and through a figure depicting the thematic structure found on page 214.

The last step was to validate the findings thus far

with each subject. Any new data that emerged from these interviews was then worked into the final product of the research. At this stage, the researcher returned to five of the seventeen subjects to validate the analysis. Validation occurred when participants saw themselves in the findings. Sometimes more information was provided that supplemented findings and other times findings were questioned and clarified to reflect that participants' experience. For example, as Kathy read about the emotions participants experienced, she agreed and stated " It's like a roller coaster of emotions." This statement was utilized to name the theme that discussed the emotional responses of participants.

Participants were either verbally told about the findings or were given a typed summary of the findings and then asked "How do these findings compare to your experience? Have I omitted anything?" Participants usually responded to the questions by giving additional examples related to the themes. One participant cried as she nodded her head in agreement and said "Yes this is it". Another pointed out that one of the sub themes was not part of her experience. This is an expected outcome; Sandelowski (1993) points out that not all of the findings will represent all of the participants.

Methodological Rigor

Analysis of data to determine trustworthiness or methodological rigor is an important step in qualitative research in order to determine its acceptability. This generally means looking at concepts of validity and reliability. Mishler (1990) stated that validity is more a matter of practicing good science and leaving a visible and auditable trail, and less a matter of being right about the phenomenon being studied. Sandelowski (1993) stated that one of the most significant threats to phenomenological validity is the assumption that validity is dependent on reliability. This is because reliability is based on the assumption that reality is repeatable and there can be consensus of that reality. However, in the naturalistic paradigm, reality is multiple and constructed, not singular and tangible, and therefore in qualitative studies repeatability is not essential.

In this study, trustworthiness was established utilizing the guidelines of Lincoln and Guba (1985). They identified four factors necessary for trustworthiness. These factors are credibility, transferability, dependability, and confirmability. Although there is considerable debate about reliability and validity issues in phenomenological research, Lincoln and Guba's criteria for evaluating the rigor of phenomenological inquiries are still the most accepted criteria in the nursing profession (Beck, 1994).

Credibility, or the ability to find truth in the findings, is similar to validity in quantitative studies. Credibility in this study was established by verifying statements participants made by telephoning them within one week of being interviewed and seeking clarification. At this point, modifications for accuracy of the findings was established. Credibility of the findings was established by interviewing selected participants to see if the description that was developed was true to their experience. Information obtained in this interview was incorporated into the final description of findings.

Transferability is concerned with describing the sample setting and findings in great enough depth in order to enable anyone interested in making transfer of information possible. In other words, transferability does not refer to the researcher making applications of the findings to other samples, but describing the study in enough detail so that those reading the study can make such conclusions. Transferability in this study was established by describing the methodology and findings in sufficient detail to allow the reader to make judgements concerning applicability to other populations.

Dependability is concerned with stability and trackability. Sandelowski (1986) stated that a study can be tracked or auditable when another researcher can clearly follow the trail of decisions that the investigator used in

the study. A study is also auditable when another researcher could arrive at similar or comparable conclusions given the investigator's data. In this study dependability was established in several ways. The dissertation committee reviewed selected transcripts and analyses and drew comparable conclusions. Participants were also contacted within one week after the interview to seek clarification as well as verifying meanings of what was said. In addition, information that is important for auditability as identified by Sandelowski (1986) was described in this study. This included such information as how the data were collected, how long data collection lasted, and the nature of the setting. This information can be found in the body of the study as well as in the journal kept by the researcher.

Confirmability is the last criterion utilized to determine trustworthiness and is concerned with interpretational objectivity. In this study confirmability was established by bracketing or setting aside assumptions as they became evident to the researcher. Methods used to establish dependability also contributed to confirmability such as auditability.

CHAPTER 4

Presentation of Findings

This study sought to describe the lived experience of how people integrate chronic illness into their lives. Four major themes with minor themes and sub-themes emerged as participants told their stories. These are presented in Figure 1.

Losses were central to all people's experience in integrating their illness. While the intensity of the losses varied, the ability to participate in life as desired was no longer possible. The loss of being capable as a minor theme emerged as people could no longer function at a level equivalent to what they had been capable of prior to developing the illness. Loss of control in their lives and a gradual increase in dependency and decrease in choices contributed to this sense of being incapable. A loss of connections, a second minor theme, emerged as participants felt different from the rest of the world, isolated both emotionally and physically; they sensed that no one really saw who they were, but only saw their illness.

A roller coaster of emotions occurred as participants experienced losses and made changes in their lives. It was a ride that was exhausting as they found themselves with so many feelings that seemed to be constantly changing. Minor

themes of frustration, guilt, anger, depression and fear dominated participants' lives as they came to live with their chronic illness.

Making changes was a theme that emerged as participants shared all the activities they had to do and the difficulties in doing them in order to live with their illness. Participants changed not only what they did, but also how they thought and felt. Struggling to make and then sustain these changes emerged as an unending task and contributed to the sense of a roller coaster of emotions.

Lastly, gaining control of an altered life direction emerged as participants dealt with the consequences of loss and change. Gaining control of their life with chronic illness occurred through seeking support, learning about the illness, defining the illness and finding meaning in the illness.

Insert Figure 1 about here

Each of these themes will be presented and illuminated with participants own words. As themes are discussed, an apparent overlap occurs between the themes. This is due to the interrelatedness of the themes, and some occurring concurrently rather than in a singular progressive manner.

Confronting Loss

Living with chronic illness means confronting loss. While loss is an inescapable part of everyone's life, loss associated with chronic illness is unexpected, unrelenting and/or accelerated compared to the losses that people normally experience with age. Sometimes these losses are major and devastating, and other times the losses are minor and more of an annoyance. The losses need not be major to be significant. The fact that things have changed is enough to disrupt the rhythm of peoples' lives. The two losses that emerged from the data were the loss of feeling capable and the loss of connectedness with the world.

Loss of Feeling Capable

As adults most people feel capable in some aspect of their life. They are competent parents, proficient employees, great tennis players, excellent housekeepers etc. When chronic illness occurs, the body's physiological processes no longer function adequately and this limits the ability of people to participate in activities and fulfill responsibilities proficiently. When the body no longer functions efficiently and effectively, there is a loss of doing, a loss of freedom and independence, and a "loss of being in the driver's seat". As each of these losses are experienced, whether singularly, or together, they contribute to a loss of feeling capable.

Loss of Doing. Much of what people do in life on a daily basis is taken for granted. Getting up in the morning, getting ready for the day, going to work, taking children to school, doing things to maintain their homes and enjoying recreational activities are expected to be done automatically without much thought. When suddenly it takes great effort to get out of bed, a considerable amount of time to get ready for work, more planning and effort to accomplish simple tasks, or inability to do the task at all, one realizes these were valued activities that gave meaning to being a capable human being.

Chronic illness is about the loss of doing where "I can't" represents a statement of truth and not a lack of effort. Participants could no longer garden because they could not get up after they were down on their knees; they could not thread the needle on a sewing machine because of their shaking hands, or they could not lift anything heavy because of strain on their heart.

Barbara S. was an elderly woman who described herself as "a doer". She had enjoyed gardening, hiking at a local national park, swimming and particularly ice skating. She prided herself as being one of the first people to utilize a local ice skating rink when it first opened. Now she could not participate in any activity that was important and enjoyable to her. She could not do housework, go to the store, sew, or garden, let alone go ice skating because of

the weakness and shortness of breath she experienced from her chronic obstructive pulmonary disease (COPD). She could not effectively function in the role of mother, wife, or homemaker. Even though she was alive and physically with people, her inability to do anything for anyone left her feeling as if she was not really present at all. She stated:

As if you don't count. As if you're not needed. I'm not needed anymore. What can I do for anybody, you know? They don't need me anymore. I don't feel like I'm in there anymore, like a part anymore. I feel pushed off to the side.

Barbara had almost complete loss of significant roles in her life which resulted in a loss of feeling part of life.

While we talked she became short of breath, but insisted on continuing. I let her continue as I felt her need to be needed by me and to share her story.

Kathy, a young mother of three, was very involved with her children and valued family life. Her primary role was that of homemaker and she took pride in caring for her children. She was involved in their activities and wanted to raise her children to the best of her ability. She also had to deal with the pain and fatigue of rheumatoid arthritis. She told her story of being pregnant with her third child.

Throughout the entire pregnancy it was as if the arthritis was cured basically. I just felt wonderful. And they told me, I continued seeing a rheumatologist throughout the pregnancy and he told me that when the baby was six weeks old I wouldn't be able to move. Of course I thought he was crazy. I thought you don't

know how I feel. And the day before I went in for my six week check-up I couldn't get out of bed.... I had this tiny baby, I could not move. So I remember on December 16th taking my first gold injection and the doctor saying hopefully by the 4th of July you'll be able to walk again. And I cried and this is the hard part...my mother and dad came and moved in with us and took care of Katie. I wasn't able to lift her out of the crib. I couldn't change her diapers. After the six week point I never got up with her again during the night, because if I would get up during the night I couldn't function during the day.

Although Katie was now six years old the memory and pain were so vivid she became tearful in telling this story. Kathy had to be a bystander while others cared for her newborn infant. Her ability to be the kind of mother she wanted, the kind she had dreamed about, the kind she had been to her other two children was lost. As a mother myself and one who cherishes the memories of holding my babies in the middle of the night I too cried and also felt this loss deeply.

Participants could no longer function as the spouse that they had been and wanted to be. Instead of doing enjoyable activities together, couples were doing activities to take care of the illness; ie buying medicines, going to doctors and taking their treatments. Even when they were together, they could not do what they had enjoyed doing as a couple such as going shopping and eating out at restaurants. Often the illness prevented the couple from being able to engage in activities they had hoped to do in later life such as travelling, while at the same time it imposed activities on the healthy spouse that they never had wanted such as

housework, and grocery shopping.

Loss of doing did not occur for participants who developed the chronic illness when they were young children. Judy had been diagnosed with diabetes since the age of seven. She really could not remember a great deal about her life before diabetes. Because diabetes had been with her for most of her life, there was no loss of what she had done previously.

Because I've had diabetes all my life, I have not lost any significant roles. I have been able to do what I have wanted in life. Diabetes is just a small part of who I am.

However, Judy did miss the opportunity to do something that she could only dream about. Judy had never become a mother because she had been told by her physician that if she got pregnant it would make her diabetes worse and she could lose her eyesight or damage her kidneys. Judy had prided herself on her ability to care for her diabetes and was complication free. The thought of complications occurring because of a pregnancy was not acceptable to her. Although she had dreamed of becoming a mother, she had not anticipated such detrimental consequences. Therefore, she was not willing to risk the possibility of her health worsening for the sake of having a baby. Although she is now a step mother and she states that fulfills her need of being a mother, she still wonders what it would have been like to have given birth to a child of her own.

Loss of opportunities or the chance to do something in

their life resulted for other participants as well. Obtaining a certain job or schooling for a career did not occur for Harriet because of the physical limitations of her illness. Harriet was very active, but felt her asthma had prevented her from becoming a physical education instructor. Although she was unsure if she really would have become a physical education instructor, the possibility was lost.

If I would not have had asthma first of all, I think I would have been a physical education instructor because I liked swimming and gym, and even though I was not very good I loved basketball and I was fast on my feet and I loved to run relays and I loved volleyball and baseball. There's been a lot of times in my life that if I had to do over, I would like to have healthy lungs absolutely. I would of, I think, I would have gone to more places; I probably would have gone to college.

Harriet thought about what she could have done if she had not been limited in her activity with her asthma. She might have been a physical education instructor. However, having asthma meant that she could not even consider the possibility.

Inability do activities that were important in feeling capable meant that there was a loss of self esteem. Barbara L. had shared how her self esteem had definitely been affected by her lung disease. She was unable to do much of anything anymore because of her severe shortness of breath despite continuous oxygen. She could not go to the store, cook, or clean. It was even difficult for her to walk across the room.

I don't have my self-esteem, it has been sitting in the bottom of the toilet and uh the bottom of a dirty

toilet come to think of it. I think that's mostly the fact that I can't do what I did before.

Barbara could not feel good about herself because she could no longer accomplish anything that she felt was significant. Her self esteem was so low that she used the metaphor of sitting at the bottom of not just a toilet but a dirty toilet at that. There was nothing she could do that gave her a sense of accomplishment. Feeling this way was especially difficult for her because, prior to her illness, she had been very active. She was very knowledgeable about Indian Art and had utilized this knowledge in owning and operating an Indian Art Store.

Ann also could do very little for herself and felt badly because of this. Ann had an additional loss of self esteem because of her appearance. She walked with a limp, and the fingers of both her hands were bent, making it difficult for her to use them. She was very thin and wore slippers because of the deformities in her feet. During the two hours that we taped, she had said she felt okay about herself. Yet when I turned off the tape, she talked for a little more and then told me "I feel really ugly, just look at the way I look." She may have felt it was safe to tell me this because the tape was off, but it was almost as if she was admitting it to herself more than she was to me. I felt how difficult this was for her but was unsure what to say. It was true, physically she was not attractive, however in the short time I had talked with her I saw a

beautiful person sharing her story in order to help others. Perhaps I felt it would be too corny or shallow to tell her this. Perhaps it was that this news took me by surprise and left me momentarily speechless. She had been so open and so confident in what she had shared on tape. In retrospect, there was so much I could have said, but instead, for a few moments we sat in silence and then I thanked her for sharing her story with me.

Not all participants voiced a loss of self esteem. Those who developed their chronic illness as a child, did not remember feeling a loss of self esteem because they could not remember what life was like and how they felt about themselves before being diagnosed with their illness. If I had talked to their families, I might have received a different perception.

In addition no loss of esteem occurred when the losses did not have an impact on activities that contributed to a sense of self. Rocky had developed diabetes as an adult. He still participated in activities that were important to him. Although he had to change the way he ate, this was not a major disruption in the way he lived his life and therefore made no impact on his self esteem.

Loss of Freedom and Independence. As participants lost their ability to do, they also lost their freedom and independence. The illness required participants to be prepared to take care of their illness. They no longer

could just get up and go without thinking about their illness. Sometimes the preparation for a particular activity was overwhelming and prevented participants from participating in the activity at all.

Barbara L. was a middle aged woman who had really enjoyed going places like the grocery store or seeing friends or just getting outside and enjoying the sunshine. She was now tied to her oxygen on a continuous basis and was unable to get out because of the hassle of getting her oxygen connected to a portable source.

If I want to go for a walk, I have to unplug this oxygen tube and turn the tanks off and then drag the thing with me and we go for a walk. I mean thirty minutes later before you're ready to go out the door you don't want to go out the door. I mean you figure, well what's the sense, you know, I'm exhausted now, I'm not going for a walk.

Being dependent on the oxygen prevented her from getting out because, by the time she had made all the preparations associated with her oxygen, she was too tired. She also talked about the tubing limiting her activity even in her home "And I go as far as my tether goes and that's it." She referred to her oxygen tubing as her tether. Her tether had become her lifeline. She could not go anywhere in her home or outside without it. No longer was she free to get up and go, but had become almost a prisoner of her own home.

While some of the losses of freedom are major in terms of preventing the most basic activities, others are minor, but still significant and important to the person

experiencing them. Judy had wanted to use a particular purse when she was going out, but the purse was too small and her glucose monitor did not fit into it.

It's a burden when I have to think so much ahead of time to plan that I've got to have insulin, I have to have my syringes which I generally do all those things anyway but when I want to go out to dinner late at night and I want to take a cute little purse, well my big little tester won't fit in that little purse along with my insulin and my wallet and my keys. And that's sort of silly and all but..and you may ask why don't I get a purse big enough, well that's because I want to take the little purse I picked out. Sometimes it's just the little things, but the little things add up.

Judy had lost the freedom to choose and the purse represented only the tip of the iceberg of all those losses of choice and resulting compromises she had to make. Her diabetes had to be considered and planned for in activities in which she participated.

As participants lost their freedom and abilities to function in life, they became dependent on other people to do for them what they could no longer do for themselves. For some people this meant that a family member assumed the household chores such as cooking, cleaning, and grocery shopping as well as helping with personal activities of daily living such as bathing, walking around the house or even eating. It also meant, that if participants left their home, they depended on others to assist them with each step throughout the course of their outing; for example, having oxygen available when they were traveling and also at their final destination. Having to depend on others made people

feel like a problem or a burden to those around them. Ann, a woman with multiple chronic illnesses, felt like somebody else's responsibility.

You feel like a problem. I'm this big problem. I've always been a problem to somebody. I'm always somebody's responsibility; somebody has to be aware of what's wrong with me and what to do about me.

Losing this independence and gaining a sense of being a burden contributed to a loss of self esteem. People could not do what they had done before having the illness, and had to depend on someone else for fulfilling daily responsibilities.

No Longer in the Driver's Seat. Related to this loss of doing and loss of freedom was the loss of control over their life. While loss of doing had meant a decreased ability to participate in life because of limitations of the illness, loss of control meant no longer being in charge because of the unpredictability and demands of the illness. Things that people had been able to control such as planning on when to do something was now, at best, tentative. Christine had used the metaphor of no longer being in the driver's seat, she was no longer the one deciding what would happen to her when she talked about having cancer. Christine was a very independent young woman who managed a family, job, participated in activities she enjoyed and happened to have diabetes and breast cancer. She stated she was a "a control person" and really kept her diabetes under control because there was much she could do to accomplish

this. However, her breast cancer was out of her control. "There's this hidden agenda of cancer, I don't know what those little cells are doing." She talked about not having control over the cancer because it had its own agenda. There was no diet, exercise or medication that really could keep this illness under control. As we talked she started to cry, and I turned off the tape recorder at her request. Talking about the cancer and not having control over what was happening in her body caused her great distress. In managing the diabetes, she exerted a specific effort and achieved measurable control. She was in the driver's seat. However, the cancer meant being a passenger watching the road, but not being able to go where she wanted. She could not put forth the effort in the form of a treatment regimen, she could not measure the effects of her work on the cancer cells. Control was an extremely important part of who she was and having an illness that caused a loss of this was devastating to her.

Other participants also experienced a lack of control over how their illness might be that day or what they might encounter if they did decide to do something. Further, their choices about what to do when roadblocks arose in the process of participating in an activity were limited. Participants with arthritis might plan to do something but then they might be unable to move or be too exhausted because of the results of the illness. Participants with

diabetes might experience hypoglycemia which could result in a loss of consciousness. Participants with lung disease were wary of going to public places because of the smoke. Even in areas designated as 'no smoking', it was still difficult for people to breathe because of nearby smoke. In addition, participants might not be able to complete a desired activity they had begun. These unfulfilled expectations contributed to the previously described loss of self esteem.

Annette, a lady in her sixties, had been a real estate agent and enjoyed getting out with friends or shopping. She had Chronic Obstructive Pulmonary Disease (COPD) and was on continuous oxygen, but for her that presented no obstacle for her as she used her portable oxygen with ease. Annette was wary of going places because of what might happen. "Today I picked up a lady to take her to exercise class and she had on a perfume that was life threatening." In this case Annette encountered perfume which caused her to become extremely short of breath resulting in a life threatening experience. Annette was no longer in the driver's seat. She could not control what was in the environment that she might encounter. Situations like this meant she was powerless. Although she prepared herself as best as possible by taking extra medication and inhalers with her, the potential for an adverse outcome was always a cloud that hovered over her.

Some participants did not experience a great amount of loss of control because they were able to implement a medical treatment plan that helped to control the symptoms of the illness such as taking insulin to control their blood sugar, medications to help with pain etc. However, even in the best of circumstances, there was always the potential that something might happen that people could not control such as hypoglycemia, flaring of arthritis, or shortness of breath. The appearance of these complications would result in a situation where the participant was in crisis and would be dependent on someone else to take control and help them through the crisis.

Loss of Connectedness

As participants experienced a loss of feeling capable, they also experienced a loss of connectedness where they no longer related to other people in the same manner they had before having a chronic illness. Having the chronic illness left participants feeling different, isolated and seen only as an illness and not as an individual with an illness.

Loss of connectedness meant participants were dealing with a situation that made them feel different from other people. They were dealing with all that the illness brought into their lives with which other people did not have to deal. While most people were making decisions about what to have for dinner based on what would taste good, participants were making decisions about what to have for dinner based on

what the food would do to their illness. Loss of connectedness also meant participants were isolated. Their illness prevented them from being with other people. Sometimes this isolation was because participants physically could not get out and see people and sometimes participants emotionally could not talk to people.

Lastly, loss of connectedness meant participants were not seen as unique individuals beyond their illness. Only seeing the illness prevented others from learning about the individuality and personalities of participants. Feeling different, isolated and not being seen meant a loss of connectedness with the rest of the world.

Feeling Different From Other People. Feeling different from other people kept participants from feeling connected to others. They were now participating in activities that "normal people" did not. Participants saw themselves as different from other people even if there were no physical outward signs. For example, even though there was no outward sign of having diabetes, some participants felt different because they lived by a set of rules that others did not have to follow. No one knew Tandy had diabetes by looking at her, yet, she knew she was different from everyone else. No one could really understand what she was going through unless that individual also had diabetes.

You could never tell I had diabetes by looking at me. But I live by a different set of rules from everyone else. I have to eat certain foods and eat at certain times. I have to constantly be aware of my

diabetes. The only people who could understand that were the people at camp. We were alike and could share in the same jokes about having low blood sugars.

Participants were different if they knew of no others who had their illness or if others who had the illness were quite different from themselves. Kathy was diagnosed with rheumatoid arthritis as a young adult and when she went to the doctor's office, she only saw old people which emphasized how different she was. She didn't even have an equivalent set of life experiences as related to her illness to share.

When I was first diagnosed with it (arthritis) I went to the University of Utah and of course I was always the youngest one in the waiting room. The people there were always fifty years older and they were all in wheel chairs. Actually that was the worst part in the beginning. It was just going to the doctor and looking at everybody in the waiting room... even going into the doctor's office here, it's always older, older people. It would be hard to talk to them about it (arthritis) because they are not in the same stage of life as I am. Their children are all raised and you know they're not in the same stage of life as you are anyway.

In the doctor's office, Kathy felt out of place. Everyone was older and more crippled than she. This situation heightened her awareness that she was different in two significant ways. First she was young and most of the people were older. She could not possibly relate to these people because they were confronting different life issues than she. Secondly, she was not as crippled as the other people. While some people used walkers, were in wheel chairs or could hardly hold a pencil because of the deformities in their hands, Kathy did not have any of these

disabilities or deformities, at least not yet. Not only did this make her feel different but raised her fear about her own future with her illness. Each time she goes to the doctor's office, she is confronted with a preview of what her life may become.

The Lone Ranger. Isolation was a significant part of the participants' experience. Ann utilized the metaphor of the lone ranger to describe this isolation.

But you know I was kind of like the Lone Ranger in one sense. It was true they (her family) were ah, they were around me and helping me, but I was the one who was living it, I was the one to make it or break it.

Even though Ann had supportive people around her, she felt all alone with her illness. She was the one who had to live with every aspect of the illness every single day and there was no one who could really help her with that.

For those who were limited in their mobility, they physically could not get out and be with friends or were not able to keep up with their friends and would, therefore, avoid some group activities. Still others would not leave their home because they were uncomfortable with people staring at them as they limped or carried the oxygen tank.

Some participants indicated that their friends were uncomfortable around them because of the way they coughed, felt uneasy about the oxygen tubing or were frightened that something might happen and they wouldn't know what to do. Annette shared that most of her friends no longer invited her to go places even though she might be standing a foot

away as they planned their outing with others.

I think the oxygen tank sort of makes people pull back and they feel that they won't invite you to go certain places because it is a little bit of an obvious thing to carry an oxygen tank around on a stroller. And now it's a rare thing that I'm invited to go with them (friends). Like they should ask me first, I'd like to have a choice.

Annette also felt that she made people feel uncomfortable by the way she coughed. Although this activity was essential for her to help her clear her airway, people did not understand and just didn't like being around a person who did that sort of thing and made those noises.

Ruthie was a middle aged woman with asthma and bronchitis. She also experienced a decrease in friends which she thought was due to a lack of understanding about the illness.

I do have or I had some friends. They call me very seldom now ...I think that's a case of them not knowing how to deal with this themselves or afraid they won't know how if something happened.

Not only did Ruthie experience a loss of friends, but even when she called on a friend in time of need the friend did not come.

I was going in the hospital for bladder surgery and I didn't have anybody here to help me. So I called her (a friend of many years) and since I'm gonna be alone, I thought it would help me if...if somebody would be there when I came out of surgery and I asked her and she said, well couldn't you get somebody else, I'm kind of busy lately.

Ruthie cried as she told me this. She felt abandoned and alone. She had only asked her friend to be with her, to sit with her and talk with her, and her friend refused.

Participants were emotionally isolated. They could not talk to other people, even their loved ones, about having the illness fearing it would be too painful to talk to their husband or their parents. For the participant it was painful living with the illness, experiencing all the losses the illness imposed. However, it was even more painful for participants to think about how the illness affected their loved ones and conjectured how their loved ones were feeling and handling the participants' illness. Judy remembered an episode when she was first diagnosed with diabetes at the age of seven and in the hospital. Her mother was about to come in the room and give her daughter an insulin injection for the first time.

My dad came into the room first and said no matter what, no matter how much it hurts, don't let on to your mother.

As a young girl she understood that her having diabetes was so painful for her mother that she was not to tell her how painful it was for herself. These individuals were not only isolated but felt "between a rock and a hard place." People did not talk to loved ones about the illness because they wanted to protect them; however protecting their loved ones left them feeling alone with their illness.

People were isolated not only because they did not talk to their loved ones about their illness but they were not open to other people with the illness. Ruthie, who already was isolated because of a decrease in friends, isolated

herself further because she was apprehensive of the consequences of telling anyone about having asthma.

I didn't want to tell anybody that I had asthma, that's all. Not many people are going to give you a part in the play if they think that they can't depend on you.

Repercussions of telling people might result in not being accepted, later being rejected by other people, or feeling different from other people. For those participants whose appearance showed a physical aspect of the illness, there was no choice about telling people because the illness was visible. But for those people where the illness was not visible, disclosure was a choice that they pondered. As Judy stated, telling other people about her diabetes was like "coming out of the closet." She had never let other people know she had diabetes when she was a child and this isolated her. But now letting people at work know about her illness was a freeing feeling. She was no longer locked up with her secret, but had shared it with others which not only lessened the burden of keeping this information to herself, but also comforted her to know that her co-workers could help her if she got into trouble with her diabetes. While Judy had a positive outcome in revealing that she had diabetes, the consequences of disclosure were usually not known ahead of time. Choosing to tell people would decrease isolation and provide support, but choosing to tell people might also result in loss of a job, position, or acceptance of who they were. The decision to tell, to come out of the

closet was one that was not made lightly.

Sometimes participants could not tell people about having an illness because of what was occurring in society. Judy remembered her mother not telling anybody about Judy's diabetes because she didn't want people to know they had syringes in the house.

Well, you know, that's real interesting because it was during the sixties and it was so drug-oriented back then and my mom was very concerned about anyone knowing we had syringes in the house.

Judy did not talk to anyone about her diabetes and she didn't personally know anyone her age who had diabetes. These factors contributed to feelings of isolation, both physical and emotional.

Not only was a sense of isolation caused by the social and emotional loss of encounters with friends and families, but there was a loss in relationships as people had known them. Participants felt the illness had interfered with their sexual lives. It was difficult to even be close when they were short of breath, had oxygen coming from their nose or splints on their hands. People could no longer share intimacy as they had before. Kathy stated "It's hard to feel sexy when you have hand splints on in bed" A lack of intimacy drove Kathy further into isolation. If she could not be close to her husband physically, it was hard to get close emotionally.

For other people there was a positive change in their relationship because of confronting the potential loss of

the spouse. This potential loss resulted in a closer relationship. Rocky talked about how his wife seemed to kiss and hug him a lot more, and he felt this was due to her feeling that she almost lost him because of his by-pass heart surgery.

Not Being Seen. Participants' individualities and personalities were not "seen" by other people. Other people saw the limp, the deformed hands, the oxygen tubing, everything about the illness, and nothing about them. Indeed life for participants had changed. What they could do, their choices about doing things and how much control they had over the illness and its consequences had changed. However, each participant perceived self as the same person, and that the illness was only part of who he or she was...not the illness.

While not being seen occurred in many situations and with all kinds of people, participants felt that not being seen most frequently and acutely happened in interactions with health professionals. Physicians saw only the disease and not who they really were. In fact, physicians could not see beyond all the symptoms of the illness. Several participants indicated that doctors looked at them as only a symptom or illness. With this approach the doctor was patching up a symptom or treating the illness and not looking at the person as a whole. If they could not see participants for who they really were, then how could the

physician possibly be able to help the participant live with the illness. Not looking at them as individuals left participants feeling unimportant and not cared for. Long waiting times and then an abrupt short visit with unanswered questions reinforced this feeling of not being cared for.

I feel sometimes they (doctors) really get used to saying "well, no, you can't do this and you can't do that" and they don't really know what you can do because they only know you on what they've seen in your medical thing. Well I think doctors forget that uh not everybody knows what the devil they're talking about and they're too embarrassed that they don't know what that word meant or what this medication does. I think that they have got to get past the stage of being that way, treating a patient like they're a human being. They forget to say "Do you have any questions?" They give you five minutes of their time, into the room that's it. They don't have the time to listen to that person say they didn't feel right or that hurt me. even if it had nothing to do with what they're treated for, give them the courtesy of listening to what's going on.

Doctors did not spend enough time with participants to see them as individuals. "But I think they see so many people in a day, we just all look alike. I'm sure they don't even know who we are." Participants thought this was due not only to a lack of time but to the splitting of specialties. Being a specialist meant that the doctor was concerned only with that part of the individual that was of their practice domain. For example, if the physician was a cardiologist, then any concerns that the patient had outside of the heart was beyond the cardiologist's expertise and often those concerns would be ignored or the patient told to refer those questions to their primary care physician.

Having this narrow view of the participant limited the physician's ability to appreciate the entire experience of the patient and in providing care that helped the patient to live with a chronic illness.

Sometimes physicians did not really see people because they had assessed them once, but never accounted for the fact that the illness and the individual were constantly changing. The participants' life was not static, but changing in response not only to the progression of the illness but to ongoing growth that is part of life in general. Judy stated:

Sometimes I think doctors put us in a little box and leave us there. I am like silly putty and evolving as a person and as a person with diabetes. They (physicians) need to take this into account in order to know what's happening with me.

Even when physicians did pay attention to the participant's illness, they failed to see that the same illness was different for each individual. George, a gentleman with diabetes, knew of other people with diabetes but that the illness was different for each person. "We're all different. You cannot put diabetes people into one category." Ruthie, a woman with asthma, knew that her asthma was different from other people's asthma, "You can't go by another friend's approach to it (asthma). Everybody's different." She knew that what worked for one person with asthma might not work for the other. This was also true of medicines. Annette knew of other people with lung disease

who were taking medications that were helpful to them, but these same medications had not helped her at all. "We all react differently to medicines." Yet, even though each person saw that he or she was unique and consequently the illness was also unique, the participants believed that physicians did not see them or their illness as unique; this resulted in being treated in an assembly line fashion, with the same treatment for the same illness.

Some participants noted that doctors did not communicate very well with their patients. Kathryn stated that the physician needed to listen to the patient in order to find out about the whole person.

You can't just walk in that room, take their blood pressure, and ask how they're feeling - then charge them 60 to 100 dollars for that instant of your time. Give them an opportunity to tell you what's going on. And if it's not anything to do with what you're treating them for, say "well maybe we should send you to this doctor to see because I don't do that".

Kathryn recognized that the problem a patient may have may be outside the realm of that particular physician, however she understood that the physician should not ignore or not listen to the problem, but refer to someone who could help the patient with the problem.

Jan talked about an encounter with her physician when he did not communicate effectively, and Jan's needs were not met.

He started screaming at me that it was my responsibility to know the medications I was taking. I sat there and didn't know if he was coming back. I was so angry and upset; that was the last time I went to see him, needless to say.

The physician and Jan did not communicate effectively about what he expected of her. Also, the physician did not understand what Jan's understanding was of her part in taking care of her asthma. In this particular instance, Jan was feeling badly about herself because of the weight she had put on (from being unable to get outside and exercise when the weather upset her asthma). The physician's response of yelling at her just confirmed her already low self-esteem.

A lack of understanding also contributed to participants not being seen as unique individuals. When Kathryn was hospitalized, the intensive care nurses did not understand that even though she was intubated and could not talk, she could hear and did not appreciate them gossiping about love affairs while caring for her. She also felt the nurses should have known that a strong perfume would make patients, particularly lung patients, nauseated. There was also a lack of understanding of the effect of perfume on her condition by her physician:

And it may be perfectly acceptable when you're not sick (wearing perfume) but when you're sick, strong perfumes, along with all that junk in your nose and all the medications makes you feel nauseous and I would literally throw up. And my own doctor would come in early in the morning and with a very very heavy perfume cologne or after shave and I thought OH NO!

This lack of understanding meant that Kathryn suffered needlessly. The physician's behavior demonstrated a lack of sensitivity to his patient.

Not being seen was accentuated by the physician's lack of seeing the whole person, lack of time, the numerous specialties contributing to seeing only one aspect of the patient and lack of sensitivity. Yet, another explanation was that physicians just weren't good at dealing with the emotional aspect of living with chronic illness. Kathryn stated:

I think the medical community has neglected the emotional side of the illness. Physicians are so busy diagnosing and treating the illness, they fail to see how the illness is with that particular patient and therefore miss the opportunity to really help the patient live with the illness.

Physicians' inability to see and respond to their patients was a slap in the face for some people. The one place that participants had hoped to be seen and obtain help in living with their illness turned out to be a place that only contributed to their lack of connectedness in the world.

Riding a Roller Coaster of Emotions

A multitude of feelings occurred as participants dealt with the losses and changes that varied in intensity. Sometimes a single feeling dominated the participants' life and other times several feelings occurred concurrently. Sometimes, feelings occurred for brief periods and other times they seemed endless. An "emotional roller coaster" was the metaphor used by Kathy as she described her emotional ride with chronic illness. One moment she was thankful for what she had and the next moment she was green

with jealousy for what she didn't have. Anger and frustration would rise in response to her difficulty in preparing breakfast for her children, but would quickly turn to guilt as she felt badly that she could not be the mother she wanted to be. The ride was exhausting as she climbed up one emotional hill only to find herself speeding rapidly down the other side. The emotional responses that characterized the ride were feelings of frustration, guilt, anger, depression, and fear.

Feeling Frustrated

A feeling of frustration occurred when responsibilities could no longer be fulfilled. It was frustrating not to be able to do what was done before and doubly frustrating to watch someone else do the task.

Jan had really liked doing things herself, such as mowing the lawn, painting the house, and generally fixing things. Her asthma prevented her from participating in these activities any longer because they would trigger an asthma attack.

I live with a lot of frustration. I find it real difficult. Some people can kick back and say oh let somebody else do it, I don't care. But, it's real hard for me. I don't like it. I like to do things myself. I mean, I've painted the house. I do, you know, I do those things. I don't like other people doing them. But I've had to let go and let them. It's hard, real hard.

A sense of failing to live up to self expectations occurred. Sometimes a desired activity would be started, but could not be completed. It was as if they could occasionally see the

top of the mountain, but could not quite make it to the summit. In some circumstances people, usually family, had to take up the slack on household duties as well as help the ill individual with personal activities.

Feeling Guilty

Barbara L. cried as she told about how her husband takes care of her and how guilty she feels about this.

I feel guilty because of him, because I can't sleep in bed with him-because it's too cold, it's too hot or too dusty or whatever in the bedroom, so I'm sleeping on the couch since I came home from the hospital and a lot of nights, he ends up sleeping on that chair, that lounge chair over there or he'll sleep on the floor...he just does everything, absolutely everything and he worries too much about me. He does my hair, he helps with my bath, he's been doing all the cooking.

Feeling guilty also occurred when the family could no longer function as it did before. Kathy stated having the illness was a financial burden which prevented the family from doing or having things they desired. They could not take a vacation to Disneyland because it was cost prohibitive due to the expenses from her illness. The vacation was also out of the question because she could not walk for any great distance due to her pain and fatigue. She also felt guilty when she lost her temper with her young children because, when the illness was flaring up, she would take it out on her children by yelling at them inappropriately.

Feelings of guilt also occurred when the medical treatment plan was not followed. Tandy put it this way.

It makes me feel bad that I didn't do it (check blood sugar). It feels like I'm guilty when I was a teenager and eating candy bars... Sometimes there have been times where I just forget about it (diabetes) all day long and don't check my blood sugar at all and I feel real guilty.

Tandy felt guilty because she felt she was doing something wrong; she knew she was supposed to check her blood sugars and didn't.

Lastly, feeling guilty occurred when participants felt responsible for causing their illness. This was particularly true of people who had been smokers and developed COPD. Interestingly, George had stopped smoking, but then had eaten a lot of sweets, and felt this caused his diabetes and felt guilty about this.

Feeling guilty was an emotional response that seemed to stay with participants. They were unable to forgive themselves for not being able to fulfill responsibilities. If they believed they had caused the illness, then this unforgiving feeling was even stronger. Constantly feeling frustrated and guilty was a draining experience and contributed to feelings of exhaustion. When exhausted, the participant had even less tolerance for daily annoyances and was more susceptible to emotional hills and valleys.

Feeling Angry

A feeling of anger occurred in response to the losses the chronic illness had dealt people. The anger was often tempered by jealousy as it seemed that everyone else was able to do things so much easier and better than the

participants. Billy was angry that he was not as strong as he used to be, "Oh it pisses you off (having diabetes and heart disease). I used to be strong like a bull, but no more, I'm weak as a little kid." Ann compared herself to others and didn't feel as competent, "I was angry that everybody was faster than me, more capable than me."

While some participants felt guilty about not following the medical regimen, others were angry at themselves when they made a mistake. Billy was really trying to follow the diet, but having trouble doing so.

I eat too much, I think I'm trying to follow a 1500 calorie diet, but like last night, you do all kinds of stupid things. It makes you mad. Its stupid and you get mad about it because you screwed up.

They were also angry at themselves when they knew there was a familial risk of getting diabetes or heart disease but they had done nothing to prevent themselves from getting the illness. They had continued to eat high cholesterol foods, or had become overweight. They believed these activities contributed to developing the illness, and they were angry at themselves for their behavior.

The anger was compounded when the treatment prescribed did not help alleviate symptoms. Harriet was angry because her inhaler not only didn't help her, it seemed to make her lung disease worse. She coughed more and felt sicker in spite of her physician telling her that the inhaler prescribed would alleviate her shortness of breath.

What made me angry was that they put me on this inhaler

and it didn't work. It never made me feel good....I was angry because what they were doing was not helping me. I wasn't feeling any better.

For Harriet, even though she did what she was told, her illness not only did not get better, but it got worse.

Other participants were simply angry at the way they were treated in the physician's office. Often long waiting times and quick visits added to this anger. Questions never seemed to get answered and often the physician and staff seemed ill prepared to care for the participant and his illness. Barbara felt the office staff and her physician were disrespectful and incompetent. The nurse had scolded Barbara over the telephone "Bad girl, your theophylline levels are low. You haven't been taking your medication like the doctor told you." What really happened was the physician had told her to take less of her theophylline, but that information had not been recorded in the chart. Consequently the nurse inappropriately scolded Barbara and this made her terribly angry. Another episode that triggered Barbara's anger was when her physician had told her "I'm the doctor, you're the patient. Don't tell me what to do." This condescending paternalistic attitude from her physician left Barbara so angry that she stopped seeing this physician and sought out another to care for her.

Feeling Depressed

Most participants experienced feelings of depression or discouragement intermittently during the course of their

illness. For some, they had lost so much and they became depressed when they thought about the losses. Kathy talked about not being able to participate with her family. "Two years ago I was really depressed. There was a family volleyball tournament and I couldn't play." Although this was only a game, it represented all that Kathy could not do, but so desperately wanted to. As she sat and watched, she contemplated all she could not participate in, most importantly all the family activities she was excluded from because of her physical deformities and pain of arthritis. Being confronted with this inability to participate at a family event was more than Kathy could tolerate and triggered an episode of depression.

Other times depression was due to the physical changes that had occurred. Ann stated, "You slowly see your hands and feet and your knees are changing and that's a very discouraging factor." Even though Ann was taking treatments and doing her exercise, her arthritis was ravaging her body and there was nothing she could do about it. This was particularly true when everything was being done to control the illness, yet the illness progressed. As Ann stated "Doctor changed my inflammatory medicine, but even that didn't work and that was very depressing." There was no medical treatment that seemed to help control the symptoms or progression of the illness.

Not only did inability to participate in activities and

inability to control the illness result in depression, but the continual losses that occurred both in life as well as the result of the illness initiated further depression in participants.

Because depression strikes, because I felt like every time I turned around I was losing something else. I lost my leg; I thought I was losing my eyes; I lost my husband; I lost two children.

Ann had multiple losses due to her illness and circumstances of her life as a whole. Her first husband had committed suicide, she remarried a second time and divorced, and two of her children died. She also had severe rheumatoid arthritis, diabetes and heart disease which imposed further losses on her life. As each loss occurred, it triggered depression in Ann, particularly since she seemed to experience more personal tragedy as well as more chronic illnesses in her life than most people. There seemed to be no balance, no positive side to the teeter-totter, as if there was no center fulcrum to balance the positive and negative aspects of her life.

Feeling Afraid

Fear was an initial reaction to the diagnosis of chronic illness. This fear was basically a fear of the unknown. Not knowing what the illness would do, or how it would change participants' lives left people to conjecture and worry about how they would handle the illness. When Annette was asked how she felt when she found out she had emphysema, she responded: "I was scared to death...I was so

afraid it (emphysema) would shorten my life." Annette imagined the ultimate fear that her life would prematurely end because of her illness.

Fear occurred intermittently throughout the illness as participants periodically experienced symptoms that indicated their illness was out of control, such as a severe hypoglycemic reaction or shortness of breath. Ruthie described her fear,

I'd be gasping for air and I lived by myself and it was especially frightening at night, because I felt trapped. And at night I always kind of felt really kind of scared and trapped...

Annette described similar feelings of not being able to get her breath, but even more so that she might not live through the night.

I'm still scared that I'll go to sleep and not wake up or that I might start gasping for breath and not be able to get my breath.

For Ruthie and Annette the fear of losing their life from their chronic illness was always with them as they had episodes with their illness where that fear was a real possibility.

Fear escalated when something happened that seemed to indicate something was further wrong with their body. Billy described how he felt when his heart beat became fast or irregular,

And it still scares me when something beats wrong. I couldn't get it to go down (heart beat) and it scared the shit out of me, but I did get it to go down.

Billy's irregular heart beat was a signal that all was not

right within and might ultimately mean his death was near. Anytime Billy's pulse became rapid or irregular, he became fearful of what that ultimately meant to his survival. So fearful was he of this happening, that his wife went with him whenever he left the house.

Participants not only experienced a fear of dying, but a fear of what life might be like if they experienced more loss as a result of their illness. Becoming dependent was a fear expressed by Christine.

I'm just not going to be dependent. That's a real fear. And I think that's part of the fear of cancer is that I see that as leading to dependency and I don't want to be dependent.

For Christine, the fear of dependency was far greater than the fear of death.

Participants also experienced fear related to the treatment plan rather than the illness. People were afraid of the side effects of the medicine or what was next in the treatment plan if the current plan did not improve the symptoms. This fear prevented people from taking medicines, making changes in their life-style, and even listening to what their doctors had to say. Kathy would not take a medication prescribed for her arthritis because she was so fearful of all the side effects she had read about the medication.

But see the side effects from that (methotrexate) is two and a half pages long, so I haven't found a way to do that yet (take the medication)...But when you read all the side effects, it's scary to sign away to do that....I read about all the side effects and I was

just terrified of them.

Kathy had previously had a fear of gold injections and only consented to taking that medication when she was desperate, when she could no longer move. At that point in time her fear of being unable to fulfill responsibilities was greater than her fear of the side effects of the medication and she consented to taking the gold.

While fear prevented some participants from participating in prescribed treatment plans, for others it was a motivating factor. Ann followed the prescribed diet and took her insulin because she was afraid she would die if she did not follow the treatment plan.

I was told in the hospital by the nurses that cared for me, this was a disease that would have it's complications and I could die from it and that I must take the insulin and I must follow the diet ...they did an excellent job of teaching me my basics, in that respect, thoroughly and I was afraid not to do it.

Fear of dying or fear of a shortened life span also motivated participants to follow through on other medical recommendations such as stopping smoking.

Making Changes

Life is about change. From the time people are born until the day they die, they are constantly faced with changes. However, chronic illness produces changes that are unexpected and unwanted, and brings people face to face with their own mortality. People, and often families, must change the way they live their life to meet the demands and consequences of the illness. Making these changes means

giving up old habits and replacing them with routines that are a constant reminder of the illness in their life. Participants struggle as they are presented with all that is required while at the same time they are experiencing losses and emotional swings.

Changing the Routine

Participants changed their daily activities in numerous ways. Some changed their surroundings to accommodate the illness. Sometimes this meant changing items in their own home and other times it meant staying away from things in their surrounding environment that could be injurious to their health. Ruthie knew that being near smoke or dust would start her asthma to act up and she would have difficulty in breathing.

I stay away from smoking and I stay away from areas that have smoke. I'm very sensitive and perfume juices, I stay away from them. If there's you know I try to stay away from dust and the wind and any toxic fumes or odors and I have a terrible time learning to say would you please mind not smoking.....I'm in the process now of trying to get my sleeping area changed completely. In other words I'm trying to get those large pieces of furniture out of there so that I can put something smaller in there so that I can move them around and clean. The large pieces get dust and dirt behind them. I'm trying to get all the knick-knacks out so I don't have all these dust catchers and so forth.

Although Ruthie talked about what she had done to change her environment or what she needed to stay away from, sometimes it was not possible to do what she knew was best for her. When her neighbor had a fire in the fireplace, smoke from their chimney bothered her breathing, but there was nothing

she could do about it. Even when it was possible to change the environment, it was often difficult for her to do so. Ruthie was uncomfortable in asking people not to smoke even when they were in a non smoking area. She felt that people might think of her as a complainer when in fact she was only trying to prevent a situation of breathlessness. The day I interviewed her she had come to my office at the University on an extremely windy day. When she appeared I told her we could reschedule, but she insisted she was OK and proceeded to talk with me. Her presence in my office, despite the wind conditions outside, reinforced to me how important it was for her to tell me her story.

Sometimes changes involved doing things differently, rather than changing the environment in order to keep the illness under control and continue life as normally as possible. This involved everyday things such as cooking, cleaning, bathing, and even breathing. Barbara S. would sit down frequently while she washed and dried her dishes. Annette would take a sponge bath rather than a regular bath in order to conserve her energy. Kathy rearranged her pots and pans so they were easily accessible. Many times people made choices about what they were going to eat and what their activity level would be depending on how it would affect their illness that day. Part of these routines were dependent on how the illness was that day (blood sugar level, degree of pain, ease with which they could breathe)

and other times the routine was dependent on outside situations (the weather or timing of meals,).

People also changed their routine by changing the way they thought about things. What they used to see as important such as a clean house was not necessarily important anymore. Kathryn talked about cleaning her house.

And I found out its okay if that floor doesn't get vacuumed but once a week..If someone were to walk into my house and it was a mess, I would have been most embarrassed. It doesn't bother me anymore.

Jan talked about the way she thought as a more relaxed attitude towards getting things done.

I take a more relaxed attitude; I can't do this or I might be able to do if I just sit down and rest or if I take a nap, I might be able to get up later and do it later; if not I'll do it maybe tomorrow.

Jan and Kathryn both changed their attitude about what was important in life; and it was not a clean house or getting everything done that was planned for the day. A shift in values occurred as participants realized that, in order to live with the illness, they had to rethink what was really important in their life. Kathryn talked about what was important,

All those crazy things that were so important - they're not anymore. Its each day is a gift and you take it. And you say thanks and you go and do things that you think you enjoy.

Some changed their thinking about their understanding of their own mortality. They believed that either their time to live was shortened because of the illness, or that the capabilities that they had at the moment might change

because of the illness. Therefore they no longer procrastinated when it came to things that were important. Ann talked about this perceived time compression, "What I wanted to do for the rest of my life, I'm trying to squeeze it all in a couple of years and I appreciate waking up every morning. Getting down to the bare facts and little things that are important and letting the dust go." Rocky talked about purchasing a telescope because he really wanted it and since his heart surgery, felt he would go ahead and get it because he might not be here tomorrow. Janette also told about not putting things off anymore, like purchasing something for the home.

But I don't put off things often now as I used to. You know, I thought, well maybe next year I'll do it, but I tend to do a little less of that now...and other things that I might have put off and said I don't need it. I now decided that I want it.

Ann saw her priorities change when confronted with the possibility of not being able to walk.

I was a young woman, but I didn't care if I was going to have to wear braces on my legs, or use cane or crutches, that wasn't important to me, it was important that I walked.

Ann did not care how she looked anymore, only that she could walk. For Ann and other participants, priorities and the relative value and issue of things had changed. The losses that they had been presented with forced participants to change the way they thought about living their life. Things that had seemed unimportant or taken for granted were now

seen as important and valued, while things that had seemed so very important seemed to become more trivial and unimportant in their life. This change in thinking did not occur automatically, but gradually as the realization that life was now different because of the presence of their chronic illness.

Adding New Routines

Participants changed much of their day by adding new exercises, medications or foods. People revised what they did on a day-to-day basis to live with their illness. Because the illness was constantly at the forefront of their life, routines related to living with their illness were indelibly etched in their memory. Tandy explained her routine with diabetes.

First thing I do when I wake up before I do anything is I check my blood sugar. Its like a habit now. I get up and set it up and I do it... usually then I'll make a decision on what I'm going to eat for breakfast and based on that my blood sugar, then I'll decide how much insulin to take, so I'll take a shower and start getting ready. And about twenty minutes later, I'll eat. Once in a while I'll check mid-morning, especially if I woke up with a low blood sugar. Since there's such a long time between lunch and dinner usually most of the time I'll check again in mid-afternoon about three o'clock just to make sure you know. Also sometimes with work it's difficult to take insulin half an hour before we're going to eat so my blood sugar tends to be a little higher in the afternoon. A couple of hours after lunch I usually take insulin and eat right after it. Then dinner time I do the same thing. And then bedtime. I don't usually eat before I go to bed, but I always check my blood sugar before I go to bed.

Tandy's day was filled with activities that she needed to do in order to keep her diabetes under control; for her, all

these activities had become part of her life.

For some participants, the routines they implemented interfered much more with their daily activity. Anna told about her routine which included her activity and how it affected her illness as well as when her pills would take effect.

I take all my pills and that usually takes about 15 to 20 minutes to get into my system, so I sit here and read books, the paper, whatever and do the dishes. Now while I'm doing all this like doing the dishes, but worst of all I'll have to sit down and get back up and sit down; by that time it's maybe 10:15 or 10:30 and this morning I went out and walked around the pool ten times. So by 11:00 I'm fading; 11:00 is my breathing pill, Albuterol, and about 5 or 6 minutes it really works and this morning after I took it, I blew up a couple of balloons, I know it sounds silly but I did, and then I went off.

Blowing up balloons helps Ann to expand her lungs which allows her to breathe more easily. Her whole day revolves around doing activities to help her breathe. Because of this, she is limited in her ability to really be active and to live the kind of life she would prefer to lead.

Added routines also included visits to doctors and specific treatments such as laser eye treatments. Even outings to their physicians required planning. Each participant needed to make sure that he or she had the necessary supplies (food for low blood sugar, inhalers, pills if he or she was going to be away during a medication time, oxygen etc). For those who saw more than one doctor (endocrinologist, rheumatologist, pulmonary specialist, etc.), this added still another activity to their life that

they had to do as well as carry on with the general activities of daily living. Not only was seeing the doctor time consuming, often taking an entire morning or afternoon, but these visits added to feeling not being seen and being cared for as previously described. These visits also added to their frustration as participants' needs were not met and treatment regimens did not fulfill expectations. There were some people who did not mind the visits to their physicians and were satisfied with their visits, but they were in the minority.

Struggling with Change

Changing daily routines and adding new routines to their life was difficult for participants to accomplish. People struggled with giving up what they were used to, what they preferred, and substituting unwanted activities to their daily lives. Billy talked about how difficult it was to change his eating habits, particularly since much of what he had been eating all his life was not compatible with keeping his chronic illnesses under control. He used to eat lots of foods high in fat. Now, because of his heart disease, diabetes, and arthritis, he not only needed to eat less of his favorite foods, but he had to eat less overall in order to lose weight.

I don't eat fat meat no more, period, I cut it off. That bothers you because you were brought up that way and you've been doing it that way forever. You get a plate full of food at a restaurant because you're hungry and you come to the point you know you shouldn't eat anymore of it, it was born into you, like your

parents said you will clean that plate off and you still do it. Now that's a fact, and when I was a little boy they'd tell you to eat that fat meat boy , don't you know that the kids out there are dying because they have nothing to eat and you'd eat if and then pretty soon you got to like it and now you can't handle that stuff you like. Like my favorite thing on earth above anything is I like ice cream and can't have that anymore. ...You go out to dinner and they got the best looking ladies, the best fat fluffy two million calories there, you can't have that. What the heck - that's demoralizing.

Billy struggled with this change required in his eating behavior because he really loved to eat and much of what he was supposed to do now focused on the way he was used to eating, and the way he was used to eating was no longer acceptable. Not being able to eat what he wanted made things unpleasant.

Kathy struggled with the change of slowing down as well as taking medication for the rest of her life. This was difficult because she had been a go-getter all her life. "Taking care of myself. Learning to pace myself, which are real hard things for me cause I'm, you know, I go til I drop and I can't do that any more." She also found it difficult to take medicines because she had been raised to not take medicines for anything. Now she had an illness, rheumatoid arthritis, where the main treatment was pacing herself, taking medications for pain and slowing the progression of the disease. Annette, who also liked to be on the move, found that her COPD made her tired and slowed her down. "You sit down to rest and you become so fatigued. You give into this fatigue and that's one of the things I find so

difficult to live with." Annette struggled with no longer being able to do all that she wanted and learning to pace herself in order to accomplish desired tasks.

Implementing changes also presented participants with dilemmas, struggling between who they were and what they wanted, with the demands of the illness routines. They were faced with making changes in their life that had equally undesirable outcomes. Sometimes these changes forced participants to make choices between what was best for their illness control and what was best for their emotional happiness. Very often, these two choices were not compatible, thus stifling their attempts to find a suitable compromise. Kathy was confronted on a daily basis between making choices that would help keep her illness in control versus attaining a perception of being the mother she wanted to be.

One day Katie (her daughter) wanted us to walk to McDonald's for lunch. Now I knew if I walked that distance, I might not be able to walk back, or worse yet, I would be unable to move the following day. If we didn't walk I would feel I wasn't being a good mom because I couldn't do a little thing like walk to McDonalds. What was I to do?

In the end Kathy went to McDonalds and called her husband to take them home. She was happy that she made it to McDonalds, even though she ended up with pain sufficient to prevent her walking home. However, for that day she was able to fulfill her role as the mom she wanted to be.

Other dilemmas arose for participants with more than

one chronic illness. These people had difficulty in knowing which illness was causing them problems or even if the problems they were experiencing were related to their illness. Were they nauseated because their blood sugar was high or were they getting the flu?

Ann not only has arthritis, but diabetes and coronary heart disease as well. Each illness is severe, often one flaring more than the other, yet it is difficult for her to problem solve solutions when she is unsure as to which illness is the culprit.

I get very confused between my two chronic kinds of illnesses, my arthritis and my diabetes. I don't know if I'm feeling this way because of my arthritis is so active right now or I'm feeling this way because of my diabetes.

Because she is unsure which illness is acting up, she does not know what course of action to take in order to feel better. This results in bearing with the symptoms or allowing the symptoms to flare up for a longer period of time as she tries to find out by trial and error what is wrong and what to do.

An additional struggle occurred as participants made changes while they concurrently experienced loss and a roller coaster of emotions. Making changes, experiencing loss, and resultant roller coaster of emotions added a layer to their life that made any additional change or frustration seem almost unbearable. Sometimes this was related to the illness and sometimes it was just something happening in

their life. Ann had multiple chronic illnesses and multiple losses in her life. Each time something happened in her life, she felt it as an additional burden. She described that "I felt like I had another brick on my back; it was just one more thing I had to put up with." Brick after brick occurred for her as she developed complications from her illness and then experienced the death of her husband, moving to a new location, supporting herself and her children. For some, bricks can build up until a wall is constructed that separates the person and their illness from the rest of world.

For other participants, simply having the illness created a layer so that when any little thing came up (a child was sick, or they were late for an appointment), it was difficult to handle because they were already handling the daily routines of their illness. As Jan put it as "It's one layer, and its when something is added onto the top, that's when its hard to cope."

Not only did having the illness add a layer that made it difficult to deal emotionally with life, but the illness also caused people to experience physical symptoms of other illnesses more severely. Leah talked about how having a cold would always seem to be worse because of having diabetes.

Most importantly, the changes implemented by participants are not temporary, but require a lifetime

commitment and that results in struggling to maintain and sustain the changes for a lifetime. As Judy stated "You can never take a vacation from it" (the routines of their chronic illness). Everyday participants are implementing changes in their daily lives to take care of their illness so they can carry on with the business of life. Trying to look toward a future of unending changes is not possible for many of these people. A day by day attitude towards time results, making the unrelenting task of chronic illness care bearable.

Not only is the illness unending, but even when the person is following their treatment plan, the illness can become unstable or take a downward turn and a complication can occur. Therefore, what is achieved today may not be achievable tomorrow. This also leads to a time perspective on living in the present and not looking toward the future.

When Judy was a child people had told her there would be a cure, and still there was none. "Don't worry, in ten years they'll have a cure for diabetes...it didn't happen...Maybe that's why I get so emotional, sad. Because when I was their age, I was told there was going to be a cure." Now Judy does not look toward the future; she believes there will be no cure in her lifetime. It is easier for her to believe this than to live with the let down and disappointment.

Gaining Control of an Altered Life Direction

Experiencing loss and making changes in their daily lives altered the life direction of participants. They were now on a road that was unchartered and unplanned. For some it was a 90 degree change and they were traveling an unknown road, headed in a direction they did not want to go. For others the chronic illness presented a minor change in their life course, but it still was an unwanted one. People dealt with the change in their life direction by participating in activities aimed at gaining control of what was happening to them. These activities included seeking support, learning about the illness, approaching the illness, and finding meaning in the illness. Seeking support helped people to feel connected, less isolated and assisted them to see what others had done to deal with their illness. Learning about the illness helped people to make changes in their lifestyle and implement medical management plans. Defining the relationship between the participant and illness helped participants to know who they were and how to deal with all the changes imposed by the illness. Lastly, making meaning of the illness helped people to answer the underlying question of why did I get this illness? Why me?

Seeking Support

People sought support for many reasons. Talking to people who understood what they were going through helped them to feel like a person and connected to other people.

People were also able to gain information which helped them to make the changes in their lifestyle required by the illness. It was important for Annette to have someone to talk to for emotional support.

It's very important to have someone that you can call and say uh, you know, say a prayer with me or do something. I just feel down. And it's amazing after I did that, I had a couple of people call me that were down. So it works. Everyone needs a support group I guess. And with better breathers we have that because once a month we go and there's new ideas and things, so that works.

For Annette, knowing that she can call someone at times of emotional distress, and having a place to go for information provides her a way to help her along the tract of her emotional roller coaster as well as gain new information to help her live with her illness.

For other people having support helped them feel not so alone with their illness. Tandy lived with her mother and sister. Going to diabetes camp had been such a helpful experience for her in feeling less alone with her diabetes.

It (diabetes camp) kind of makes you feel like you're part of something bigger, you know you're not dealing with it (diabetes) by yourself.

Camp also provided Tandy an opportunity to feel understood. The campers would tell private jokes to each other related to diabetes that only people with diabetes would understand and appreciate. For Tandy, going to camp helped her feel that there were other people just like her going through similar experiences, and she was no longer the one who was different.

Being in the majority, you know being around so many other people who have the same problems and the same concerns. It's hard to explain as you walk in you become part of a family and everybody's there.

Support not only helped people feel less alone and that they belonged, but also being with other people with the same illness inspired them to try harder at implementing the changes required by their illness.

People found support in friends, in their spouses, in support groups, and even in reading a page in a magazine where people with the same illness share experiences about their illness. Although most people agreed support would be helpful, not all people had the support they desired.

Barbara S. lived with her husband, but felt he didn't help her or understand her as much as she would like.

But as far as any support, there has been none. I don't mean no support. I don't want anyone to fall over himself and say - you poor thing; you can't do this or can't or that, but I do want somebody to show understanding.

Other people wanted support but could not obtain the support they needed. Ruthie was a widow and really wanted someone to live with her. She believed it would be helpful to have someone around the house to talk to quite simply, so that she would not be alone. However, she thought that no one could live with the restrictions of her life. She contemplated filling out an application for a roommate, but then reconsidered.

I have really seriously thought about that if I would find a roommate ... but I have thought, no God, I would put in such restrictions, I can't do that to

people. It is my house, true, but I would have this no smoking, no perfume, no, none of those things... she couldn't use a lot of strong cleaners either. And it just seems like it's so many things that I'd have to say you can't do this, you can't do that, and you know.

Ruthie desperately wanted someone to talk to, someone who understood, but for Ruthie this kind of support was out of her reach. Ruthie had to settle on having neighbors that would just keep an eye on her, and in some small way this comforted her to know that somebody was watching out for her. This support was better than no support at all.

Annette stressed the importance of having someone to talk to even though she had always been a very private person.

I try to talk to someone, but then I've always been a very quiet person, a private person and its hard for me to call someone and say hey I'm feeling a little blue today. But I have done that a few times.

Though it was hard for Annette to reach out to someone, she did so because it helped her not only to understand her illness but to have someone who understood what she was going through. Annette most succinctly put it "You need to be with people. I think everybody does."

Learning About the Illness

Barbara L. was on continuous oxygen and talked about knowing as much as possible about the illness so that you knew what to do about the illness and how to control it. This included such things as knowing about exercises for her lungs (blowing up balloons), learning that some of her medications caused her to have diarrhea, and discovering

that taking a nap in the afternoon would help her get through the evening etc. She stated:

Get all the information that you can from any source that you can because the more you know about it (the illness), basically the more you know what to do about it.

Most of this learning came through the daily life experience with the illness. While going to the doctor, support groups, and reading about their illness was helpful, much of what participants learned came through trial and error.

I'll say the main thing that most people with asthma need to educate themselves, and there's a lot of trial and error in the process of educating themselves, so you know what to do to control it (the asthma).

Much of what was learned resulted in people knowing what works for themselves. George, a gentleman in his sixties, learned that if he sang a song to himself while he exercised his blood sugar would go down more than if he exercised alone. He believed this was true because it was hard to worry or think about anything else when you've got a tune in your head. Other people talked about actively experimenting with the routines of the illness to see what worked and what did not. For example, people with diabetes would eat different foods and see what the effect was on their blood sugar. They would find that, although a particular food was supposed to be OK on their diet plan, it would make their blood sugar rise.

People obtained information not only through life experience but through several other ways as well. Support

groups such as the Better Breather's Club were quite helpful because not only did they have meetings to exchange ideas, but they also sent out a newsletter. Some people went to the libraries and others even called medical centers in other parts of the country to find out what they could do to help live with their illness.

Participants found that once they knew about their illness, they began to know more about what worked and didn't work than the doctors or other health professionals. Judy stated. "I know more about me and diabetes than the medical profession." Judy was quick to point out that, although health professionals knew about the illness, they did not know how it was with her. Often it was the doctor who did not see she was unique with her illness (as previously discussed). The doctor did not respect the self-learned knowledge of the patient, and this resulted in another point of frustration for that individual. Instead of being praised by health professionals and utilizing the information gained by the patient to make living with the chronic illness more tolerable, the information became a point of frustration for both the patient and the health professional. Judy experienced this frustration when she was in the doctor's office. A nurse was going to check her blood sugar and the nurse started to use the middle pad of Judy's finger. Judy told the nurse it would be better to use the side of her finger because it wouldn't hurt so much.

The nurse said it didn't matter, but for Judy it did. Rather than respecting what the patient knew was true for her, the nurse ignored Judy's request and Judy felt frustrated, further feeding into the already discussed theme of 'not being seen'.

Learning about the illness was not only important for participants, but for people surrounding them, including their friends, family and the general public. "I don't think there's enough public awareness." Most people do not really know a lot about specific chronic illnesses which may lead to staring, and contribute to the person's loss of connectedness.

They look at you with such pity. Well, you know, this thing does come out, it doesn't grow in the nose, it looks stupid but its there.(oxygen tubing)

Barbara S. utilizes continuous oxygen to help her breathe. She does not like how people stare at her with the oxygen tube. She believes if others knew more about the illness and that the oxygen tube is just some equipment to help her breathe, they would not stare at her.

A lack of knowledge from people not only caused them to stare at participants, but would result in actions that were actually injurious to the ill participant's health. Ruthie had an experience where she politely asked someone to stop smoking, but she was met with a great amount of resistance.

So I went over and in a very low tone, so I wouldn't embarrass him and said, "Would you mind sir, to go into the smoking section with your cigarette?" And he got very angry and he cursed me out and he ground out his

cigarette, but it was obvious, he was very angry. In this episode the gentleman did not know that his smoking could possibly trigger an asthmatic attack for her if he did not stop smoking.

Participants also experienced times when they were having trouble with their illness and people responded inappropriately because they did not know enough about the illness or what to do in order to help them. Again Ruthie related an experience where she believed the public did not really understand asthma. She was having an asthmatic attack, but people just walked away.

These other people that walk away from me when I'm in trouble is because they don't know what to do with me. Its not that they don't like me or think less or anything like or that they even possibly even think I'm pretending. Its that they don't know how to handle the situation.

Learning about the illness was an important activity for participants. This knowledge gave participants some control over a seemingly uncontrollable situation. However, not all participants sought information concerning their illness. For some, there were times during the illness that information was actually avoided rather than sought out. Leah did not want to know about her diabetes initially.

I am quite interested in diabetes now, which I wasn't. At first it was a dirty word to me. I wanted no part of it. But I think you change.

Leah had not been ready to hear information concerning diabetes. She first had to get used to the idea that she

had diabetes. Another participant felt that she was so upset about finding out about the illness and so busy asking the question "Why me, Why me?" that she couldn't learn about the illness. These participants were not ready initially to learn about the illness, but then eventually sought out information. Some participants were never ready to actively seek out information. Kathy, the young woman in her thirties with rheumatoid arthritis, was a person who did not really want to know about her illness, even though she said she did. She had arthritis for many years, yet she knew very little about the medications she was taking, the usual treatments for her illness and the latest research concerning treatment of her illness. I was quick to get her on the mailing list for the Arthritis Foundation and to tell her about resources for information. It was only on reflection that I realized her way of living with the illness was to try and ignore it, which included not reading about it and not talking to other people about the illness. For her, the information about the illness and how it would progress was too frightening for her to think about; she handled this by not actively seeking information.

Approaching the Illness

As participants told about living with their chronic illness, it became evident that how they approached their illness was an important aspect of how they dealt with the consequences of loss and change. Participants' approach

helped them with the physical and emotional aspects of the illness. Participants saw their approach as helping them to live more fully with their illness. Although this approach was important, they believed that their doctors were not very good at helping them with the emotional part of their illness. "I think the medical community has neglected the emotional side of the illness" This in part reflects the theme of 'not being seen'. If physicians could not really see participants' personalities and uniqueness, it would be difficult to help them emotionally with the illness. Four approaches emerged as participants shared their stories. These included: accepting the illness, looking on the bright side, "if wishes were horses" and master of my own destiny. These approaches were not mutually exclusive and could occur concurrently. These approaches could also vary depending on how the illness was that day.

Accepting the Illness. Accepting the illness as part of self meant accepting the losses and changes the illness had imposed. Participants accepted the illness as part of themselves in two distinct ways.

Those who saw the illness as part of themselves were able to view the illness as just a piece of who they were. Sometimes this was a small piece and other times it was a large piece, depending on the demands of the illness at that time. For those participants who had developed the illness as a child, it was just part of who they were. Because they

could not recall what life was like before developing the illness, they could not really imagine what life would be like without the illness. However, they were quick to point out that they did not define their entire selves by their illness, but that they were much more than that.

Christine, a young woman with type I diabetes of thirty four years, stated "I am not my disease, it's only part of me. I have a personality, a soul, and a mind." Tandy compared having diabetes to simply having another role. She was a sister, a student a mother and a diabetic. The illness was a part of who they were, but not all of who they were. However, there was no separation between them and their illness. Judy wondered where did she begin and her diabetes end, what was really her and what of her was the result of having diabetes?

Am I am the way I am because of me or because I have diabetes ?Now that I'm older and more mature, I wonder about that. I was married before and I wonder how much of the marriage problems were due to my diabetes or was it just me? How much did the diabetes play into it and that I didn't recognize it?

Judy wondered how much did diabetes play into who she was and how she interacted with the world. As we spoke, she realized that she was probably a combination of both, but the fact that she wondered about this at all demonstrated how much the illness was integrated within her.

Other participants carried the illness around like a suitcase. Although the illness was with them, it was not part of them. These participants had developed the illness

as an adult. The illness never helped to define who they were. For some of these participants the illness was an insignificant part of their life and for others the illness was a tremendous burden. The illness may have changed outwardly how they looked or what they could do, but for those who developed the illness as an adult, the illness was not part of them. People did not see themselves as a diabetic or arthritic. Barbara L. felt she was essentially the same person inside. "I'm the same person you know, so I huff and puff a little bit more, you know. I can't walk as fast as they can, but I'm the same person." The illness was present, there were changes, and even though she felt her illness was severe, she still was the same person. Barbara L. was able to separate herself from the illness. Indeed she had changed, she was physically different and unable to participate in life the way she had before. However, her personality was the same, her essence was unchanged.

Separating illness from self meant that the participant could be feeling fine, but that their illness could be terrible. Kathy stated:

I couldn't get out of bed. My husband had come home to take me to the doctor's office; on the way there he said "What are you going to tell the doctor today?" I said "I'm going to tell him that I'm fine; I have a problem with my knee" ...That's how I felt inside, I was fine that day, except for my knee and of course I couldn't get out of bed because of it.

Although Kathy was unable to walk, she felt that she was fine. In other words she, her inside self, was fine but her

illness, her arthritis, was not doing well at all. Separating herself from the illness allowed her to be OK even when her arthritis was flaring.

The other aspect of accepting their illness was in terms of accepting what was going on in their life. There were many different explanations of acceptance. Some were very similar to the attitude of taking responsibility for it, but people called this acceptance.

You have to accept the problem that you have. I know I have the problem (asthma). I know I'll have the problem the rest of my life, but what you do is do something about the problem such as stay away from cats, all stress, fireplaces, smoke, cigarette smoke and cigar smoke, and pipe smoke is worse, and stay on your program.

Staying on her program meant taking medications and doing what the doctor recommended. People also said you accept it by learning about the illness and learning to live with the limitations of the illness. For some it was not only to learn to live with the limitations of the illness but to live with the idea that it's not going to go away. Some people stated that this was an intellectual acceptance and not an emotional one. In other words they could accept intellectually but not emotionally. Emotionally meant that is was okay, that they were not angry about the limitations imposed by the illness.

Some people talked about accepting the illness and giving in to it.

You have to accept it (illness). It's like when I went in for the operation, what can I do about it?

I have to accept the fact that they're going to do it. Okay and when you accept it and say okay and do it.

They stated that it was okay to have the illness and you just had to do what you could do to live with it. Jan, a woman in her fifties, with asthma, talked about the idea that if you really accepted your illness you would be serene, but when I asked her if she had accepted her illness, she said yes, but when asked if she felt serene she said no.

I think if you really accept that you've got it and it's not gonna , you know, like a cold, it's not gonna go away next week, then you do the best you can with, try to be on your diet and do your, you know, your sedentary exercises and your, whatever you need to do. Then you just go along and do the best you can and you're happy with it cause you know it's not gonna get any better. Then you could try to keep it from getting worse the best and longest you can.

Jan defined what acceptance was, stated she had accepted the illness, but when confronted with her own definition she really had not accepted her illness.

Other people talked about accepting illness as a negative thing. Accepting was simply a 'giving up' kind of an attitude.

If you accept something in my case I feel this way. If I was to accept this (her illness) and say okay, this is what I got, um, I think I would just sit in the end probably just sit down somewhere and wither away, but I tolerate it and I'm still willing to fight.

Barbara fights the illness by doing much of what the people who accept the illness are doing. She has simply attached a different label for the same approach to the illness. Jan,

another woman with heart disease, also felt the same way with the addition that if you accepted the illness there was nothing you could do about it; on reflection, she too is a fighter because she takes her medicines and does what is necessary to fight the illness.

Still other people looked at fighting the illness as a negative approach, and believed that some people fight against the illness instead of working with it. They do this by denying what is happening to themselves or becoming angry that they have the illness. Although there were different labels, the basic intent of fighting the illness versus accepting it was essentially the same. Each person was approaching the illness by trying to do something in order that they could live with the illness.

Christine talked about having diabetes and believing that God gives you what you can handle. "You know just sort of accepting life. God gives you whatever, and you just take it and run with it." Barbara, also believed that God hadn't given her more than what she could do, but even that belief was beginning to be questioned.

I know what everybody says and I know it to be true. He doesn't give you anything worse than you can handle, you know, but I really think enough is enough.

While some people believed that God gives you what you can handle, others believed that things happen just because they happen. George talked about "You know what's gonna happen is gonna happen. There's not much you can do about it.

Devil May Care."

Looking on the Bright Side. An attitude of being positive, doing their best and looking at the bright side was an attitude expressed by participants. This approach to their illness helped participants to deal with the life direction their illness had taken.

I'm a real go getter. If I didn't have that, (attitude of wanting to do her best) I would be sitting in a rocking chair and knit, and knit a stole or knit a sweater.

People talked about not letting the illness beat them, of conquering the illness by doing everything they could do to control the illness. Harriet, a lady in her seventies who had been diagnosed with severe asthma, was full of energy as I talked with her. She told me how important it was to keep positive.

So I do my program and I have a positive attitude and I like people and I want to keep busy, I want to be involved and I really feel like that I couldn't fake it.. I couldn't function without my inhalers.

Her program was everything the doctor had prescribed for her to do, but her attitude reflected the importance of keeping positive in order to do what she wanted to do. However, she talked about the importance of her being able to be involved and do what she wanted. If she could not do that, then she would not have a positive attitude. This demonstrates the interplay between physical and emotional aspects of the illness.

Some participants kept positive by focusing more on

what they could do rather than what they couldn't do.

Annette tried to focus on keeping positive.

I try to dwell more on what I can do and be thankful that I'm not in a wheel chair and that I'm not in the hospital. So you have to think about the good things, the positive things.

Although this was difficult for her to do on the bad days, she said she would remember and think about the days she could do things and that would get her through that particular moment. Sometimes this meant really focusing on the fact that things could be worse. Annette tried to view her illness in comparison with what other illnesses she could have and that there were worse things than having emphysema. "I realize I could have something worse that's more fatal and debilitating." Leah also talked about this way of looking at life and said "I have a philosophy in life that you don't look who has it better than you, you look at the one who has it worse and you do that and you're OK". She also believed that at least she had an illness like diabetes that she could control and still function. Jan also believed that she could control her asthma enough so that she could be productive, "It could be worse. I can live with it (asthma), and I think I can learn to live with it and be as productive in society as anybody else". George saw in his exercise class people with diabetes plus other illnesses he thought would be much worse to have and so considered himself fortunate.

Being positive meant having a sense of humor for some

of the participants. Barbara L. said she didn't really know how she would deal with her illness if it wasn't for finding humor in the situation. Sometimes this meant laughing at herself and other times it meant finding something to laugh about. Laughing not only felt good, but it kept her life bearable as she dealt with her COPD.

Master of My Own Destiny. Some participants saw not only a positive, and accepting approach as important but that they also had a vital role in controlling their illness. People are responsible for taking care of their illness. This included doing what the doctor said as well as keeping the doctor informed of what was going on.

I have to feed information back to him (the doctor) and I have to learn things myself about it. I have to know about it (the illness) too in order to take care of myself.

This self care responsibility was important for people in helping them "not to get a whole lot worse right away." Christine was a very positive young woman with diabetes and felt the attitude of being responsible for yourself and taking part in what happens to you gave her control of the illness. Having control of the illness didn't necessarily mean physical control of what was going to happen, but it did mean mental control.

That (being in control) allows you to be sort of master of your own destiny. And it may not be the master of your physical destiny, but it certainly can shape your emotional destiny...I mean you can tell your mind anything, you can't always tell you body what to do, but you can control your mind.

Christine talked about getting this control by knowing about the illness and taking part in the decision making of what the medical treatment was to be. This attitude of being in control gave her power to make a choice about what was going to happen to her so she was not a victim of her illness.

For some participants there was an increase in independence that came with being responsible. This occurred particularly for participants who were diagnosed with diabetes mellitus as children. The illness imposed limitations on eating, required taking injections, and having an increased awareness of activities. As children they learned to do these things for themselves and this actually made them more responsible and independent. Tandy, at age seven knew by looking at a plate of food approximately how many bread, fruit, and meat exchanges there were and what would fit into her diet. She also gave all her own injections. These abilities were certainly far beyond the ability of most seven year old children.

"If Wishes were Horses". Not all participants had a keeping positive, in control position and/or accepting approach to their illness. Their attitude reflected one of trying to ignore the illness or as Barbara S. stated "to escape it".

They help me escape (activities she does) They're ways to escape (doing puzzles and clipping the grass). I get into something else , I'll read or you know, I'm a great one for diving into a book, fantasy or murder mysteries or whatever, I read like, God, seven or eight library books a week.

Barbara's attitude toward her illness was to get involved in something so she did not have to think about the illness.

Ann recited the beginning of a mother goose rhyme about wishes and talked about what she would like to do in her life. "If wishes were horses, I'd get on one."

Participants did activities that would make the illness go away, temporarily in their mind or would take them away from the illness. Barbara talked about getting rid of her oxygen.

But I keep telling myself on good days that I'll be able to do things I used to do. And that someday I won't be dependent on the oxygen. I got this thing (illness) under control. If I keep this up, take my vitamins and take my medication, it will go way and then pretty soon I can get rid of all this stuff.

There was no physical way that Barbara would ever get off her oxygen, and logically she knew that. But it helped her to think about that possibility. This let her see herself without the oxygen which was a very pleasing thought. In medical circles this certainly would be labeled as denial, but for these people it created avenues to allow them to keep going.

Not only did people hope for things to happen with their illness, but they hoped for things that would give them great pleasure. Sometimes this was owning their own business, moving closer to family, or travelling to familiar places. People always described these hopes and dreams in great detail and with great pleasure. Billy relished in telling me about his desire to take one more trip in a

trailer.

I want to get me a little trailer. I want to hook it to the back of my car and I want to go to Branson, Missouri and up to Tennessee and just make a big circle. We did it about five years ago. I came back, I lost 50 pounds, seriously. I got tan, I felt fantastic. I felt so good, I would like to do that one more time. Just close up the house, put it all in storage and take a three or four month trip.

As Billy expressed his desires, his eyes were bright with excitement and he smiled. Thinking about doing what he would really like, remembering a time where he felt good, gave him a break from the daily routine of dealing with his chronic illnesses.

Finding Meaning. People tried to answer the question "Why did I get this illness?" in order to make sense of the illness in their lives. Some people answered the question by giving very scientific medical reasons for what caused the illness. Kathy stated "cause the doctors say that they think it's inherited (arthritis)" or as Harriet talked about "What causes asthma is your inflammation in your lungs, I think that's true." These two ladies gave medical reasons but went no further. They had gotten the illness; it was out of their control; they had nothing to do with it.

Other people believed they had a role in causing their illness. George believed he helped bring the illness on because of his own behavior.

And I figured cutting out smoking is what really brought it on (diabetes). Cut out smoking and switched to candy... It's my own fault. When I retired I was even less active than I normally would have been, so that to me is what brought it on (diabetes).

For George, this left him feeling angry. Jan also was angry as she believed a specific situation had brought on her asthma.

If I hadn't done the pool (cleaned the tile), if I'd known, that the dust was gonna get up in my lungs, I never would have done either of these things. Maybe its self anger.

Annette too felt she helped to cause her illness "I wasn't living right, I was working hard, not taking care of myself..and ah sitting behind the desk and having a cigarette maybe, just helped with my downfall." Leah fluctuated between believing she helped cause the illness and that she deserved it. "I had done things wrong. I deserved what I got because I had been wrong." to believing the illness just happened "I don't feel that I deserved it (her diabetes) either. You know it just happens." Her being wrong was referring to her eating the wrong or unhealthy foods and gaining weight.

Ann seemed to be searching for the cause of her illness. The illness was inherited to some extent, and occurred because of specific situations in which she helped and played a role.

I think it (emphysema) started many, many years ago when I was young. My doctor found a scar in my lung. I was doing gardening work, I worked out in the fields and the dusty hay. I did this all the time, now I was exposed to all of this dust on the farm, dust in the feed, so that dust was getting into my lungs, but it was getting into everybody's lungs. My father died of emphysema in '89...Well I figure as long as my father had it, I'd probably get it too cause I'm the only one that smokes... It was my fault, I mean the way things went, I did what I did (smoking) there's

nothing I can do about it. I can't change it and I don't think I would have changed it....I think it did, it (her inhalers) wrecked my breathing. I think that it put me to where I am now.

While some people tried to find meaning in their illness by trying to explain what caused the illness, other people tried searching for a deeper meaning of the illness by asking why. They tried to give meaning to the illness by believing something good could come from it. As Tandy talked about it, she said "I wouldn't say there are some good things about having it (diabetes) but I think some good things can come out of it." Being a role model for children and helping them to see that she can live with diabetes is something good coming from Tandy having diabetes. This gives children hope that they can live with diabetes too. This ability to help other people not only helped Tandy find meaning in the illness, but helped her feel good about herself and even helped her change her ways and manage her illness better "I knew these little kids were looking up to me as a role model and that changed me cause I didn't want them doing what I was doing." Tandy also stated that she probably was healthier because of her diabetes. "I think I'm probably healthier than I would be, you know in the way I eat.. I'm a lot more conscientious about what I'm doing." She also saw herself as more disciplined than her friends concerning what she ate. She felt she was able to plan and be more prepared for outings such as picnics or going to the lake than most of her friends. She really thought about

what to bring and planned for unexpected events such as bringing a first aid kit, extra clothing or food. This ability left her with a sense of accomplishment when her friends were left feeling hungry or cold.

Tandy also explained how a loss of self esteem could occur with children and she, as well as health professionals, could help children not lose their self esteem through a simple choice of words. Tandy was 21 years old and had diabetes. She had been a counselor at diabetes camp and believed it was important for children to avoid attaching their self esteem to their blood sugar level. She felt this could be accomplished by telling children they are "checking" their blood sugar, not "testing" it. Testing implied that it is a test and you either pass or fail. You did good or you did bad. If the child fails the test (has a high blood sugar) the child feels that he or she is a failure which results in a loss of self esteem. Although she said using the word check may sound like a small matter, she felt it was really important and would encourage all health professionals to do the same.

Judy also believed that she took better care of herself and ate better because of her diabetes. Also diabetes gave her the ability to be more empathetic or understanding with people. Judy felt that it was important to see something good coming out of the illness. She believed this helped a person to get control of the illness, "I mean I think if you

can take and turn a negative experience somehow into something positive, then again it gives you that control."

Harriet also felt good about herself when she talked about helping children with asthma.

I feel that God left me here for a reason. And maybe he left me here to do what you and I are doing today... to help somebody else and that's my big thing is to help somebody else. These babies and these little ones are growing; I go to the hospital to try and help them with the asthmatic children; I screen them for the schools.

She also felt good about herself because she could still fix things around the house and felt she was doing what she could.

While some people did not see any personal good coming out of their illness for themselves they did see it for their family members. Kathy talked about how having arthritis might help the children to be more sensitive and understanding toward other people with arthritis. She also believed that because she herself could not do a lot of the household duties that her children had to do them and this promoted a sense of responsibility. "They realized they have to help and I don't think that's harmful for them. I think they've actually benefitted from this."

For some, being able to deal with their illness and still carry on with the business of life gave participants a sense of accomplishment. Kathy felt worthwhile because she could still do the things that were important to her and get through times when her arthritis was flaring up.

I am really worthwhile, I can really pull through this and it's really hard and you make it through it, it really is an accomplishment.

Both Judy and Tandy felt pride as children in giving their own insulin injections and as adults in being able to manage their diabetes and function with their jobs and family. Tandy actually said she felt "pretty cool" about doing all that she did to care for her diabetes. She had an insulin pump which required a certain sophistication and knowledge to be able to use. Tandy felt good about not having any complications of diabetes. She attributed this to taking good care of herself.

Reflections

The themes presented reflect the experience of how people made chronic illness a part of their lives. This process was found to be multidimensional and included considerable variation. The phenomenon did not occur in a linear progression nor in stages but each theme occurred over time and often concurrently with other themes. The following poem was written and chosen as a way to express this phenomenon.

I Can't

by Susan Rush Michael

"I can't" is a phrase that's a part of her day,
And nobody, nobody likes it that way.
"I can't" is weaved into her work and her play.
She can't, but she tries, for there's no other way.

Her kids are awake and need to be fed,
She gets them their breakfast, but oh how she dreads...
The effort it takes, the pain and frustration
To do simple tasks, she wants a vacation.

But chronic illness has moved in and it won't go away.
It's an unwelcome guest and forever it stays.
It's a burden to her, an unwanted dimension
Of pills, pains and problems in unrelenting succession.

Look at her children, how can they know,
How much she loves them, when she yells at them so
Look at her husband, trying to be strong,
He's tired of her illness and things that are wrong.

Her parents, how it hurts them, to see her distress,
Struggling to walk, struggling with such mess.
Her doctor, he listens and knows her disease,
Prescribes the latest treatments, but he never sees.

Surrounded by people, surrounded by friends,
Yet she's alone, she can't talk to them.
No one really knows her, there's nowhere to go,
Silently, alone, a long road to hoe.

Frustrated that she can no longer do,
Jealous that she's not "normal" like you.
She depends on others, she feels guilty and fears
What the future will bring her as it seems to draw
near.

So she stays in the present and lives her today,
And savors simple pleasures as they come her way.
But the struggle arises between can't, must and
 shouldn't,
Changing everything in life to accommodate couldn't.

No time to think what all of this means,
To live with this illness, it isn't her dream.
She's there in the trenches, she's doing her best,
Keep positive, keep fighting, take time to rest.

So she's not going where she wants to in life,
Her path has been changed and encountered much strife.
If all she can hope for from all of her pain,
Is somehow in some way her children are better for it,
Then her "I can't" but "I tried" is not all in vain.

CHAPTER 5

Discussion of Findings

This chapter discusses the findings of this inquiry in relation to what is known in the literature concerning integration of chronic illness. The research question asked "What is the experience of integrating chronic illness into one's life?". This question was asked in order to understand this phenomenon while clarifying the role of acceptance within the experience. Integrating chronic illness was found to be a complex, dynamic, and multidimensional experience for participants, supporting the findings of Packard, Haberman, Woods, and Yates (1991). Packard's group found that numerous difficulties or demands existed among women with nonmetastatic breast cancer, diabetes, and fibrocystic disease. The authors also recommended further research addressing how patients managed chronic illness rather than studying the impact the illness had on patients. This current inquiry reflects the beginning of looking at those aspects of chronic illness.

Four significant themes emerged from the data concerning the phenomenon of integrating chronic illness. These themes were: the confronting loss, riding a roller coaster of emotions, making changes, and gaining control of an altered life direction. The discussion is organized

around those four themes.

Confronting Loss

Loss was a theme that emerged as participants told of all the things they had done previously in life and now were limited in doing or could not do at all. As Bassin (1994, p. 27) states "people living with diabetes or another chronic health condition are also living with loss...loss need not be absolute or complete to be significant". Lindgren, Burke, Hainsworth & Eakes's (1992) identification of loss as an integral part of peoples' experience with chronic illness was reflected in the experience of these participants.

Loss of Feeling Capable

A loss of being capable occurred as the illness became a major influence in participants' decision making concerning every day activities. They could no longer do what they wanted, or when they wanted without considering needs and limitations imposed by their chronic illness. Losses occurring from chronic illness are documented in the literature (Craig & Edwards, 1983; Lubkin, 1990; Miller, 1992). Miller (1992) identifies the specific losses of physical abilities and function, self esteem, role performance, income, and social relationships. Participants in this study also experienced many of those same losses.

For participants who developed their chronic illness as a child, the losses were less severe and they did not

experience a loss of doing or a loss of self-esteem. The illness had always been with them, so their illness was a way of life with them. The illness had not taken away things in their life because it was their life. The literature does not discuss age as a variable in perception of these losses, but generalizes and puts them all together.

Mumma (1986) found a loss of independence as the loss mentioned most often by patients experiencing a stroke. In this present inquiry patients also experienced a decrease in independence. Because self reliance and independence are powerful values in American culture, this loss is significantly felt socially as well as personally. Miller (1992) addresses and elaborates on the losses of self reliance and independence and conceptualizes the loss as powerlessness.

Loss of Connectedness

Chronic illness is an isolating experience. Chapman (1984) found that there was an overwhelming sense of isolation experienced by the chronically ill. This finding of isolation is confirmed in this study. Participants became isolated not only physically, but emotionally as well. Physically they could not get out as easily because of the effort it took to get ready, the effects of the weather on their illness or wanting to avoid people staring at them. Emotionally, participants did not talk to family members in order to protect them from the pain the

participant was experiencing. Dudley et al (1980) described persons living with Chronic Obstructive Pulmonary Disease (COPD) as living in an "emotional straitjacket" where people avoided emotional experiences and limited social interactions.

Participating in illness routines left participants feeling that they were 'different'. This sense of feeling different contributed to their loss of connectedness.

Also contributing to their loss of connectedness was the feeling that other people did not really see who they were, but only saw the illness. This is depicted in the poem "The Crabbed Old Woman". In this poem an elderly woman wants to be seen for more than her physical appearance. Although she is now old, wrinkled, and unable to do what she did as a youth, she talks about her past when she was once a young vibrant woman. Seeing a person beyond their chronic illness means not only seeing what's important in their life, but seeing their past as well. Barbara S. had loved to go ice skating. Although she could no longer participate in that activity, ice skating was an important part of who she was.

The one setting where participants hoped they could be seen for who they were was with their physicians. However, participants found that this was not the case. Kleinman (1988) sought to explain the difference of expectations between doctors and patients through the concepts of disease

and illness. While patients experience illness which is "how the sick person and the member of the family or wider social network perceive, live with and respond to symptoms and disability" (Kleinman, 1988, p. 3), the physician sees disease as, "an alteration in biological structure or functioning" (Kleinman, 1988, p. 5). The physician focuses on treatment of the biological dysfunction the disease has created, but does not see or treat the disease's broader influence on the individual's life which is considered the illness. The physician casts the patient's illness problems into narrow technical issues and disease problems.

Another aspect of 'not being seen' is that the physician neither has the time, nor the skill to communicate with patients, and if he or she is a specialist, is only interested in the disease process within the narrow confines of the specialty. Everett Koop, the former Surgeon General of the United States, also saw these as differences between physicians and patients. Koop (1994, p. 8) stated "If you talk to people who receive health care, the number one concern is, 'My doctor is not the kind of man or woman I want a doctor to be. He doesn't listen to me,'" or 'When I talk to her, she doesn't understand me.'" Koop also indicated that the patient is more than a biological problem or disease and believes that doctors need to listen and find out about the patient as well as the disease process. "The patient is more than aches and pains he or she brings to

you. You may come in to see the doctor about a pain in your elbow, but you may have problems that are economical, emotional, psychological, or spiritual" (Koop, 1994, p. 10).

Riding a Roller Coaster of Emotions

Reactions to loss have been well documented in the grief literature (Rando, 1984; Sanders, 1989; Worden, 1991). Much of what is known about grief in chronic illness is borrowed from the grief responses of the terminally ill or the bereaved survivor. Fraley (1992) discussed applying the stages of grief identified by Kubler-Ross to the losses of chronic illness. She stated "these stages can be applied to any experience of grief or loss" (Fraley, 1992, p. 64). Chapman's (1984) research concerning the psychological adjustment to chronic illness supports the application of Kubler-Ross's stages of grief to the losses of chronic illness. The experience of participants in this study does not support the conclusions of Fraley or Chapman. First, there was a fluidity and movement of the emotional response that participants experienced. While some of the emotions are the same as those identified in the literature, particularly anger and depression, there were no specific stages that participants seemed to move through, but rather specific events that reminded them of or reinforced the losses of the illness. Secondly, with chronic illness there is no end to the loss. Although there is an initial loss, it's ramifications continue for a lifetime where the

participant must actively engage in activities to control the symptoms and progression of the illness. These activities are constant reminders of the losses imposed by the illness. In addition, further losses occur as complications or exacerbations are experienced. Lastly, participants' emotional milieu was compounded by the emotional response to implementing changes to control their illness. Examples include frustration and anger over changing eating habits, while at the same time experiencing those same emotions in response to the losses imposed by the illness. This emotional turmoil left participants fatigued which further contributed to inappropriate emotional responses (yelling at children). Therefore, extrapolating what is known in the grief literature concerning death to the experience of those with chronic illness suggests few similarities to the roller coaster of emotions participants experienced in this study. However, Gould's (1994) work concerning grief education supported this theme. He placed students in small groups and asked them to describe their behavior and feelings in a situation where they experienced loss. One of his groups described loss as feeling like a ride on a roller coaster. Gould (1994, p. 72) stated "The rapid movements of the roller coaster represent the unpredictable swings of emotions and sudden grief attacks that grieving people experience". Gould explained that this description of grief teaches that "grief is not an orderly

process of sequential stages; rather, it is a confusing, unpredictable experience that everyone experiences in a slightly different way". While this description exemplifies what was found in this study, Gould's conclusions are not as widely integrated into the current literature as the staged model of grieving.

What may better reflect participants' experience in the current study is the concept of chronic sorrow, specifically as it related to their experience of depression. Depression occurred periodically during the course of participants' illnesses. Pereira (1984) stated that the depression can be a result of loss of control, feeling dependent on others, isolation as well as the physical symptoms and complications of the illness itself. Pereira saw depression as part of the process of grieving over loss, and expressed the need for people to work through this depression in order to reach acceptance. Chronic sorrow, on the other hand, is an episodic sadness that recurs throughout one's lifetime, occurring in varying intensity and at different times for the individual (Olshansky, 1962). Olshansky (1962) originally introduced the concept of chronic sorrow to explain the parental response to the lifelong and episodic sadness of having a mentally disabled child. Participants in this study experienced episodes of sadness that were triggered by events that reinforced their limitations. Kathy could not participate in a family reunion volleyball

game and she became depressed. She further identified other times throughout her illness that triggered episodes of crying. Even participants who had their illness for many years stated there were times when they became depressed over what they could not do because of their illness. The importance of this conceptualization is that the episodic nature of the depression is seen as a natural response rather than unresolved grief or a neurotic reaction. Teel (1991) analyzed the concept of chronic sorrow and found in the review of the literature a great amount of support for this concept. This inquiry supports the conclusions of Teel (1991). While much of the literature has been done with families of chronically ill children (Phillips, 1991; Warda, 1992), there is an increased interest in broadening the research base related to chronic sorrow to include adults with chronic illness (Lindgren, Burke, Hainsworth & Eakes, 1992).

Feeling frustrated and guilty were also minor themes within the theme of riding a roller coaster of emotions. Wheeler and Dace-Lombard (1989) emphasized that living with chronic illness is living with continued loss and daily life is frustrating and sometimes enraging. Frustration occurred as participants were unable to do what they had done previously and often watched others do for them what they used to do for themselves. This also evoked feelings of guilt as they could no longer fulfill responsibilities,

requiring the assistance of others. Lubkin (1990) stated that the chronically ill often feel responsible for their illness (they smoked, they ate the wrong foods etc). This self-blame was reflected in participants' experiences. Barbara particularly felt this way as she stated, "If I had just listened to my doctors, I wouldn't be in the boat I'm in today. But I didn't stop smoking and now look at me". Even though Barbara had been diagnosed with COPD six years ago, she still expressed how guilty she felt about causing her own illness. The guilt did not diminish over time, but remained with her and was a constant source of pain.

Anger is well documented in the grief literature as a reaction to loss (Parkes, 1965; Sanders, 1989; Schneider, 1984) and is reflected in this inquiry. However, rather than just occurring at the beginning of the illness, anger flared intermittently throughout the course of the illness. Participants' anger was often interrelated with guilt and frustration. As participants could no longer do what they desired, when they desired, they became angry. Often this anger was displaced toward family members which resulted in additional emotional turmoil, particularly frustration and guilt.

Participants also experienced fear. Much of their fear was related to the uncertainty of their future; would their life be shortened, would they become dependent, and/or would complications occur? Everyday fears were equally

distressing such as: What do these symptoms mean, will I have a hypoglycemic reaction today, and will I encounter a smoke filled environment? Uncertainty in chronic illness is well documented in the literature (McSweeney, 1993; Morse & Johnson, 1991; Price, 1988). Hodes & Charles (1992) stated that chronic illnesses such as arthritis often follow an unpredictable course with an uncertain future. This unpredictable course often results in patients responding emotionally to each new situation. For some patients Hodes and Charles (1992) found that the emotional turmoil caused by uncertainty is often worse than the physical pain.

Mishel (1990) has also written about chronic uncertainty in chronic illness, but this inquiry does not reflect his conceptualization that uncertainty is a natural phenomenon and increases the person's possibilities for growth. Most of the participants in this study reacted to uncertainty with fear of what was going to happen and did not see it as an opportunity for growth.

Making Changes

Much of what is discussed in the literature concerning adaptation and adjustment to chronic illness is focused on the reaction to the losses that the individual has experienced and their perceptions of these losses. Integrating chronic illness is more than grieving losses and involves making changes and dealing with a change in life direction. As Miller (1990, p. 376) stated "At the

time when persons with chronic illness are most vulnerable, they are also challenged to change life-long behavior patterns." Making changes was a theme that emerged as participants told of all they had to do to integrate their illness into their lives. Additionally these changes had to be made and implemented for a life time. This theme included changing the routine, adding new routines and struggling with the change.

Miller (1990) identified three distinct types of behavior change in chronic illness as removal, replacement, and addition. Removal implies that people must eliminate behaviors such as smoking. Replacement as a behavior change suggests that people must substitute one behavior for another, for example, foods high in cholesterol must be replaced with low cholesterol foods. In addition, people must supplement or expand their usual behavior pattern, such as taking medicines, treatments, or keeping doctors' appointments. The behavior changes of removal and replacement were reflected in the emergence of the subtheme of changing the routine. Participants removed items that were hazardous to their health or avoided situations such as smoking areas. The behavior change of addition emerged in the subtheme of added routines. Participants added specific treatments and the taking of medications to their daily lives.

Changing the Routine

Chronic illness necessitated that participants change their daily lives by changing their environment, the way they did things, and even the way they thought about things. Changing routines involved a large part of the participant's day and is reflected in Lubkin's (1990, p. 265) statement that "the day-to-day management of many chronic illnesses is complex and time consuming".

Participants physically changed their environment by moving furniture so they could get around more easily, changing their kitchen so pots and pans were more accessible, and even eliminating items in their environment that contributed to dust collection and consequent breathing problems. They also changed the way in which they did things, such as eating differently and taking rest periods when doing dishes or cooking. Of course some activities were eliminated altogether such as recreational activities or even going out to dinner with friends and family.

Participants also changed the way they thought about things and often what they valued. Sometimes they were thankful just to get up in the morning. Instead of feeling that a clean house was most important, they enjoyed being able to do a puzzle or read a book. Harvey (1992) indicated that values are changed in order to adjust to physical disability and chronic illness. This was reflected in this study.

Adding New Routines

New routines were also changes that participants were required to make which they often found time consuming. Taking medications, treatments, and going to doctors are all activities which were added to their life. For some participants, taking care of their illness required them to focus all their time and efforts on implementing these routines, while for others they could spend minimal time with added routines and continue with the rest of their daily routines with minimal inconvenience.

Much has been written about what is required medically in order to live with chronic illness. Goodall and Halford (1991) indicated that the management of diabetes requires numerous self-care activities such as insulin injections, oral hypoglycemic medications, strict calorie controlled diet and regular exercise as well as a modification of all these activities depending on individual glucose levels. Dunn (1990) emphasized that these activities require a lifetime of monitoring. With the publication of the results of the Diabetes Control and Complications Trial (The Diabetes Control and Complications Trial Research Group, 1993), even more emphasis has been placed on the importance of staying abreast of these activities in order to minimize future complications.

Struggling with Change

Miller (1990) briefly discussed the idea that changes required by chronically ill individuals are often unpleasant and therefore demoralizing. Participants in this study gave depth to this statement. Billy felt the eating changes that were required of him were difficult and demoralizing because he had always eaten a specific way, really enjoyed his food and now he was expected to give up what he enjoyed greatly in life; the way he ate. Woods, Haberman and Packard (1993) confirm that activities related to controlling symptoms of the illness are difficult not only when first initiated but throughout the course of the illness.

Making changes is also difficult because not only must changes be implemented, but they must then be modified on a daily basis and for a lifetime. Judy had talked about how she could not take a vacation due to the changes in her life and the consequences of those changes. McSweeney (1993) stated that the majority of persons are unable to sustain behavior change over a long period of time. Walker (1991) utilized the metaphor of "shaping the course of a marathon" when discussing all that is required to live with chronic illness. While this accurately depicts the effort that is needed, it falls short of describing the unending aspect of the effort and might better be described as "a never ending marathon."

These changes often present dilemmas for people.

Although it has been suggested in the literature that people need problem solving skills in order to learn how to live with a chronic illness, little attention has been given to the actual dilemmas that confront chronically ill people. Participants were often faced with having to make a choice between two actions that produced equally undesirable outcomes. Kathy described wanting to walk to a fast food restaurant with her daughter. If she did, she probably would not be able to move the following day because her joints would be inflamed and painful; if she didn't, she would feel she was not being a good mother to her daughter.

Gaining Control of an Altered Life Direction

Illness is always an interruption and one of the major things it interrupts is an ongoing life course...(in chronic illness) the life is not so much interrupted as it is reshaped. The illness, no matter how well managed, becomes woven into the fabric of that person's world and into that person's meanings. (Benner & Wrubel, 1989, p. 125,136).

This conceptualization of chronic illness is well supported by the findings of this inquiry. Participants experienced loss and made changes in their life which took them in a new life direction. These losses and changes required participants to actively deal with these changes for a lifetime. White, Richter and Fry (1992) suggested that the disruption caused by chronic illness must be managed in addition to the everyday life events if one is to find meaning and purpose in life. In this inquiry the four sub-themes that emerged in gaining control of an altered life

direction were: seeking support, learning about the illness, approaching the illness and finding meaning.

Seeking Support

The significance of social support and its beneficial effects in chronic illness is well documented in the literature (Goodenow, Reisine & Grady, 1990; Sexton & Munro, 1988; White, Richter & Fry, 1992). Barstow (1973) specifically stated that having a supportive person in the chronically ill individual's immediate environment is probably the single most important factor in adjusting to chronic illness. The data that emerged from this inquiry reflected the idea that chronically ill people desire and seek support; however the support that was desired by participants was often unavailable.

Participants sought support to obtain information, decrease the feeling of being alone, and gain understanding from others. Gulick (1994) also found these types of supports to be important for people with multiple sclerosis. In fact, she added an informational component to the instrument she was utilizing in her study as she believed it would be a significant factor. This study's results supported that participants sought support from people with the same illness in order to find out what they could do to improve their lives.

While some participants were able to meet these support needs, others failed. Sexton and Munro (1988) found that

46% of their study population (women with COPD) talked problems over with their husbands, while 7% stated they had no one with whom they could talk. The results did not clarify what was meant by "problems". In this present inquiry, participants talked to spouses about problems concerning their illness, but did not reveal their inner selves or emotional concerns. Therefore, if a questionnaire had been given to participants in this study, they too may have said their support needs were met when in reality participants felt their emotional support needs were not being met leaving participants to feel isolated and alone. Without an adequate definition of the term, it is realistic to believe that perhaps a larger percentage of the study population could not get their support needs met. Regardless of the meaning of problems, support was unavailable for some participants in Sexton and Munro's study and was reflected in this inquiry.

White, Richter, and Fry (1992) found that support groups were beneficial for meeting both informational and emotional needs of patients with diabetes. The authors suggested that there may be a bias in their findings because the sample consisted of well-educated women who were members of a national diabetic support group; however, they hypothesized that a survey of non members would result in similar findings. In the present inquiry, some of the participants felt they could not talk to their husbands or

other family members about what they were really feeling because they did not want to further burden their loved ones. Christine did not want to talk with her husband about her feelings in order to protect her husband from the pain she was experiencing. Ruthie wanted a roommate, someone to talk to, but felt no one could live with the restrictions that her illness imposed on her life; and Annette found it difficult to seek out support because she had always been a very private person. Barbara S. found that her husband was just not as supportive as she wanted him to be and expanded on this theme during the second interview with her. She believed that this was true because he was a man and not used to being nurturing. This is supported by the results of Belle (1982) and Gulick (1994). These researchers found that women provide more support than they receive. Gulick (1994) also found that men with multiple sclerosis perceived higher levels of affect, affirmation, and aid support from their wives than women with multiple sclerosis did from their husbands.

Although all participants agreed support was helpful, for some it simply was not available. A lack of support occurred because participants knew their loved ones were experiencing their own pain about them having the illness, and they did not want to add to their loved one's pain. As participants talked with me, they confided that much of what they were talking about had never been previously shared

with anyone, thus confirming that participants did not talk to others about factors surrounding how they made their illness part of their lives. While this was true for those people who had stated they had no support, it was also true for participants who had stated they did have supportive persons in their environment. It seemed that the actual interview process provided benefit to the participants in that it gave them the opportunity to talk about their illness. Mathew, Lannin, and Mitchell (1994) also found this to be true in their interviews with women who had breast cancer. The interview created a situation where patients could talk openly about a frightening and often bewildering experience. The benefits of participating in a qualitative research interview were further discussed and elaborated on by Hutchinson, Wilson, and Wilson (1994). These authors list several categories of participant benefits: catharsis, self-acknowledgement, sense of purpose, self-awareness, empowerment, healing, and providing a voice for the disenfranchised. In the present inquiry it seems possible that participants may have been sharing things they had never shared before because the interview provided a voice for them, the disenfranchised. Participants had been unable to tell their story about integrating chronic illness because no one really wanted to hear.

Learning About the Illness

Most participants sought ways to learn about their illness with much of what participants learned coming through actively experimenting. As George, a participant in the present study stated, "You learn what works for you through a trial and error approach". Braden (1993) indicated that most people with a chronic illness learn to self-manage their conditions during most situations that arise except for acute episodes. Much of the information gained occurred through support groups, newsletters and even the library. Most participants found doctors were not helpful in providing information that helped in living with the illness, such as how to deal with pain, side effects of medicines, fatigue, and emotional response. This concurred with Tough's (1985) work on how adults learn and change. He found that most people who implement intentional change (or in the current inquiry, learn what to do about their chronic illness) choose, plan, and implement the change on their own. He called these changes a "do-it-yourself-operation". He further stated that people often obtain significant help from acquaintances within support groups, but rarely obtain help from professionals or books. The findings from chronic illness participants agreed that doctors were uninformative about how patients could live with their illness. A possible explanation for viewing physicians as non helpful is found in Kelly's (1988) own subjective experience with

ulcerative colitis. He stated:

For a physician simply to provide information is to ignore the fact that information is interpreted by the patient on the basis of extant beliefs and knowledge. Doctor-patient communication is based on negotiation...The implication for practice is that attention should be paid to both the patients ideas and beliefs about the illness and should be allowed to express anxieties, doubts and fears...What the patient will be expressing, more or less articulately, is their particular ideas about what is happening to them. This is important because it is after all what determines their behavior to a greater or lesser extent.

Kelly reinforced the notion of "not being seen" which compounds participants' perceptions of physicians as not providing information that is helpful in integrating the illness into their lives.

Interestingly enough, while some participants stated that nurses were nice, none really saw them as an information resource nor sought their expertise on learning about their illness. Also, no one mentioned educational programs that were specific to their illness as valuable resources of information.

On the other hand, some participants did not want to learn about their illness. Even when they said they did, there was an obvious gap between what was currently available knowledge about their illness and what they knew about the illness. Leah stated she just wasn't ready to learn about diabetes at the time she was diagnosed. However, she has now had the illness for approximately 20 years, and was very interested in knowing what were the latest developments in diabetes care. Kathy has rheumatoid

arthritis, but did not really know what the current treatment was such as the latest available medicines or the latest surgical treatments. Gulick (1994) also found patients with multiple sclerosis had low information scores concerning their illness. She postulated that perhaps patients realized there is no known cure and may think that little or nothing can be done to ameliorate the symptoms of their illness. Kathy had stated that her physician recommended a joint replacement even though joint replacements only lasted about seven years. Since she was 36 years old, what was she to do in seven years? Perhaps this information alone kept her from actively seeking current information concerning her illness.

Once patients learned about their illness and how to manage it, they felt they became more knowledgeable about their illness than their physician. This usually was a source of frustration for patients, particularly if they changed physicians. Barbara S. had changed to a new physician and he was going to place her on medications that she had previously taken and she already knew did not work for her; however her physician insisted that she try. Her physician invalidated her experience with her own illness which contributed to her frustration. She perceived her physician both as a non valuable source of information and as one who denied her individuality.

Lastly, patients felt that most other people were

unfamiliar with chronic illnesses. This lack of information lead to the participants being stared at, helped inappropriately and avoided by people in general. Perhaps this reflected an overall impression that society does not want to recognize the imperfect, remain ignorant about chronic illnesses in general and physically avoid chronically ill people in particular.

Approaching the Illness

An important part of redirecting their lives was how participants approached their illness. Approaches to illness were neither constant nor mutually exclusive; sometimes people were positive in their approach and tried to look on the bright side, appreciating the small pleasures in life, and other times they wished things were different or really wanted to ignore their illness. At the same time participants were trying to be positive, they might vacillate between accepting and ignoring their illness.

The original interest in this inquiry emerged from an attempt to understand the experience of integrating chronic illness into one's life and the role acceptance played in this integration. Assumptions were that acceptance played a major part in that process. However, acceptance appeared as only a minor piece in the very complex experience of making chronic illness part of participants' lives.

There has been a great deal of literature concerning the acceptance of chronic illness (McBride, 1993) which has

resulted in the presentation of numerous definitions and multiple understandings of what acceptance means. Part of the confusion in understanding acceptance in chronic illness revolves around the issue of what the chronically ill are accepting. An additional source of confusion arises between the apparent incongruity between what the literature states is acceptance and participants' actual experience of acceptance. The two issues that were critical in understanding acceptance in this inquiry were: what were participants accepting, and what did acceptance mean to the participant?

Participants described acceptance in terms of their relationship with the illness first and then in terms of their daily life. As participants spoke it became clear that they either saw their illness as part of them that was within them or as part of them that they carried like a suitcase. This distinction occurred between participants who had developed the illness as a child (they saw the illness as within them) and those who had developed the illness as adults (they saw the illness as extra baggage). Corbin and Strauss (1988) also saw this differentiation of acceptance, but did not distinguish age of onset of chronic illness as a variable. These authors discussed acceptance in reference to the severity of the illness and it's necessity to be incorporated into the biography or life course. They call this process contextualization which can

occur in varying degrees from the illness being discounted, (it's not part of me), to being very well integrated, (the illness is me and my identity revolves around the illness and the associated work). For the most part, the authors believe this integration lies somewhere between those two extremes where the illness is part of the biography but not fused with it and people state that their chronic illness is part of them, but there is more to them than just the illness.

Participants also talked about accepting the consequences of the illness in their life. Participants' meanings of acceptance varied. Some accepted their illness indicating that they acknowledged the illness in their life; they were not happy about it, but what could they do? Others' acceptance of illness meant they acknowledged the illness and this was okay. Still others stated they did not accept their illness but still acknowledged the illness and followed the medical regimen. Barbara S. had stated she would never accept her illness because acceptance meant giving up; therefore she would fight it. However she fought the illness by following the prescribed treatment plan. Her non-acceptance still acknowledged the illness. Obviously a difference exists in what acceptance meant to these participants. This confusion of meanings is also reflected in the literature. Wolf's observation that "acceptance needs a more precise definition" is as true today as it was

17 years ago (Wolf, 1972, p. 1414).

Other approaches participants utilized were 'looking on the bright side' and "if wishes were horses". These approaches reflected either being positive about the illness or trying to ignore the illness. The two approaches were not mutually exclusive. Some participants talked about feeling thankful for what they could do and at the same time wishing that they could go ice skating or take a desired vacation. While Long and Sangster (1993) see these as dichotomous approaches with participants doing one or the other, the data from this inquiry did not confirm those findings. Participants were able to experience both approaches simultaneously or vary between one or the other depending on what was immediately occurring in their life or their illness.

The last approach that emerged was that of "master of my own destiny." The literature results (Caldwell, Pearson & Chin, 1987; Strickland, 1978) suggested that perceiving control over one's environment facilitates adjustment to chronic illness. Having the approach of being in control or responsible was reflected in this inquiry. Helgeson (1992) stated that illness is a situation where one does not have complete control, but some aspects of the illness that are controllable. Christine believed that she had control over her emotional destiny but not her physical destiny. She also exerted control over much of what she did with her

diabetes management. While the amount of control that participants had over their illness varied, most took on some of the responsibility of caring for their illness which helped them to be masters of their destiny.

Finding Meaning

The ability to find meaning in illness was important in dealing with a change in life direction. Participants were active in this endeavor in varying degrees. While some participants gave superficial reasons as to why they had gotten ill, others sought a deeper understanding of the illness in their lives. A possible explanation for this lack of finding meaning for some participants is that the daily activities produced by the illness in their lives were often time consuming leaving little time to reflect on why they had the illness and what the illness meant in their life. Another possible explanation is that taking time to reflect was too painful. This might be concluded because participants shared thoughts and feelings with the researcher that they admitted had never been shared with anyone before. At times participants would say one thing and then later go back and say something else which contradicted what they had said earlier in the interview. Frequently participants would preface what they said by "I never really thought about this before but," or they would comment, "what I told you before isn't exactly what I meant". Perhaps as they became comfortable in the

interview, they could later reveal what they really were experiencing. What seemed to be happening was participants were beginning to think and reflect about their experience. For some it was a self-discovery of understanding their experience. Donnelly (1993) also commented that families experiencing a chronic mental disorder did not always find existential meaning in their illness, but gave no possible explanations for this. Woods, Haberman & Packard (1993) found that the demands of finding meaning continued throughout the course of a chronic illness and not just during the early post diagnostic phase. Finding meaning appeared to be an ongoing activity that participants in this study reported.

The importance of altruism emerged as participants described how having the illness helped them to help others. Harriet found great satisfaction in helping children with asthma and believed that having had asthma herself gave her the ability to understand what these children were going through. Tandy pointed out that having the illness was not a good thing, but good things could come from it. Even though she was able to help children with diabetes, she still would rather not have acquired diabetes. Many participants were eager to help the author because they believed that, by agreeing to be interviewed, they would be helping others to understand their experience with chronic illness. In turn, participants believed this understanding

might assist people with chronic illness to have a better experience than otherwise possible.

CHAPTER 6

Strengths, Limitations, Implications
and Recommendations

The purpose of this chapter is to review the study for its strengths and limitations, discuss some of its implications for nursing and provide recommendations for further research. Strengths and limitations specifically address the methodology of the study. Implications and recommendations are directed towards both nursing practice and research, and are organized around the four major themes that emerged from the study: the losses, a roller coaster of emotions, making changes, and gaining control of an altered life direction.

Strengths and Limitations

Strengths and limitations include those related to qualitative research as well as those specific to this study. This discussion is organized around the four criteria for methodological rigor as outlined by Lincoln and Guba (1993). These criteria are credibility, transferability, dependability, and confirmability.

Credibility

Credibility is concerned with the ability to find truth and is comparable to validity in a quantitative research. In this study, credibility was established by telephoning

participants within one week of their interview and asking for clarification and accurateness of what had been recorded and understood by the researcher. A limitation in the process of these telephone discussions was that they were not tape recorded. While extensive notes were taken, there may have inadvertently been some information that was not recorded and consequently omitted from the final analysis. However, any corrections or additional information that was obtained was utilized to establish credibility of what was said by the participant.

An additional interview was conducted with five of the seventeen participants to determine if the final analysis and structural description was true to their experience. Additional information was obtained from this interview which was incorporated into the final results.

A limitation related to credibility was that the re-interview of the five participants took place approximately a year and a half after the original interview. Although rapport was instantly re-established with participants who needed no reminder of who I was or what we had talked about, one would question if the participant could remember what was discussed in the first interview or perhaps was simply being polite to the researcher. Sandelowski (1993) also addressed participants' motives at any time during the interviews and the consequent threat to credibility.

A further limitation of this study was the inexperience

of this investigator in the research method of phenomenology. As an investigator, utilizing the phenomenological method for the first time, utilizing novice interview skills, and a beginning ability to analyze and search for deeper meanings could be a threat to credibility. Although the investigator went back to participants within one week of the initial interview to confirm the accuracy of transcripts and initial meanings, and then went back again to five participants to establish credibility of the entire findings of the study, this process assumes that informants are truthful with information.

Transferability

Transferability is concerned with the extent to which the findings of a particular inquiry are applicable in other settings or with other subjects. This criteria is determined by describing the setting and findings in great enough depth in order to allow anyone interested in making transfer of information possible. Rather than being generalized to similar populations, it is the reader of the study who picks out what is applicable to him or her self in a given situation.

In this inquiry an extensive description of the phenomenon of integrating chronic illness by participants was provided which would allow readers to apply the findings to their situation or themselves.

Dependability

In qualitative research dependability is concerned with stability and trackability. Measures are taken to provide enough description to accurately represent the phenomena. An "audit trail" is maintained by the researcher which provides additional description of how the researcher gathered data and made decisions concerning analysis.

A strength of the inquiry is that dependability was well established. This occurred through multiple pathways. First the method utilized to analyze the data was described in order for the reader to understand the process of data analysis. Secondly, throughout the inquiry, a journal was kept which expressed the thoughts of the researcher concerning impressions of data and assumptions about the data as they arose. In a more general way, the journal was utilized to re-examine data, look at decisions about the analysis, and record hunches and impressions. The journal also provided a way by which others could determine how decisions were made regarding the data and how the themes emerged.

Lastly, the dissertation committee served as a source of dependability. They reviewed analyses of participant transcripts as well as the final analysis.

Confirmability

Confirmability is concerned with the interpretational objectivity of the researcher and is accomplished by setting

aside assumptions.

In this study the researcher bracketed initial assumptions and stated them in the first chapter of the dissertation; however, an additional assumption occurred as the inquiry progressed concerning the definition of integration of chronic illness. I realized that in asking the question "How do you integrate chronic illness into your life", I had assumed in the definition of integration that participants integrated their illness into themselves and their life. As the discussion of findings pointed out, this was not always the case. While some participants described the illness as a part of themselves that was inseparable, others carried the illness around with them like a suitcase. Therefore integration meant the illness was part of their lives, but not necessarily part of themselves. Although the research question included this assumption, participants were still able to verbalize how they made their chronic illness part of their lives.

A strength of this inquiry was that initial transcriptions with analyses were given to dissertation committee members for input. Similar conclusions or findings were drawn by the researcher and committee members.

Implications and Recommendations

Implications for nursing and recommendations for nursing research will address the issues raised by the current inquiry, and will be organized around the four

themes of the losses, a roller coaster of emotions, making changes and gaining control of an altered life direction.

Confronting Loss

Participants' loss was ongoing and did not seem to end with the diagnosis of the illness or learning the skills necessary to live with the loss. Further deterioration or complications of the illness meant that new losses occurred as time passed. Also, once all participants experienced loss, although some more than others, it was a significant part of their illness experience. However, because the loss is hard to evaluate it often goes unnoticed by health professionals. Therefore, a recognition of the experience of loss and initiating an ongoing assessment of losses should occur in order to understand the chronically ill person's efforts to integrate chronic illness. Perhaps the development of an assessment guide to facilitate this assessment would be helpful in the clinical setting. If health professionals do not have this information, they cannot know what the individual is dealing with or what efforts they have already made. Research needs to address how the specific loss of feeling capable influences the ability of patients to understand and follow medical treatment plans.

Participants' loss of connectedness has great implications for practice and research. Participants' descriptions of lack of connectedness with health

professionals is alarming. The one place that they should expect to be understood and consequently helped is unavailable to them. Rather than health professionals decreasing participants' feelings of loss, health professionals become a source of participants' loss. How can this be corrected in light of the current health care climate? Participants cited lack of time, inadequate communication skills and specialization of their physician as contributing to their sense of not being seen as an individual or understood. The dilemma for the health care provider becomes one of how to assess loss and connect with people when the health care system is being driven by economic forces that limit time with patients and their families. Assessment and rapport development both take time; but as these participants would argue, time well spent. Adding lectures for medical students regarding impact and meaning of chronic illness would be a way to initiate a physician's awareness to the entire issue of seeing beyond the illness to the patient. Addressing being seen could also occur for residents in their grand rounds as a significant component of treating their chronically ill patients.

Perhaps future studies could address the effect of 'not being seen' by health professionals on the ability of patients to implement medical treatments. Outcomes of this type of research might indicate that there is a connection

and would justify taking time to assess loss in the chronically ill.

The importance of understanding the losses the chronically ill confront is critical if health professionals are to understand how people integrate chronic illness into their lives and provide interventions to assist in this integration. While loss in chronic illness is unique, perhaps an understanding of this loss can help facilitate an understanding of other losses in life that occur.

Baker and Pinder (1989) stated:

To understand the experience of disability or chronic illness may enhance our understanding and ability to come to terms with those other kinds of losses which are endemic to the human condition...We may better understand similar human condition problems, thereby enriching our lives. The disabled and chronically ill have much to teach us if we have the ears to hear.

Riding a Roller Coaster of Emotions

Participants were on an emotional roller coaster which often left them fatigued and hindered their ability to manage everyday life. This emotional roller coaster seemed to have no end. As health professionals continue to ask people with chronic illness to make changes in their lives, they need to understand this underlying emotional instability in their patients and evaluate the impact of these emotions in managing their chronic illness. Questions of how does this roller coaster of emotions influence participant's ability and willingness to implement changes needs to be addressed. Understanding the emotional drain

imposed by a chronic illness and the fact that it goes beyond the immediate diagnostic period is also important. Conrad (1990) has suggested that how emotions are managed and how they affect illness are still unexplored issues in living with chronic illness. Nurses are in the best position to help patients with this emotional roller coaster. Suggesting support groups to the community to meet the needs of chronically ill individuals as well as facilitating the support groups themselves would significantly address the emotional needs of the chronically ill. Recommending a referral to a psychologist, suggesting an anti-depressant, or utilizing alternative therapies available to nursing such as guided imagery, journaling and bibliotherapy could also assist chronically ill individuals.

Research needs to address these issues in longitudinal studies which will provide a picture of what is involved in managing these emotions over a long period of time and how these effect the person psychologically as well as physically.

Continuing to borrow theories from the death and dying literature to describe what is occurring in chronic illness is not adequate and does not reflect the experience of the participants of this study. Perhaps a starting point, as alluded to in the discussion of findings, is the exploration of the concept of chronic sorrow. The literature is just beginning to address the potentially significant role of

this concept and its parameters in chronic illness. Qualitative studies examining what chronic sorrow in chronic illness means to one's life would contribute to the body of knowledge concerning living with chronic illness.

Making Changes

Participants changed their routines and added routines to integrate chronic illness into their lives. In making these changes participants were often faced with dilemmas. Educational programs provide knowledge, skills, and problem solving, but do not tend to address dilemmas that surfaced in this inquiry. Health professionals need to understand that making changes to solve problems imposed by chronic illness is more complex when the proposed solutions create a dilemma. Developing educational programs that address dilemmas and provide avenues to discuss them may assist the chronically ill to better handle these dilemmas when they arise. Research questions could include exploration of what are the common dilemmas people with chronic illness face and how people manage these dilemmas when they arise. Qualitative studies aimed at understanding the nature of these dilemmas and how they are resolved could provide a basis for determining what the content of educational programs or support groups should be to assist the chronically ill in this aspect of integrating chronic illness into their lives.

Gaining Control of an Altered Life Direction

Gaining control of an altered life direction included seeking support, learning about the illness, approaching the illness and finding meaning in the illness. Implications for nursing practice and recommendations for research are addressed for each.

Support was seen as helpful to participants, but they could not always obtain the support they needed. Even when there were people in their physical environment, participants found it difficult to talk to these people honestly about how the illness was with them, their frustrations, their pain and in general how they were really doing with the illness. The most significant implication is that these participants' emotional needs are not being met, yet there are no easy answers. For those participants who cannot physically get out, the possibility of having a telephone directory of people they could call would be helpful. Perhaps a "buddy system" could be formed. Ann had suggested that she would love to have someone's telephone number to call. While this author attempted to initiate this idea at the American Lung Association, the people there did not see this as important and consequently nothing has been done. Although this intervention would help some people in meeting their support needs, it would not help the person who has people in their environment but cannot talk to them. Further research needs to look at what

participants want from supportive others and how they can get the support they need. Research also needs to address the effect of feeling isolated on the course of the illness and the ability for participants to manage their illness.

Some spouses were really anxious to relate their experience with their mate's illness during interviews. Barbara L.'s husband told this researcher, out of hearing distance from his wife, that listening to the spouse was important because there was the real story of what was going on. "Nobody's paying attention" Barbara's husband exclaimed in reference to what he was going through. Although some studies have begun to look at the effect of chronic illness on spouses and family members (Lewis, Woods, Hough & Bensely, 1989; Northouse, 1989; Sexton & Munro, 1988) further research needs to address how these significant others influence the integration of chronic illness into their loved one's life.

Lastly, a possible gender difference may exist between support received by males versus females. The subject population was predominantly females in the present inquiry so it did not surface readily. However, one participant stated that she felt her husband was not as supportive as she would like him to be in part, she believed, because he was a man and was not as nurturing as a woman would be. Further research is needed to determine what effect gender has on providing support to people with chronic illness.

The way in which participants gained knowledge about their illness has numerous implications for nursing practice and research. Most patients did not see their physicians as adequate providers of helpful information about living with their illness, and omitted nurses altogether when talking about what helped them learn about their illness. Although participants learned in other ways, inadequate information from their physicians resulted in feelings of role insecurity in patients with heart problems making behavior changes (McSweeney, 1993). This source of uncertainty concerning what to do in living with the consequences of a specific illness like heart disease further contributes to the general uncertainty that is already present in participants with a chronic illness.

Nurses need to develop interventions that will be seen as helpful by patients in integrating chronic illness. Initiating and maintaining information hot lines concerning specific chronic illnesses could assist patients to obtain information easily. Questions need to be asked that would include patient's perceptions of what they need from nurses. This type of information would provide a foundation for effective nursing interventions aimed at helping participants learn about their illness and about changes that must be made in their life as an ongoing activity. Descriptive research studies addressing what patients with chronic illness saw as their informational needs, as well as

how this information could best be provided would provide a foundation for developing interventions aimed at providing the necessary information to assist in integrating chronic illness into their lives.

Most participants experimented in order to learn how to live with their illness. Often participants would do things that their physicians did not know or things that they believed their physician did not need to know. These activities included utilizing anything from keeping a journal about their experience with their illness, to aromatics, to singing while exercising. Not telling health professionals their self-management techniques again leads to an inaccurate picture of what participants are doing with their illness. This leaves health professionals at a disadvantage as they may not really be helping these people because they do not really know what patients with chronic illness are doing on a daily basis.

Implications concerning approaches to illness are particularly relevant to acceptance for two reasons. First, acceptance has often been viewed in the literature as an important activity in integrating chronic illness, even if there has been no consensus as to the definition of acceptance. Physicians often become frustrated with patients who are not following the prescribed treatment, often believing that non-acceptance of the illness is responsible for this action. Physicians then direct their

efforts at getting patients to accept their illness. For someone like Barbara L. this would only be a wasted effort. Barbara said she would never accept her illness, because for her acceptance meant that it was okay to have the illness and it would never be okay with her. However, she not only acknowledged her illness, but followed the treatment plan as best she could. Therefore, discussing the importance of accepting her illness would only provide the basis for an argument. Without a clear conceptualization on how acceptance is being used by the patient as well as the health care provider, frustration may arise because there is no commonly understood language.

Second, integrating chronic illness emerged as a complex experience where acceptance was only a small portion of the overall picture. Therefore, it would appear that health professionals' preoccupation with the importance of acceptance when it did not emerge as a major theme is an unwarranted activity. Clearly, additional questions need to be addressed. Perhaps the most obvious is what do health professionals perceive as important in integrating chronic illness.

The last implication is concerned with finding meaning in life since chronic illness has become a part of it. Participants sought to find meaning in their illness experience, but often did not reflect deeply. This isn't surprising as participants really had no one to talk to and

were so busy just living day to day with all their illness and life demanded. If participants are to find meaning, then perhaps nurses are in the best position to help them with this task. Coordinating discussion groups with a primary focus of finding meaning or individual client centered counseling could assist the chronically ill in their journey to find understanding and meaning of their illness in their life. Further research would need to address how finding meaning in chronic illness affects the quality of patients' lives.

Conclusions

Many implications for nursing practice and research were discussed related to the findings of this inquiry. As frequently occurs in research, many questions have also been generated with no solutions proposed. However, valuable information has been obtained that illuminates the experience of integrating chronic illness and proposes future directions for nursing research concerning individuals living with chronic illness.

One of the five research priorities for the National Center for Nursing Research for the years 1995 through 1999 has been identified as testing interventions for coping with chronic illness (Donnelly, 1993). Understanding all that is involved in how people make chronic illness a part of their lives will provide a basis from which these interventions can be proposed. Because of participants' willingness to

share their stories of their daily life with chronic illness, an initial understanding of this complex phenomenon was developed and presented.

In conclusion, who knows better about chronic illness than those living with it. King (1994), editor-in-chief of the Diabetes Interview and a person with diabetes, describes life with diabetes:

Many people think that diabetes is just a disease, but it's not. It is much more than that. A disease is something that happens to your body. Diabetes affects every aspect of your whole life. It's more than a medical problem, it takes over your mind too. It's more than a simple adjustment of medicine and nutrition, it requires a complete retraining of your lifestyle. Nothing is spared, no part of your life is left unscathed (King, 1994, p. 2).

To those who live a life with chronic illness, it is imperative that we as health professionals understand what that means. This understanding provides the bridge between health professional and patient so that the health professional may cross over and touch patients' lives in a positive way by realizing the immense and complex undertaking with which the chronically ill are faced with in their lives.

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APPENDICES

APPENDIX A
PARTICIPANT BIOGRAPHIES

Subject Biographies

Christine is a young woman in her thirties who is married, lives with her husband, and has one child. She has a master's degree and is employed as a professional in the criminal justice field. Christine describes herself as a person "in control" and expressed her experience with diabetes in a very positive and assertive manner. She emitted a 'certain force' or 'high energy'. Christine was diagnosed with diabetes mellitus type I at the age of five. She utilizes an insulin pump to receive her insulin. She also had been diagnosed with breast cancer within the last two years.

Ann, a woman in her fifties, is currently married to her third husband. Her first husband had been an Air Force Officer with paranoid schizophrenia and had committed suicide after eight and a half years of marriage. This left her a widow with three children and, at the time this occurred, she believed she was going blind from retinopathy. After four and half years she married again and had another child, but this marriage only lasted for five years. She was able to raise her children and has now been married for the last seventeen years to her present husband. However during that time two of her children have died. She stays active by coordinating and facilitating a support group for people with rheumatoid arthritis through the Arthritis

Foundation. She has also been an active volunteer with the local American Diabetes Association (ADA). Elizabeth walked with a limp due to the deformities and pain of her rheumatoid arthritis. She also had diabetes mellitus type I and coronary artery disease. She was diagnosed with diabetes at the age of twelve. She had rheumatoid arthritis for ten years and coronary artery disease for eight months. She also has the complications of neuropathy and retinopathy. She takes numerous medications and stated she did not follow an ADA diet, but rather developed her own.

Kathy is in her thirties, married and has three school age children at home. She is a homemaker, but also does some transcription work for doctors in her home. Kathy had been diagnosed with rheumatoid arthritis for eleven years. She has a slight limp in her walk and ulnar drift is apparent in her hands. She took gold injections and Medrol for her arthritis. She did not take anything regularly for pain because she really did not believe in taking medications. Her arthritis has been a very isolating experience.

Judy is in her thirties and was recently married for the second time. She and her husband have just moved into a brand new home. Judy worked full time and was active as a volunteer in the American Diabetes Association. She is very articulate in expressing her thoughts and behaviors about

living with chronic illness, but did not talk about diabetes on an emotional level. She has no children of her own, but has step children from this second marriage that do not live with her, but whom she sees frequently. Judy was diagnosed with Diabetes Mellitus Type I at the age of seven.

George is a gentleman in his sixties who lives with his wife. He had been a merchant marine and is now retired, spending much of his time volunteering at the YMCA by helping with the exercise classes for people with diabetes. He had been diagnosed with hypertension but took himself off his blood pressure medication five years ago and stated his blood pressure has been fine ever since. He had also been diagnosed with Diabetes Mellitus Type II five years ago. He controls his diabetes with the oral medication, Micronase, and has a regular exercise program that he follows every day.

Leah is in her fifties and lives with her husband, their cat, and a dog. She and her husband are both retired, but very active. They both volunteer at a local hospital and like to travel. Leah had diabetes mellitus Type II for the last twenty years and hypertension for twenty-nine years. She controlled her diabetes with multiple injections of insulin each day and followed a 1200 calorie ADA diet. She controlled her hypertension with her diet as well. Both she

and her husband walk every night for exercise. Her husband also has diabetes mellitus type II and coronary artery disease.

Tandy is twenty one years old and lives with her mother and sister. Her father divorced her mother years ago so she is close to her mother and sister. She has recently started a new job that deals with the sale of diabetes products. She is a very active volunteer with the local American Diabetes Association. She helped with the children's diabetes support group (Islet Pilots) and has been a counselor at diabetes camp. She was diagnosed with diabetes mellitus type I when she was seven years old. She utilizes an insulin pump to deliver her insulin. She also has had osteoarthritis and asthma for approximately one year. She utilizes an inhaler for her asthma when needed and takes no regular medication for her arthritis.

Barbara S. is a woman in her sixties and appears very thin and frail. She lives with her husband who takes care of her. The rest of her family (sisters, children) lives in another state, so she is unable to see them very often. She really loved to get outside and garden whenever possible. She was diagnosed with COPD seven years ago. She also stated she had chronic sinus troubles. She wore continuous oxygen and became short of breath after talking for long periods of

time. She took many medications. She sat in a hard back chair with a pillow behind her to help facilitate her breathing. She went to the Better Breather's Club Meetings (support group for people with lung disease) whenever her health and weather permitted.

Annette is a woman in her sixties. She had been very active in real estate and the business community, but is now retired. She is a widow and lives in a condominium with her adult son. She attends Better Breather's Club meetings on a regular basis. She had been diagnosed with chronic obstructive pulmonary disease (COPD) seven years ago. She wore continuous oxygen, but was able to move about without difficulty. She takes numerous medications and utilizes an inhaler as needed. She also takes nebulizer treatments four times a day.

Rocky is a gentleman in his sixties who is a retired engineer, but remains very busy. He is President of his Masonic Lodge, volunteers at the hospital, and loves to travel. He lives with his wife, his cat, and dog. He had been diagnosed with diabetes mellitus type II for five years. He also had coronary artery disease and had bypass surgery approximately six months ago. He controls his diabetes with an oral medication (Micronase), follows a 1500 calorie ADA diet, and exercises regularly. He takes several

medications for his heart disease (Cardizem, Vasotec, and 1/2 coated aspirin each day).

Ruthie is a woman in her sixties. She is widowed and lives by herself although she expressed a desire to have a roommate. She is currently taking drama classes at a University. She was very eager to share her experiences and hoped the information would be helpful to other people. She had been diagnosed with chronic bronchitis and asthma for ten years; however she felt she probably had the illnesses longer than this. Ruthie takes numerous medications for her lung diseases and utilizes inhalers when needed. She had enrolled in a pulmonary rehabilitation program that continued for eight weeks hoping to feel better and to lose some weight.

Jan is a woman in her fifties who loves animals, particularly cats. She took in any strays that came along, and even she did not know exactly how many cats were in her care. She is single and lives with a roommate and many cats. She had been diagnosed with asthma for five years. She also had osteoarthritis for 10 years and hypertension for six months. She takes numerous medications for her asthma and takes hydrochlorothiazide for her hypertension. She utilizes an inhaler when needed and also takes nebulizer treatments.

Barbara L. is a woman in her fifties and is married. Her husband takes care of her and helps her with any activity she wants to do as well as doing all the household chores. She had a sense of humor about her that came through in whatever she talked about. She loves Indian art and artifacts and believed she was an expert on the subject. She had been diagnosed with COPD for six years. She wears continuous oxygen and takes numerous medications for her COPD. When she walked any distance she became short of breath. She goes to the Better Breather Club meetings whenever her health and weather permit.

Harriet is a woman in her seventies who appears much younger. She delighted in sharing her stories and her life, particularly her younger days. She showed me the medication she took as a little girl (Powers Relief) and even demonstrated its use out in the backyard (she had to light it, blow it out and then breathe in the smoke as a girl). She lives with her husband to whom she'd been married for 53 years. As an adult she had done many things from selling Avon products to managing rental properties. She volunteers at the hospital and helps children with asthma in the schools. She is very active in other organizations as well. She had been diagnosed with asthma at the age of three and takes Theodur as well as several inhalers to control her asthma.

Janette is a woman in her sixties and lives with her husband who had been recently disabled from an accident. He had a back injury so she was spending a great deal of time caring for him. Before her husband's accident, they both had worked at the blind center. She and her husband are blind; she has been blind since birth. She had been diagnosed with coronary artery disease since 1990 and had angioplasty performed in 1991. She also stated she had chronic sinus infections for the last three years. She discussed many physical problems that had not been diagnosed.

Billy, a gentleman in his sixties, is married and depends on his wife to go with him whenever he leaves the house. He was concerned that something might happen to him and he would not be able to handle it by himself. He enjoys fixing things and likes to work with computers. He dreams about traveling for months in a motorhome before he "leaves this world." He had multiple chronic illnesses including osteoarthritis for eight years, chronic bronchitis, diabetes mellitus type II and coronary artery disease for eighteen years. He takes many medications (over ten). He takes insulin once a day for his diabetes and tries to follow a 1500 calorie ADA diet.

Kathryn is a woman in her fifties who lives with her husband. Her family lives close by so that she sees them often. She is very involved in the Daughters of the Revolution (DAR). She is also involved in genealogy and this interest takes her traveling to all parts of the country which she enjoys very much. She has chronic bronchitis and coronary artery disease for the last six years. She had bypass surgery in 1987. Currently she takes no medications because she felt she didn't need them and stopped taking them.

APPENDIX B
CONSENT FORM FOR PARTICIPANTS

University of San Diego

Consent to Act as a Research Subject

Susan Rush Michael, a doctoral student at the University of San Diego, is conducting a research study to better understand the experience of people who have a chronic illness. Since I have volunteered to participate in this study, I understand that I will be asked to answer questions about my experience with chronic illness.

This interview will take approximately 60 to 90 minutes during one interview time which will be tape recorded. I may be asked several questions at a later date to be arranged between the researcher and myself. Participation in the study should not involve any added risks or discomforts to me except for the possible minor psychological discomfort that discussing my chronic illness may create. If I experience any discomfort as a result of the research process I may contact the researcher at 739-3360. I may withdraw from the study at any time.

I understand my research records will be kept completely confidential. My identity will not be disclosed without consent required by law. I further understand that to preserve my anonymity only grouped data will be used in any publication of the results of this study.

Susan Rush Michael has explained this study to me and answered all my questions. If I have other questions or research related problems I can reach her at 1-702-739-3360.

There are no other agreements, written or verbal, related to this study beyond that expressed on this consent form. I have received a copy of this consent document.

I, the undersigned, understand the above explanations and on that basis, I give consent for my voluntary participation in this research.

Signature of Subject

Date

Location

Signature of Witness

Date

Signature of Researcher

Date

APPENDIX C
THEMATIC INTERVIEW GUIDE

Thematic Interview Guide

Tell me how you've integrated chronic illness into your life.

(feelings thoughts, actions)

How do you live with your illness on a daily basis?

How has the illness changed the way you see yourself?

How has the illness changed your outlook on life?

What has the chronic illness prevented you from doing ?

There's a term that some people use when talking about how they have come to live with their illness. The term is "acceptance". What would you picture that term to mean?

Is there anything else you would like to tell me related to this phenomenon?

FIGURES

Figure Caption

Figure 1. Thematic Scheme of Integrating Chronic Illness
Into One's Life.

