

HEALTH WITHIN ILLNESS: EXPERIENCES OF THE
CHRONICALLY ILL/DISABLED

by

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B.S.N., University of Victoria, 1986
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A Dissertation Submitted in Partial Fulfillment of the
Requirements for the Degree of

DOCTOR OF PHILOSOPHY

in Interdisciplinary Studies

We accept this thesis as conforming
to the required standard

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Abstract

Chronic illnesses and disabilities are the number one health problems in North America, and are the health challenges of this era. Many studies have investigated the illness experience for people with chronic conditions, but little is known about how people with chronic conditions experience feeling healthy. Recent studies indicate that people with chronic illnesses/disabilities perceive themselves to be predominantly healthy. What follows from these studies is the need to know more about how health is experienced by this client group. The purpose of this study was to investigate this phenomena of health within illness. Specifically, the research question was: What is the meaning of feeling healthy for people with chronic illnesses/disabilities.

An interpretive phenomenological investigation was undertaken with eight participants living with a variety of different chronic conditions. The results of this study provide two important findings. First, the participants described their healing journey which brought them to the experience of feeling healthy, and seven essential themes emerged to describe this healing experience. These themes included; (a) In the Beginning, (b) Hitting the Wall, (c) Turning Around, (d) Letting Go, (e) Opening Up, (f) Letting In, and (g) The Gift. Second, the participants described their experience of feeling healthy and six themes emerged to describe this experience. These themes included; (a) Honouring the Self, (b) Seeking and Connecting with Others, (c) Creating Opportunities, (d) Celebrating Life, (e) Transcending the Self, and (f) Acquiring a State of Grace. The rigor of this study was considered to by attending to the

auditability, credibility, applicability and confirmability of this research method and results.

The results of this research were then compared to theories of growth and change as a result of crisis, theories of developing consciousness, self identity, social support, hardiness and resilience. Also, these results were compared with other definitions of health. Recommendations were made for further research and theory development regarding the conceptualization of health within illness. Finally, the implications of incorporating a health within illness perspective for clients, nurses, and the health care system were discussed.

The reconceptualization to include the experience of health within illness would contribute to an expanded focus for client care, and to the promotion of health.

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Table of Contents

	Page
Abstract	ii
Table of Contents	iv
List of Tables	vi
List of Figures	vii
Acknowledgment	viii
 CHAPTER ONE: INTRODUCTION	 1
Identification of the Problem	6
Significance of the Study	8
The Purpose and Rationale for the Study	9
 CHAPTER TWO: LITERATURE REVIEW	 15
The Etymology of the Word Health	15
Commonly Used Definitions of Health	18
Philosophical Foundations of Health	22
Health Within Illness	25
Research Related to Health Within Illness	31
Significance of the Study	33
Summary	39
 CHAPTER THREE: METHODOLOGY	 41
Philosophical Considerations	42
Research Method	51
Bracketing	51
Data Gathering	55
Data Analysis	66
Reliability and Validity	71
Summary	80
 CHAPTER FOUR: PRESENTATION OF FINDINGS	 81
The Pilot Study	81
The Participants	83
The Healing Journey	97
In the Beginning	99
Hitting the Wall	103
Turning Around	105
Letting Go	107
Opening Up	109
Letting In	111
A Gift	115

Experiences of Feeling Healthy: The Themes	118
Honouring the Self	120
Seeking and Connecting with Others	127
Creating Opportunities	132
Celebrating Life	136
Transcending the Self	141
Acquiring a State of Grace	144
 CHAPTER FIVE: DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS..	 150
The Themes: A Literature Comparison	152
Growth and Change as a Result of Crisis	153
Developing Consciousness	155
Self Identity	156
Social Support	157
Hardiness and Resilience	158
Comparison with Selected Definitions of Health ...	162
Implications for Practice and Education	166
Implications for Theory Development	172
Implications for Research	174
Limitations of the Study	176
Conclusion	181
 References	 209

List of Tables

	Page
Table 1. The Healing Process	117
Table 2. Experiences of Feeling Healthy: The Themes	147

List of Figures

	Page
Figure 1. The themes of the healing journey portray a spiralling, synergistic, evolving and expansive process.	100
Figure 2. The experience of feeling healthy with the rich mosaic of themes.	121
Figure 3. The synchrony of the themes of the healing journey and the experience of feeling healthy which illustrates the wholeness of this experience for people with chronic illnesses/disabilities.	149

Acknowledgements

To all the participants of this study, I wish to say a very special "thank you." They taught me about their courage, their wisdom and the triumph of the human spirit. They have expanded my consciousness and helped me see the beauty of life.

I wish to convey my deepest gratitude to my two supervisors Dr. Marcia Hills and Dr. Vance Peavy. Marcia's support and enthusiasm were an inspiration to me. As she challenged my thinking and helped me move to deeper levels of understanding, she also conveyed to me her unwavering confidence in my ability. Under such guidance and support I felt empowered and energized as I conducted this study. With Vance, I came to understand the full import of academic integrity. His attention to the philosophy of qualitative research afforded me the opportunity to expand my thinking and to examine my own beliefs and values about the nature of people in their environments. Vance has great wisdom and I feel privileged to have been one of his students. Under his guidance I believe I have benefitted both as a person and as a scholar.

To my three committee members, Dr. Carolyn Attridge, Dr. Don Knowles, and Dr. Martin Collis I wish to express my sincere gratitude. Carolyn challenged my thinking in many ways. As a nurse-scholar, she paid particular attention to the rigour of my study and in doing so I came to appreciate the importance of rigorous inquiry. Don, despite the fact he was on a sabbatical leave, always gave willingly of his time and expertise. I am particularly grateful for his careful editing of my work and also for his ability to ask some critical questions which greatly strengthened my research method and results. Martin's excitement and

enthusiasm about the results of this study were most encouraging. His valuing of this study boosted my confidence about the importance of this work.

A special "thank you" goes to my husband, Cliff. His faith in my and in my ability has always bolstered my self-confidence and determination to pursue my career. His unwavering support, encouragement and caring have been an enormous source of strength to me.

To my friends and colleagues who have stood by me through this time, for their caring, support, understanding, encouragement and reassurance, I wish to say to each one of you "thank you." I feel very privileged to have you in my life.

CHAPTER ONE

INTRODUCTION

Health as such does not exist. It is your goal that determines what health ought to mean even for your body . . . The concept of normal health . . . must be given up . . . Of course, health might appear, in one case, like the opposite of health in another. Health and sickness are not essentially different . . . We must not make distinct principles or entities of them . . . Actually, there are only differences in degree between these two kinds of existence . . ." (Nietzsche, cited in Jaspers, 1965. p. 112).

This quote from Nietzsche exemplifies the notion that health and illness are not separate entities, instead, each is part of our existence and may appear to us in differing degrees at different times in our lives. The important principle here is that health and illness coexist. Instead of viewing health and illness as separate concepts and in opposition to one another, the basic tenet is the coexistence of health and illness. Tillich (1961), the renowned theologian, supports this view by suggesting that health and illness are existentialist concepts and health is not health without the essential possibility and existential reality of disease. Tillich suggests that it is not the conception of health that is important, but rather the meaning of health, and for him, health only becomes meaningful when confronted by illness. Newman (1986) also advocates the notion of health within illness by suggesting a synthesized view of health and illness whereby health includes illness and illness includes health. Each of these authors is making the point that within our experiences of health exists the possibility of illness, and within our experiences of illness exists the possibility of health. This proposition of the coexistence of health and illness is essential to this present research because this study investigated the experience of feeling healthy

for people living with a chronic illness/disability. To illustrate the importance of the phenomenon of health within illness an exemplar case study from my nursing practice will be given.

Jane, a person with insulin dependent diabetes, is visiting the health clinic for her first prenatal examination. In the course of the examination, her physician suggests that Jane immediately see an obstetrician who will monitor her pregnancy closely. The physician further suggests that Jane visit an endocrinologist (diabetic specialist) regularly and make bi-weekly visits to the health clinic. Further, he suggests that Jane check her blood sugar three times each day and monitor her weight closely. Jane's physician states that he is upset that Jane is pregnant. He had warned her of the dangers of pregnancy since Jane is an unstable diabetic. He questions Jane about her wish to be pregnant, suggesting it could be terminated if she so wishes. Jane reports that she is delighted with her pregnancy and is looking forward to the prenatal period and to having her first child. She reassures her doctor that she can feel when her blood sugar is unstable and that she will pay particular attention to "what her body tells her."

In this case example, it is apparent that the physician and the client have very different perspectives associated with this pregnancy. The physician's perspective includes:

- considering Jane's condition unstable;
- the possibility of complications for the client or the child;
- worrying about the long-term adverse effects for the mother or child;
- feeling responsible for Jane's medical care;

- feeling frustrated that Jane did not follow the physician's advice, instead, she became pregnant;
- viewing the next eight months as problematic.

Jane has a different perspective regarding her pregnancy. She:

- feels excited and happy;
- is confident that she can manage her condition well;
- understands her body well enough to be aware of any change in her condition;
- feels frustrated with her physician's lack of trust in her ability to monitor her own condition;
- feels disappointed that her physician does not share her excitement with her pregnancy.

From this example it is clear that Jane experiences a sense of feeling healthy while still acknowledging her medical condition. For Jane, the notion of health within illness exists. Conversely, the physician is predominantly concerned with the diabetes and the potential physical problems for both Jane and her baby. For the physician the concept of health within illness is not an important consideration, the physical condition of his client is of paramount concern.

Although this case example illustrates the relationship between Jane and her physician, in recent times, nursing education and practice has also adopted this medical model approach to client care (Watson, 1988). This approach requires that health care providers work with clients from a problem orientation, with little regard for the health-illness experiences of the client. As the case example is discussed, the role

taken by the physician is synonymous to the role taken by the nurse in modern health care practice.

Jane and her physician see the pregnancy and delivery from very different perspectives and each person has legitimate feelings and concerns which need to be acknowledged and understood. Jane's physician has been educated from a medical perspective. This perspective focuses primarily on the detection and diagnosis of disease, to the alleviation of symptoms and whenever possible, to cure the medical condition. As Illich (1976) points out, "Society has transferred to physicians the exclusive right to determine what constitutes sickness, who is or might become sick, and what shall be done to such people" (p. 6). The physician's emphasis is on an objective, problem-oriented approach to disease and disability. The primary focus is on objective assessment and problem identification. Nursing education and practice in recent times have also followed this medical perspective.

In contrast to the physician's perspective, Jane considers herself to be predominantly healthy. In this sense, Jane's experience is subjective. She acknowledges the consequences and limitations of her illness but her subjective experience of feeling healthy predominate. Jane's chronic condition plays only a small but salient part in her life as she fully experiences it.

These differing perspectives of the client and the health care professional can be summed up as differences in emphasis and focus. The health care professional focuses on the medical problem and on the objective measurement of disease or impairment. The notion of health within illness is not a salient issue. In contrast, the client focuses on

an overall subjective life experience, with the experience of the disease or impairment as a small part of the wholeness of the life experience. From the client's perspective, the concept of health within illness is essential to the client's total life experience.

Kleinman (1978) provides an explanatory model for elucidating the different perspectives of both the health care professional and the client. In this model, disease denotes a malfunctioning or a maladaptation of biological and/or psychological processes whereas, illness signifies the experience of the disease. In this sense, the term disease applies to the objective measurement by the health care professional in making judgements about the physical or psychological condition of the client. Assessment about the presence or absence of disease is considered to be the responsibility of the health care professional. In contrast, illness is considered to be the subjective experience of the client. Kleinman, Eisenberg and Good (1978) expand on Kleinman's original model by describing disease in the Western medical paradigm which emphasizes diagnosis and treatment of abnormalities in the structure and function of body organs and systems. Illness, on the other hand, represents the personal, interpersonal and cultural reactions to disease or discomfort. These factors govern people's perceptions, labelling, explanation and valuation of the discomforting experience.

The importance of understanding the conceptual difference between disease and illness is particularly relevant to this present study. From the Western medical paradigm, disease signifies the client's condition as problematic and possibly debilitating. The objective opinion of the health care professional takes precedence over the subjective experience of the

client. In contrast, illness signifies the subjective experience of the client. In this sense, it is possible for a client to have a medical disease and yet not experience illness, or conversely, to experience feelings of illness without a medical disease being diagnosed.

Although this explanatory model is useful in exploring the differing perspective of the client and the health care professional, the overall emphasis remains on illness or disease. This emphasis fails to acknowledge the important possibility that a person may feel healthy while living with a disease or an impairment. Therefore, the purpose of this study was to explore this possibility and to gain a greater understanding of the experience of feeling healthy for people with chronic conditions. This shift in perspective to one of health within illness becomes more crucial for people with chronic illnesses/disabilities because of the long term nature of chronic conditions and the need for continued interaction with health care professionals.

Identification of the Problem

Chronic illnesses and disabilities are the number one health problems in North America, and are the health challenges of this era (Black, Dornan & Allegrante, 1986; Thorne, 1993). Developments in bacteriology, immunology, pharmacology and public health have resulted in a profound decrease in the mortality rates from communicable and other acute diseases (Lubkin, 1990). People now mostly suffer from chronic illnesses and disabilities which have become "the equivalent of plagues and scourges of yesteryear" (Strauss et al., 1984, p. 2). The vast majority of people who visit health care facilities suffer from one or more chronic disabling condition. The long-term nature of chronic

disorders means that treatment of such disorders must shift from the elimination of the disease (as with acute disease) to the maintenance of function (Black, Dornan & Allegrante, 1986).

Advances in bio-technology and surgery have also resulted in a higher prevalence of chronic conditions. Before the advent of pediatric and neonatal intensive care units, many infants died from their associated disease or disorder. Technology has also played an important role in organ transplantation and in treatment (e.g., renal dialysis) so that people live longer than would have been possible without these technological interventions. In many instances, the results of technological treatment have led to the proliferation of chronic disorders to the multiplicity of chronic conditions and to additional iatrogenic disability (Strauss et al., 1984).

Precise figures for the number of people suffering from chronic illnesses or disabilities are not available. However, during the period from July, 1965 to June, 1967, the Public Health Services in the United States conducted a survey which indicated that approximately 50% of the population (excluding residential institutions) had one or more chronic condition (Strauss et al., 1984). In Canada in 1978-1979, the Laboratory Centre for Disease Control conducted a survey of Chronic Disease Epidemiology and over 15 million chronic conditions were identified in the Canadian population (Canada Health Survey, 1978-1979). That is, in a population of 25 million, there were 15 million chronic conditions identified. This survey identifies the number of chronic illnesses or disabilities reported by the population, not the number of people with chronic conditions. However, it would appear that the survey figures in

the United States during the 1960's of 50% of the population with one or more chronic condition might indicate a similar percentage in Canada. What is known is that the prevalence of chronic conditions in the Western world is rising each year (Conrad, 1987) and it is the top priority concern for health professionals (Perdue, 1981; Thorne, 1993).

In the present study chronic illnesses or disabilities were considered from a physical perspective and did not include psychological or sociological health conditions. The definition of chronic conditions used in this study comes from the Commission of Chronic Disease (Mayo, 1965) which states:

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, may be expected to require a long period of supervision, observation, or care (cited in Perdue, 1981, p. 15).

The reason for limiting this study to chronic physical conditions was to focus on one aspect of chronic illness/disability. I make the assumption that experiences of health and illness may differ for clients with chronic sociological or psychological conditions. Therefore I chose to limit my study to only one aspect, namely, physical illnesses or disabilities.

Significance of the Study

The significance of this present study is that chronic conditions are now Canada's number one health problem and will remain so in the foreseeable future (Thorne, 1993). Considerable theory and research has been conducted on the illness experience of chronic conditions (Charmaz, 1983, 1987; Conrad, 1987; Corbin & Strauss, 1987, 1988; Gerson & Strauss,

1975; Matson & Brooks, 1977; Lubkin, 1990; Perdue, 1981; Schneider & Conrad, 1983; Strauss et. al., 1984; Thorne, 1993; Weinberg, 1984), however, much less is known about the experience of health within illness. In order to provide effective care to people with chronic conditions the experiences of both health and illness need to be acknowledged and understood. This present study attends to the experience of feeling healthy while living with a chronic condition, and as such, it is one attempt to redress the balance by focusing on the health experience of people with chronic illnesses/disabilities.

The Purpose and Rationale for the Study

Traditionally, illness and impairment have been diagnosed and therefore defined by health care professionals. It is the physician who clinically assesses the client's condition and deems whether or not a problem exists. In this model, the client plays the passive role of object to the physician's assessment. As Illich (1992) suggests, the medical profession "objectifies people as bodies or psyches" (p. 217). The subjective experiences of the client may be considered, however these experiences play a peripheral and minor role (Gadow, 1990). Control is the domain of the health care professional who diagnoses the condition and determines the course of treatment (Benner, 1990). In acute, episodic illnesses, this dominant health professional model has remained comparatively unproblematic. When considering chronic illnesses/disabilities, this model is oppressive to the client as it denies client's an active, participatory and controlling role in their own health care (Benner, 1990). Because of the long term and complex nature of

chronic conditions, clients become very familiar with how their illness or disability relates to their overall life experience. They become the best experts on themselves (Corbin & Strauss, 1988). This client expertise is based on the subjective experience of the chronic condition, and this experience must be acknowledged and understood by health care professionals for effective client care (Gerson & Strauss, 1975, Thorne, 1993). Such acknowledgement requires a shift in the relationship between clients and health care professionals. The relationship can no longer be one of control by the health care professional, but rather a participatory partnership between the clients and their care givers (Gerson & Strauss, 1975; Thorne, 1993). Such a relationship would involve a shift to greater client control which is essential for effective client care (Gadow, 1990; Thorne, 1993).

Recent studies suggest that people living with chronic conditions feel predominantly healthy (Health & Welfare, Canada, 1987; Stuifbergen, Becker, Ingalsbe & Sands, 1990). Respondents in these studies suffered from a variety of chronic conditions. They completed a health conception scale and a health self-rating scale and between 60-73% of the respondents rated their current health as good to excellent. These results indicate that a large percentage of people with chronic conditions feel healthy. These are significant findings. As a sequel to these findings it is now important to gain a better understanding of how health is experienced by the people with chronic illnesses/disabilities. One of the recommendations by the Health and Welfare Canada Survey (1987) was that such a study be undertaken. This present study attends to this recommendation by exploring

and describing the experience of feeling healthy for people with chronic physical conditions.

Nursing has been described as "a human science of persons and human health-illness experiences" (Watson, 1988, p. 54). According to Watson, nursing views human beings as experiencing subjects and is concerned with the subjective experiences of the client's health-illness condition. It is therefore the ethical and moral responsibility of nurses to expand their knowledge of these experiences (Watson, 1988). As nurses begin to focus on the subjective experience of the clients' health-illness condition, this shift in focus will inevitably lead to greater client control (Gadow, 1990). This shift to client control is particularly necessary for people with chronic conditions because of their prolonged and continued relationship with health care professionals and with the health care system (Gerson & Strauss, 1975; Thorne, 1993). Of particular importance for this client group is a broadened perspective to include health within illness. Therefore, the purpose of this study was to explore and describe the meaning of the experience of feeling healthy for people living with chronic conditions. Specifically the research question addressed in this study was: What is the meaning of feeling healthy for people with chronic illnesses/disabilities?

The knowledge gained from this study has the potential to lead to a critical consciousness (Friere, 1988) for both clients and health care professionals. This critical consciousness could lead to a consciousness shift (Watson, 1990), or a transformation of perspective from an emphasis on the objective measurement of illness or impairment, to the subjective experience of illness and health. In this sense, the results of this study

provide one example of how to liberate the way we perceive health and illness. The effects of such a transformation could benefit clients, health care professionals (particularly nurses), and the health care system.

The benefits for clients with chronic conditions could be twofold. First, this shift in perspective to include health within illness provides for a greater opportunity for clients to consider the possibility of feeling healthy within their chronic condition. This change in perspective, to include the experience of feeling healthy within their illness/disability could benefit clients in a second way. As clients and health care professionals shift their focus to examine the health-illness experiences of the client, this exploration of the client's subjective experience would take precedence over the objective, problem-oriented approach of the health care provider. This shift in focus would lead to greater client control. Because of the complex and long term nature of chronic conditions, clients become the best experts on themselves (Corbin & Strauss, 1988; Thorne, 1993). As health care professionals begin to focus on the subjective experience of their clients, this client expertise will be acknowledged. Such acknowledgement would lead to greater client autonomy as clients make choices about their own health care needs. As Watson (1990) points out "individuals have the right to decide for themselves about all personal matters, including health" (p. 34).

Nurses would also benefit from this transformation in perspective in that they could return to their original mandate of care whereby "the protection and the enhancement of patient subjectivity is a central concern" (Gadow, 1980, p. 34). This original caring mandate can be traced

back to the work of Florence Nightingale and is considered the foundation of nursing's philosophy (Watson, 1988). Watson believes that nursing in recent times has lost its philosophical way in following the biomedical technocure mandate and foregoing its original commitment to client care. Watson described the technocure mandate as the emphasis or focus which is placed on technology and cure in modern health care practice. Returning to client autonomy and to focusing on the subjective experiences of clients will facilitate nursing's philosophical shift from technological interventions and cure back to the primacy of caring and client-centred care (Benner & Wrubel, 1989).

Finally, this shift in perspective has the potential to lead to the reduction in health care costs as the subjective care of the client takes precedence over expensive and often inappropriate technological interventions. As Watson (1990) points out, the technocure mandate of the health care system is more wasteful and more expensive as it focuses on the need to cure or "fix-it," and thus often unnecessary, intrusive and wasteful treatments are performed. This is particularly true for people with chronic illnesses/disabilities (Thorne, 1993). Also, this shift in perspective, to include health within illness, would lead to an emphasis on the promotion of client health and well-being.

Watson (1990) calls for this shift in perspective when she advocates that "The relationship between curing and caring, between treatment and healing, and between disease and health become inverted--thereby identifying knowledgeable caring as the highest form of commitment to patients, families and society" (p. 45). This study is part of that

commitment, namely to return to the subjective experience of health within illness, particularly for people with a chronic illness/disability.

CHAPTER TWO

LITERATURE REVIEW

O health! health! the blessing of the
rich, the riches of the poore! who
can buy thee at to deare a rate,
since there is no enjoying this
world, without thee?

(Jonson, 1588, p. 48).

Much has been said about health over the centuries and still it remains an elusive phenomenon, one that is difficult to define or to measure. What is health, who should define it, what should it encompass, and how should health be defined? The single factor which permeates all discussions of health is the inherent complexity of the topic (Health & Welfare Canada, 1987). The concept of health has not been fully explored and it remains unclear what health means to both consumers and to health care professionals (Wondolowski & Davis, 1991). As Phillips (1989) commented, "health is an enigma, both from a theoretical and a research perspective" (p. 103).

The Etymology of Health

Words are powerful symbols, and symbols convey meaning. The word health has undergone profound changes in meaning over the centuries. These changes reflect the cultural and sociopolitical environment of a society and thus, the treatment of illness and the restoration and promotion of health have different meanings at different times in history. According to Jago (1975), the Anglo-Saxon word "health" has enjoyed enormous popularity to the point of over-use. Some of the more common uses of the word health identified by Jago are: health care, health attitudes, health education,

health sciences, health information, health status, health indicators, health department, health planning, health monitoring, health profession, health manpower, health needs, health aide, health problems, health industry, health practice, health survey, health promotion, health centre, health food, health insurance, and health benefits. In all of these examples, the word health, instead of being a noun, becomes an adjective, and in North America, the inaccurate adjectival use of the word health predominates (Keller, 1981). What is also apparent is the misuse of the word health when the word "illness," "disease," or "sickness" would be more appropriate. For example, the name health care is really a misnomer for illness or injury care. Similarly, health insurance and health benefits are really insurances and benefits awarded to people if they become ill or disabled. This misuse of the word health is reminiscent of Orwellian "double speak" whereby people are influenced to alter the original meaning of a word in order to conform to the prevailing perspective. With the word "health" as it is now often used, as a misnomer, when illness or impairment, would be more accurate, we are in danger of promoting illness, and to perpetuate the "health" care system, instead of truly promoting health.

A search for the meaning of the word health can begin with dictionaries and a thesaurus. The Random House Webster's College Dictionary (1991) defines health as: a general condition of the body or mind with reference to soundness and vigour; soundness of body or mind; freedom from disease or ailment. Similarly, the Oxford Dictionary (1978) defines health as soundness of body or mind, and also includes the performance of a toast drunk in a person's honour. The Collins Thesaurus

(1986) provides a number of cognate words including: fitness, good condition, haleness, robustness, salubrity, soundness, strength, vigour, well-being, as well as, condition, constitution, fettle, form, shape, state and tone. The British Medical Dictionary (1961) defines health as: a normal physical state, i.e., the state of being whole and free from physical and mental disease and pain, so that all parts of the body carry on their proper function. An American medical dictionary, Stedman's (1972) defines health as: the state of the organism when it functions optimally without evidence of disease or abnormality.

According to Keller (1981) the word health derives from the West Germanic "xailipy" meaning whole and deriving into the German word "heil" which means liberated from sin and attainable of eternal bliss. Keller goes on to explain that the German and Old English word "gesund" (which means healthy) is derived from the German "swinde", meaning strong, quick, strict or hard. The word swinde was the forerunner to the English word sound which often implies fitness, accuracy, morality and in recent times, technical adequacy.

In contrast to Keller (1981), Klein's Etymological Dictionary (1966) states that the word health was derived from the Middle English "helthe" and from the Old English "haelo" which means wholeness and is derived from the Old English word "hal." Jago (1975) suggests that we should readopt the word "hal" because of the abundant misuse of the word health, in order to return to the original meaning of health which is "whole." We should adopt Jago's suggestion and become sensitive to the misuse of the word health in our language. If the word "hal" were substituted for the word "health," it would raise our consciousness about the appropriate and

inappropriate use of the word and we would thus be more likely to return to the original meaning of health which is a wholeness. Wholeness in this sense refers to a unity of the mind, body and spirit.

Commonly Used Definitions of Health

Unquestionably, the single and most enduring and often quoted definition of health is that of the World Health Organization (WHO) which states that "health is a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity" (1947, p. 29). Although this definition is still the most often quoted today, it is not without its critics (Stuifbergen, Becker, Ingalsbe & Sands, 1990). The criticisms have focused on its abstractness, simplicity, "woolliness," lack of suitability for scientific interpretation, placement of too much power in the hands of the health care professionals, and in setting a false goal for medicine (Breslow, 1972; Goldsmith, 1972; Kass, 1975; Keller, 1981; Kottow, 1980).

In contrast to this criticism, Dolfman (1973) lauded the WHO definition for its positive connotations. He suggests that in this definition, health is viewed as the possession of distinct qualities instead of being the absence of anything. Dolfman further suggests that the definition extends and enlarges those factors which must be considered in the assessment of an individual's health.

Similarly, Susser (1974), after first being critical of the WHO definition, came to think the criticism ill-advised. Susser remarked that although the definition is utopian and rests on an aspiration to an ideal and unattainable state, there is more danger in encouraging the fallacy

that what can only be narrowly measured should also be narrowly conceived and defined. Susser goes on to suggest that with imaginative methods, this utopian definition may be made operational. More recently, the WHO has revised its definition of health to incorporate the notion of health as a resource for everyday living. This definition states that health is "the extent to which an individual or group is able, on the one hand, to realize aspirations and satisfy needs and, on the other hand, to change or cope with the environment" (WHO, 1984). This definition moves away from the utopian or unattainable goal of the early WHO definition (1947) to a more realistic and attainable goal. Also, whereas the early definition suggested a product or a goal to be achieved, the latter WHO definition describes a process or a way of being and becoming. This latter WHO definition has received widespread acceptance (Health and Welfare Canada, 1987; Pender, 1987; R.N.A.B.C., 1990; and Woods et al., 1988).

Another widely used, and often cited definition of health is presented by Smith (1981). Smith suggests a continuum for health with four descriptive types contained within the continuum to provide structure. These models (or descriptive types) are the clinical, the role performance, the adaptive and the eudaemonistic models of health. Smith sees these models as not being mutually exclusive, but rather a progressive expansion of the concept of health with the clinical model being the narrowest conception.

The clinical model focuses primarily on the elimination of morbid physical or mental conditions and relief from any concomitant pain. According to this model, objective signs and symptoms of abnormal physical or mental functioning are labelled illness, and the absence of such

objective signs and symptoms will connote health. According to Smith (1981) the clinical model was explored through the models of modern medicine and provides the narrowest view of health. This model has a negative conception because it emphasizes illness not health, and negates the notion that a person, who has signs and symptoms of disease, could be considered healthy.

Smith's second model is that of role performance which was derived from the work of Talcott Parsons (1958) in which health is defined as "the state of optimum capacity of an individual for the effective performance of the roles and tasks for which he has been socialized" (p. 167). According to this definition, as long as the individual can perform roles effectively, then that person is considered healthy. It is assumed that the relevant role is one in which the individual earns or otherwise receives income. However, this definition poses a problem in that a person has many roles, some of which may be in conflict with one another. Effective performance in one role may preclude adequate performance in another. This conflict raises the question of relative values and hierarchies of needs. Health, in this model is manifested by the performance of social roles with maximum output, whereas illness is seen as a failure to perform one's social roles. According to Smith, this model builds on the clinical model by adding social and psychological standards to the idea of health, however, the model is limiting because it can lead to a routine, inflexible, and mechanical idea of health.

The third model, the adaptive model, is more expansive than the first two models and builds upon them. According to Smith, the adaptive model is derived from the work of Dubos (1965) in which health is seen as

a "condition of the organism in which it can engage in effective interaction with its physical and social environment. The characteristic mode of this interaction is adaptive behaviour' (p. 45). In this sense, illness is seen as a failure in adaptation, or a breakdown in the ability of the organism to cope with changes in the environment, whereas health is seen as the ability to maintain flexible adaptation to the environment and to interact with the environment for maximum advantage.

The most comprehensive and expansive conception of health is found in the fourth model identified by Smith (1981) and named the eudaemonistic model. This model builds upon and expands the three preceding models and incorporates the work of Maslow (1962) in which health is described as an ideal of human nature, directed toward fulfilment, complete development and self-actualization. Health, in this sense, is seen as a condition of actualization or realization of this potential, and is viewed as exuberant well-being. In contrast, illness is seen as "enervation and languishing debility" (Smith, 1981, p. 45).

According to Smith, the first two models (the clinical and the role performance) conceptualize health as physiological and sociological soundness, whereas the latter two models (the adaptive and the eudaemonistic) conceptualize health in terms of change and growth and the quality of life.

Smith's four models point to a diversity in conceptualizing health. Although Smith's eudaemonistic model considers the symbolic, intuitive and connected meanings of health where growth, expansion, rhythm and fulfilment are taken into account, health care professional's predominant meanings of health remain in the clinical and scientific realm. There is

some movement by health care professionals to move beyond a deficit model where health is viewed as the absence of disease or infirmity, however, the overwhelming majority of health care professionals still hold this deficit view of health. Wondolowski and Davis (1991,) having extensively reviewed the many and varied definitions of health, state that: "Traditional medicine promulgates the stance that eradication of a pathological disruption is the path to health" (p. 113). The reasons for this narrow focus in the conceptualizations of health can be traced back to the philosophical foundations.

Philosophical Foundations of Health

The clinical and scientific focus on health is derived from and greatly influenced by the reductionist philosophies of the 17th century (Jago, 1975; Keller, 1981; Kottow, 1980; Weber, 1979). According to Weber (1979), these reductionist philosophies are exemplified by Bacon, Hobbes, Descartes, Skinner and Hume. The contention of these philosophies is that each phenomenon be reduced or broken down into small units, and everything in the world can be understood from a mathematical perspective (Travis & Callander, 1990). Decartes in the 17th century constructed a model of man and nature which our contemporary culture still implicitly accepts. This Cartesian universe is dualistic in that there is considered to be a mind-body split. In this sense, consciousness and matter are two distinct and irreducible forms differing both in substance and in kind. Both consciousness and matter contain specific attributes, but these attributes are not shared by the other. According to Weber (1979) Decartes contended that physical matter is visible, divisible, subject to scientific

description and quantifiable. Such matter is lifeless and inert and is acted upon by external forces. In contrast to physical matter, Descartes considered consciousness as non-material, invisible, indivisible and alive. In this sense, the essence of consciousness is being self aware, intentional and purposive. This philosophical position is exemplified by the translation of Descartes' phrase, "I think, therefore I am" (Weber, 1979).

The fundamental principle of Descartes' philosophy is that it irrevocably places man and nature, mind and body, into two distinct and separate domains with no possibility of interaction (Weber, 1979). This Cartesian split or separation has had a profound effect on modern conceptions of health and phrases like, "it's all in the mind," and "his symptoms are psychosomatic" are still considered plausible and reasonable today.

At the same time that Descartes' philosophy was becoming known, Illich (1976) describes how the human body began to be objectified. It was during the renaissance period that the practice of dissecting corpses for medical knowledge became common practice. Thus the body was moved from the religious and spiritual realm into the realm of object and became a tool for teaching.

The behaviourist philosophies of more modern times have originated from the philosophies of Descartes and others, and the work of B.F. Skinner is a particularly clear example of Descartes' influence (Weber, 1979). According to Weber, Skinner modified the philosophy of Descartes by stating that matter is the only variable needed to account for behaviour. In this

sense, there is no mind in addition to the brain, consciousness is a misnomer, or an abstract and non-material entity.

This reductionist perspective provides no opportunity to acknowledge the possibility that people may be diagnosed with a chronic and/or disabling condition and still consider themselves to be predominantly healthy. From the reductionist perspective both health and illness would be seen as mentalistic and of little explanatory power. The physical nature of the chronic condition would provide for only one explanation, namely an illness orientation.

Although the conceptualization of health has been most profoundly influenced by this reductionist perspective, a competing and radically differing view of health is emerging, namely the holistic perspective. This emerging perspective considers the interrelatedness, integration, rhythmicity, and the unity of the mind, body and spirit (Moch, 1989; Parse, 1990; Pender, 1990; Quinn, 1989; Watson, 1988, Weber, 1979). The holistic perspective is gaining widespread acceptance as nurses and other health care professionals react to Cartesian mind-body dualism (Weber, 1979).

Weber (1979) suggests that holistic health conforms to a philosophy of non-dualism in which matter and consciousness are but two expressions of a single state. There is an interconnectedness, a oneness which unites all beings through integration, not reduction. In this sense, there is no Cartesian split or separation between the body (matter) and the mind (consciousness), instead there is a oneness or a unity which is indivisible. Any apparent reduction would favour consciousness as the primary nature of reality (Weber, 1979). As Smith (1975) suggests,

consciousness "makes itself a body" (p. 70) and consciousness is in every way its sovereign.

The emphasis in holistic health is placed upon consciousness and spirituality. The basic thesis is that a spiritual reality underlies and gives rise to our physical reality (Weber, 1979). Holistic health is also considered to be an expansion of consciousness, a move toward self realization, self actualization and authenticity (Maslow, 1962). This is a dynamic process pushing toward greater growth and self awareness, "a spiritually motivated thrust at all levels of existence that culminates in an increasingly self-conscious cosmos" (Weber, 1979, p. 70). From this philosophical discussion on holism, it is apparent that the possibility exists of feeling healthy while living with a chronic illness and/or a disability. That is, a person can move toward an expansion of consciousness, self realization and self actualization, and thus experience feeling healthy while being physically ill or disabled.

Health Within Illness

To understand the concept of health within illness, the client's subjective experience of feeling healthy has to be incorporated into the subjective and objective assessment of the illness. If health care professionals devote their attention to only the clients' illness, this negates the clients' experience of feeling healthy. From a nursing perspective, the concept of health within illness is attracting considerable interest. Moch (1989) suggests that the perspective of health within illness views illness as an event which can promote the expansion of the human potential. As Moch points out "in a health within illness

view, the experience of illness can accelerate personal growth through increased awareness and transformational change" (p. 24).

Parse (1990) suggests that health is a process of unfolding which may occur regardless of the client's health-illness condition. According to Parse, the client actively participates in his or her own health process. That is, the person actively participates in creating his or her own health and becomes the creative author in his or her own health process (Parse, 1990). In this sense, health cannot be prescribed by societal norms, but only by the person living the health (Parse, 1981). Each person is the source of his or her own health experience, and thus the creative author. As Parse (1990) points out,

Health is a non-linear entity which cannot be described as good or bad, more or less, it is just the way the human is. Health is co-created through the human-environment interaction that is lived in rhythmical patterns of relating that incarnate the meaning that the human being gives to situations (p. 137).

In this sense, health is viewed as patterns of relationships with the environment. Within the human-environment interrelationship health is the unfolding of the person's interconnectedness with their world. Parse's philosophical stance provides an opportunity for a person to open up to the possibilities of the experience of feeling healthy, regardless of his/her physical condition.

Parse's (1990) notion of people being creative authors becomes significant when considering health within illness because it leads to an understanding that health is a concept which is individually created and defined. In this sense, no one definition of health can exist, only a clearer understanding of how health is experienced by different people at different times in their lives. As Parse (1990) suggests,

Health is not static: it is a flowing process which incarnates the different ways of being of an individual. These perspectives of health, then, are distinct, and clearly evolve from different belief systems that lead to different health care strategies (p. 137).

In this sense, people's perceptions of health and illness vary over time and under different circumstances. That is, people's experiences of health and illness continue to evolve, thus health care strategies need to be flexible to meet the evolving needs of clients.

Parse's (1990) contention that people are creative authors of their own health is important in this present study. If people create their own health experience, then asking people to describe their meaning of feeling healthy is not only possible, it is desirable. In this way, a broadened conceptualization of health can be attained. Once this broadened conceptualization of health within illness is described and acknowledged, then people with chronic and/or disabling conditions can be creative authors in incorporating the experience of feeling healthy within their chronic condition.

Newman (1986) goes further in her theory of health within illness to suggest that illness is a manifestation of health. In making this suggestion, Newman rejects a dichotomous or polarized view of health and illness. Instead, she suggests a synthesized view based on a fusion of opposites in that one orientation fuses with the opposite orientation to create a new synthesized view. "In this case, 'disease' fuses with its opposite, absence of disease, 'non-disease', and brings forth a new concept of 'health'" (Newman, 1986, p. 9). This synthesized perspective incorporates illness as a meaningful part of health. Jantsch (1980), in writing of a self-organizing universe also makes this point by suggesting

that our thinking transcends opposites to leave a complementarity in which opposites include each other. Thus the tensions within illness allow for patterns of expanding consciousness to emerge which are manifestations of health.

Pender (1990) also rejects the notion of a health-illness continuum and supports a unitary perspective of health within illness. As Pender (1990) points out, "an 'either-or' dichotomy precludes the existence of high levels of health in the presence of a disability or chronic illness" (p. 116). This author makes the point that health is the primary life experience with illness being superimposed on health (Pender, 1987). In this sense, health can exist without illness, but illness cannot exist without health as its context. "When illness occurs, it is synthesized as part of the on-going health experience modifying it in varying ways--changing the quality of the experience, and decreasing or increasing overall feelings and perceptions of health" (Pender, 1990, p. 116). Pender's (1990) contention here is that a person has an intrinsic experience of feeling healthy, and the illness experience becomes synthesized into the essential experience of health. That is, the experience of health is an essential and intrinsic experience. However, this experience can be transformed to incorporate a health-illness experience. Pender further suggests that there is no single, universal health pattern which all people share. Instead, health must be viewed as lived experiences which will represent many differing realities. Only the person experiencing health "can reveal the hidden meanings that they create for health" (Pender, 1990, p. 117).

Pender's (1990) contention of a unitary perspective of health within illness is important to this present study, particularly in her suggestion that illness cannot exist without health as its context. That is, a person living with a chronic illness/disability will experience the chronic conditions within the larger context of the experience of health. From such a philosophical position it is apparent that understanding the person's experience of feeling healthy is of equal importance to understanding the person's experience of their chronic condition. Although Pender suggests that the experience of health will represent many differing realities, in this present study, similar and recurrent themes did emerge.

Quinn (1989) talks of wholeness when considering health within illness and suggests that wholeness incorporates both illness and health. In fact, for Quinn, wholeness expands on both health and illness to include relationship, relatedness and connection. This wholeness, or harmony of body, mind and spirit is greater than the experiences of health within illness. As Quinn (1989) explains, "the absence of any physical parts or loss of function of any parts does not negate wholeness, nor does the presence and proper functioning of these same parts ensure wholeness" (p. 553). This view of wholeness is similar to Newman's (1986) view of expanding consciousness in that both conceptions point to a potential for growth, expansion and an opening up to the possibilities of the human potential.

Other nurse theorists have advocated a philosophy consistent with the concept of health within illness. Peplau (1952) identifies illness as a process of reorienting feelings and strengthening the personality. Chick

and Meleis (1986) who, within their theoretical concept of transitions, speak to the development of human potential, and to increasing harmony in life. Watson (1988) proposed that health be considered a unity and harmony within the mind, body and soul with an openness to the world and to increased diversity. These expansionist views of health provide for the opportunity for the coexistence of health and illness.

Ideas consistent with health within illness are emerging in health-related theory development. Dossey (1982) considers that illness is an opportunity to move to higher levels of complexity, and to an enlightened state of being, beyond illness. Siegel (1986) speaks to a healing process which may occur with serious illness. Such healing is possible, even up to the time of death. Sacks (1984) talks of his personal experience with illness and how this experience provided him with the opportunity for coming to know about the wholeness and completeness of his personhood. Of particular note in these health-related theories is the importance of focusing on the subjective experience of the client. These theories emerged as researchers and clinicians began to pay attention to the lived experience of the client's health-illness condition. This attention is congruent with the present study which focuses on the experience of feeling healthy within a chronic physical condition.

Another interesting notion about health within illness is put forth by Tillich (1961) and Leonard (1989). These authors suggest that health is not health without the essential possibility and the existential reality of illness. Tillich (1961) considers that it is not the conception of health that is important, but rather the meaning of health which only becomes meaningful when confronted by illness. Similarly, Leonard (1989)

makes the point that it is only when our health fails that we can develop insight into the taken-for-granted understanding of health.

The perspectives of Tillich and Leonard are important to consider in this present study because of their broadened conceptualization of health within illness. If health can only be described and understood from a perspective of ill health, then this study has the potential to explore and describe health from the only possible perspective, that is, from people who live with illness/disability.

Research Related to Health Within Illness

Although there is considerable theoretical support for health within illness, there is a paucity of research. The studies most relevant to this theoretical perspective focus on the crisis associated with illness and suffering and on the shift or personal change that occurs as a result of crisis (Moch, 1989). Thus, the studies focus on personal change, however, they bear relevance to the health within illness perspective (Moch, 1989).

Descriptive research studies have been conducted on personal changes that occurred as a result of an experience with cancer. Harrell (1972) concluded that such changes involved an increased empathy and awareness of the human potential. Similarly, Taylor (1983) suggested that the personal changes included an increased consciousness of life. In reporting on personal experiences with breast cancer, Bornemann (1984) described a greater aliveness and a stronger bond with others, and Smith (1979) described an increased closeness with family. Steeves and Kahn (1987) studied the effects of suffering in people's lives and these researchers reported that the meaning in people's lives changed as a result of

suffering. Suffering can be equated with illness/disability, particularly for people with chronic conditions. Therefore, studies about suffering and crisis may be related to the development of the health-within-illness conceptualization (Moch, 1989).

These studies of crisis, cancer and suffering focused on the changes that occurred within the person. The personal changes have to be extrapolated from these studies and the assumption made that such changes constitute the experience of health. That is, Moch (1989) suggests that studies of personal change as a result of crisis can be equated with health within illness. In order to acknowledge this equation the assumption must be made that personal change is synonymous with health. Moch does however make the suggestion that, "Research on health within illness is needed to support the theoretical base of nursing that is consistent with this view".

Health within illness has also been studied quantitatively. People's perceptions of their health while suffering from a disability were studied by Stuifbergen, Becker, Ingalsbe and Sands (1990). One hundred and thirty-five individuals completed a health conception scale and a health self-rating scale. These participants suffered from conditions ranging from visual, neuromuscular and neurocognitive impairment as well as other chronic medical conditions. Despite these impairments, 73% of the participants rated their current health as good or excellent. Similarly, Health and Welfare Canada (1987) conducted a Canada-wide survey on people's perceptions of health while suffering from activity related health problems, and 60% of these respondents rated their health as good to excellent.

The results of these two studies investigating people's perceptions of health while living with a chronic condition are significant in that they point to between 60-73% of the respondents perceiving themselves to be healthy. This issue is critical. The Canada Health Survey (1978-1979) reported that there were 15 million chronic conditions identified in the Canadian population. The Health and Welfare Canada (1987) study was a Canada-wide survey and so it is justifiable to generalize this finding to the Canadian population. If 60% of Canadians with a chronic condition report perceiving themselves to be healthy, then more needs to be known about how health is experienced by this client population.

Significance of the Study

From this overview of the research conducted to explore health within illness, it is evident that considerably more research needs to be done to fully explore this theoretical perspective. In studies exploring the personal changes which occurred as a result of crisis, illness or suffering (Bornemann, 1984; Harrell, 1972; Smith, 1979; Steeves & Kahn, 1987; Taylor, 1983), the assumption had to be made that personal change is synonymous with the experience of feeling healthy. Moch (1989) makes the suggestion that such an assumption should not be made, instead, studies should be conducted to gain a better understanding of how health is experienced within illness. In the studies focusing on people's perceptions of feeling healthy while living with a chronic condition (Health & Welfare Canada, 1987); Stuifbergen, Becker, Ingalsbe & Sands, 1990), the reports indicate the number of people who perceive themselves to be healthy. These results provide no explanation about how health is

experienced by this client group. As health care professionals, knowing that a significant percentage of the respondents felt predominantly healthy is only part of what we need to know. Understanding more fully how health is experienced for this population could contribute to the promotion of health for people with chronic disabling conditions. One of the recommendations of the Health and Welfare, Canada study (1987) was to conduct research in order to gain a better understanding of how people with activity related health problems experience health.

This present study attends to the exploration and the description of the experience of feeling healthy within a chronic condition, and in doing so, it attends to the recommendations made by health researchers. Phillips (1989) makes the plea for nurses to conduct more studies into the experience of feeling healthy when he states, "Research should focus on elucidating how changes in health situations emerge . . . this requires nurse researchers to move their focus of study from illness and disease to health, which is a shift from the traditional health-illness research to the study of people's experiencing of their health" (p. 103). Pender (1990) makes a similar plea with her statement

"Only individuals can reveal the hidden meanings that they create for health. Although health has many different shades of meaning, there are recurring themes or commonalities that persons report as expressions of health when queried as to what health means to them. The critical question is, 'what are the varying human patterns most indicative of health?'" (p. 117).

Other nurse researchers (Leonard, 1989; Moch, 1989; Parse, 1990) suggest that more needs to be known about how health is experienced, and from the perspective of health within illness the significance of this understanding has many ramifications.

The importance of this study is that it attends to the health experience within illness. The results of this study will provide a voice and an opportunity for people with chronic health conditions to experience health within illness. In this sense, as more is known about the experience of feeling healthy while living with a chronic condition, the greater is the opportunity for this client group to expand their perspective to incorporate the possibility of experiencing health within illness. With this expanded perspective comes the possibility of a shift in focus from illness to health. The significance of this shift could have a positive effect on health care providers (particularly nurses), on clients, and on the health care system.

The concept of health within illness attended to in this study provides nurses with an expanded conception of illness to include health. This is an important shift, from the predominant illness model to a model of health, which provides an opportunity for nurses to have a transformation in perspective. As nurses become aware of the potential for health within illness, they will be more sensitive to the phenomenon and open to creating experiences where health can be explored and understood. The nurse, as a creative author can rewrite his or her story which includes health within illness. In this sense, the nurse would create a reconceptualization of illness to incorporate a synthesized view of health and illness. As the nurse creates this reconceptualization, she or he is more likely to enact that story, that is, to act in ways that are conducive to the promotion of health. That is, if the predominant story is illness, then the nurse is more likely to practice from a deficit perspective and with a problem orientation, whereas if the predominant

story is health, the nurse is more likely to practice from an enabling and empowering perspective in the promotion of health and well being.

This shift in perspective could also significantly alter how nurses work with their clients. The perspective of health within illness calls for a new relationship with clients, to an authentic caring partnership and a shift from the control paradigm to the care paradigm (Benner, 1990). That is, the care of the client, from the client's perspective, would take precedence over the need of the nurse to control the client's treatment regimens. This caring partnership considers clients as trustworthy and truthful and in the best position to create their own stories, to express their experiences and to make choices based on these experiences (Thorne, 1993). Nurses in such a partnership would be truly open to explore and understand the experiences of their clients and to explore with clients what they need in terms of health and healing. If health is individually defined, then nurses need to listen attentively to their client experiences and to work with them in ways that are liberating and empowering. This is an ontological shift rather than an epistemological shift; a focus in a way of being with clients rather than focusing on theoretical knowledge which often denies or even contradicts the person's experience. For nurses, an awareness of the possibility of health within illness could lead to the development of egalitarian relationships with clients, which would promote a shift from medical control to client control and to setting a context for client choice. Such a shift in perspective could benefit nurses as it provides an opportunity to return nursing to its philosophical roots, back to the primacy of caring (Benner & Wrubel, 1989; Watson, 1988).

This shift in perspective could also benefit clients. As clients become aware and sensitized to the possibility of the existence of health within illness, they too can recreate their stories to embrace this perspective. If clients are unaware of the possibility of experiencing health within illness, then the stories they create will be around their illness experience. As clients become aware of the perspective of health within illness, they have an opportunity to recreate their stories and acknowledge their experiences of health. With this new awareness comes the possibility of making choices, and a sense of powerfulness to act upon the choices they make. These clients would feel empowered to take responsibility for their experiences, and to make healthy and informed choices.

This possible shift in client perspective is similar to the potential shift that nurses could make. Nurses and clients could form egalitarian partnerships in promoting health and well-being. These new egalitarian nurse/client partnerships which incorporate the experience of health within illness have the potential to effect the health care system. As Moch (1989) suggests, "Full incorporation of the perspective of health within illness would revolutionize health care" (p. 23).

The benefits to the health care system of adopting the perspective of health within illness are twofold. First, it is predicted that this shift in perspective could lead to a reduction in health care costs as the subjective care of the client takes precedence over expensive and often inappropriate technological interventions. Watson (1990) makes the point that the technocure mandate of the health care system is both wasteful and expensive as it focuses on the technological cure of the client, and to

the overwhelming need by health care professionals to "fix-it." Such technological interventions are often unnecessary, intrusive and wasteful, and frequently do not lead to a cure (Illich, 1976, 1992). This is particularly true for people with chronic illness and/or disabilities where intrusive, invasive and often painful interventions are performed without paying attention to the subjective experiences of the client (Corbin & Strauss, 1988). A shift in focus whereby the client is cared for as an autonomous, experiencing, whole person would call into question many of the expensive and invasive technological interventions. Such a shift would reduce health care costs as well as improving client satisfaction and quality of life.

The second benefit to the health care system of adopting a health within illness perspective involves the promotion of health. Canada has played a leading role in the development of a health promotion perspective (Lalonde, 1974; Ottawa Charter, 1986) and this initiative has been strongly endorsed in British Columbia (RNABC, 1990). The rhetoric of health promotion has now been taken up by the health care institutions. However, the principles of health promotion within those institutions are yet to be actualized. This study presents one example of the reconceptualization of health within illness, and thus it provides a health promotion perspective. It is not expected that one study will lead to health care reform. Instead, as the body of knowledge is expanded to incorporate a synthesized view of health and illness, such health care reform is more likely to be actualized. This study provides an example of this shift in perspective which incorporates the notion of health within illness. Such a shift would provide an opportunity to change client-health

care worker relationships to an egalitarian power sharing partnership which would promote collaboration and client empowerment. This shift is in line with the principles of health promotion and could lead to the actualization of a health promotion perspective within health care.

Summary

Chronic illnesses/disabilities have become the number one health concern in Canada today. This concern is threefold. First, there are a growing number of people who live with one or more chronic condition. Second, the financial costs for caring for these clients is mounting. Finally, and of particular importance, the traditional medical model of health care professional control has been found to be inadequate and inappropriate for this client population (Strauss et al., 1984). What is needed is a shift in perspective, which inverts the commitment to cure over care and promotes client care as the ethical and moral ideal (Watson, 1988). One way to promote this shift is to expand our illness perspective by incorporating a perspective of health within illness (Moch, 1989). This health within illness perspective is particularly necessary for people with chronic illness and/or disabilities as it promotes a shift in focus to include the subjective experience of the client, in particular, to their experience of feeling healthy while living with their chronic condition. Before such a reconceptualization or shift in perspective is possible, more needs to be known about the phenomenon of health within illness. The purpose of this present study was to attend to this need, namely, to explore and describe the meaning of the experience of feeling healthy for people living with chronic conditions. Specifically, the

research question was: What is the meaning of feeling healthy for people with chronic illnesses/disabilities? The potential significance of this study could be in an increased awareness and a sensitivity to health within illness for both clients and nurses. This increased awareness could lead to greater client autonomy, the promotion of an egalitarian caring relationship between the nurse and the client as well as opportunity to promote client health and well-being.

CHAPTER 3

METHODOLOGY

The research question posed in this study was: What is the meaning of feeling healthy for people with chronic illnesses/disabilities? The importance of understanding the meaning of the experience of feeling healthy for people with chronic conditions led me to a human science perspective and to an interpretive phenomenological inquiry. Interpretive phenomenology is ideally and logically suited to contact, evoke, describe and elaborate on the meaning of lived experience (van Manen, 1990). Often referred to as the Rigorous Science of Meaning (Knaak, 1984), phenomenology seeks to explore and understand the structure and meaning of human experience. For the study of feeling healthy for people with chronic conditions, interpretive phenomenology provides a way to explore the deeper meanings of the participants' experiences, to gain a fuller understanding of those experiences, and ultimately, to assist in the pursuit of what it means to be human (van Manen, 1990). The assumptions underlying the perspective of this research project include:

1. Holistic Perspective: To study a "whole" phenomenon, and to avoid breaking down the phenomenon into ever smaller segments or parts (Patton, 1990). There are multiple constructed realities that can be studied only holistically. That is, such realities require a research approach that studies the phenomenon as a whole, instead of breaking the phenomenon down into small, decontextualized units. From this perspective, prediction and control are unlikely outcomes. However, a level of understanding or consensus will be achieved (Lincoln & Guba, 1985; Guba & Lincoln, 1990).

2. Subject-Object Inseparability: The inquirer and the "object" of inquiry interact and influence one another. That is, the knower and the known are inseparable (Lincoln & Guba, 1985).

3. Cause and Effect: All entities are in a state of mutual simultaneous shaping so that it is impossible to distinguish causes from effects (Lincoln & Guba, 1985; Guba & Lincoln, 1990).

4. Truth and Reality: There is no ultimate and essential truth "out there" which is divorced from the knower. Therefore assertions of truth and reality are inextricably bound by peoples' biographies, their culture and their history. In this sense, all assertions to truth and reality are relative (Nielsen, 1990; Guba & Lincoln, 1990).

5. Inquiry is value bound: "Inquiries are influenced by inquirer values as expressed in the choice of problem . . . and in the framing, bounding and focusing that problem . . . by the choice of paradigm . . . by the choice of substantive theory to guide collection and analysis of data and the interpretational findings . . . and by the values that inhere in the context" (Lincoln & Guba, 1985, pp. 37-38).

These assumptions are important to my study of health within illness because they attend to the holistic, intersubjective nature of this phenomenon, and to the existence of multiple realities. In this sense, the researcher and the participant are fully engaged in the research process.

Philosophical Considerations

My choice of research method is an interpretive phenomenological study of the meaning of lived experience. In this regard I am predominantly influenced by the work of van Manen (1990) in coming to a

decision about the appropriateness of this methodological choice. According to van Manen, interpretive knowledge reveals the meaning of human expression. Interpretation in this sense is a description of lived experience as it is expressed in symbolic form (van Manen, 1990). That is, in order to describe the lived experience, it has to be first mediated by expressions such as talk, action, a text, or a work of art etc. When experience is thus mediated by expression, it becomes an act of interpretation. According to van Manen (1990), lived experience involves our immediate, and pre-reflective consciousness of life. In this sense, the lived experience has a temporal structure in that it can never be accessed in its immediate manifestation, but only accessed reflectively, as past experience. van Manen suggests that our simple presence, our non-reflective consciousness precedes our thematizing or use of language which enables the experience of the pre-reflective consciousness to be manifested in reflective consciousness. It is van Manen's contention that through conversations, daydreams, meditations, and other interpretive acts people assign meaning to a phenomenon. That is, lived experience is pre-reflective, immediate and implicit, a simple presence, and our reflective consciousness which is often manifested in language is fed by the pre-reflective consciousness.

van Manen (1990) attributes the evolution of his philosophical stand in part to the previous hermeneutic or interpretive philosophies of Heidegger and Gadamer, and I too will explore these philosophical positions as they relate to my research. Heidegger (1962) maintained that to be human is to be interpretive and, in order to understand human experience, we need to study the way human beings are. That is, we need to

move from an epistemology (the study of knowledge) to an ontology (the study of being-in-the-world). Heidegger contended that all cognitive attempts to develop knowledge are expressions of interpretation. In this sense, understanding occurs in our engagement with the world, and experience is formed through interpretation of the world. However, according to Heidegger, all conscious understanding and the act of interpretation is dependent on our situatedness, or context. That is, understanding is mediated by our personal biographies, and our cultural and historical situation. In this sense, interpretations come to us in a "forestructure" (Heidegger, 1962) of understanding.

According to van Manen (1990), Gadamer (1975) elaborated on Heidegger's notion of forestructures of understanding, especially the forestructure of "prejudice." Prejudice, in this sense, establishes our situatedness in tradition which makes understanding possible. Like Heidegger's notion of forestructure, prejudice involves our situatedness in our own personal biographies, our historical time and our cultural context. However, Gadamer (1975) goes further than Heidegger in contending that we cannot gain insight into our original being-in-the-world because all our understanding will be mediated by our prejudice.

For Gadamer (1975), hermeneutics is universal because the understanding of our situatedness happens simultaneously with our understanding of the meaning of experience. Gadamer called this "effective historical consciousness" which entails a dialogue between one's own tradition and the text. This opens the possibility of new meaning being created in the horizons of each. This fusion of horizons takes place through language. This is a central tenet of Gadamer's hermeneutics, in

that language is the dialogical fusion of horizons of text and interpreter which comes together through conversation. A common meaning is developed which transcends the subjective meaning of either partner. "What emerges in its truth is the logos, which is neither mine nor yours and hence so far transcends the subjective opinion of the partners to the dialogue that even the person leading the conversation is always ignorant" (Gadamer, 1975, p. 331). In this sense, interpretation is the fusion of the horizons (and situatedness or prejudice) of each partner to the development of a common meaning which transcends the meaning of either partner in the dialogue. Thus, knowledge is co-created by this fusion of horizons. In my research, it was important for me to be cognizant of this forestructure or prejudice so that I could attend to the mediation that occurs between the original being-in-the-world (i.e., our pre-reflective consciousness) and the persons' interpretation or the meaning attributed to his/her experience.

Other scholars have also described the mediation which occurs between our pre-reflective consciousness and the interpretation or meaning of experience. Instead of describing the fore-structure or prejudice as the mediating influence, Combs (1982), Combs and Avila (1985), and Merleau-Ponty (1962) suggest that people access experience through perception.

According to Merleau-Ponty (1962) perception "is the first access to things and the foundation of all knowledge" (p. 9). Merleau-Ponty suggests that all forms of co-existence are based on perception. That is, all knowledge is derived through perception and perceptions are presupposed and influence the meaning people attribute to experience. Past experiences

evoke meanings which influence how a person perceives present experiences. In this sense, something about the present experience prompts the perceiver to put into play a certain association, or call up a certain memory. These data then become part of the perceptual field and the more meaningful data become the figure (or the significant perceptions) and the less meaningful data become the ground (or the context of the experience).

Combs and Avila (1985) describe perception as the beliefs, values, feelings, hopes, desires and the personal ways in which people regard themselves and each other. In this sense, Combs and Avila equate perception with personal meaning in that a person's perceptual field of feelings, attitudes and convictions are the personal meanings a person brings to an experience.

Combs (1982) suggests that the development of personal meaning is a creative act occurring as a consequence of people interacting with the world in which they live. The act of perceiving is influenced by a person's sense organs, their social and cultural condition, the effect of time, the opportunities open to them, and on their personal needs. Of all these influences, Combs (1982) contends that the fulfilment of human needs exerts the greatest influence on how people perceive and make meaning of an experience, and the fulfilment of the need is based on a person's beliefs and values. In this sense, a person interprets or makes meaning of an experience based on his/her perception of the relative importance of that experience which is based on a person's beliefs and values.

It appears to me that the philosophies of Heidegger (1962), Gadamer (1975), and Merleau-Ponty (1962), and the learning theories of Combs and Avila (1985), and Combs (1982) have many principles in common,

particularly with regard to the mediation that occurs between pre-reflective experience and the expression of that experience. Each of these scholars suggest that people make meaning of an experience based on their personal biographies and their situation in time and place (i.e., historically and culturally situated). For Heidegger, this situatedness is called "forestructure," for Gadamer, he considers the "prejudice" which such a situatedness entails, for Merleau-Ponty, the situatedness is in the perceptual field, and for Combs and Avila (1985), perception is based on a person's beliefs and values which provide personal meaning to an experience. The important notion considered by these scholars is that experience is not "pure," but is mediated by personal biographies and historical and cultural/contextual situatedness which may be accessed through dialogue. Within this dialogical exchange, the situatedness of each person fuses together through conversation. From this fusion, a common meaning is developed which transcends the subjective meaning of either partner; thus through simultaneous interpretation, a common meaning comes forth.

In considering the different philosophical positions of Heidegger (1962), Gadamer (1975), Merleau-Ponty (1962), and the learning theories of Combs (1982), and Combs and Avila (1985), as well as the philosophy of the lived experience advocated by van Manen (1990), these are the principles I attended to while conducting my research into the meaning of the experience of feeling healthy for people who are chronically ill and/or disabled:

1. Lived experience has a temporal structure and cannot be accessed in its immediate manifestation, but only accessed reflectively, as past experience (van Manen, 1990).
2. Access to experience is mediated by a person's biography and his/her historical and cultural/contextual situatedness (Gadamer, 1975; Heidegger, 1962; Merleau-Ponty, 1962; van Manen, 1990).
3. Descriptions are the arbitrary imposition of meaning on the flow of memory. People discount some and highlight other experiences, therefore, they are interpretive (Merleau-Ponty, 1962).
4. A person interprets or makes meaning of an experience based on his/her perception of the relative importance of the experience (Combs, 1982).
5. It is the meaning a person gives to an experience which is important to understand (Combs & Avila, 1985; Gadamer, 1975; van Manen, 1990).
6. Personal meanings are made evident by acts of expression such as talk, action, a text, or a work of art, etc. (van Manen, 1990).
7. Perception is based on beliefs and values which are influenced by personal biography and by historical and cultural/contextual situatedness (Combs & Avila, 1985).
8. Through dialogue people assign meaning to an experience (Merleau-Ponty, 1962; van Manen, 1990).
9. Interpretation is the creation of common meaning which transcends the meaning of either partner in the dialogue (Gadamer, 1975).

These philosophical principles are congruent with my own beliefs and values and with the intention of my research. It appears to me that the study of the meaning of human experience can be accessed through a

dialogical exchange with the experiencing person. In this way, as we engage in a conversational relationship, the meaning of the experience can be brought forth as a co-creation. These considerations guided me as I talked with my research participants in that I was constantly aware that the experiences they described to me were mediated by their personal biographies as well as by their situatedness in both historical time and in a particular context. In this sense, I was aware that there is no essential or fundamental truth, but rather an interpretation of their experience which was inevitably bound in time and place. Also, I was aware that the point is never reached whereby all the participants' experience is fully uncovered and interpreted. Instead, as Heidegger (1962) reminds us, we never fully uncover an entire experience, but rather, we are always on the way to that discovery. Another important aspect I considered was that I too brought my own pre-suppositions and pre-understandings to the dialogue and together with my participants we engaged in an interpretive conversation whereby a new meaning was co-created.

Nurse scholars also support the need for human science research to address some salient nursing questions (Chenitz & Swanson, 1986; Field and Morse, 1985; Leininger, 1985; Moch, 1989; Morse, 1991; Munhall & Oiler, 1986; Parse, 1990; Parse, Coyne & Smith, 1985; Phillips, 1989; Watson, 1988; Wilson, 1985). For example, Munhall & Oiler (1986) contend that "Nursing deals with wholeness, perceptions, experiences, multiple realities, appearances of phenomena, and the existence of phenomena" (p. 74). As such, these authors suggest that human science research is an appropriate methodological choice. Similarly, Watson (1988) states that the epistemology most suited for nursing is a human science perspective.

This position is based on the contention that nursing has been defined as "a human science of persons and human health-illness experiences that are mediated by professional, personal, scientific, aesthetic, and ethical human care transactions" (Watson, 1988, p. 54). In this sense, Watson suggests that some salient nursing questions need to focus on health-illness experiences which would lead the researcher to a human science perspective.

As this overview of some of the more influential nurse scholars suggests, the trend in nursing research is to move to a human science perspective and to qualitative research methods. The reasons cited for these changing trends are that nursing knowledge should focus on a holistic, intersubjective, and process-oriented view to the discovery of knowledge in order to gain an understanding of the experience of health and illness. This philosophical stand is consistent with my own philosophy regarding the discovery of nursing knowledge. That is, in order for nurses to better care for their clients, they must first gain an understanding of a client's particular and unique experience. The emphasis is thus placed on the health-illness experience of the client rather than on the external health-illness condition. This stand is particularly important when studying the meaning of the experience of feeling healthy for people with a chronic illness/disability. In this way, the client may gain self knowledge, self control, and a readiness for healing regardless of their medical condition. It appears to me that this philosophical approach is important for effective and meaningful nursing care, and research methods which are consistent with this philosophical stand are essential for the discovery of nursing knowledge.

Research Method

In this section I will describe the process I undertook in conducting my research, and wherever necessary, I will explain the rationale for my decisions. Again, in attending to the research process, I was predominantly influenced by van Manen (1990). van Manen suggests that interpretive phenomenological research may be seen as a dynamic interplay among six research activities. These are:

1. Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualize it;
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;
5. Maintaining a strong and oriented relation to the phenomenon;
6. Balancing the research content by considering parts and the whole (p. 30-31).

The first research activity suggested by van Manen (1990) is to turn to a phenomenon which seriously interests us. I have highlighted my interest in this study in the introduction to this dissertation, which was to explore and describe the meaning of the experience of feeling healthy for people with a chronic illness/disability. The subsequent five research activities suggested by van Manen (1990) will be attended to as I describe my research method. As I attended to the first research activity suggested by van Manen, I became aware of the need to make explicit my own beliefs, values and assumptions regarding health within illness. I attended to this issue as I considered the use of bracketing.

Bracketing

The initial step in conducting interpretive phenomenological research is bracketing whereby the researcher carefully delineates her

presuppositions. It is the researcher who formulates the research question, and who collects, transcribes and analyzes the data. Because of this personal involvement, the orientation of the researcher should be made explicit at the onset of the study. As Osborne (1990) points out, "Bracketing is a process of articulating the researcher's presuppositions and biases through a process of rigorous self reflection so that those who read the report of the research will be able to take the frame of reference of the researcher into account" (p. 11).

Although bracketing is an essential first step in interpretive phenomenological inquiry, there are two disparate philosophical positions regarding its' use. Phenomenological researchers who follow closely the philosophy of Husserl, for example, Colaizzi (1978), De Koning (1982), Giorgi (1970), Spiegelberg (1982), and van Kaam (1966), contend that in order to come to an understanding of the essence of a phenomenon, the researcher must first bracket or suspend all prejudgments, presuppositions and all extant theory regarding the phenomenon. These scholars contend that it is only possible to explore the essence of a phenomenon when one is free of all existent knowledge. Spiegelberg (1982) calls this 'reductive phenomenology' in that all beliefs in reality or validity of a phenomenon are bracketed. Bracketing, in this sense, can be defined as "detaching the phenomena of our everyday experience from the context of our naive or natural living, while preserving the content as fully and purely as possible" (Spiegelberg, 1960, p. 133).

In contrast to this view of bracketing, interpretive phenomenologists such as van Manen (1990), Pinar (1981), and Gadamer (1975) suggest that bracketing is neither useful nor desirable. According

to van Manen (1984, 1990) we cannot ignore our pre-understandings because this denial might lead to unconscious biases affecting our reflections. Instead, van Manen suggests that we should make our understandings, biases, assumptions, beliefs, pre-suppositions, and theories explicit so that we can use this knowledge against itself and thus expose the concealments and the gaps in this knowledge. Similarly, Pinar (1981) suggests that "as we attune ourselves to the situation, allowing the problematic . . . the unknown, the tension . . . to state itself through us, the situation comes to form through us and thus our sensibilities do not merely pre-condition knowledge, they make it possible" (p. 180). In the same vein, Gadamer (1975) states that the researcher requires a certain sensitivity which includes neither neutrality nor extinction of oneself, but rather the conscious assimilation of one's own preunderstandings or presuppositions. Gadamer calls this "effective historical consciousness." The dialogue between one's own presuppositions (our assumptions, biases and pre-understanding) and the data from the participants opens up the possibility for new meanings to be co-created.

In this study, I took the philosophical position about bracketing suggested by van Manen (1984, 1990), Pinar (1981), and Gadamer (1975) in deciding to neither suspend or bracket my pre-suppositions, biases, assumptions, beliefs, and extant theory. Instead, as Gadamer (1975) suggests, I consciously assimilated this knowledge of my own foremeanings or presuppositions with the meaning of my participants so that we could be opened up to the possibilities of new meanings being co-created. In this sense I was aware of my own beliefs, values and assumptions regarding health within illness. With this awareness I conscientiously engaged in

dialogue with my participants to explore their presuppositions. As our conversations evolved, new meaning was co-created from this dialogic exchange.

In order to be fully aware of my own presuppositions, I conducted a thorough literature review on the theory and research available on health within illness. I also made explicit my own assumptions regarding health within illness. These assumptions arose from my extensive work with clients with chronic illnesses/disabilities. They include:

1. The experience of feeling healthy is unique to each person and it can only be explored and understood from a personal perspective.
2. Some experiences of feeling healthy will be shared by other people.
3. There is an experience of health within illness.
4. People with chronic conditions can and do experience feeling healthy.
5. People, depending on their life experiences and the experiences of their chronic condition, will experience health and illness differently, although there will be commonalities among these experiences.
6. Generally, health care professionals view people with chronic conditions to be in a deficit position, that is to be predominantly sick.
7. People with chronic conditions who are in a stable trajectory consider themselves to be predominantly well or healthy.

This exploration of the extant literature, and of my own assumptions about health within illness was done to follow Gadamer's (1975) suggestion that neither neutrality nor extinction of ones foremeanings or presuppositions is possible or useful. Instead, this exploration was

conducted to become more conscious of my own foremeanings. In this way, I acknowledged these pre-suppositions, and thus I was less likely to project or impose them upon my participants, but rather, I used these pre-suppositions to engage in meaningful dialogue with my participants and to engage in the process of co-creating meaning. Through this process, the exploration of the meaning of the experience of feeling healthy for the chronically ill and/or disabled came to light.

Data Gathering

1. Selection of participants. "The selection of a sample has profound effect on the ultimate quality of the research" (Morse, 1991, p. 127). In human science research, the selection of an adequate and appropriate sample is critical. Because the goal of phenomenology is to understand everyday experiences, it is important to select participants who have extensive experience of the phenomenon under study. Morse (1991) describes four types of samples: (1) purposeful samples, (2) nominated samples, (3) volunteer samples, and, (4) total population. The purposeful sample is selected according to the needs of the study. The sample is purposeful in the fact that different informants may be interviewed, at different times during the study. Nominated samples are usually obtained by eliciting the assistance of an informant already in the study to propose the selection of another participant. The volunteer sample or solicited sample occurs when the participants identify themselves. Finally, the total population may be the sample if participants work, for instance, in a confined area or live in a nuclear family where each participant has the same opportunity to experience the phenomenon under study.

The most important aspect to consider in choosing participants is that they be knowledgeable about the topic under study and be able to reflect and provide detailed experiential information about the phenomenon (Morse, 1991). It is not necessary for the participants to have detailed theoretical knowledge about the phenomenon, rather that they have experiential knowledge and are able to clearly articulate that knowledge to the researcher. The participants must be willing to share their experience with the researcher, and they must be willing and able to critically examine their experience and their response to that experience. Participants who speak superficially or exaggerate their experiences should be avoided. Also, participants should be encouraged to talk about the profoundness of their experience rather than give opinions or ratings. In this sense, the researcher and the participants go beyond intellectual and theoretical suppositions, and to engage in a deep and meaningful conversation with one another. In this way the researcher penetrates the deeper layers of the participants' lived experience.

Based on the knowledge I gained from Morse (1991) about the types of samples which may be accessed, and the criterion of a self reflective participant, I was able to make appropriate choices regarding the selection of participants for my study. First, I chose participants from the volunteer and nominated groups. I telephoned several counselling and support agencies working with people with chronic conditions and asked if they might have any clients who would be willing to participate in my study. From these volunteer participants, other participants were nominated. Two people who were known to me personally also agreed to participate in my study. I will describe the agencies involved and how

each participant became known to me as I introduce them in the section reporting my results.

In conducting my search for participants I was looking for people with chronic illnesses or disabilities who would consent to be interviewed on two or three occasions. Also, I was assessing potential participants who could be reflective of their experience of health within illness, and who could clearly articulate their experiences to me. As Harding (1975) points out, each person "must be ready to articulate and amplify whatever meaning (s)he finds and make what sense (s)he can of events" (p. 204). I made this assessment from a telephone conversation I had with each potential participant prior to arranging an interview. During the telephone conversation, potential participants were asked (a) if they have experienced feeling healthy within their illness, and (b) to articulate an example of their experience of feeling healthy. People were asked to participate if they responded positively to the first criterion and distinctly and with thoughtfulness to criterion number two. Each potential participant responded positively to criterion one, however, I experienced some difficulty in criterion number two. For instance, one potential participant spoke in the third person and when I asked her how the experience she described affected her personally, she was reluctant to bring the experience into the personal realm. I did not invite this person to be part of my study because I assessed that it would be difficult for her to be deeply self reflective. I was also aware that I wanted to avoid participants who appeared to exaggerate their experience. However, I did not experience this problem in choosing my participants. Finally, I chose participants who suffered from differing physical chronic conditions. The

definition of a chronic illness/disability was confined to physical realm and was articulated in the introduction to this study.

Researchers who have devoted their research work to exploring chronicity (Conrad, 1987; Corbin & Strauss, 1988; Gerson & Strauss, 1975; Roth, 1987; Strauss et al., 1984) suggest that a diverse sample of participants, that is, people with a variety of chronic conditions, be required. Their rationale for this suggestion is that the experience of chronic illness is similar across many chronic and/or disabling conditions and that the data and the findings are richer for this diversity of participant experiences. Conrad (1987) suggests that by limiting the participants to one medical condition, "other interesting or contrasting features of a phenomenon may be overlooked" (p. 23). This same author suggest that participants be chosen who are in the same category which best reflects their illness or disability. Conrad suggests three categories: the "lived-in," (or stable condition); the "mortal," (or declining condition); and the "at-risk," (or unstable condition), and that the researcher should choose participants from one of these categories in order to fully explore the participant's experience. I chose participants who were in the "lived-in" or stable condition. I made this choice because it was my assumption that people are more likely to experience feeling healthy if they do not feel imminently threatened by a relapsing or declining condition.

Eight people participated in my study. The decision to include eight participants was made to meet the requirement of redundancy suggested by Lincoln and Guba (1985). The sample size was determined by informational considerations, and sampling was discontinued "when no new information is

forthcoming from newly sampled units; thus redundancy is the primary criterion" (Lincoln & Guba, 1985, p. 22). At the time of interviewing my sixth participant I began to hear familiar and similar experiences; there appeared to be a repetition of the experiences expressed by the previous five participants. I continued to interview two more participants to be sure that no new information was forthcoming and indeed the repetitive and familiar themes continued to emerge.

2. Ethical considerations. Certain ethical considerations were attended to at the onset of this study. The participants were informed of the purpose of the study, the potential risks and benefits of participation, the data generating method, and the assurance of privacy and confidentiality. A consent form was signed by each participant prior to the onset of the study. Confidentiality was ensured in the following ways: (1) participant names did not appear on the transcripts, (2) participant names did not appear on the audio-tapes (only a code number identified the participant), (3) the code numbers which identified each participant were kept locked in a separate office. This identifying information will be destroyed at the completion of the study.

No potential risks were anticipated to the participants of this study. The benefit gained by participants was in being fully listened to, and to fully engage with me in the exploration of their meanings of feeling healthy within their illness/disability. Participants spoke of new insights and new learnings that occurred for them as a result of this research study. Participants were appreciative and enthusiastic about being included in this study and they were very supportive and

enthusiastic about my research question. There was considerable agreement among my participants that such a study was long overdue.

Participants were informed that two or more interviews would be required with each participant and of their right to withdraw from the study at any time during the research project. They were also informed that they could have access to the transcriptions of their interviews, and that all questions they may have about the study would be addressed. Copies of the findings of the research will be made available to each participant at completion of this study. A copy of the letter of consent is to be found in Appendix A.

3. Data gathering: The dialogical relationship.

The point of phenomenological research is to "borrow" other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole human experience (van Manen, 1984, p. 44).

In order to come to an understanding of the meaning of the experience of feeling healthy for people with a chronic illness/disability, it was essential to ask them about their experiences. This "asking" can take the form of an interview or by establishing a conversational relationship (Carson, 1986). Carson (1986) considers the phenomenological investigation to be one of engaging in a conversation rather than in conducting an interview. He states that the interview is conducted in an effort to gather information about the perceptions and practices, whereas the conversation implicates a revealing of something held in common. According to Carson (1986), it is essential to allow the meaning to emerge through language, and thus the questions should remain open and not cut off too readily by opinions or conclusions. Only when we

remain open to the question in our conversations can there be surprising insights for both the researcher and the participant. With this rationale in mind, I joined my research participants in interpretive conversations. This dialogical relationship provided for a joint reflection of the phenomenon of health within illness whereby I remained committed to, and genuinely present with my participants, so that a deepening of the understanding of the experience both for myself and for my participants could evolve.

The generation of the data for this research was performed by engaging in audiotape recorded interpretive conversations with my eight participants. Conversations were conducted mostly in the participants' homes. However, I met with one participant in his office and a second participant in my home. My aim was to talk with people in an atmosphere conducive to open and exploratory dialogue and so the comfort of each participant was of primary concern. It was during the conversations with each of my participants that bracketing became a central issue for me to attend to. Kvale (1987) suggests that the conscientious researcher will be able to distinguish between questions that lead to greater understanding and questions that lead to confirmation of presuppositions. I likened this process to an empathic way of being with my participants in that I brought to the conversation all my presuppositions but held these in abeyance as I entered into an understanding of the experience of my participants. In this way I acknowledged and was aware of my own pre-understandings. However, as we deeply explored the participant's experience, I brought my own perspective into our conversation only in as much as it provided for a penetration into the deeper layers of the participants' experience. That

is, the exploration of the participants' experience was participant oriented, rather than researcher defined.

I visited the participants on three separate occasions and I will describe the purpose and the process of each conversation.

1. Conversation One: Ethical Considerations and Exploratory Data Gathering

On the first occasion I received informed consent from my participants. The purpose of the first conversation was to explore in depth the essential descriptions of the meaning of feeling healthy within each participants' illness/disability. My intention was to be fully present to the participants. I focused on the process of how each participant expressed his/her experiences, so that I could best understand the meaning as it is lived by that person (Kvale, 1983). I began the initial conversation with an orientation to my study and then with a broad open-ended question such as "Can you describe for me what feeling healthy is like for you?" From this broad open-ended question we engaged in more indepth exploration. Each participant was different in how the indepth part of the conversation unfolded. For some participants, the use of examples was most helpful, for others the use of analogies and metaphors provided indepth exploration, for others the listing of adjectives and then an indepth exploration of those adjectives was most useful, and for one participant (an artist) she described how she would paint a picture of feeling healthy. In most cases, a combination of these strategies was used as we explored together their meaning of feeling healthy.

For my part, the conversations were conducted in such a manner that the participant did not feel interrogated, but rather, a mutual quest for understanding occurred. I responded to each disclosure by confirming an

understanding, summarizing their disclosures, and when necessary, by further questioning. In this way, the fully present researcher facilitates the expression of insight in the participant so that there is a broadening of horizons by both partners in the research endeavour. I was also cognizant of the fact that the act of reflection and coming to an understanding takes both silence and conversation (Kvale, 1983). These initial conversations lasted from one and a half to three hours in duration.

Following each conversation I followed the guidelines proposed by Becker (1986), Carson (1986), Kvale (1983), and van Manen (1984) in that each conversation was transcribed verbatim from the audiotaped sessions. I then performed a thematic analysis on each audiotape and transcript. These analyses contained the essential themes that I thought emerged from our conversations with verbatim examples included to exemplify the themes. After the completion of each thematic analysis, I gave my interpretations back to each participant. This analysis provided the starting point for the next conversation.

2. Conversation Two: Confirmation, Clarification and Elaboration

The second conversation had two purposes. The first purpose was to assess the accuracy of my interpreted analysis, and the second purpose was to continue to explore more fully each participant's experience of feeling healthy. This second conversation was more semi-structured in nature and was similar to those proposed by Becker (1986) and Kvale (1983). Although my intention was to remain open to fully hearing and exploring the participants' descriptions, there were five essential questions I wished to address. These were:

(a) Does my analysis of our first conversation fit with how you experience feeling healthy?

(b) Are there any parts of my analysis that you would like to change?

(c) Are there any parts of my analysis you would like to clarify further with me?

(d) Are there any parts of my analysis that you would like to more fully elaborate on?

(e) Having read my interpreted analysis, are there additional areas of your experience of feeling healthy that you would like to tell me about?

These questions were asked of the participants in the course of our second conversation. Quite often I did not need to formally ask these questions as the answers emerged within our dialogue. The most encouraging part of this second conversation was the validation by the participants regarding my analysis. Each participant voiced approval, and for some even surprise at the accuracy of my interpretations. As one participant said, "I feel that you know me even more than I know myself, this has given me new insights into my own experience." For another participant, she stated, "You provided me with some order and clarity to my feelings which were sort of jumbled up before."

This second conversation continued to explore in depth the meaning of feeling healthy for my participants. Because the second conversation was a continuation of our original explorations, we were able to penetrate the deeper layers of the participants' explorations. On three occasions, participants had thought about our original conversations and were eager

to add more to their descriptions. These second conversations lasted from one to two and a half hours in duration.

3. Conversation Three: Exploration of Essential Themes

The third conversation with the participants was conducted in a variety of ways. After the analysis of the second interview was completed, I gave each participant all the validated and unidentifiable analyses of all the other participants. In this way, each participant read the unidentifiable analyses of all the other participants. It had been my original intention to have a focus group session with all the participants present. The reason I wished to conduct this focus group was to see if we could all reach consensual agreement about the essential themes inherent in the analyses. Although I recognized that each participant had unique experiences of feeling healthy, some common themes emerged. I wanted to provide an opportunity for the participants to engage in the identification of these common themes.

The focus group with all participants present was not possible for a variety of reasons. Three participants felt unwilling to meet as a group. They explained that their disclosure to me had been so personal and private that they would feel vulnerable meeting the other participants as a group. One participant lived a distance from the research project and she could not make the journey for this meeting. Another of the participants required surgery and was unavailable for the group session. Finally three participants joined the focus group.

Although the focus group was small, my original intention, that of reaching consensus about the essential themes inherent in the analyses, was fulfilled. Having made a preliminary analysis of the essential themes

as I saw them, I went to each participant a third time with the question: "Having read the analyses of each of your fellow participants, what themes stand out for you as being most noteworthy?" Both in the individual conversations and in the small focus group meeting, the essential themes highlighted in the results section of this dissertation were identified, discussed and consensual agreement reached. Again, these third conversations were tape recorded and transcribed. These final conversations lasted from one to two and one half hours in duration. Of particular significance in the third conversations was the extent to which each of the participants was surprised at the similarities between his/her stories and those of the other participants. As one participant said "I had to keep reminding myself that these weren't my papers," and another one said, "I would read this and say, I remember feeling I wanted to say this and I didn't, and I'm so glad that someone else did." In this way each participant's story validated the other participants' stories. What is of particular note is that each participant was very surprised to learn that other people expressed feeling healthy in such a similar way as he/she did. Before this study, each participant thought his/her feelings were unusual and unique.

Data Analysis

Data analysis was performed following the guidelines for phenomenological analysis proposed by Hycner (1985) and van Manen (1984, 1990).

After the interpretive phenomenological conversations were transcribed, the process of thematic analysis commenced. The first step was to get a sense of the whole (Giorgi, 1975), or to gain an overall

impression of the conversation as a context. This involved listening to the audio tape a number of times, and at the same time, reading the transcript. This process provided me with a context for the emergence of specific units of meaning and themes later in the analysis process. I listened, not only to the words, but to the paralinguistics such as intonations, emphasis, and pauses. At this point I made notes in my journal about the impressions, thoughts and issues that arose for me as I listened to the audiotape recordings and read the transcriptions. My intention was to remain open to comprehending the participant's experiences as a whole.

The next step was to delineate units of general meaning (Hycner, 1985). Again, this step of the analysis process has to be done with a sense of openness to the data as a whole. That is, I endeavoured to elicit the participants' own meanings. In this sense, I did not consider how the units of general meaning addressed the research question. Instead, I attempted to get to the essence of the meaning as it was expressed by the participant. I did this by staying close to the transcription, or to the literal data. The result was the delineation of units of general meaning. Hycner (1985) defines units of general meaning as "those words, phrases, non-verbal or para-linguistic communications which express a unique and coherent meaning (irrespective of the research question)" (p. 283). In this process, I included all units of general meaning. I conducted this process by highlighting and underlining units of general meaning and making notations on the right half of the transcriptions. The result was a clear and condensed analysis which remained true to the literal words of the participants.

Delineating the units of meaning which are relevant to the research question was the next step. It was important at this stage to identify what the participants said and responded to, which illuminated the research question. Hycner (1985) suggests that only relevant information gleaned from the conversations should be included in delineating units of meaning, and all irrelevant information should be discarded. In this study, the units of meaning were taken from the entire transcript as there appeared to be no irrelevant information included. That is, all units of general meaning had relevance to the research question.

The next step involved the clustering of units of relevant meaning. I attended to this by first identifying the words or phrases which appeared to exemplify the experience of feeling healthy for the participants. This is a rigorous process of examination of each individual unit of relevant meaning. The purpose is to try to elicit the essential element of that unit of meaning given the research question. I gave these units of relevant meaning a preliminary title. Based on these preliminary titles I then looked over my list of words or phrases and judged which words or phrases naturally clustered together. I went over these clusters of meaning to assess which ones could again be collapsed into a general theme. Finally, the common themes were examined to see which central themes emerged. The important element at this stage of the analysis process was to search for central themes which seemed to express the essence of these clusters. Again, I gave these central themes preliminary titles. This process was taken partly from my previous experience of qualitative data analysis, and partly from the data analysis steps outlined by Hycner (1985) and van Manen (1990). It was at this stage that

I wrote the summary of my analysis of each individual conversation and returned the summary to each participant. I also shared my analysis process with two nurse colleagues who are also human science researchers. My intentions at this stage were two-fold. First, I wished to elicit their judgements regarding the analysis decisions I had made. Second, I requested their help and support in beginning to identify the emergent general themes.

The second and third conversations were transcribed and analyzed by exactly the same process as the first conversation.

Before I engaged in the third conversations, I looked for common themes which seemed to emerge from a combination of all the previously analyzed data. The first step was to search for themes common to all or most of the conversations (Hycner, 1985). These themes I labelled "general themes." The second step was to identify themes which were unique to one conversation, or to a minority of conversations. There was one conversation which contained some unique characteristics and these variations were noted as counterpoints to the general themes. While clustering the themes into general themes I was cognizant of not losing sight of individual differences within the themes. I attended to this concern by choosing verbatim quotes from the participants' transcriptions which best exemplified the general themes. After I had extracted the general themes, I went back to my participants for a third conversation. At this stage the participants had all received the validated and unidentifiable interpreted analyses of each of the other participants. A detailed account of this process was given in the data gathering section of this chapter. My intention was to involve the participants in

identifying the emergent general themes and to engage in creating titles for the themes. This process involved moving back from studying parts of the data to studying the whole, or the general context of the data. These general themes constitute part of the results section of this dissertation.

The final stage in the data analysis process is the contextualization of the themes (Hycner, 1985). This was done by placing the general themes back into the context of the experience of feeling healthy for people with chronic illnesses/disabilities. I attend to this process in the discussion section of this study as I compare and contrast the emergent general themes from this study with other relevant literature. The entire process of data collection and analysis took six months.

From this description of the data analysis, it might appear that the process is linear and sequential. In fact, the analysis process did not proceed in such an orderly fashion. Instead, although I followed the steps for data analysis suggested by Hycner (1985), and van Manen (1984, 1990), and these steps did provide me with direction and purpose, the actual data analysis process is much more intuitive than these proposed steps might suggest. I spent many hours listening to the tape recordings and reading the transcripts to immerse myself in each participant's experience. As van Manen (1990) suggests, "Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful intervention, discovery or disclosure--grasping and formulating a thematic understanding is not a rule-bound process but a free act of 'seeing' meaning" (p. 79). In this regard, I found myself drawn to

Heidegger's (1962) notion of a hermeneutic circle which is one of participation and distancing. That is, I moved into the data, taking it apart and extrapolating order and meaning, thus fully participating in the data, and at the same time, I continually stood back from the data and attempted to grasp its wholeness, its entirety and to ask myself about the fuller meaning of the experience; thus the act of distancing. As Leonard (1989) explains:

Through systematic analysis of the whole, we gain new perspectives and depth of understanding. We use this understanding to examine the parts of the whole, and then we re-examine the whole in light of the insights we have gained from the parts. The interpretive process follows this part-whole strategy until the researcher is satisfied with the depth of his or her understanding. This interpretive process has no clear termination (p. 51).

Reliability and Validity

Although the terms reliability and validity belong to the naturalistic paradigm of scientific inquiry (Guba & Lincoln, 1981), these terms will be used in this study as the foundation for a differing terminology in qualitative research. Sandelowski (1986) suggests that "the debate surrounding the methodological rigor of qualitative research is confounded by its diversity and by lack of consensus about the rules to which it ought to conform and whether it is comparable to quantitative research" (p. 29). She considers three factors which complicate the debate. First, the diversity of qualitative methods renders one style set of rigor criteria inadequate. Also, in many instances, the qualitative method used is not clearly distinguished from quantitative methods. Finally, applying the criteria of one tradition to another is nothing more than self-justification, and the belief that any method is without bias is flawed.

It would appear that the writings of Lincoln and Guba (1985), and Guba and Lincoln (1981) have provided the most expertise and guidance for judging the rigor of qualitative research. The later works of these authors (1989, 1990) build on the evaluative methods outlined in their previous treatise. Sandelowski (1986) has adapted the work of Guba and Lincoln (1981) to provide a framework to assess for rigor in nursing research. This framework considers four aspects: (1) consistency, (2) truth value, (3) applicability, and (4) neutrality. I have used this organizing framework to consider the rigor of this present study.

1. Consistency or auditability. Guba and Lincoln (1981) propose that auditability be the criterion for rigor of consistency in qualitative research. Two criteria are assessed to provide for auditability. First, another researcher should be able to follow the decisions in the data analysis made by the original researcher, and second, another researcher should be able to come to similar conclusions given the original researcher's data, research perspective and situation. In order to provide evidence of the test for rigor in achieving auditability in this study, I have followed the 12 steps outlined by Sandelowski (1986).

1. I have provided evidence about how I became interested in studying the experience of feeling healthy for people with chronic illnesses/disabilities.
2. I have made my personal assumptions about health within illness explicit and the existent theory and research has been explored. This was done to acknowledge my pre-understandings and pre-suppositions.
3. The specific purpose of the study has been provided.

4. A description of the participants and the criteria for their inclusion has been provided. A fuller description of the participants is covered in chapter four of this study.
5. The impact the researcher had on the subjects (and vice versa) is explored in this chapter and in chapter four of this study.
6. Evidence has been provided about how the data was collected.
7. The length of time involved in data collection has been given.
8. A description of the settings where the data was collected is provided.
9. An explanation of how the data were analyzed, transformed and interpreted has been given.
10. Evidence has been provided about how the data were weighted and why those decisions were made.
11. An explanation of the inclusiveness and exclusiveness of the themes developed to contain the data has been provided and will be further elaborated upon in chapter four of this study.
12. A detailed description is provided for the specific techniques used to determine truth and applicability in the following pages.

2. Truth value or credibility. "The truth value of a qualitative investigation generally resides in the discovery of human phenomenon or experiences as they are lived and perceived by subjects, rather than in the verification of a prior conception of those experiences" (Sandelowski, 1986, p. 30). Guba and Lincoln (1981) suggest that credibility be the criterion against which the truth value of qualitative research be judged. These authors consider three criteria against which a qualitative study may be judged credible. First, is there faithful interpretations of human

experiences so that those people who have the experience would easily recognize the interpretations (of the experiences) as their own? Second, a study is considered credible when other researchers or readers can recognize the experience when confronted with it, even though they have only read about it in the study. Finally, the investigators should describe and interpret their own experiences and behaviours as they work with their research participants. In this way, the threat of "going native" (Miles & Huberman, 1984. p. 230) or becoming enmeshed with the participants can be offset by deliberately focusing on how the researcher was influenced by, or influenced the participant.

I will address each of the three criterion for truth value as outlined by Guba and Lincoln (1981) and Sandelowski (1986).

1. Faithful interpretation of the experiences was attended to by providing the participants with my interpretations of the tape recorded, transcribed and analyzed conversations. These interpretations contained selected verbatim examples to clarify meaning. Further conversations ensued based on the initial interpretation so that greater clarity of meaning of the participant's experience was assured. The process of participant confirmation and clarification of their experiences continued until the participants and myself agreed that the experience had been fully explored and clearly presented.
2. Recognition of the experience by other readers and researchers was attended to by providing the results of this study to practising nurses, other clients with chronic conditions, and nurse researchers. The results of this study were given to two practising

nurses who are also nurse researchers. Having read over the results they both exclaimed that the experiences were clearly understandable and very interesting. Each of these nurses commented that the results of this study added to and deepened their understanding of the experience of health within illness. I was an invited keynote speaker at a conference for people with chronic illness, their family members and health care professionals where I presented the preliminary findings of this research. At the end of my address I asked the audience to complete an evaluation regarding the usefulness of my research findings. The questions I asked in the evaluation were: (1) Was my talk describing the experience of feeling healthy within illness helpful to you? (2) If you answered "yes" to the first question, would you please explain to me what was most helpful to you? (3) If you answered "no" to the first question, would you please tell me why it wasn't helpful to you, and what I might do in the future to make it more helpful? I received 95% of the questionnaires back and all answered in the affirmative. I will include some direct quotes from the conference participants responses: "Our daughter has a chronic illness and it is difficult to fully understand her true feelings about her illness. While we can't stand in her footsteps and truly understand, hopefully we have received more understanding of ; and downs. Also we can relate to the themes of feeling heal , self that she may feel too." A nurses's response was "I have nursed for 30 years. I agree that the medical profession has to change a great deal and treat people with chronic conditions holistically'y You gave us some new ways of

looking at how better to work with these clients." A participant who was newly diagnosed with multiple sclerosis said, "I am just beginning the journey you talked about. It gives me hope and a form of instruction to see the process and know that I am on the path and it can lead me to the place I want to be. At this point encouragement is a great motivator. These people you discussed are the people I want to get to know. I think I could learn so much from them. Everyone could." Another participant responded by saying, "it [my address] reinforced my present beliefs. Some different terms used to express similar thoughts that I can use to discuss with others." Finally, another respondent said, "I have experienced all of these levels and have obtained a level of wellness I am comfortable with--but I am ready to move on! You have encouraged me to continue." These selected participant responses from people with chronic illness, their family members and health care professionals affirm the value of this present study and speak to the credibility of the research findings.

3. I attended to the third criterion, that of describing and interpreting my own experiences and behaviours as I worked with my research participants by keeping a personal journal, and by engaging in dialogue with other nurse researchers as I collected, analyzed and wrote up the results of this study. In my journal I documented by own personal process, about how each conversation with my participants went, and what my overall impressions of the conversations were. I posed myself many questions such as, "why did you choose to ask this question?" and I critically analyzed my

behaviour and my experiences as the process of data collection and analysis continued. I also kept an open dialogue with several nurse researchers as I discussed my process, what had worked well for me and how I could see myself improving on subsequent visits. These nurse researchers helped me critically analyze my process as well as providing me with support in my endeavour. I was particularly cognizant of getting too close to my participants so that the process of participation and distancing (Heidegger, 1962) would be compromised. I am confident that this process provided me with the balance I needed to move from assessing the data as a whole, to moving to analyze the data in smaller units, and then moving back to judging the data as a whole again.

3. Applicability or fittingness. Sandelowski (1986) considers the issues of sampling procedures and representativeness in evaluating the rigor of qualitative research. She suggests that in sampling procedures, participants should be selected because they can illuminate the phenomenon under study. Any person's experience which describes well the research phenomenon can be considered appropriate information. Sandelowski warns against an "elite bias" (Miles & Huberman, 1984, p. 230) in that participants are often chosen because they are more articulate, high status or accessible than other members of the group. I have described how I chose my eight participants. I chose the first eight people who volunteered to be part of my study and who met my two criteria for inclusion. These two criteria were, (a) that they had experienced health within illness, and (b) could articulate an example of their experience of feeling healthy. One person was excluded because I assessed her to have a

difficulty in describing her experience at a personal level. It should be noted that it was very easy to find eight participants. In fact, several other people volunteered to be part of my study after I had judged that I had reached redundancy. This ease in finding participants is important to note because it would appear that although I could find no other research that investigated health within illness for people with chronic conditions, health within illness is not an unusual phenomena for this client group.

Representativeness in qualitative research refers to the data as well as to the participants in the study. I have attended to the representativeness of the data by providing prototypical verbatim examples from the transcribed conversations. Also, the titles of the themes were chosen by the participants, and are presented verbatim. As well as providing typical verbatim examples from the transcribed conversations, I have also presented atypical or contradictory verbatim examples whenever they were represented. This evidence is found in the results section of this study.

The threat of "holistic fallacy" (Miles & Huberman, 1984, p. 230) creates the illusion that the data are more patterned, regular or congruent than they actually are, and that the conclusions contain all the data. In fact, in this study there was congruity among the participants. At our third conversations, the participants expressed surprise at the similarities of their experiences among each other. Although each participant described their experiences quite differently, the essential themes were very similar. The major difference noted was in one participant who had been disabled since he was four months old. Because he

did not remember another way of being, he explained that his experience of feeling healthy was quite separate from his disability and he did not want to explore his experience from a health within illness perspective. In this case, we explored his experience of feeling healthy and after the conversations were analyzed and validated by the participant, it was obvious that his experience of feeling healthy was very similar to the other seven participants.

Guba and Lincoln (1981) suggest the criterion for fittingness be established in three ways. First, the study will meet the criterion for fittingness if the findings "fit" into contexts outside the study situation. Second, the readers must view the findings as meaningful and applicable in terms of their own experience, and finally, the results of the study must "fit" the data (both the typical and the atypical) from which they were derived.

I have provided evidence of the first criterion for fittingness by presenting the preliminary findings of this research to a workshop of people with chronic disabling conditions, their family members, and health care providers. I asked the workshop participants with chronic conditions whether these results related to their own experiences. These participants reported overwhelmingly of the "fit" of these results with their own experiences of feeling healthy. Also, these workshop participants described the benefits they had gained from learning more about the experience of health within illness.

The second criterion, that of assessing the meaningfulness and applicability of the findings was also addressed. I asked the health care providers at the workshop to assess these preliminary research results in

terms of this second criterion. These workshop participants commented on the usefulness of these results both in terms of expanding their knowledge of health within illness, and also in considering how to promote health for people with chronic illnesses or disabilities.

Finally, the third criterion, that the results of the study "fit" the data, was established in two ways. First, each participant was instrumental in developing the themes that represent the final results, and second, each participant exclaimed how the results fairly and comprehensively represented their experiences of feeling healthy.

4. Neutrality or confirmability. Neutrality refers to the issue of researcher bias (Sandelowski, 1986), and Guba and Lincoln (1981) suggest that confirmability be the criterion for neutrality in qualitative research. These authors suggest that confirmability is achieved when auditability, truth-value and applicability are established. I have discussed how I met the criteria for auditability, truth value and applicability as I attended to the rigor of my study.

Summary

An interpretive phenomenological research method was applied to study the question: What is the meaning of feeling healthy for people with chronic illnesses/disabilities? The philosophical considerations were attended to which provided the rationale for this choice of research method. The steps for data collection and data analysis were outlined. As well, the ethical considerations, and the issues of bracketing were attended to, and finally, attention was paid to the rigor of this study.

CHAPTER FOUR

PRESENTATION OF FINDINGS

The purpose of this research was to explore and describe the experiences of feeling healthy for people with chronic illnesses/disabilities. Prior to conducting the research, I undertook a pilot study with one participant. This pilot study provided me with important insights and information about the experience of feeling healthy within illness. Because of this important new learning, I will include the results of this pilot study as well as present the overall findings of this study. The research question which guided this study was: What is the meaning of feeling healthy for people with chronic illnesses/disabilities? In reporting the results, I have divided this chapter into four sections; (a) the pilot study, (b) introduction to the participants, (c) presentation of the healing journey, and (d) description of the meaning of feeling healthy for people with chronic health conditions. Whenever possible, the participants' voices are presented to provide for a vivid and descriptive account of their experiences and to ensure the phenomenon speaks for itself (van Manen, 1990). Each of the participants will be introduced by an agreed upon name.

The Pilot Study

I undertook a pilot study with one participant with a chronic illness in order (a) to gain greater expertise and understanding in the art of phenomenological conversations and (b) to learn to analyze and interpret the conversations efficiently and accurately. I asked the pilot

study participant to consent to talk with me about her experience of feeling healthy while living with her chronic illness. I also asked her to provide me with feedback on my analysis and interpretation. In this way the pilot participant and I became co-participant and co-researcher. I particularly asked this pilot participant to provide me with feedback regarding my ability to fully engage with her in a conversation which would explore and uncover her experience of feeling healthy. The questions I asked of this participant at the end of our conversation were:

(a) Can you describe for me how you experienced our conversation regarding your experience of feeling healthy while living with your chronic illness?

(b) Did we fully explore this experience together?

(c) What other strategies or questions might I have used to more fully explore this experience?

(d) What other suggestions do you have for me in conducting future conversations?

I gained new insights from the feedback provided by this pilot participant, the most important of which was to allow for silences so that participants could explore their experiences more fully. I learned to ask less questions and to follow the participant in a deep and meaningful conversation. I analyzed and transcribed this pilot conversation and returned my interpreted analysis to the participant. This process provided confirmation regarding my choice of the research question and my ability to analyze and interpret the participants' experience.

I discovered a very important aspect of my study from this pilot project. My pilot participant explained that in order for me to understand

and to explore fully her experience of feeling healthy, I would also need to know how she came to her experience of feeling healthy. She called this process her healing journey. She explained that her healing journey was an integral part of her experience of feeling healthy and, therefore, this journey must be explored and understood. Because of the apparent significance of this finding, I altered my approach to incorporate an exploration of the healing journey with my subsequent study participants.

The Participants

Helen

Helen, age 46, was born in Sweden and at the age of 3 years she came to Canada where she grew up in Montreal, Niagara Falls, and Toronto. She studied Home Economics at Ryerson College and worked as a chef and as a dress designer. Helen has had many career changes since that time, including working for IBM and the government. She considers that she has not yet found a career that she feels is right for her.

Helen is a single parent of a 10 year old son. She was diagnosed with Multiple Sclerosis (M.S.) almost a year ago although she had undiagnosed symptoms for 10 years prior to her diagnosis. Helen has no financial support and she relies on GAIN, an income supplement for people who are disabled and unemployed. She describes herself as living in poverty, however she says, "I refuse to live like a nobody, I want things for my son and I want things for myself, and I will get them."

At the present time, Helen is not well enough to work. She suffers severe fatigue and some lack of co-ordination. She told me her M.S. is the type that is progressive, without remissions or exacerbations. Despite

this fact, Helen talks of wanting to do something meaningful in her life. She is an active member of the M.S. Society and she attends and sometimes helps initiate workshops and support group meetings. In the future, she hopes to play an advocacy role for people with disabilities.

I first came in contact with Helen through the M.S. Society. I had telephoned to talk to the co-ordinator of the Society about my study, and to request volunteers. Helen volunteered immediately. On the first two visits we met in Helen's apartment. For our third conversation, Helen agreed to be part of a focus group which met in an office at the University of Victoria.

Helen seems to be a quiet, thoughtful, and contemplative woman. She considers her only luxury to be a stereo system which she bought from money bequested by her mother. She enjoys a variety of different music, but explained that she is mostly drawn to traditional and contemporary music which is more serious and contemplative. Helen also enjoys reading and she reads as much as possible within the constraints of her illness. Currently, she is exploring Native Indian spirituality.

Sally

Sally is a 43 year old single woman who has had Rheumatoid Arthritis for 14 years. In December 1979, while living in the Kootenays, Sally began to have severe joint pains which started in her wrists and then moved to different areas of her body. It took six months before a diagnosis was made. Because she had to visit a specialist in Vancouver at that time she was entirely alone when her illness was diagnosed. Prior to the onset of her illness, Sally had been physically very active; she ran regularly and

was an avid skier. As well, Sally worked full time as a nurse in labour and delivery, a job she described as "very stressful." Sally described her life at that time as being busy and full. Although she considered she had a lot of friends, when she was diagnosed she felt unsupported because the people in her life did not understand what she was going through. It was a time she speaks of as being "very alone." In the early part of her illness, Sally said she was in denial. She tried to live her life as she had before the diagnosis and, in particular, she did not pay attention to herself, either physically or emotionally. In this sense Sally said, "I kind of got what I needed, not what I deserved, but what I needed. I didn't need a life threatening condition to wake up."

Since those early days, Sally explained that she has done a lot of "waking up." The first real transition occurred when her relationship with her boyfriend broke up and she described herself as devastated. Out of those feelings of devastation came the realization that she needed to take care of herself, and that became her mission. Within the past two years Sally said she has worked hard at becoming "more awake" and has undergone many therapies, the most helpful of which was some intensive counselling. As Sally said "in the last six months, peace has finally emerged."

For many years following Sally's diagnosis she had to take a disability pension. During that time she returned to university to complete her Bachelor of Science in Nursing degree, and more recently she is completing her Master's degree in Counselling Psychology. Sally is now beginning to counsel women.

I had known Sally for a number of years before I asked her to be a participant in my study. The reason I asked Sally was that on many

previous occasions, when I had talked with her about my research interest, she had been both encouraging and supportive. We met for the first two research conversations in Sally's living room. Our third conversation was conducted as part of a focus group.

Sally explained that she has devoted many years to self exploration and self understanding. This exploration has occurred as part of her university courses as well as through following different healing modalities, and in considerable reading and reflection.

Sally appears active and vibrant despite her obvious deformities. She has a sense of fun and playfulness, and so, as we explored her many deep and meaningful experiences, we also enjoyed some laughter and joy. Sally said she is committed to a healthy lifestyle, she explained that she enjoys cycling, she eats well and she meditates daily. She is politically active, a strong feminist and a strong advocate for women and for people with chronic conditions.

Scott

Scott is a 28 year old man who was born with Spina Bifida, a congenital malformation of the lumbar spine and the spinal cord. This malformation was repaired when Scott was six weeks old and he spent the first twelve years of his life virtually unaware of his birth defect. When Scott was twelve, he began to experience foot drop. To begin with, he and his family thought he was just clumsy as he progressed into adolescence. The foot drop got worse, and eventually the scar tissue in his spine began to increase and his lower abdomen and limbs began to slowly lose their motor and sensory functions. This slow deterioration happened over Scott's

adolescent period and he described how he fought the progression of the deterioration by lifting weights. The weight lifting caused further damage to his spine but, despite this knowledge, he continued to weightlift because, as he explained, "when you are a teenager, your body image is everything." By the time Scott was 18 he was in a wheelchair. There is continued and gradual deterioration of his lower spine with spastic paralysis and muscle wasting of his lower abdomen and limbs.

Scott has a Bachelor of Social Work degree. He is married with a 2 year old daughter. He works with other physically challenged people as a counsellor. He is also a consultant to architects and engineers in planning buildings and facilities for people with disabilities. He also acts as a client advocate.

Scott was introduced to me following a meeting where I discussed my proposed research. He volunteered to participate in my study. On all three occasions, I met Scott in his office. We closed the office door, transferred the telephone to the main switchboard and held our conversations at his desk. The third conversation was very short and so we followed it up with a telephone conversation.

Scott is a young, strong looking man. As he spoke, he often used his hands, and he was very expressive and animated. He is involved in many wheelchair sports and he plays competitive basketball. Scott explained that he does not allow his disability to confine his activities; he has learned to scuba dive and most recently he is learning to surf. Scott appears to have a lot of vitality and energy which exhibits itself as a forceful presence.

Sheila

Sheila is a 37 year old single woman who was diagnosed with Multiple Sclerosis five years ago. For a year prior to her diagnosis she was having symptoms which were diagnosed and treated as psychiatric problems. As Sheila explained, "the diagnosis came as a relief, it gave me liberty, justification; here, I have a little label, see!" For the first three years following her diagnosis, Sheila explained that she had no energy, she felt drained and she could hardly walk around a block. She had continual fatigue and lacked coordination and felt clumsy. In those early days, she still tried to persevere as a teacher, and even enrolled in a graduate degree program until she finally realized this endeavour was impossible for her at that time.

On looking back on her career, Sheila said that she really did not enjoy the rigid structure of the school system, and she felt that despite being a good teacher, she never really fit in. She is now on a disability pension and she is grateful for the opportunity she has been given to re-evaluate her life. As she explained, "I had given myself a four year plan to get out of teaching, but this came along and took care of that."

I contacted Sheila via the M.S. Society when I requested volunteers. The first two conversations were held in Sheila's home and the third conversation was part of the focus group at the University of Victoria. Sheila appears to be a bright, intelligent and sensitive woman. She explained that she thinks very deeply about her life, as well as being concerned for society in general and for the well-being of our planet. She is an avid reader and suggested to me many interesting and insightful books on healing, both from a personal and an environmental perspective.

In the last two years, Sheila's health has begun to improve. She undertakes many different healing modalities. Because she describes herself as a person who tends to stay "in my head," Sheila does a lot of body work including massage therapy, chiropractics, acupuncture and acupressure, as well as taking special herbs. As she explained, "much of my healing work has occurred through my body." Sheila is also an active member of the M.S. Society where she conducts and attends workshops and some support group meetings.

Malcolm

Malcolm is a 24 year old single man who contacted polio via the administration of the polio vaccine when he was four months old. His left leg is totally paralysed except for some movement of his toes and some hip flexor movement. He is also paralysed in his right leg above the knee, and his right knee is also somewhat affected. When Malcolm was four years old he had surgery to lengthen his achilles tendon and he was then fitted with leg braces. Since that time, Malcolm has walked with leg braces and crutches. He uses a wheelchair only for wheelchair sports.

Malcolm explained that he was encouraged to grow up as an able bodied child. He was encouraged to ascertain his own physical limitations and, as a result, he said that he considers himself to have very few limitations which he explains are "merely mechanical." As Malcolm explained,

Being encouraged to ascertain my own physical limitations (by trial and error) made me understand that my disability is only physical, or mechanical, and is unrelated to any other aspect of myself such as emotions, personality, intellect, etc. My disability results in physical limitations, the other limitations I have are entirely my own, as a human being.

In this respect, Malcolm is quite different from the other participants in that he never knew another way of being. He grew up with his disability, whereas the other seven participants had to come to terms with their illness/disability. For this reason, Malcolm did not describe a healing journey. He explained that he had not experienced this aspect in his life. He focused exclusively on his experience of feeling healthy which he stressed had no bearing on his physical disabilities.

Malcolm appears to be a serious, thoughtful person who exhibits much self-discipline. He described himself as an effective problem solver and someone who is good at managing and organizing his life. He is a recent graduate with a Bachelor of Arts. In the future, he hopes to take a graduate degree in English and teach at a community college. Malcolm is working as a consultant to the Commonwealth Games. His consulting work includes planning and judging the accessibility and availability of wheelchair access and other facilities for spectators and athletes with disabilities. Malcolm is a wheelchair athlete and competed in the Seoul Para-Olympics, coming fourth in the 5000 metre race.

I was introduced to Malcolm through Scott. Both these men play wheelchair basketball and Scott told people of my study and Malcolm volunteered. The first conversation was held in the living room of my house, and our second conversation occurred over lunch in a restaurant. Malcolm declined to be interviewed on the third occasion. He explained that because he had not experienced the healing journey, he thought he would have nothing more to contribute to my study.

Lyn

Lyn became a quadriplegic in 1971 at the age of 24. She was on the way to her wedding when she and her fiancé were involved in a head-on car collision. Despite the extent of her injuries, and the knowledge that she would remain paralysed from her neck down, she and her fiancé married at her hospital bedside eight days following the accident. Lyn explained that for the past 22 years she and her husband have remained very much in love and provide much mutual support to each other.

Although Lyn is a quadriplegic, she has some traces of movement in various upper body muscle groups with some degree of sensation. She is able to manoeuvre her own electric wheelchair and therefore, she has some degree of independent movement. As Lyn is getting older, her circulation is diminishing which causes cramping and pain in her legs. Also, Lyn suffers from frequent urinary tract infections and she is finding that her stamina is diminishing in the last few years.

Following the motor vehicle accident, Lyn was hospitalized for 23 months in various institutions. She explained, "that was our honeymoon." Lyn is now a well renowned artist and has had many successful art exhibitions in B.C. and in Nova Scotia (her home province). As well, she has choreographed several dance performances and provided workshops devoted to learning more about people with disabilities. Lyn has also received many commendations and awards, including the Vanier Award. Before her accident, Lyn was a registered nurse and she has recently attended university to complete her Bachelor of Science in Nursing degree. Lyn intends to work in mental health as an art therapist in the Fall. She is presently self employed as an artist and, with her husband, owns and runs

an art gallery. Lyn's paintings are known in different parts of the world and acquisitions have been made in Holland, the United Nations in New York, the Human Services Administration in Washington, D.C., as well as throughout Canada.

I have known Lyn for many years and she has been an inspiration to me in wanting to explore this present study. Despite her obvious and profound disabilities, Lyn insists that she feels predominantly healthy. This led me to wonder how health is experienced for people with chronic illnesses/disabilities, and thus to my present research question. Our first conversation for this study was held in Lyn's home and our second conversation was held at my home. Because Lyn lives some distance from me, our third conversation occurred over the telephone, after she had written a lengthy and detailed account of her impressions of reading each of the other participant's stories.

Lyn appears to be a dynamic, energetic yet thoughtful and caring person. She explained that she can be serious and intense, particularly when she is painting or studying. However, she can also be exuberant and joyful. She described herself as being committed to helping people with chronic conditions, which she does by providing educational workshops, individual counselling and art therapy. Lyn is politically active, both at the municipal and federal level. She is also a strong advocate for people with disabilities.

Ann

Ann is a single 36 year old woman who has had severe asthma since she was a year old. To compound this problem, Ann also developed a weak

diaphragm which has resulted in her going into respiratory failure on a number of occasions. Ann has had a permanent tracheostomy since 1986 and she has been on continuous or intermittent ventilation since that time. In the past five months, Ann has been improving to the extent that she has been almost entirely free of her ventilator and there is consideration of removing the tracheostomy tube.

Ann has spent more time in hospital over the past 10 years than she has spent out of hospital. As she said, "It was part of my identity." It is only in the last three years that this trend has reversed. In 1985-86 Ann spent 14 months in hospital, seven of which were in the intensive care unit. A part of that time she was continuously ventilated and her tracheostomy tube was cuffed which made it impossible for her to speak. She said, "I hated that, I like to be able to talk." She would write copious notes to the medical staff, to such an extent that they started to give her smaller note pads. This tactic did not deter Ann; she just wrote smaller!

Ann was born in Africa and lived first in Zimbabwe, then Zambia, and she finally went to boarding school in South Africa. At age 11 she and her family moved to Canada.

Since Ann's recovery process, she has started to enjoy new hobbies and to consider new options in her life. She enjoys quilting which she is just learning, and she is in the process of making a quilt for her sister's wedding present. Ann has also started ballroom dancing and her goal is to dance the "Blue Danube Waltz" with her father at her sister's wedding. Ann has recently started bible study and she attends bible

classes at the home of a local Mennonite church member. She also enjoys reading.

Despite Ann's continual and severe illness, she became a registered nurse, and worked periodically in acute care nursing. More recently, Ann has completed her Bachelor of Science in Nursing degree, completing most of her courses by distance education. These courses were undertaken during her long hospital stays. At present, Ann is on a disability pension, but she is hopeful that in the future she will be able to return to her profession. This return is one of her goals.

I first contacted Ann at the recommendation of a nursing student who had heard about my research. Our three conversations took place in Ann's living room.

Ann appears to be a quiet, thoughtful and reflective person. She has had many challenges in her life including being told on two occasions that she was dying. She is very soft spoken, which is partially due to her tracheostomy tube, but it also appears to be a personal characteristic. Although our conversations were very thoughtful and reflective, we also had moments of joy and humour. As she explained "I love to laugh."

Catherine

Catherine is a 37 year old single parent who was diagnosed with Muscular Dystrophy (M.D.) when she was 18 years old. Catherine was brought up in a household where her father was an alcoholic and she describes those days as "living in an environment of stress." When Catherine was in her early adolescent period she turned to alcohol and drugs, as she described, "I went berserk." Looking back on those years, she explained

that she was running away from her emotions and from her life. Catherine married when she was eighteen. Three weeks after her marriage she was diagnosed with M.D. She explained, "It was really difficult because I wasn't prepared for marriage, let alone being prepared for this." After Catherine's diagnosis, she decided to have a child because she realized that this would be her only chance. Nine months after her marriage she became pregnant, a decision which was not supported by her husband. When her daughter was 10 months old she and her husband separated and divorced. Her ex-husband has had no further contact with Catherine or her daughter. Catherine's daughter is now 17 and Catherine has been alone in bringing up her daughter throughout that time. Just recently, Catherine has met a man to whom she is very close, and she now describes her life as being more fulfilled. Her new partner has also suffered a severe disability from which he is recovering, and his experience has greatly enhanced his ability to be supportive and caring of Catherine.

Catherine described herself as a sensitive person who internalized her emotions a great deal when she was younger. She considers that this is the reason she turned to drugs and alcohol and became so self destructive. After Catherine's diagnosis, she explained that she spent four years trying to deny her condition during which time she continued her destructive life style. When she was 22 she felt she could no longer ignore her condition. This realization forced her to confront her diagnosis and her life. As Catherine explained, "the illness saved my life, it forced me to choose life at 22."

Catherine now has limited movement in her body and uses a scooter when she leaves her home. Because of her own illness, she now counsels

other people with chronic illnesses. She explained that she is an intuitive person and because she has had similar experiences, she is able to help others move beyond their blocks, to new levels of self awareness.

I met Catherine as a result of telephoning a counsellor who works with people with chronic illnesses/disabilities. I explained the purpose of my study and requested volunteers. Catherine telephoned me as a result of that request.

Catherine appears to be a thoughtful and sensitive woman. She has devoted much of the past 10 years to self exploration and self healing. She has followed many different healing modalities and explained that the most effective have been the ones that work predominantly on her body. She is now an excellent resource person to other people with chronic illnesses or disabilities, helping them access the healing modalities that would be most helpful to their healing.

On the three occasions I visited Catherine, we met in her home. In her living room are some beautiful stone carvings which she has done. She explained that her creativity is an important part of her healing. Although Catherine is thoughtful and sensitive, she also exhibits great joy and enthusiasm, and on many occasions we enjoyed times of laughter.

In summary, I have introduced the eight participants in this study. Despite their differing chronic conditions and different personalities, these participants had many experiences in common. In particular, except for Malcolm, who had never known life without his disability, each participant described the healing journey as an integral process in coming to experience feeling healthy while living with their chronic illness/disability. As I describe the healing journey and the experiences

of feeling healthy, I will use participants' words to entitle the themes. Also, I will include verbatim quotes from the participants to breathe life and authenticity into the participants' experiences.

The Healing Journey

The healing journey emerged from the data as an essential process for the seven participants who had become ill or disabled later in their lives. These participants had experienced life without a chronic illness or disability. Because of this previous experience the participants described the healing journey as an essential process which led them to experience feeling healthy. Therefore, as our conversations evolved, the exploration of the experience of the healing journey was integral to the exploration of the experience of feeling healthy. The participants also stressed the point that they still experience elements of the healing journey. In this sense, the healing journey led the participants to their experiences of feeling healthy, but they have not left the experiences of the healing journey, instead, they continue to experience this healing journey, but with new knowledge and new awareness. Sally explained this experience when she said:

The process of healing is a spiral process, a sense of wholeness The journey is a spiral, the process is a spiral. The issues come back, they come around and now I learn, here I am dealing with it, I came through it and so I have changed. I have learned something about myself and the next time it comes around I know more about myself, I am in a different place, still the spiral, still the same issue, but I am in a different place.

In this sense, as the participants became aware of their experiences of feeling healthy, they experienced the healing journey in a different

way. They explained that they had more self awareness and more confidence in their ability to attend to the important issues in their healing.

As the participants experienced their healing journey they talked of moving toward a sense of wellness. They described this process as a "journey," "a process of discovery," an "unfolding," and an "evolution." These descriptive words characterize the movement and growth involved in the participants' healing. As Catherine explained:

Everything is in motion, everything is always moving, things are always changing, an ebb and flow There is a lot of healing and a lot of clearing and sorting out that goes on with this . . . it is like a snake getting a new skin.

Like a snake shedding an old skin and getting a new one, the participants spoke of a sense of renewal which brought with it a sense of wonder and joy. Witness Sheila's comment:

The true meaning of my life lies in the journey The journey is an evolution, with awakening, not static, not an orderly linear thing. I find this so enlightening and empowering, to look at this as a journey instead of focusing on the illness. It is a journey of my soul.

In this sense, although the healing journey involved many struggles and many painful emotions there was also a sense of an evolution to new awareness and new experiences. Helen described this experience when she said, "This is my spiritual journey of self exploration, self love and self acknowledgement."

Seven themes emerged which seemed to capture the healing journey. These themes include:

1. In the Beginning
2. Hitting the Wall
3. Turning Around
4. Letting Go

5. Opening Up

6. Letting In

7. The Gift

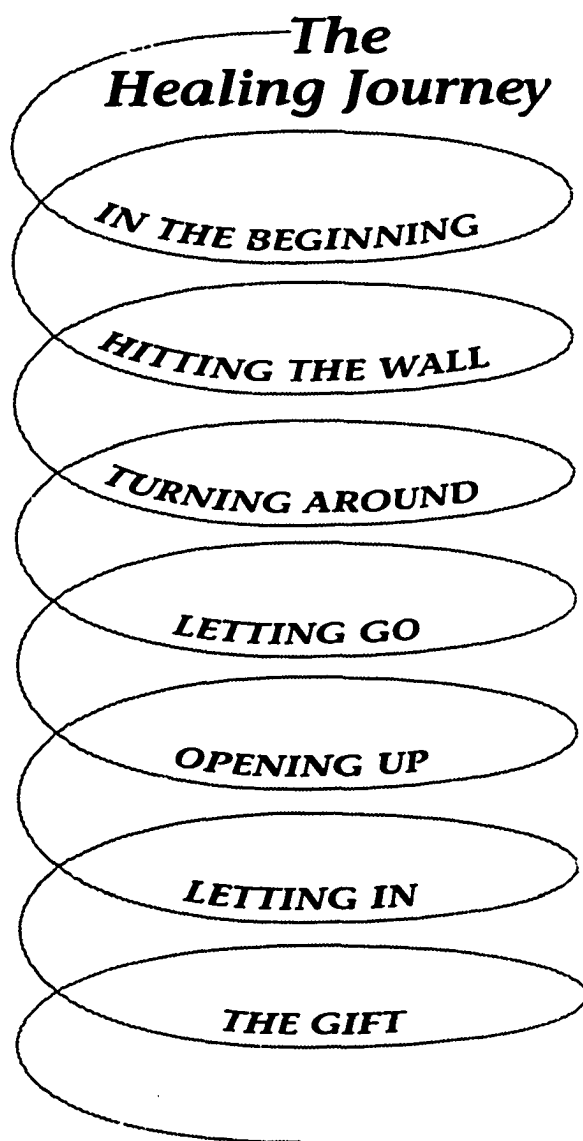
Figure 1 provides a visual image of this healing journey as a process of continual motion and evolution. The spiral illustrates the interconnection, the interrelatedness and the movement that occurs between the themes of the healing journey. In this sense, although there appears to be a hierarchical order to this healing journey, in essence, it is more a continuous, cyclical process which is expansive and evolving.

As I present the seven themes which represent the healing journey, it is important to be reminded of Sheila's comment that the journey is not a "static, not an orderly linear thing." Instead, although I present the healing journey as an orderly progression, it is more as Sally described it, "a spiral," or as Catherine described the continual movement and an "ebb and flow."

In the Beginning

The beginning of the healing journey started with the onset of symptoms, the diagnosis, or the accident. For each of the participants, this starting point was somewhat different. For Lyn it started with her motor vehicle accident and the severance of the spinal cord in her neck. For Scott, it was the realization that he was not being a clumsy adolescent, the scar tissue from his Spina Bifida was beginning to deteriorate his spinal cord. Catherine's Muscular Dystrophy caused severe fatigue and muscle weakness, and Sally's Rheumatoid Arthritis caused sudden and very severe joint pains. For Helen and Sheila, the onset of

Figure1. The themes of the healing journey portray a spiralling, synergistic, evolving and expansive process.



their Multiple Sclerosis was more insidious, and the diagnosis was elusive for many months or years. For Ann, although she had severe asthma since she was a year old, the diagnosis of her weakened diaphragm and the need for artificial ventilation came later in her life.

For Lyn, Scott, Catherine, Sally and Ann, the onset of their symptoms, the diagnosis or the accident represented a crisis in their lives. In contrast, for Helen and Sheila, whose Multiple Sclerosis had been misdiagnosed or undiagnosed for a long time, their diagnosis came as a relief. Although Sheila and Helen's initial experience at the onset of their diagnosis was different, all seven participants went on to experience similar emotions in the beginning of their journey. In the beginning the participants talked of the shock of their diagnosis. Although Helen and Sheila were relieved at the initial diagnosis, later they began to experience the shock of the implications of their diagnosis. With this sense of shock the participants talked of denial, anger and despair. Sally described this time:

The onset of my illness was a spiritual crisis. There was this hollowness, and a sense of running away. I felt so awful, the devastation, the despair, not wanting to be alive. I didn't want to look at my own vulnerability, I wasn't listening to the pieces saying, 'help, help, help'. There was this gripping, this holding on to old ways which needed to be let go of.

Similarly, Scott talked of this time of anger, depression, isolation, and denial when he explained:

I refused to pay attention to my deteriorating body. I went through a period of self hate and depression. I had an "I'll show you" attitude. I was learning life the hard way, the lessons life teaches me. I went through it alone.

The participants talked of feeling very low, with a sense of bleakness and despair. Catherine and Scott purposefully isolated

themselves from the people in their lives. They felt that they had to endure these feelings of anger, sadness and despair alone. They talked of a false pride and of not wanting others to know their vulnerability. In this sense they closed themselves off from all overtures of help from others. For each of the participants it was a time of feeling very alone. Sally explained that none of her friends or family seemed to understand what she was experiencing, and Ann tried desperately to protect her loved ones from the full impact of her illness.

This period was also characterized by strong feelings of fear. Catherine described it as "quaking in my bed fear." For the participants this fear was mostly a fear of the unknown. Suddenly their life as they had known it was no longer available to them. They talked of fearing the future of how their illness or disability would progress and particularly what physical changes would occur. At this time, Scott began to weight lift. Although he was warned that it might further deteriorate his spine, he felt the need to exhibit a strong upper body to boost his self esteem. Also, Scott struggled for five years with crutches before he relinquished the struggle and accepted a wheelchair. Lyn hated people dressing her, doing her hair and making her up and she was often angry and critical of their efforts. Overall, this period was characterized by a sense of despondency and a low self esteem. Witness Catherine's expression:

I had so much harsh self judgement, which contributed to a contraction within me, a rigidity, a stiffness and a building up of walls which were impermeable When I looked, I saw what I didn't want to see. I was very prejudicial against myself.

The participants also spoke of this time as a period of confusion with a sense of feeling vulnerable and powerless. Lyn, Ann, Catherine and

Scott had to rely on others to help them with their daily tasks, and Sally, Helen and Sheila had to reduce their activities and make changes to their life styles. Because of these experiences, the participants began to feel out of control in their lives. They resented relying on others, or reducing their expectations or activities. This resentment led to a sense of powerlessness and a lack of control. Scott explained this experience when he talked of being hospitalized, "when I went into hospital I gave over my self control to the doctors and nurses. As I lost this control, I began to feel physically weaker." Similarly, Sheila talked of visiting her physician, "When I walked into my doctor's office, I gave myself over to him. I realize how much power I was giving away when I did that." In this sense, as the participants experienced the onset of their chronic condition and their diminished physical abilities they experienced a sense of vulnerability, powerlessness and lack of control. Helen summed up this bleak period when she said, "The lows were right down there, a lot of grieving for a lot of things."

Hitting the Wall

Many of my participants "hit the wall," or "bottomed out." They sunk to their depths. At this time, six participants either attempted to, or contemplated suicide. They talked of thinking that there was no purpose in living. As Catherine looked back on that dark time she explained:

Sometimes there is such a snowball effect of trying to cope and integrate and adjust to this change in your life that you have to hit bottom before you can get off that. It is like a merry-go-round, a roller coaster, it is an ever increasing panicky thing. You are trying to run away because you don't know how to cope with it.

Scott made four failed suicide attempts. Lyn tried to overdose on one occasion, and Ann made two suicide attempts over one weekend. Sally,

Catherine and Sheila contemplated suicide, but did not make an actual attempt. At this point, the participants could see no future for themselves. Scott could not bear the anticipation of further deterioration of his spine. At this stage, Scott's self image was closely aligned with his physical body, and he could not tolerate the thought of further physical deterioration. Ann had been told that she might have to remain on a ventilator for the rest of her life, and this thought was intolerable to her. Lyn could see no purpose to her life. She could see no usefulness in her life, and no hope for a meaningful existence. Catherine, Sally and Sheila feared further progression of their illness. All of these experiences contributed to the participants *hitting the wall*. They did not know how they would cope, or what new symptoms or deformities might occur. They were also receiving so much advice, and for Sally, such large doses of medication, that they felt out of control with a sense of hopelessness for their future. Catherine described this experience when she said:

If this is what life was all about, then I would rather be someplace else. It is giving up an identity, that is what dies. When you get to the place where you think you would rather die, it is not me that's dying, it's my identity that I have had of myself as somebody who was a victim, out of control, and we are trained to really identify with that victim status in our culture.

In this sense, Catherine is not so much talking of her own physical death as a death of her identity as a victimized and out of control individual. Catherine further suggests that our society in general, and health care professionals in particular, encourage people with chronic conditions to adopt this victim role. For Catherine, gaining this awareness led to a turning point in her healing journey. Similarly, as the other participants came to the realization of their attempted suicide, or

to their contemplation of suicide, this acted as a turning point in their healing journey.

Turning Around

The participants talked of this theme in their healing journey as a turning point. For some this was a rapid turn around, and for others, it was more of a gradual movement away from suicide ideation to confronting the challenges of their chronic condition. Sheila described sitting in her physician's office and describing to him some of her experiences and she heard herself saying that she might contemplate suicide. She could not remember thinking of suicide before this comment, and the shock of hearing herself verbalize this consideration provided a definite turning point. She explained, "I was so shocked, and then I thought, no this isn't what I want, and I began to think differently about myself and my illness."

Scott made four failed suicide attempts and after the fourth attempt he began a very slow turn around. He explained:

I fell asleep, I fell asleep because I was so tired, and I woke up next day and realized what I had been thinking about the night before [to commit suicide], and at that point I started to deal with what it was that I was going through and I realized that although physically my body couldn't heal, my mind was beginning to heal and my heart was beginning to heal. It is like I got my life back, I took it back. I then started to stop pretending, and hiding, and being an empty shell.

In this sense, as Scott awoke from contemplating his fourth suicide attempt, he began the slow process of turning away from suicide ideation and to begin to heal. He began to take control of his life and to change his attitude and his behaviour toward himself. This was a time when the participants talked of beginning to take control of themselves and their lives. They moved from feeling powerless, vulnerable and out of control,

to taking steps toward asserting control in their lives. Catherine talked of this gradual turning around and to becoming more assertive:

I gave up looking for a cure. I began to ask myself what I can do to increase the health I have, and I stopped waiting. This was a really big step, to move from the doctor said 'this' therefore that is my reality, to live according to this prescribed thing. And it took a long time to say 'no, that is only one opinion', and not being furiously angry with them, because that gives them the power too. But moving through the steps . . . I am going to go through this without the expectation of necessarily getting better, but I am going to quit resisting my emotions and discover what is on the other side of my fear. I am going to express who I am, I'm not going to deny my desires, I'm not going to deny my dreams, my goals, I am not going to deny what I want.

For each of the participants, this turning around process was somewhat different. Scott began to realize his mind was healing and he was beginning to confront the challenges of his disability. Lyn returned home from the hospital after her failed overdose with a prescription for the same medication she had taken as an overdose. She explained that her physician suggested that only she could be responsible for her life and that he understood she would do what she thought was right. As the physician explained this sense of self responsibility, Lyn began to feel more responsible for herself and her life. With this new sense of self responsibility, she began to make meaning of her life. It was soon after this episode that she began to take her painting seriously. Catherine began turning around by becoming more assertive and taking control, and Sheila gradually moved from self pity to self love. Although Ann remained ventilated, she began to appreciate the smallest events in her life. This sense of appreciation was new to her. As she began to turn around she began to set small and very realistic goals for herself. She explained:

I have to take baby steps. I think that is part of my health.
I have always given myself little goals I know I can manage.

If I set mini-goals and realize them, even if I know they are really realistic, even by reaching them, it makes me feel open to the sky. Because I have reached this little goal, then I can move on to the next little goal. I have reached a lot in my life with little goals.

Sally turned from denying her feelings and experiences to confronting the experiences of her illness, and to becoming more understanding and self aware.

Letting Go

As the participants began to describe this letting go process, Catherine was insistent that I fully understand the verb "to let." She explained:

I think the word let is a very active word, 'learn to let.' That assumes that I don't have to do everything for myself. It recognizes that I am part of something that is already happening. I just need to do my part.

The reason the participants were so insistent that I understand "let" to be an active verb was because they had had unfortunate experiences with health care professionals who had suggested they "accept" or "surrender" to their chronic condition. This advice had been unhelpful or even detrimental to their healing process. They considered the words "acceptance" and "surrender" to be passive and to suggest a process of acquiescence, or giving in, which was the antithesis of their experience. Perhaps Catherine's words best exemplify this notion:

Acceptance is important, it is sort of letting go, but it is not enough because it can be misconstrued as acquiescence or indifference. My neurologist said I should accept my illness. I will never accept it, I will adjust to it, but never accept it.

The participants played an active and participatory role in letting go of their debilitating emotions and their unrealistic expectations. This process led to a sense of empowerment. Scott described this experience when he suggested that the word adjustment is more appropriate than acceptance because adjustment suggests active participation:

Adjustment means having choices, and the kind of choices I make depend on the kind of adjustment I make. This requires action and leads me to a sense of empowerment and feeling healthy.

Catherine described the courage it took to begin to let go:

Letting go requires courage and a leap of faith. I had to let go of that fear and desperation and come to a place of asking God, of trusting and letting go. Letting go of an old frame of reference, old ways, the "shoulds," not feeling comfortable in my own skin, always pushing myself.

The participants considered that letting go of their debilitating emotions was an essential process in their healing. Helen suggested that as she struggled to deny her experiences, she prolonged her negative and debilitating emotions. She explained:

The more I struggle against it, that's what hurts, that's what hurts so much. You know, I can spend days, months, fighting against something, years, and if I give in to it, kind of letting go, and just letting myself feel, and the feeling isn't as bad as all that anticipation, it goes quite quickly. The pain doesn't need to be prolonged, it doesn't need to be so intense.

In this sense, the participants saw the process of letting go as an essential step in their movement toward healing.

Sheila also talked of letting go, and she suggested that this process is a continual experience for her. She is aware that she often blocks negative experiences and emotions, and she has to be aware of this and allow herself to face these experiences. She explained:

The letting go, I'm not finished, there will always be more, there is a continual awakening and a freedom to explore There is a lot of letting go of attachments, of having things go a certain way, and a lot of acceptance . . . not blocking. I am now more open and less likely to judge myself and others harshly.

Letting go was a critical element in the participants' healing journey. Before the participants could move forward, they had to let go of their debilitating emotions, to their sense of resistance and denial, and to their unrealistic expectations for their future. This movement took courage and an element of trust. The participants took an active, participatory role in this process which led to a sense of empowerment.

Opening Up

When we are willing to fully experience a particular feeling such as fear, anger, loneliness or confusion and embrace that emotion without judgement, the blocked energy releases quickly and the feeling dissolves, allowing us to feel more peaceful and open.

Shakti Gawain.

The participants talked of opening up to new experiences. Instead of blocking or denying their experiences and emotions, they became open to them with a sense of exploration and anticipation. Catherine explained how she moved from feeling blocked by a wall of fear, to considering the wall a membrane which she could move through, to fully explore her fear, and to expand her awareness. She said:

I am always open to whatever is happening in my life . . . and let the awareness come . . . I have to be present, aware and conscious. It is like coming home.

Sally also talked of an opening up, to moving away from the blocks she had created, and to start having a caring and sensitive dialogue with herself.

She explained:

I think a lot of my problems were around blocked energy, and this causes weakness. I had to learn to open up. There is this dialogue I have with myself, between me and my symptoms. When something happens, saying 'what is going on?', 'What does this mean?', 'What do I have to do here?' I am now sensitive enough to listen to my body and hear what it is saying. I often talk to myself, particularly if I am upset, I will say 'What are you afraid of?' 'What is the worst thing that can happen?' 'What can we do together?' 'What is it you need?' Often there is a little voice inside me saying 'you have to take care of me'.

In this sense, Sally trusts her inner voice. She is now opening up to listen to it more carefully; as she explained, "I listen to the wisdom of my body."

With this growing sense of awareness came a new appreciation for life. Instead of the fear, the isolation and the anger of their early experiences, the participants began to see life from a new and more positive perspective. Witness Scott's comment:

I began to reach out. I started to experience. I think the next thing was a real appreciation for raindrops, you know, the rain hitting my face and I'm alive and experiencing this, and living this right there in that moment and I'd go, 'this is great!'

Similarly, Helen began to experience a sense of anticipation and excitement as she opened herself up to new experiences and to new possibilities in her life. Like Sally, Helen began to trust herself and to listen to her emotions instead of feeling constricted and bound by debilitating emotions, she explained:

I am beginning to trust my intuition, to listen to myself. I am opening up to myself, letting myself in. This is exciting, really exciting, the true excitement, and I think I am only beginning to learn.

As the participants began to open up, they moved away from blocking and denying their experiences and emotions, to allowing these sensations in. With this experience came a sense of anticipation and exploration. The participants became sensitive to their physical and emotional needs and to trust their inner voices and their inner knowing. With these experiences the participants came to a new appreciation for their lives, and to an excitement and an anticipation for their future.

Letting In

The process of letting in involved three important issues. First, the participants began to explore different healing modalities, which, in turn lead to a second issue, an altered relationship with health care professionals. The third issue involved a slowing down process, as the participants began to fully appreciate and acknowledge their healing journey.

As the participants opened up to explore new experiences, they also began to acquire new skills and new learning. Of particular note was their exploration and participation in different healing modalities. For some of the participants, the healing modalities which were most helpful were the ones that worked on the body. Some healing modalities the participants talked of were acupuncture, acupressure, therapeutic touch, chiropractics, naturopathy, homeopathy, massage therapy, vitamin and herb therapy, diet, biofeedback and yoga. For other participants, the healing modalities they found most helpful were those which focused on the mind, the emotions and the spirit. Some of these healing modalities included meditation, visual imagery, dream work, counselling, art and music therapy, following Eastern

Philosophies, and reading and attending workshops to learn more about their health problems and about themselves as people. They also talked of following traditional religious practices, and for two participants, they followed Goddess type religions.

The important element for the participants was to reach a balance between their minds, their bodies and their spirit. For the participants who considered that they were more cognitive in their approach to healing, the body work provided a balance to this approach. In contrast, the participants who focused their healing through body work, their balance was sought through also attending to their minds, their emotions and their spirit. The participants talked of this balance as "channelling the mind, body and spirit," and although they mostly favoured one healing modality over others, they all partook of many forms of healing.

In following these healing modalities, most of the participants sought the help of others. Scott, however, preferred to do his healing work alone and from within. As he explained, he can only be helpful to others after he has healed himself from within, "and this is a very personal and private process."

As part of the healing process and the exploration and experimentation with different healing modalities, Sally suggested that it is not so much the healing modality as the belief and value she places on its efficacy that is important. She explained:

There were times when I tried different diets, naturopathic remedies and different forms of healing. I went through the motions and hoped for improvement, but I didn't actually believe in them. It really isn't so much what you do, it is what you believe. If you believe in something, all things are possible.

The different healing modalities provided an opportunity for the participants to look far beyond their physical limitations, and to begin to acknowledge and embrace other important aspects of their lives.

Catherine explained:

It is the value I place within myself, that I know, even if my physical body crumbles, I will still be me. That is the process of discovery. I am getting acquainted with so many other parts of myself than just the relationship I have with my physical strength and body.

In this sense, the participants talked of a re-definition of the self which minimized the body's physical condition.

As the participants began to take responsibility and control for their own healing and to explore different healing modalities, they found that their relationship with health care professionals tended to become unsatisfactory. The health care professionals tended to adhere to the tenets of traditional medicine, discounting the benefits of complementary healing modalities. However, this discounting was not always the case. Sally and Sheila searched for and found sympathetic physicians. On the whole, the participants' relationship with health care professionals was strained. For each of the participants, they had come to understand that the health care professionals' opinion was just that, one opinion.

Depending on the relationship the participants had with their health care professionals, they tended to take one of two paths. The participants either told their health care professionals very little about their healing journey and the different healing modalities they were pursuing because they feared ridicule and disapproval. As a result, they engaged in a covert caring for the self. Alternatively, some of the participants tried to educate and change the perspective of the health care

professionals. This second option only occurred if there was an element of trust in the relationship. All the participants avoided (wherever possible) health care professionals who would not allow them some degree of autonomy and control. Each of the seven participants who explored and described the healing journey, suggested that the health care professionals played a very small part in the healing process. Plato alluded to the health care professional's inability to promote healing with his words:

The cure of many diseases is unknown to the physicians of Hellas, because they are ignorant of the whole, which ought to be studied also; for the part can never be well unless the whole is well.

Plato.

The third issue of letting in involved the participants ability to slow down. Helen, Sheila and Sally had had stressful careers which they had put before their own personal needs. Helen likened herself at this time to the White Rabbit in Alice in Wonderland, of rushing from one task to another and never slowing down enough to take stock of her life. Each of the participants now appreciate their ability to take life more slowly and Ann referred to, "having time to smell the roses." Helen's experience of her slowing down process provides insight to this radical change of pace:

It's almost like travelling on a jet plane and suddenly I am walking. It's like that kind of traumatic difference, and I am just learning how to enjoy walking . . . I have been the white rabbit for so long, rush, rush, rush, not really paying attention, the trip has to be done, whereas now I think I am on a journey and the destination is unknown. I like that, it is not important. I like the journey, finding out more about myself, that is big, right there, finding out more about myself.

As the participants slowed down and began to fully experience their healing journey, they began to create opportunities for self reflection and new learning. Instead of being caught up in the frantic pace of life, they had learned to become more peaceful and tranquil and to let in new experiences and new learning.

The Gift

As the participants described their healing journey, they all spoke of their illness or disability as a gift, and of feeling grateful for its occurrence. Catherine described the transformational quality of this gift when she said, "The best thing that ever happened to me, I can say that, it really is because of the way I feel, the personal changes in my life, I am much clearer now about what I want." In this sense, Catherine sees her Muscular Dystrophy as a gift because she has gained much self awareness. She also talked of gaining new knowledge, and she now has the ability to take personal responsibility and control for her life.

Similarly, Ann sees her asthma and her weakened diaphragm as a gift because she has learned to become exquisitely sensitive to her life and to her surroundings. She now has such a heightened appreciation of her life. She explained:

It is a gift my illness has given me. I appreciate the little things. I feel I get more out of life because of the ill health I have had at times. I have got so much out of life that some people never, never get out of life, and that's the appreciation piece.

Scott also talked of his Spina Bifida and his disability as a gift. Like Ann, Scott talked of an added appreciation for life and for a joy in

living. He said, "I look at my life now, and the things that I am doing, and the joy. I never had that before."

Although I have included quotes only from Catherine, Scott and Ann, each of the seven participants spoke of his or her illness or disability as a gift. They considered their chronic condition to be a gift because of the new awareness they had acquired, their new learning, and their ability to take control of their lives. Similarly, the participants talked of an added appreciation in their lives, with an exquisite sensitivity to beauty, and to a sense of joy and wonder.

As the participants explored and described their healing journey, they described their transformation from feeling a sense of dis-ease to experiencing a sense of ease. That is, as the spiralling process of healing progressed they moved from a sense of incongruity within themselves, to a sense of congruence within themselves and their worlds. They talked of moving from feelings of constriction to experiences of expansion and creativity. They also talked of changing the wall that blocked them to a membrane they could transcend; and they moved from a sense of imbalance to one of balance. In the early stages they talked of a franticness which became replaced by a sense of relaxation, and a sense of rigidity which moved to one of flexibility. In the beginning they talked of feeling heavy and bounded; now they have moved to a sense of buoyancy, energy and vitality. In the early days there was self judgement which has now become self acceptance, and a sense of disconnectedness which has become a feeling of connectedness within themselves and their world. There was a feeling of disharmony and feeling spiritually bereft, which has now become an experience of harmony and spirituality. They

talked of having moved from a frantic "doing," to becoming more conscious of their "being," and of gaining a deeper understanding of who they are. In this sense, they have moved from a state of unconsciousness to an expanded consciousness. Because of this transformation from a state of dis-ease to a state of ease, they considered their chronic condition a gift. Table 1 provides an overview of the descriptors drawn from the conversations with the participants.

Table 1

The Healing Process

Dis-ease	Ease
Incongruence	Congruence
Constrictions	Creativity, expansion
Wall	Membrane
Imbalance	Balance
Franticness	Relaxation
Rigidity	Flexibility
Heavy, bounded	Buoyancy, energy, vitality
Self judgement	Self acceptance
Disconnectedness	Connectedness
Disharmony	Harmony
Spiritually bereft	Spirituality
"Doing"	"Being"
Unconsciousness	Expanded consciousness

In this section I have explored and described the healing journey as the seven participants experienced it. I will finish with an analogy from Scott to exemplify the healing journey. He said:

It is an incredible force in nature, and at the same time, it is incredibly beautiful. It is extremely destructive because it is destroying the mountain, but it creates something, it creates rock . . . I look at my whole life, my life has been wonderful, beautiful . . . I have destroyed myself, but at the same time I have created myself. Out of the rock that I

was, I became lava and destroyed it all because I was going through a bad spell At the end of it there was rocks again, but stronger and different It is about what is going to happen, this new creation. This rock is going to be reformed, it is going to be smoother.

In this analogy, Scott points to each theme of the healing journey. *In the beginning* there was anger, denial, resentment and confusion which led the participants to *hitting the wall*. In Scott's analogy these phases are considered in destructive nature of the volcano. From this destructive force, Scott's analogy points to a new creation which is similar to the *turning around* process of the healing journey. As well, this creative process involves *letting go* of old expectations and desires, *opening up* to new possibilities, and to *letting in* new experiences. Scott's analogy also describes *the gift* of his disability when he talked of the beauty and wonder of the volcano.

The analogy of a volcano is a useful one for this study because it reminds us that volcanos may erupt at any time. Similarly, the healing journey is never over. Instead, as Sally explained, as the participants continue to experience the different phases of the healing journey, they do so with new awareness and a deeper understanding and acknowledgement of their healing process because they now consider themselves to be healthy. As Sheila explained: "The true meaning of life lies in the journey. The destination is the dream, the vision, because it is openended, it is out there".

Experiences of Feeling Healthy: The Themes

As the participants explored and described their healing journey, they also explored and described their experience of feeling healthy. I

engaged in three conversations with each of seven of the participants and two conversations with Malcolm. From these data, six themes emerged which describe the experience of feeling healthy while living with a chronic illness/disability. These themes were:

- (1) Honouring the self
- (2) Seeking and Connecting With Others
- (3) Creating Opportunities
- (4) Celebrating Life
- (5) Transcending the Self
- (6) Acquiring a State of Grace.

The titles for the themes came from the participants' own words. The third conversations were conducted after each participant had read all the validated and unidentifiable analyses of the other participants. The intention of this third conversation was to try and reach consensus about the essential themes inherent in the analyses. There was general agreement that these themes best captured the participants experiences of feeling healthy.

In presenting these themes, I have endeavoured to recount and reveal the phenomenon of feeling healthy for the people in my study. I have endeavoured to present the themes in all their complexity so that the reader can "come to a deeper understanding of the nature or meaning" (van Manen, 1984, p. 37) in order to "gain insightful descriptions" (van Manen, p. 38) of how the participants experience feeling healthy within their life. Therefore, the voice of each participant has been included whenever possible because of their clarity of expression. This process also creates

a text which is original, evocative, knowable and auditable (van Manen, 1990).

Figure 2 provides an illustration of the experience of feeling healthy. Although these themes have been separated from the full text, and from the lives of the participants, this is an artificial separation. These themes in fact overlap, interrelate and intertwine, to provide a rich mosaic of the life of each participant, and of their experiences of feeling healthy. These themes are dynamic and alive, they contain movement and energy and are not static or solitary. One part can be revealed and understood only temporarily before it is drawn back into the whole.

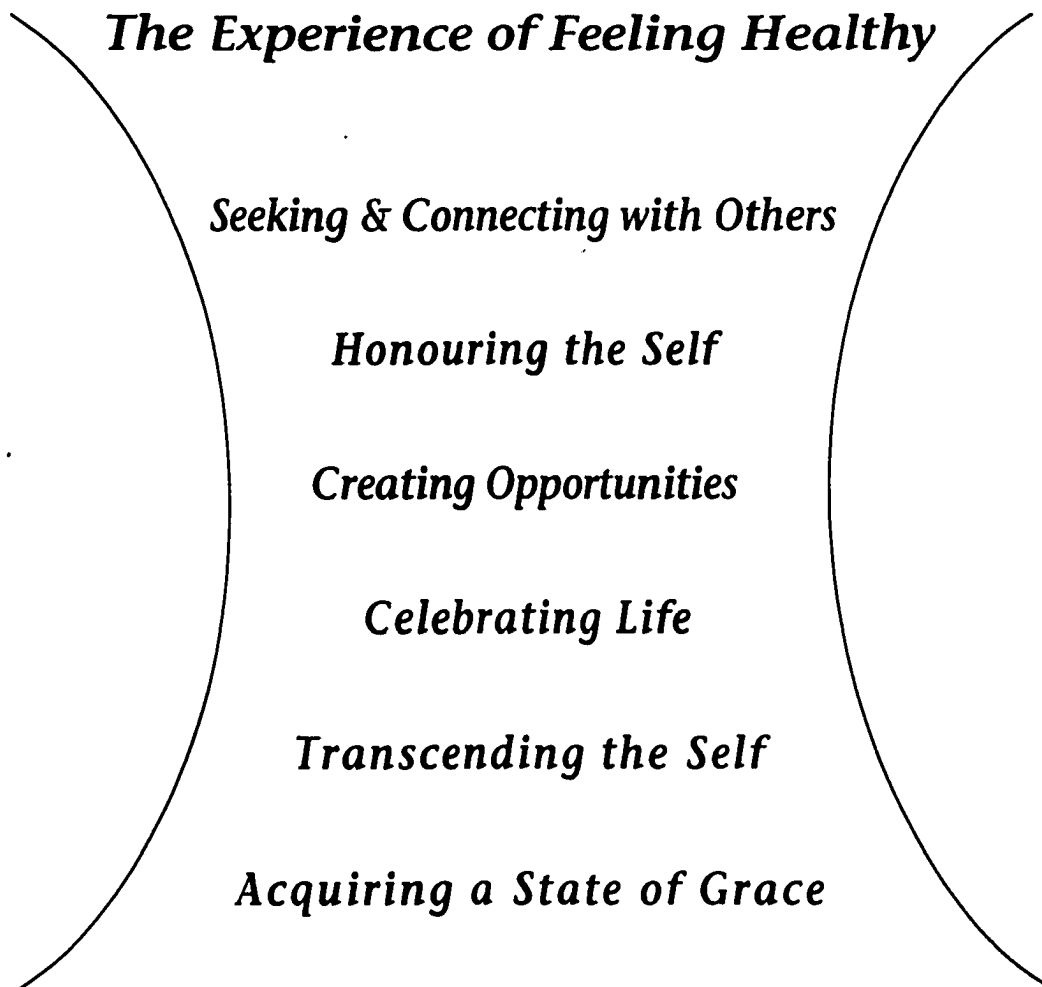
Honouring the Self

Above all things, reverence yourself.

Pythagoras.

Honouring the self involved a self respect and a self love. The participants talked of becoming assertive, self defining, self protective with an ability to express their needs, desires and actions. In order to come to this place of self definition, the participants talked of an incredible self awareness. This self awareness included a self knowing on many levels. The participants talked of learning more about themselves as people, how they think and feel, as well as to how they react to other people and to their environment. They also talked of learning to listen "to the wisdom of the body," and to pay attention to the body's needs and desires. In this sense, there was a sensitivity to and a caring for their bodies; a self nurturance. As the participants became more assertive and self defining, they talked of feeling empowered to make choices for

Figure 2. The experience of feeling healthy with the rich mosaic of themes. The concave lines illustrate the expansive nature of the experience of feeling healthy which is non-sequential, dynamic, alive and synergistic.



themselves and of being self responsible. There was a sense of feeling more grounded and mature. The participants also explained that they had shifted the focus of their lives from concentrating on their "doing," (to their physical tasks and performance) to focusing on their "being" and paying attention to their personal authenticity.

The participants described their chronic illness/disability as a catalyst. Catherine explained that having Muscular Dystrophy had forced her to assess within herself what is important to her. She spoke of a certain urgency in this assessment because the experience of her illness requires that she pay attention to her needs with some immediacy. She explained that before her illness she could procrastinate, or not pay attention to her needs, but now her illness has forced her to pay attention and to become more aware. Witness how she described this process:

I have come to what is important to me, what truly gives me strength and energy and joy and nourishment, and what doesn't. I am very motivated to make choices, not hang around in limbo, and I think that is a sign of health. It is my ability to make decisions based on what is truly important, and to do that, I need to know what is truly important to me.

Catherine's illness has provided an urgency to her becoming more self aware, and she wonders if this personal clarity would have occurred for her, had she remained well. She said "I really doubt it would."

The catalyst to becoming self aware also came about because of the behaviours, opinions, and judgements of other people. Often the participants were judged by their illness or their disability rather than on who they were as people. This was particularly true for the participants with obvious physical disabilities. Scott, Lyn, Malcolm and Catherine are in wheelchairs, scooters, or on crutches, and these obvious

signs of their disability often resulted in other people deciding what they could or could not do. Other people made judgements about their physical (and often psychological) limitations. Such judgements often created anger and resentment in the participants, but again, these inappropriate judgements acted as catalysts to their growing self awareness. For Malcolm this was a particularly important process which is well exemplified when he said:

It forced me to look at myself more which was a positive thing too. When people confront me with this image they have of me that I know is wrong, then it intensifies my own sense of who I am, it makes me even stronger.

The participants also talked of a need and a desire to become more self defining in order to establish greater clarity about their own needs, desires and opinions. Scott talked of the physical barriers for wheelchair movement. He talked of curbs without ramps, and stairs or escalators with no elevators, of doors which were too narrow, or no specific parking facilities. Lyn talked of trying to manipulate her wheelchair in the snow and the slush, and how she sometimes needed to ask for assistance. These physical barriers prompted the participants to speak out, to ask for assistance, but to go further and to insist on adequate facilities for people with disabilities.

Honouring the self involved the participants' relationship with health care professionals. They spoke of becoming more assertive and taking control of their lives. After years of living with their illnesses/disabilities, they were the best authority on themselves. They knew treatments that worked and the ones that do not work and they spoke of needing strength and tenacity to make their needs known. They talked of

their experiences of being hospitalized, and how in the early years they gave over their power and control. In this sense, the health care professionals followed the prescribed treatment regimens regardless of the needs and desires of the participants. Again, these experiences acted as a catalyst, the participants started speaking up for themselves, insisting on certain treatments and refusing others. As Ann explained "I became very non-compliant!" Scott described his experience of self definition when he said:

Health is about being in control of myself, and making my own decisions. That is the most important thing. I am feeling empowered to make choices, to speak out and let my thoughts and feelings be known to others . . . being clear about who I am, what my focus is so that I can make those choices.

Helen also talked of her relationship with others in her life, and how she has become more self defining:

When I deal with people, I clearly state my own needs and opinions. If people are not respectful of that, I choose not to have them in my life. It is taking control, 'wait a minute, isn't this my life here?'

In this sense, the participants became the best authority on themselves. After years of the experience of living with their chronic conditions they knew what was important for them. This was true for all of the participants, and they spoke of the struggles they often had to go through to become heard and respected. With this new sense of their own authority, they moved from relying on the opinions of others, to valuing and respecting their own opinions. Catherine explained how this had not been an easy process for her. She had been enculturated into believing in "expert opinion," and to follow "expert advice." As she became more self aware and assertive, she moved to respecting her own authority more. She explained:

I have become the authority on myself. I am continually affirming that I have my own opinion about this. I am not accepting what someone else says as all there is to say.

Honouring the self involved all aspects of the participants lives, including honouring their bodies. They talked of an "exquisite sensitivity" to their bodies, and this was particularly important for Scott and Lyn because they already had reduced sensation which can lead to recurrent bladder and kidney infections. Scott explained:

I have to pay particular attention to my body. It is like talking to my body, but with a precise language which gets me in touch with the smallest changes in my body.

Although Scott and Lyn have the most need for total body awareness, all the participants spoke of this added dimension in their lives. Sally acknowledged a respect for the messages her body sends her, she said:

I really believe my body is infinitely wise. It knows what is right for me, it knows what is healthy and what is healing for me. My body's wise ways of telling me.

Helen and Sheila talked of tuning in to their bodies and paying close attention to what their bodies need. Ann described how she cares for her body with gentleness and respect and gives it the nourishment and rest it requires.

Catherine talked of the relationship she has with her body in a somewhat different way. She explained that she is able to distance her mind and her spirit from her body in such a way that she can look upon her body much as a loving parent would look upon a young child. She explained, "I have learned to love my body, to treat it as I would a baby, with gentleness and love." In this sense, Catherine acknowledges and pays attention to her body both subjectively and objectively. She is able to

distance herself from her body, to look upon it with kindness and affection, but she is also aware of her body's sensations and its needs.

With their growing self awareness the participants talked of changing their sense of identity. Earlier in their lives they focused much of their attention on their physical or career goals. They talked of acknowledging their personhood in terms of their accomplishments. This sense of identity has now changed. The participants now focus on learning more about themselves, and to gaining self knowledge and self acceptance. As Catherine explained, "my new job description is self awareness." This shift in priorities from "doing" to "being" is an important aspect for the participants. Catherine spoke clearly to this shift when she said, "I can't do all the things a mother is supposed to do, but I can be a loving mother . . . The real inner knowing of my being really saved my bacon."

As the participants grew in their self awareness and became attuned to their own needs and desires, they became more self defining and assertive. This experience led to a heightened self esteem. Ann spoke of liking herself much more, and Lyn said "yeh, yeh, I like myself, I like myself a lot!" This feeling moved beyond self acceptance to a strong sense of having a pride and a commitment to themselves. Helen described this experience when she said:

I nurture myself. This comes from a place of loving myself. It takes a special person to be able to handle this kind of challenge, so I am realizing that I am special, that I've got a lot more to give. So it is an awesomeness, in the real sense of the word.

With this sense of pride, the participants described a resurgence of their energy and vitality. Catherine explained that as she became more attuned to herself, she experienced an exuberance in her life. She said:

You know, there is something vital inside of me that I can't deny. I have to love it. There is this self embracing which is an active, vigorous pursuit . . . and learning to listen to myself and honour myself and trust myself . . . There is a sense of keeping time with my inner rhythm, that is central, it is to do with not judging myself harshly. There is a sense of buoyancy that occurs when I am in a place of non-judgement with myself, and that is where the well-spring of my vitality comes.

As the participants explored and described their experience of feeling healthy while living with a chronic condition, their ability to honour the self was an essential theme. Sally summed this theme up when she said, "I have got in touch with my own authority. I don't put myself aside as readily as I used to, I honour myself more. I fully believe in myself, and with that belief, all things are possible."

The participants described an increased self awareness with an ability to make choices and be self defining. The participants also talked of self nurturance and self love which led to an increased self respect and a sense of empowerment. Each of these attributes contributed to the theme of honouring the self, and to the participants experiences of feeling healthy.

Seeking and Connecting With Others

This second theme of the participants' experiences of feeling healthy involved their relationships with other people. The participants moved from wanting to be isolated to moving outward, to seeking and needing to connect with others. This theme covers three different aspects in the participants' movement. The first aspect involved seeking new people in the participants' lives. They talked of recognizing their need for support and validation, of seeking help, and for some, the

acknowledgement of their need for a loving personal relationship. The second aspect involved the participants' need for a reciprocal caring relationship, a need for balance between their giving and receiving. The final aspect involved the participants' commitment to helping others.

As the participants experienced the healing journey they talked of coming to a deeper and fuller understanding of themselves and their worlds. With this deeper understanding their need for relationships with others changed. The participants found themselves seeking new friendships, and searching for people who were on similar journeys to themselves. For some, this meant that they had little in common with people they thought had been friends before their chronic illness/disability. Helen described this experience when she talked of having more time for people. "Now that I am not being the white rabbit, I have time for people. People in my old life are still too busy to sit down and have tea and really talk." Sally also talked of this shift, which she called a "weeding out process." The participants said that some of their old friends still remained close friends, but many of their truly close friends are new to them since the onset of their illness or disability. The participants recognized they were the ones who have changed, as Sally said, "I am now attracted to people who are more grounded and mature." Helen summed up this experience of reaching out to new friends when she said:

I put out a certain kind of energy, and meeting people more that think the way I think, and those are the people who are more important to me. So rather than the plastic connections, I had a falling away and I'm finding there are deeper connections with people who are important to me. I am seeing those connections more . . . I am learning that people are more important to me than anything else.

Support and validation from other people was also a very important aspect in the participant's lives. Lyn talked of being in their art gallery and people coming in and admiring her paintings, they would say to her "You should go on." To Lyn this validation of her art work was crucial to her motivation and self esteem. Lyn often talked of her experiences by describing how she would paint them and when I asked her how she would paint support she said, "Support looks like a series of hands and arms encircling and embracing one another."

Ann talked of the times when she was critically ill and she said that the support and love of her family and friends "really is what kept me going." Sally talked of support and care from friends as a source of personal nourishment. She said, "For me, giving and receiving support is essential. I am grateful and caring of friends, they feed me."

Catherine and Helen talked of validation and support in terms of needing a loving partner in their lives. Helen recognized that such a loving relationship is missing at this time. She described feeling an emptiness in her life. She also said, "but I trust that it will happen, I just have to be open to it." Catherine has been in a new relationship for three years, and she talked of the importance of this loving man in her life. She said, "It is just so healing and wonderful, basically because I know someone accepts me for who I am. What I needed was some love and care and acceptance and he gave me that."

The participants also talked of their need to reach out to others and ask for help, a transition that was not easy to make. Catherine talked of being "fiercely independent" in the beginning when she was "determined to go it alone, and not ask for help." This experience was similar for

each of the participants. Scott said, "The hardest thing I ever had to do was to start asking for help." For the participants, this help could be on an instrumental level, to help them with tasks they could no longer do, or it could be at a more personal level. In the performance of tasks, the participants were clear that they did not want people to assume they needed help, as Catherine said, "Ask me first, check with me, and don't take over from me if I look like I am struggling or being too slow. I will ask if I need help."

The help of others was also very important to the participants on a deep and personal level. Sally described this need when she said, "I need people to understand me at a very deep level, to truly listen to what I mean. The most important thing they can do for me is just listen, to try to get a sense of my story." In this sense the participants talked of the need for caring, supportive and genuine friendships. They talked of seeking new people in their lives, ones who could connect with them at a deep and meaningful level.

As well as reaching out to others for help, support, validation and friendship, the participants talked of the reciprocity of caring. Ann talked of the love and support she had received over the years when she was critically ill, and she now wants to return some of that caring. She recently gave a surprise birthday party for a close friend. She said, "This made me feel so good, I haven't been able to do that before." Sheila talked of the balance she needs to keep between giving and receiving, she said:

I used to give, give, give without being mindful of my own needs, now this is more balanced. Being able to take and being able to give . . . I get reinforcement, I get acknowledgement, and then that goes in a cycle of giving and receiving.

Within this balance of giving and receiving, all the participants talked of being committed to helping others with chronic illnesses/disabilities. This helping of others comes in many forms. Sheila talked of wanting to share her new knowledge with others, "For me, part of my vision, my mission, my purpose in life is to share whatever I am learning." Sheila shares this learning by providing workshops at the Multiple Sclerosis Society. Helen talked of helping others by providing support and she does this by initiating and facilitating support groups for people with M.S.. Scott, Malcolm, Lyn and Helen talked of their role as client advocates. Malcolm is a consultant to the Commonwealth Games and is responsible for the availability and acceptability of access for people with disabilities. Scott also works as a consultant to architects and most recently worked with the Ferry Corporation to provide better wheelchair accessibility. Lyn and Scott also provide seminars to the public to educate people about the important issues for people with disabilities. In thinking of her future, Helen talks of wanting to become a client advocate, particularly in helping people obtain disability pensions and other important aids.

Of particular importance to the participants was their commitment to helping people with chronic illnesses/disabilities on a more connected and personal level. Because of their own experiences with the healing journey they talked of a heightened awareness and a greater sensitivity to the needs of others. Catherine talked of being "fully empathic to the concerns of others." As she explained, "as one sensation is dulled [the physical body] other sensations are heightened which leads me to a greater sensitivity to what other people are experiencing." Scott, Sally,

Catherine and Lyn are counsellors, and Scott and Catherine devote much of their counselling to people with chronic conditions. Catherine explained her mission in helping others to affirm their own health when she said:

I am helping other people. The way I do that is to affirm the health of others. Even though there may be this [the chronic condition], I affirm health for everyone. That is how to heal. This is how to heal families, it is how to heal this planet.

Sally described herself as "a healer," or "a Shaman." She told me that her healing powers come from the depths of her experience of coming to terms with her illness. She explained:

I am a healer because I have been wounded. I am a helper, I help people heal. I do that because I come from a deep centre of experience in pain and darkness of what it is like to live with something like this. So it is like, people like myself, we are born to be healers.

In the theme, *Seeking and Connecting with Others* the participants talked about their experiences of feeling healthy in relation to connecting with others in their lives. This connection took different forms. The participants talked of seeking deeper and more meaningful friendships. They described how they are able to ask for care and support, and they spoke of their need for balance in both giving and receiving care. Finally, each of the participants spoke of helping others, and this help was given in a variety of different ways. They confirmed that connecting with others and their commitment to helping were essential to their experiences of feeling healthy.

Creating Opportunities

A state of health is a state of flexibility, a state of adventure, a state of curiosity.

Catherine.

A critical element of feeling healthy for the participants was their ability to look at their illness/disability as a challenge, an opportunity to make changes in their lives, to learn, and to grow. They talked of a spirit of adventure, a sense of courage, and a willingness to take risks, and to move beyond the ordinary. They constantly spoke of searching for meaning and new learning in each experience, they called themselves "seekers." They talked of an unending curiosity and a willingness to take charge of their lives. They spoke of feeling motivated and having a strong sense of purpose, a vision and a mission. As the participants experienced this challenge they talked of a growing sense of their own creativity as Sheila explained, "I acknowledge I am working on my health, my illness was an opportunity for self exploration and creativity." In this sense their creativity was evident in their ability to turn negative experiences in their lives to positive experiences.

All the participants spoke of their sense of challenge and their spirit of adventure. They challenged themselves in caring and supportive ways. Sheila talked of nurturing her inner resources when she considered the exacerbations that might occur in her illness. She said:

I feel though that everything is here, my inner resources whatever, to go with it Whatever challenge comes up, if I choose to take it, I can have it happen . . . knowing I have my own resources, I will create what I need at the time.

In this sense, Sheila is confident that, should she choose, she can meet any challenge in her life. The participants have been challenged in so many aspects of their lives because of their chronic conditions that they have built up inner resources to meet the challenges.

Scott talked of challenge in a somewhat different way. He is more of a risk taker and is constantly challenging his body and his mind. In this

sense, Scott has an internal locus of challenge. Recently he started surfing because he thought he needed a new challenge in his life. He explained:

Right now I am going to experience things, look forward to the next new challenge. I will try anything once, life is to be lived. The minute I stop growing, the minute I stop learning, the minute I stop changing is the minute I die. You really realize that you are the only one who can disable you, and I'm not going to do that.

Scott not only meets challenges in his life, but he seeks out new challenges as a personal quest for change and growth.

Helen talked of the many challenges she had had to face in her life, the death of her mother, her divorce, being diagnosed with M.S., fighting for a disability pension, and striving for a better quality of life for herself and her son. In this sense, unlike Scott who had an internal locus of challenge, Helen's source of challenge was more external. Witness how she described challenge:

It's like, there is God sitting there, pitching things for me to catch, and everytime I got them all, I say 'oh good, I've got them all!' and then he pitches me another one.

Helen's words exemplify the continual nature of challenge in the participants' lives. They rarely consider themselves content or satisfied, instead, there is a sense of forward movement and change.

A large part of the participants' experience of feeling healthy came from their sense of creativity. This creativity presented itself in different ways. For Lyn, this creativity came in the form of her paintings, for Sally, she enjoyed creative writing and some art work, and for Catherine, she had done some beautiful stone carvings. Creativity was also talked about in another way. Scott talked of always wanting to create change in his life, "I am always motivated, always wanting to make changes

in my life." A particularly important aspect of the participants' creativity came in their ability to change negative experiences to more positive experiences. Ann talked of the time when she was on a ventilator for four months and was told she would probably remain ventilated for the rest of her life, she said:

I was thinking, let's make the best of this situation. If I can't get off the ventilator, at least I have still got my intelligence, and can still talk and communicate which is very important to me. So I had sort of accepted that if I had to always be on a ventilator, I can at least get around with some kind of a devise . . . I kept thinking I could do better than they predicted. If I didn't think that, I wouldn't have come along this much . . . I really think that is part of my health . . . Creativity is a way of taking control.

In this sense, turning negative experiences around to positive experiences required creativity. This ability was an essential part of the participants' experience of feeling healthy.

The participants talked of needing courage in their lives. Such courage also contains an element of risk. Catherine talked of moving beyond the ordinary, to pushing her limits and to take chances. Witness how Catherine now speaks of herself as a woman with courage, with a sense of her own individuality:

It is moving beyond the ordinary, its saying, 'o.k., this is where I am at, but I can do more'. Not fitting what others might expect of me, or what I might expect of myself, not needing to fit into a certain mold. You say 'yeh! so what!' I have the courage to be an individual.

Finally, the participants talked of creating opportunity by their abiding curiosity, they called themselves "seekers." This sense of curiosity required a tenacity, or as Sally called it "a stick-to-it-iveness." Catherine spoke well to this when she told me her motto, "Find out not what is wrong with you, but about how to increase what is

healthy." The participants had read extensively and undergone much personal exploration in order to come to understand themselves more fully, and to understand their illness and/or their disability better. They had become more philosophical in their outlook, and had become seekers of the meaning of life. The participants spoke of their illness or their disability as the catalyst in their seeking. Sally spoke well to this element of feeling healthy when she said:

Seeking the bigger question and knowing there isn't an answer.
I am always looking at different ways of contacting this force
. . . . My job is to make meaning of all this, part of the
healing is making sense out of it for me.

Creating Opportunities was an important theme for my study participants as we talked of their experiences of feeling healthy. They talked of feeling challenged, of having a sense of adventure with a courage and a willingness to take risks. The participants also talked of a sense of curiosity, and of being seekers of knowledge and wisdom. They described these experiences as "creative acts," of changing their negative experiences into growthful learning. They also talked of being artistically creative, and of taking charge of their lives, and of creating change. These experiences meant that the participants were fully and actively engaged in the flow of their lives, which led to a sense of empowerment.

Celebrating Life

For me it is a celebration of life, it is a kind of striving
toward--reaching our potential, reaching for the sky.

Ann.

As the participants began to talk of celebrating their lives, we often found we became quite philosophical in our dialogue. This

celebration is a deep and profound feeling, and one that each participant spoke to. They talked of having a resurgence of their energy, a sense of vitality and passion, and of feeling vibrant and alive. As Scott explained, "it is living life to the fullest, feeling alive, really alive." The participants talked of their sense of enjoyment, their playfulness, of having fun and having a sense of humour. On many occasions during our conversations, there was spontaneous laughter and joy. The participants had the ability to laugh at themselves, as well as at the situations in their lives. With this joy came a sense of wonder, they talked of gaining pleasure from "the little, small things," and of not taking anything for granted. As well, the participants talked of a sense of anticipation, of hope and of faith.

The sense of vitality, vibrancy and energy was an experience felt by all the participants. As we talked of these feelings, the participants became animated, their eyes shone, they used hand gestures and became fully engaged in our conversations. Many of the participants talked of this feeling in philosophical terms. Although they could relate it to specific experiences in their lives, they often said it was a bigger feeling than could be tied to a particular experience. Lyn, however, was able to tie it to her paintings. She talked of days when she had no inspiration, no matter what she tried, she was dissatisfied with her work. When she was feeling healthy and energized, her paintings showed that vitality and vibrancy. She explained:

When I am feeling healthy there is a lot of energy there. It is very, very active, when I feel healthy and my paintings show it. Yes, it is very, very alive. I can do anything on that page I want, I can say anything . . . It is an elation, almost euphoric, an awesome feeling.

Catherine talked of "channelling life." By this she explained she was consciously paying attention to her energy, her vitality and to the fullness of her life. She said she consciously channelled this energy for herself, and for those in her life. She explained:

I have this sense of buoyancy which is the wellspring of vitality from which a resurgence of my energy comes. I am channelling life . . . I am alive, whether my body continues to live or not, I am alive . . . I am living my life, being alive while I am alive.

Scott appears to be a man with a powerful and forceful presence. He has done a lot of wheelchair sports and has lifted weights, so his upper body looks strong and powerful. As we talked, he would lean forward in his wheelchair and engage in dialogue with me in an intense way. He said:

I have this sense of being alive and embracing life. The spirit is the energy that drives the whole vehicle, it is the lust for life, wanting to get in there, that's the energy, that's the spirit. I am talking about the spirit that drives me, the zest, the energy . . . I can live life to the fullest, even if I have no physical ability, I can still live life to the fullest because where I am living life is from within.

In this sense, Scott portrays what the other participants also discussed, that is, an intense celebration of their lives.

A sense of humour was also very important to the participants. As Catherine explained, "A good sense of humour, I think that is God in action." Sheila and Ann had attended humour workshops, and Helen often purposefully watched comedy shows on the television in order to "have a good laugh." Certainly, in our conversations, there was much laughter and joy. As Sally explained, "having a good sense of humour, that is something I nurture in my life." Ann also spoke of humour playing a vital role in her healing, "I think the ability to laugh, that's what pulled me

through." Scott talked of purposefully using humour when he wanted to make people feel less awkward when they first met him in a wheelchair. He also talked of using humour to reduce the intensity of his emotions. He described to me the anger he felt when able bodied people parked in a parking space for the disabled. Before he spoke to the person about their transgression he would try to flip the emotion, so that he could make his point with humour, something he believed would be more readily heard by the offending person. He explained, "Humour is healing to me, it helps me break the intensity of my emotions, and then I am able to look at my situation with a more healthy perspective."

As well as a sense of humour, the participants talked of a sense of joy, of playfulness and of having fun. Sheila told me that she now feels she has returned to the feelings she had when she was 25 or younger, before the pressures of her teaching career and the diagnosis of her Multiple Sclerosis were made. She described that time as a time of joy and she has now recaptured those feelings in her life. She said:

Within this energy I have a sense of excitement, and joyfulness. . . . that child, that happiness of a child, and wanting to be that, to discover again that feeling of lightness, joyfulness, of being here and now, in the moment and being joyful. I sense that this is a great time for me to be living, it is incredible.

The participants also talked of a sense of wonder, of gaining pleasure in the simplest of experiences, and not taking anything for granted. As Scott explained, "I think that is one of the wonderful things about having this disability, I get this incredible appreciation for stuff, simple sort of stuff." For each of the participants, this appreciation and sense of wonder have come about as a result of experiencing a lot of pain and sadness. As Ann explained to me, "there has

been a lot of sadness in my life, and that is why I appreciate even the smallest of things so much." Ann describes this appreciation by looking out of her apartment window and seeing the spring blossom on the trees, and the warmth of the sun beginning to take over from the winter. "I get such joy and appreciation from it all." Sally described this appreciation as "a richness and a fullness in my life," and Helen explained that despite her illness: "I have never felt better, interesting isn't it? It is feeling that there is so much more to life than I ever thought there was. I wish I could share that. It's like I know a secret and I am bursting with it."

Hope played an important part in the participants' celebration of life. Ann talked a lot about hope, and she attributes her healing to a strong sense of hope. Ann wanted me to fully understand what hope meant to her. She explained:

Hope is hoping something is possible and faith is assuming that whatever it is I am hoping for is possible. Faith is an anticipation, an expectation, faith is greater than hope. I hoped to get off my ventilator, but in the early days I didn't have the faith that I would.

Although Ann makes this distinction between hope and faith she continued to use the word "hope" in much of our conversations, and sometimes she meant she "hoped for," and at other times she meant having a faith in the outcome. An example of hope for Ann was when she bought tickets for the "Nutcracker Suite" six years in a row, and for five years she was too ill to attend. She persisted in buying tickets, and on the sixth attempt she was well enough to go, "and it was worth the wait!" Ann also talked of hope when she was really alluding to her faith when she said, "There is hopefulness there, and a trust that I am going to continue

to improve. As long as I am breathing there is hope. In a sense, there is trusting there." In this sense, hope was an inner trusting and a faith that while Ann was alive there was always the possibility for improvement.

For each of the participants, celebrating life was essential to their experiences of feeling healthy. This celebration of life involved a passion for living, with a sense of vitality and energy. The participants also talked of acquiring a sense of humour, and experiencing a sense of joy and playfulness in their lives. Celebrating life also came from having an inner trust with a sense of hope for an eventually successful outcome. For each of the participants, celebrating life was an essential attribute in their experience of feeling healthy.

Transcending the Self

Hold fast your dreams!
 Within your heart
 Keep one still, secret spot
 Where dreams may go,
 And sheltered so,
 May thrive and grow
 Where doubt and fear are not.
 O keep a place apart,
 Within your heart,
 For little dreams to go!

(Driscoll, cited in Sutton, 1991, p. 87)

Many of the experiences of feeling healthy came from the participants' ability to transcend the bounds of their physical body. The participants described this experience as an expansionist feeling, an escapism, and a freedom. They explained that this experience came about by creative visualization, daydreaming, and fantasy.

An interesting element of this theme was how the participants began to talk of their experiences of self transcendence. Catherine, Lyn and Malcolm talked of this experience in our first conversations. Scott, in

recalling our first conversation, felt it was an important part of his experience of feeling healthy, and so we explored self transcendence in our second conversation. After the seven participants had read all the interpreted analyses from the first two interviews, Helen, Sheila, Sally and Ann also confirmed that they, too, experience this sense of transcendence. Scott explained why he was reluctant to describe this experience to me when he said, "I would never tell a doctor this, or a nurse, or heaven forbid a psychiatrist, I would be put away!" There was this sense that they were pushing the limits of my imagination. Once they understood my genuine interest and openness to explore this phenomenon, they began to explain their experiences to me in detail. Catherine explained to me how she understands her experience when she said:

I think what happens is you begin to extend your sense of your physical body beyond your body. If your eyes, which are your physical body, can see it, whatever you are seeing with your physical body becomes part of it. Your physical role is extended to what you can perceive with your senses. So you get into saying whatever I can perceive with my five senses is part of my physical body. Then it opens up your world so much more to actually participate, I become bigger than just my physical body.

After Catherine had explained how she understood her self transcendence, she gave me an example. We were sitting in her living room and a jogger ran by her house and she said:

I may not be able to run down the street, but what I do is, when I see somebody running, I can feel what they are feeling. I don't separate myself from that which I can't have because I can experience it with my senses and it is part of me. There are moments I don't believe my body can't just run and jump.

After Scott's initial trepidation in talking of his experience of self transcendence, we talked of three ways he achieves this. Scott enjoys writing poetry and short stories, and he explained how "I take on the role

of a different character, I can become a different person." He shared some of his poetry with me and his poems provide insight into his ability to expand beyond his physical constraints. Scott also uses creative visualization. He gave me an example of this when he said that before he went surfing, he visualized how he would surf. He explained that his first surfing attempt was not as he had visualized, but he had a familiarity with the board, the ocean and the waves that he would otherwise not have. The third way that Scott transcends his physical bounds is through fantasy. He described this experience to me:

I am floating, I am flying. I am very grounded in reality, what is realistic, what is possible, always knowing what my limits are, always being cognizant, even at a remote level, of my environment and everything around me. There is this way of keeping me sane. I do poetry, I escape there, I become someone else, something else; imagination and fantasy. When things get rough, I take a mental vacation from myself.

In this sense, Scott can escape the constant awareness and responsibility he feels for his wheelchair bound existence. He is able to take a break from the constraints in his life. Witness also how Scott can achieve a sense of freedom through fantasy:

I imagine I am flying. I escape from my physical immobility. I can create this imaginary mobility, it makes me free. You are out there on the wing of that bird, watching it fly by. It is not an out-of-body experience, it is almost like a total empathic experience, because I am using my empathic abilities to get into their shoes and do it. I am flying in a space ship, through the stars. There is this sense of freedom, like going out and getting a breath of fresh air, then coming back in again, and getting down to business.

Lyn also talked of a sense of freedom as she transcends her physical constraints. Before the motor vehicle accident, Lyn was a ballet dancer and she still choreographs ballet and loves to watch it. She talked of her self transcendence as she watched television:

Freedom is in my mind, there are no obstacles. I am blind to my wheelchair--now I have disconnected it. When I watch ballet on T.V., of yes! I am with them all the way, it feels so good. I transcend to a point into the dance.

Lyn's experience of transcending into the ballet is similar to Catherine's experience of jogging with the runner. These participants can transcend their physical bounds and participate and enjoy a freedom of movement.

Transcending the self was an important element in the participants' experiences of feeling healthy. The participants talked of expanding beyond their physical bounds, and with imagination, fantasy and visualization they escaped all physical constraints and experienced freedom.

Acquiring a State of Grace

I think the internal work on myself has to do with changing the walls of consciousness to a membrane which can be passed through by osmosis. Maybe that's what it is; the transformational experience is all about. It is an expansionist feeling, a wholeness, a sense of spirituality, a state of grace and a trusting in God. God is my Creator, my spirituality is knowing the Creator.

Catherine.

The participants talked of a spirituality, a connectedness, a sense of wholeness, harmony, peacefulness and a sense of ease. They also talked of an intuitive inner knowing, at a deep centre, a sacred place with a profound sense of trust. As Lyn explained, "I have this instinct, an intuition .hat it's going to be OK, I'm going to make it." In this sense, the participants talked of an attunement with God, or the Creator, and an expanded consciousness.

The participant's sense of spirituality was manifested in different forms. Ann had been seeking some form of religion for many years, and

recently she has joined the Mennonite Brethren church. Ann explained that she feels most connected to this religion, but there are still areas of this religious faith that she struggles with. For the other participants, they spoke of no particular religious affiliation. In fact, Catherine said she was still releasing herself from "the bonds of Roman Catholicism." Regardless of whether the participants followed a particular religious faith, they all talked of a strong sense of their own spirituality, and an attunement with their Creator. As Scott explained, "I have a partnership with my Creator, He is here too." Ann also explained this experience when she said, "My spirituality is my essence and is greater than my soul." Sally talked of feeling blessed when she said, "Somehow knowing I am blessed, always knowing there is another force that is acting on my behalf, a piece of me knows that." Sally called this experience her "spiritual beingness." Sheila also described the sense of her own spirituality and the connection she felt between herself and her world when she said:

Spirituality is an energy, it is there all the time, it is my core. It is a sense of myself and how I relate to the wider world, relate to the belief in where I come from, where the connection is with the cosmic. There is this underlying part that connects my body, my mind and my soul . . . I find that being my spirit self has made the connection so that I can really understand, really take it in. This is at a non-verbal level. My life is larger than my mind, body, soul.

With a sense of connection to their own spirituality, the participants talked of an inner peace, a harmony, a wholeness with a sense of ease. They talked of an "intuitive knowing at their deep centre," and of self trust. Helen explained, "there is this sense of connection and wholeness, harmony and peacefulness. I feel connected to the world, to the beauty around me, it feeds my soul." Sally compared how she feels now, as

she is experiencing feeling healthy, to her earlier experiences when she said, "There is more harmony and more quality in my life than there was previously. My life was dissonance, out of tune, now there is harmony."

Lyn talked of a time last summer when she and her husband were camping at a beach, she explained:

We were sitting on the sand by the fire, watching the sunset with the gentle breeze on my face and the sound of the ocean in my ears. I had this wonderful sense of tranquillity and a sense of oneness with my universe. I am at peace with myself, this wonderful sense of peace when I am feeling healthy.

Lyn also explained this sense of her own spirituality when she described sitting in her wheelchair in her studio, preparing to paint and she said:

I have a sense of beauty and awe as I sit in my studio and watch the colours of the stain glass windows play across the room. I watch the birds feed, fly and play and I have a gentle attunement with these birds. There is a sense of gentleness and beauty, a sense of turning inward to embrace my own spirituality. This is a time I am at peace with myself.

The sense of spirituality and a connectedness with their universe were essential elements in the participants experiences of feeling healthy. They talked of getting in touch with their inner knowing, of exploring their sacred place, and to acquiring a state of grace. Within this experience the participants talked of a sense of harmony, peace and an inner trust that "no matter what, I will be OK."

In summary, the experience of feeling healthy while living with a chronic illness/disability can be described by six interrelated and interwoven themes. These themes include: *Honouring the Self*, *Seeking and Connecting with Others*, *Creating Opportunities*, *Celebrating Life*, *Transcending the Self*, and *Acquiring a State of Grace*. Table 2 provides an overview of each theme with its essential attributes.

Table 2

Experiences of Feeling Healthy: The Themes

Themes	Attributes
Honouring the Self	Self nurturing, self defining, self awareness, self respect, empowerment, making choices, caring and loving the self
Seeking and Connecting with others	Relating to others with depth and authenticity, a reciprocity of caring, commitment to helping others
Creating Opportunities	Challenge, seeking, curiosity, creativity, taking risks, tenacity, a vision, a mission
Celebrating Life	Vitality, passion, energy, hope, humour, playfulness, joy, gratitude
Transcending the Self	Expanding beyond the physical realm, escapism, freedom, fantasy, day dreaming, visualization
Acquiring a State of Grace	Wholeness, connectedness, spirituality, peacefulness, harmony, inner trust, inner knowing, ease, expanded consciousness.

Conclusion

In presenting the results of this study I have divided the participants' experiences into two sections, (a) the healing journey, and (b) the experiences of feeling healthy while living with a chronic condition. This division is an artificial separation, in fact, these two sets of results interconnect, intertwine and interrelate. The healing journey and the experience of feeling healthy are expansive, synchronistic, non-linear and synergistic. Figure 3 illustrates the synchrony of the healing journey and the experiences of feeling healthy while living with a chronic illness/disability.

I will conclude with a quote from Catherine which seems to be an effective documentation of many of the essential themes. I asked Catherine how she would describe her experience of feeling healthy to me and she said:

Health is an experience beyond the physical dimension and it is the cornerstone of my existence Feeling healthy is feeling good about who I am myself, reaching my potential in every way, shape and form. Reaching out, and reaching into myself as well as with out of myself. It is more than acceptance, it is expansion, being open to everything and everyone. It is being open and being closed, because sometimes there is overload. It is pushing the limits, while also taking care of myself, a self protection piece too, but always trying to be as open as possible within those limitations I think I need to care for myself as well as opening up my horizons, that's how I grow, how I get more out of life.

Figure 3. The synchrony of the themes of the healing journey and the experience of feeling healthy which illustrates the wholeness of this experience for people with chronic illnesses/disabilities.



CHAPTER FIVE

DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

Disease is today and has been for a long time a living experience for the man of flesh and bone in civilized societies In contrast, health is a disembodied concept. It stimulates no emotional response and inspires only dull official speeches and allegoric paintings which do not touch the heart because they deal only with an inhuman and fleshless abstraction.

(Dubos, 1965, p. 8).

The purpose of this study was to explore and describe the experience of feeling healthy, to remove the experience from an inhuman and fleshless abstraction, and to breath life and meaning into the experience of feeling healthy for people with a chronic illness/disability.

An interpretive phenomenological research design was employed to study the lived experience of feeling healthy while living with chronic conditions. In this research I endeavoured to study the participants lived experience of feeling healthy, to explicate the phenomenon as it presents itself to consciousness, and to describe the essential meanings of feeling healthy as the participants experience it. The research findings were divided into four sections. The first section described the pilot study. The second section described the participants in the study, and the third section described the healing journey and seven themes which emerged to describe and explain this process. These themes included: *In the Beginning*, *Hitting the Wall*, *Turning Around*, *Letting Go*, *Opening Up*, *Letting In*, and *The Gift*. *In the Beginning* was characterized by anger, fear, shock, resentment and confusion. As the participants experienced increasing despair they "*hit the wall*," and either contemplated or attempted suicide. From the shock of this intended action the participants

talked of "*turning around*," and "*letting go*" of the debilitating emotions and the desire to be their former selves. As they let go of these emotions and desires, they experienced an "*opening up*" to new possibilities and new horizons, and a "*letting in*" to new opportunities and experiences. Finally, the participants came to see their chronic condition as a "*gift*" because of the new awareness and new insights they had acquired.

The fourth section of the research findings provided an exploration, an explication and a description of the experience of feeling healthy while living with a chronic illness/disability. Six themes emerged which seemed to capture this experience. These themes included: *Honouring the Self*, an experience of self definition, self love, self nurturance with a sense of empowerment. The second theme entitled *Seeking and Connecting with Others* involved seeking friendship and support, the reciprocity of caring, and a commitment to helping others. *Creating Opportunities* involved feeling challenged, seeking new learning, being courageous and creating change in the participants' lives. The fourth theme entitled *Celebrating Life* included a sense of joy, humour, energy, vitality, excitement and passion. The theme *Transcending the Self* portrayed an expansionist feeling, with a sense of escapism, of fantasy, visualization and freedom. The final theme *Acquiring a State of Grace* involved a sense of deep connection within the participants themselves, and a sense of profound inner knowing and trust. The participants spoke of being at one with the Creator, with a sense of their own spirituality with feelings of harmony, rhythm and peace.

For the purpose of data presentation, the findings of this study have been presented in a linear and sequential fashion. The assumption

might be made that the healing journey and the experience of feeling healthy has some hierarchical order, in fact, the opposite is true. The healing journey and the experience of feeling healthy are expansive, synergistic, interconnected and interrelated. In this sense these phenomena are non-linear and non-hierarchical. The participants' experienced the healing journey as they came to experience feeling healthy within their illness. However, the participants still continue to experience elements of the healing journey, but they now experience this process from a different perspective because they feel healthy. In presenting the healing journey and the experience of feeling healthy I attempted to explicate the dynamic, fluid and spiralling nature of the experience.

The final stage of this study involves contextualization of the themes (Hycner, 1985), or to "turn the knowledge against itself" (van Manen, 1984, p. 46) in order to reflect and speculate upon the themes as they interface with the experience of feeling healthy for the participants in this study. As well, new literature will be introduced and discussed as it pertains to the results generated in this study. The final section of this chapter will include the limitations of this study, the implications for client care and theory development, and some recommendations will be made for future research.

The Themes: A Literature Comparison

In this section, I will compare and contrast the themes of the healing journey and the experience of feeling healthy with similar extant theory and research. Because the experience of feeling healthy while

living with a chronic illness/disability is a comparatively new notion, this comparison will incorporate literature from differing fields of study. First I will compare the healing journey with literature discussing personal growth and development as a result of crisis. I will also compare the healing journey with the theory on developing consciousness. I will then discuss the six themes of feeling healthy by comparing and contrasting these themes with theories of self identity, social support, hardiness and resilience, and finally I will compare this studys' findings with definitions of health advocated by some leading nurse theorists.

Growth and Change as a Result of Crisis

There appears to be some noticeable similarities between the theories of personal development and change as a result of a crisis and the findings of this present study. It is interesting to note that the chinese character for crisis signifies both danger and opportunity, and in discussing the experiences of feeling healthy in relation to personal growth and change as a result of crisis, the compilation of danger and opportunity is an apt characterization. Jaffe (1985) discusses a transformation, or a quantum leap of development through trauma or illness experiences and Booth (1962) and Slater (1981) consider illness to be a message to the whole person.

I have divided the literature regarding personal growth and change as a result of crisis into three sections; (a) as a result of a life threatening event, (b) from a life threatening illness, and (c) as a result of severe disability. Smith (1979) compared the experience of Vietnam warriors, survivors of Hiroshima, and survivors of concentration camps and suggested that touching death was a "condition for new growth"

(p. 443). Smith contended that growth is a personal transformation in values, goals and priorities, and of seeking new ways of living and making meaning in life. Des Pres (cited in Smith, 1979) also contended that survivors of crisis had a heightened sensitivity to beauty and were more clear-sighted about their goals and ambitions.

Moch (1989) compared the literature of people living with life threatening illnesses, particularly cancer, and suggested people made changes in their personal goals, values and relationships with others. According to Moch, these people showed a greater concern with a sense of community with others, and had a heightened awareness to the beauty of nature. Moch also reported that cancer patients had a new attitude toward life with an increase in self knowledge. Personal growth and change was also acknowledged by Klingensmith and Serdahely (1987) in their study of severely disabled people. These authors described the disability as "a way of breaking through to new perspectives" (p. 10), of appreciating life and friends more, appreciating beauty and nature, and an "intense desire to live with more immediacy" (p. 9).

These experiences of personal growth and change for survivors of life threatening events or illnesses/disabilities closely reflect the experiences of feeling healthy described by the participants of this study. There are striking similarities between the experiences of personal transformation, heightened sensitivity, a realignment of personal goals and values, and of movement toward an expanded consciousness. The participants in this study appear to equate feeling healthy with personal growth and change.

Developing Consciousness

Young's (1976) theory of developing consciousness also reflects striking similarities with the results of this research. According to Young, humans enter the world in a state of freedom. As they move through the levels of life experience they become less free and move into a structured and deterministic world with little individual identity or choice. The next stage in developing consciousness Young calls centering in which the individual breaks with the authority of the binding stage and begins to make choices. At this stage, the individual reevaluates and reconsiders her/his life and this realization makes it possible to begin the evolution back to freedom by moving through the stages of decentering and unbinding to an expanded consciousness and freedom.

Young's (1976) theory of developing consciousness is closely aligned with the study participants' experiences of their healing journey. They described the experience of binding and centering at the beginning of their journey. They also talked of the frustration and despair as they tried to assert some power in their lives. Hitting the wall, or the attempt or the contemplation of suicide provided a choice point (Young, 1976) in that a reevaluation of their lives began to occur with an evolution back to freedom and to an expanded consciousness. In this sense, the healing journey and the development of an expanded consciousness contain many similarities.

In summary, the experience of personal growth and change as a result of a life crisis, and the theory of developing consciousness have many similarities with the participants' experience of feeling healthy. It

would appear that personal growth and change and the development of consciousness are manifestations of feeling healthy.

Self Identity

The theme *honouring the self* encompassed self definition, self awareness and respect, a nurturing and loving of the self, with a sense of empowerment. In this sense, the participants felt a strong sense of their own identity with a positive self esteem. This experience is in sharp contrast to Charmaz' (1987) contention that people with chronic illness suffer a loss of self identity. Charmaz's (1987) research suggests that people with chronic illnesses often reduce their levels of expectation for self identity. These levels Charmaz calls identity hierarchies and they become visible in people with chronic conditions as, over time, they choose diminishing levels of their self identity. According to Charmaz, experiencing a chronic condition often means reducing identity goals and aiming for a less preferred identity.

The results of Charmaz's research differ considerably with the findings of the present study. In this present study, the chronic condition acted as a catalyst to the participants in developing a personal sense of self worth, and an increased ability to be self defining and self respecting. This was despite the fact that the participants suffered from many debilitating and deforming chronic conditions.

Other research findings support the results of this study. Fichten, Robillard and Judd (1989) studied college students with physical disabilities and found that the self concept of the disabled students was similar to non-disabled students and that both had positive self images. Similarly Green, Pratt and Grigsby (1984) found that people with spinal

cord injuries had a positive self concept, and Matson and Brooks (1982) found that people with Multiple Sclerosis had a positive change in self concept. These contradictory results of both low and high self concepts for people with chronic conditions appear confusing. Perhaps the research question leads to different findings. In this sense, a positive self concept may be equated with a research question focusing on the experience of feeling healthy, whereas a reduced self concept may be equated with a research question focusing on the experience of ill health.

Social Support

The theme *Seeking and Connecting with Others* included an active seeking for people with shared experiences and life goals, to a balance between giving and receiving care, and to a commitment to helping others. These findings parallel much of the theory on social support, but with some differences in emphasis. Several extensive reviews of the literature have provided evidence for both direct and buffering effects of social support on health and well-being (Broadhouse et al., 1983; Di Mattio & Hays, 1981; Gottlieb, 1983; Kessler & McLeod, 1985). Social support is process oriented and refers to the perceived meaning and expressive values of social relationships, to the reciprocity of the relationships, and to the intensity and obligation of the people involved (Kaplan, Cassell & Gore, 1977). It appears that there is a close relationship between the experience of feeling healthy by seeking and connecting with others in this study, and the effects of social support on health from previous research. However, the literature on social support stresses the benefits of having close and meaningful relationships with others in that those who receive such support will feel more healthy. There is less importance

given to the benefits of providing support to others. In seeking and connecting with others, it is the connection the participants made to others, with their commitment to helping that had particular meaning. This is not to say that social support does not consider this dimension, however in this present study the importance of feeling committed to helping others seemed equally important to receiving support. It is more a matter of emphasis than a different theoretical position. Bellingham, Cohen, Jones and Spaniol (1989) stress the importance of connecting with others on a meaningful and committed level. Such a commitment to helping others has been equated with experiences of feeling healthy and an increased self worth (Bloomfield & Kory, 1978; Carkuff, 1981; Hover-Kramer, 1989; Schaff, 1992; Vaughan, 1985; Watson, 1988). In this sense, the theory and research of social support is similar to the theme *seeking and connecting with others*. However, in this study, more emphasis was placed on the commitment to helping others than the social support literature alludes to.

Hardiness and Resilience

The theme *Creating Opportunities* has some similarity with the concepts of hardiness and resilience, but with some notable differences. The participants spoke of feeling healthy by creating opportunities for themselves. These opportunities involved feeling challenged, creating change in their lives, seeking new learning, being courageous and being fully engaged in the flow of life.

The concept of hardiness has many similarities with these experiences. Hardiness is a constellation of three personality characteristics, commitment, challenge and control (Kobasa, Maddi &

Puccetti, 1982). Commitment is defined as the ability to be involved in whatever the individual encounters, and to being active in confronting crisis. Kobasa, Maddi and Puccetti suggest that committed people, with a sense of purpose remain healthier under pressure than those who are alienated and apathetic. Challenge is characterized as a positive attitude toward change. Challenged people value change and believe change rather than stability is the norm. Cognitively, these people are flexible and integrate seemingly incongruent life events and experiences to maintain endurance. Control is the tendency to believe reinforcements occur primarily as a result of the persons own efforts and attributes. In this sense, people with internal locus of control (Rotter, 1966) have a self-perceived ability that they can influence outcomes of stressful life events.

Kobasa (1979) developed this health related concept of hardiness to explain the characteristic of people who experience high degrees of stress without becoming ill. In this sense, hardiness has been identified as a moderating and mediating variable in the stress-illness response in that it enhances coping and self management. Although the attributes of hardiness parallel some of the attributes of the theme, *creating opportunities*, particularly in facing challenges, feeling committed, and creating change in the participants lives, the effect of these characteristics on the individuals was considerably different. Hardiness is restrictive in Kobassa's conceptualization in that the constellation of control, challenge and commitment is considered effective in helping people cope or manage stressful life events and as such, it is a defensive posture. In contrast, the participants of this study talked of *creating*

opportunities in a more expansive and growthful way. The participants experienced feeling healthy in *creating opportunities* because these opportunities moved them forward to an expanded and healthy view of themselves, not to merely manage or cope with their health challenge.

Similarly, the concept of resilience has been equated with adaptation to stressful life events in that a resilient individual has the capacity to make a psychosocial comeback in adversity. Resilience is conceptualized as an aggregate of psychosocial resources namely ego strength, social intimacy and resourcefulness that promote coping efficacy (Kadner, 1989). As such, resilience is a type of preparedness that is mobilized by stressful life events in that the resilient individual is able to self-regulate internal responses and control thought processes. Ego strength enables the individual to maintain an integrated and dynamic balance between wishes, needs and reality (Kadner, 1989). If balance is maintained the ego is considered to be functioning well and to be strong. Social intimacy involves the individual's ability to develop and maintain intimate relationships. In this sense, this characteristic is similar to social support and has been noted as a critical concept in maintaining health. Resourcefulness is a skill used to monitor, control and to change unpleasant events and to minimize the effects of these unpleasant events on the individual (Fine, 1991). In this sense, if the individual is able to determine which events are controllable, and then be able to control them, effective coping is facilitated.

Although ego strength and the theme of *honouring the self* both consider the personal involvement of the individual, some critical differences can be noted. The major difference in discussing resilience is

that the ego is considered to be strong in order to manage and cope with adversity, whereas *honouring the self* is an open, expansive and growthful experience moving the participants toward greater self awareness.

Similarly, social intimacy in the conceptualization of resilience and the theme *seeking and connecting with others* both attend to the need for personal intimacy. However, social intimacy is considered necessary to enable coping whereas the study participants spoke of moving out to connect with people at a deep and meaningful level and to be committed helpers to others in times of need. Again, although the similarities of social intimacy and the theme *seeking and connecting with others* are evident, in resilience the purpose is to cope, or to manage, or to adapt to adversity whereas the study participants talked of an expansive and growthful relationship with others.

Finally, the concept of resourcefulness discussed in resilience is similar to the theme *creating opportunities*, in that negative life events may be changed to positive experiences. Here the similarity ceases. Resourcefulness is considered a necessary attribute to minimize undesirable effects of stressful life events whereas the theme *creating opportunities* involves an opening up to opportunities with the participant's intention that new and growthful experiences will ensue.

Although the attributes of hardiness and resilience have some characteristics in common with the themes *honouring the self*, *seeking and connecting with others* and *creating opportunities*, the basic assumptions underlying hardiness and resilience are vastly different to this study's three themes. Resilience and hardiness are considered defensive and coping mechanisms in reducing the harmful effects of stressful life events on

individuals, with the expectation of adequate adaptation. In contrast, the basic assumptions underlying the themes of *honouring the self*, *seeking and connecting with others*, and *creating opportunities* are of personal growth, the expansion of experiences, and the evolution of consciousness. In this sense, resilience and hardiness are restrictive in focusing on the maintenance of health and adaptation whereas this study's themes are expansive and growthful and lead to fuller experiences of feeling healthy.

Comparison with Selected Definitions of Health

To conclude this discussion section, a comparison will be made with the results of this study to three leading nurse theorists regarding their philosophy of health. This comparison will include the theories of Smith (1981), Parse (1981, 1990), and Newman (1986, 1990a, 1990b).

The theory of health advocated by Smith (1981) is still considered one of the most salient theories in nursing. A description of Smith's model was given in the literature review section of this study and therefore a brief overview will be given here. Smith divided the conceptualization of health into four categories. The first and narrowest conception of health is the clinical model which focuses primarily on the elimination of morbid physical or mental conditions and relief of concomitant pain. This conception follows the medical model, emphasizing illness, not health. The second categorization is of role performance. In this categorization, as long as an individual can perform roles effectively, that person is considered healthy. The third category is the adaptive model of health wherein health is seen as the ability to maintain flexible adaptation and illness is seen as a failure in adaptation. Smith's fourth conceptualization of health, the eudaemonistic model,

describes health as an ideal of human nature, directed toward fulfillment, complete development, and self-actualization. Smith suggests these four conceptualizations of health are progressive and inclusive in that an individual has to be clinically healthy, able to perform required tasks, adapt to her/his environment and feel fulfilled and self actualized in order to be healthy. As Smith (1981) points out regarding the four conceptualizations of health, "they are not mutually exclusive ideas" (p. 47). Although Smith's theory of health has been useful in viewing health from differing perspectives, the inclusivity of the four conceptualizations suggest that people living with chronic conditions could not be considered healthy. People with an illness/disability would not fit the criteria for the clinical model of health, neither would they necessarily be able to perform required tasks. Also, the participants in the present study were not committed to adapting to their chronic health condition, but rather to grow and expand their horizons as a result of their illness/disability. In this sense, the people in this study would fit only into Smith's eudaemonistic model of health, and because of the inclusivity of Smith's other three conceptualizations of health, they would be considered unhealthy. In order to recognize and promote health for people with chronic conditions, it is important to broaden the conceptualization of health and to incorporate the notion of health within illness.

In contrast to Smith's conceptualization of health, both Parse (1981, 1990) and Newman (1986, 1990a, 1990b) consider health from a more expansive perspective which more closely aligns with the participant's experiences of feeling healthy. Parse (1981) considers health to be a

process of becoming, or of continual development, experienced by the person. In this sense Parse (1990) suggests that health is a personal commitment whereby the individual creates or chooses his/her own health perspective. That is, health is a process of unfolding which can only be described by the person experiencing health. Parse (1990) describes this as a non-linear process "which cannot be described as good or bad, more or less, it is just the way the human is" (p. 137). The individual makes choices about health by a synthesis of values which may be implicit or explicit. In this way, individuals can choose to stay with their personal commitment of health, or they may choose to change their commitment by changing the meaning of the situation, thus changing the experience of health (Parse, 1990).

Parse's theory of health appears to be very congruent with the participant's experiences of feeling healthy. The participants in this study felt very committed to their experiences of health, and they all made choices about changing the meaning of their health experience as they became ill and/or disabled. This was a process of unfolding as Parse (1981, 1990) suggests, and the experience of feeling healthy for these participants was a personal commitment. This present study expands on than Parse's theory of health by providing a framework of how health was experienced by people with chronic illnesses/disabilities.

Similarly, Newman's (1986, 1990a, 1990b) theory of health is congruent with the participants' experiences of feeling healthy. Newman (1986) considers health to be a process of transformation to higher levels, or to a greater complexity of consciousness; in fact, health is the expansion of consciousness. Marchione (1993) describes Newman's theory

of health as ". . . the flow of life. It is a kaleidoscopic evolution of patterning, with contradictions, ambiguities and paradoxes continually synthesized into insights that lead to an ever expanding consciousness (transformation)" (p. 17). According to Newman (1990b) people are continuously active in evolving their own pattern of the whole. This manifestation of the whole involves both illness and health. Therefore there can be no separation of health and illness, but rather, a synthesis of the whole, which is health. According to Newman (1990a) a health crisis is an opportunity for individuals to more fully experience the patterns of their lives, to transcend their physical limitations, to become more fully aware, and to acknowledge their spiritual dimension.

Newman's theory of health (1986, 1990a, 1990b) appears congruent with the participants experience of feeling healthy. Newman acknowledges the possibility of an expansion of consciousness as a result of a health crisis. Newman also believes in the co-existence of illness and health as a synthesized whole, which she considers to be health. Although the participants did not talk in these terms, the themes, *celebrating life*, *transcending the self* and *acquiring a state of grace* are clear manifestations of an expanded consciousness which came about as a result of a health crisis.

Nursing is moving to embrace a more expansive conception of health which views the individual as a whole person. Such a view allows for the synthesis of both health and illness into a fully experiencing whole. Parse (1981, 1990) and Newman (1986, 1990a, 1990b) provide an expansive philosophical perspective of health wherein the possibility of health and illness co-exist. This study expands on this notion by providing a

description, or a framework of the experience of feeling healthy within illness/disability. Such a description provides a language for an expanded conceptualization of health within illness. This broadened conceptualization has the potential to lead to a perspective transformation for health care professionals as they begin to acknowledge the possibility of feeling healthy within illness. As health care professionals acknowledge health within illness, they are more likely to explore the client's experience of feeling healthy and thus promote the experience of health for these clients.

Implications for Practice and Education

A perspective transformation to include the notion of health within illness and to an expanded view of health will mean that health care professionals will need to work with clients in very different ways than have traditionally been practised. The authors of the Hastings Center Report (cited in Cooper, 1990) suggest that traditional medical models of health care delivery fail the chronically ill. The traditional medical model was developed to care for acute illnesses whereby the perspective of cure took precedence over the perspective of care. Such a model does not attend to the irreversible and long term nature of chronic illness or to the need for continuous client care (Lubkin, 1990, Thorne, 1993). Watson (1988) suggests that nurses invert this perspective and place client care as the highest ideal for nursing. Similarly, Benner and Wrubel (1989) consider a caring perspective to be essential to nursing because it enables individuals, through connection and concern, to determine what is important, to protect what is valued, and to give and to receive help.

Such care would seem essential for people with chronic illnesses/disabilities. Based on the results of this present research I suggest that providing such care would involve attending to the following:

- A recognition of a humanistic and holistic approach to health and healing.
- To view health as a potential for transcendence and expanded consciousness rather than adjustment or adaptation to the client's condition.
- An awareness of, and an acceptance for, different forms of healing modalities.
- An awareness of the person as a whole being. Acknowledging and incorporating the physical, the emotional, the mental, and the spiritual dimensions of the person.
- An appreciation of the value of different philosophies of the world in the ideals and values of health.
- An acknowledgement that the meaning of health derives from many spheres, the mental, the physical, the aesthetic, the interpersonal, the social and the spiritual.
- An acknowledgement that health is an expansion of consciousness and as such, the spiritual dimension is the most important for health and healing.
- Experiences of health and healing are facilitated by intersubjective, transpersonal caring, trusting, respectful and authentic relationships.

How can health care professionals (and nurses in particular) promote such health and healing? Quinn (1989) suggests that all healing is self-healing whereby healing is a "total, organismic, synergistic response that must emerge from within the individual if recovery and growth are to be accomplished" (p. 554). Quinn further suggests that all humans have healing capacities, and that these capacities are innate and available to us all. In this sense, the nurse functions in the capacity of a midwife to assist the birthing process of self healing. "When true healing is occurring, there is always new life arising. Healing is always creative,

bringing forth patterns and connections that did not exist before" (Quinn, 1989, p. 555). This is about birthing health and wholeness.

Similarly, Parse (1990) suggests that the nurse become "a 'nurturing gardener' rather than a 'fix-it' mechanic" (p. 139). In this sense, Parse is suggesting that the nurse be truly present to the person in a "subject-to-subject interrelationship, a loving, true presence to enhance the quality of life" (Parse, 1987, p. 167). Such a presence would be non-mechanical or routinized, but rather an authentic being with the person in an attentive and caring relationship. Parse (1990) like Quinn (1989), believe that healing is self healing and that with the nurses' authentic and attentive presence, the person will find his/her individual way to health and healing.

In considering the nurse as a midwife to the birth of healing (Quinn, 1989), and as a nurturing gardener in promoting self healing (Parse, 1990), as well as attending to my assumptions to promote health and healing, I will turn back to the participants and include some of their suggestions for promoting healing for the chronically ill and/cr disabled.

Ask me what I need, give me a sense of partnership. Don't be afraid to lose control. I would like to tell them [the health care professionals] to have the courage to be real with us. I wish they wouldn't hide their feelings of powerlessness behind their arrogance.

Catherine

The most important thing they [health care professionals] can do for me is just listen, listen, and try to get a sense of my story.

Sally

The most help he [the physician] ever gave me was one day when he said, 'look, I know you will be the one to know what is right for you.' That level of respect.

Sheila

Being willing [the health care professionals] to take risks with people, to move into the unknown and to be trusting.

Ann

Being able to pose questions rather than give answers, to promote self exploration and self examination. I am talking about challenging questions, but this can only be done in an atmosphere of trust and respect which has to be built up over time.

Helen

Be careful of your language, I am not a disabled person, but a person with a disability.

Scott

These quotes from the participants of this research speak to a partnership with health care professionals, characterized by a level of trust and respect. The participants also felt some empathy for the health care professionals who were "stuck" in a curing perspective, because they sensed these professionals felt powerless and helpless when faced with people with chronic conditions. The participants suggested health care professionals become more self aware, self accepting and self loving, and to stop trying to continually "fix" the other person. A critical element raised by the participants in caring for the chronically ill and/or disabled was an empathic, authentic partnership whereby health care professionals move into the world of the client and begin to understand the experiences of the person, and to get a sense of their story. In this sense, health care professionals need to realize that the client's experiences of their chronic illness/disability may not all be negative. Instead, the clients may also have positive and rewarding experiences associated with their chronic condition. The participants also spoke of needing to be challenged in their thinking, and to move beyond the ordinary and take risks. This would require a trusting and respectful partnership with health care professionals. Finally, the participants

spoke of needing to feel empowered. Rappaport (1981) defines empowerment as a process of "enhancing the possibilities for people to control their own lives" (p. 2). Jones and Meleis (1993) suggest the nurse act as a facilitator and resource person in mobilizing resources and in promoting client empowerment. Such actions would foster a sense of control and self-efficacy and thus promote health for people with chronic conditions.

In moving from a perspective of cure to a perspective of care, health care professionals would be able to promote health and healing for people with chronic conditions. Such care would include an empathic, authentic and trusting collaborative relationship with the health care provider. The client could become a partner with the health care professional who would take on the role of facilitator and resource person in promoting health and healing. The power differential could shift from a "power-over" model to a "power-with" model whereby the client would have a sense of self efficacy and control and thus, empowerment. This call for a shift in control is supported by many researchers studying the experiences of chronic illness (Thorne, 1993). This study has also clearly pointed to a need for such a shift, and with the numbers of people with chronic illnesses/disabilities rising, this shift is essential.

In order to attend to these recommendations for practice, the education of health care professionals will need to be transformed. Such an educational transformation will need to include a new philosophy of teaching and learning, a shift in emphasis from illness care to health care, and the incorporation of new healing modalities into the curricula.

Bevis and Watson (1989) make many recommendations and suggestions for transforming nursing education. Of particular note, these nurse

educators suggest a shift in the student/teacher relationship. These authors urge nurse educators to relinquish control of student learning, and to move into authentic, caring and egalitarian student/teacher relationships. Such a move would foster student empowerment and facilitate emancipatory learning. Bevis and Watson suggest that as students begin to experience this new sense of personal control they will value their autonomy and will thus be more likely to extend this same authentic, caring and egalitarian relationship to their work with clients. Such a philosophical shift in teaching and learning is essential if the relationship with clients is to move from a "power-over" model, to a "power-with" model. In order for health care professionals to relinquish control over client care, they must first have experienced a sense of personal control and autonomy in their own learning.

The education of health care professionals must also include a shift in perspective whereby the emphasis on health and healing takes precedence over illness and curing. This will be a radical shift for health care professionals to make. The traditional medical model which has dominated all health care education has focused on disease etiology, treatment and cure. People with chronic illnesses and disabilities (who are the majority of clients today) are not best served by this medical model of client care. The emphasis in education must shift to facilitate the client's subjective experience of health and healing. Nursing education is beginning to make this radical shift by emphasizing the promotion of health and healing into their new curricula (Hills & Lindsey, In Press).

As the promotion of health and healing takes precedence over treatment and curing, new theories and philosophies will need to be

incorporated into health care professionals' education. In particular, the differing philosophies and religions of the world will need to be considered with regards to their ideals and values of health and healing. Similarly, health care professionals will need to have a better understanding and respect for other complementary healing modalities. Although it would be impossible to fully integrate these differing philosophies and healing modalities into the educational curricula it is essential that an acknowledgement and respect of such holistic approaches to health and healing be attended to.

In summary, this study has clearly indicated a need to transform the practice of health care professionals, particularly when working with clients with chronic conditions. In order for this transformation in practice to occur, health care professionals must first be educated from a perspective which emphasizes the promotion of health and healing.

Implications for Theory Development

The results of this research inquiry add breadth and depth to the limited body of knowledge regarding the experience of feeling healthy while living with a chronic condition. The findings of this research raise many interesting questions that need to be addressed if health care professionals are to facilitate health and healing for the chronically ill and/or disabled. More needs to be known about the different healing modalities described in this study. There is still a reluctance on the part of health care professionals to embrace healing modalities which appear to contradict traditional medicine. This reluctance may be partly due to a lack of understanding. The participants in this study turned to

different healing modalities to promote their healing, and for many, their greatest sense of healing came about as a result of these differing modalities. Some theory on these differing healing modalities does exist, however, more needs to be known, and more importantly, this knowledge should be incorporated into educational programs for health care professionals.

The participants of this study had a strong sense of their own spirituality. This was particularly evident in the themes *transcending the self* and *acquiring a state of grace*. The spiritual dimension of healing have received little attention in health care education (Newman, 1989). We require a stronger theoretical base from which to augment our knowledge of spiritual health and healing. Newman (1989) suggests that knowledge development has been slow regarding spirituality partly because of a conceptual confusion between spirituality and religion. Fahlberg and Fahlberg (1991) attempted to alleviate this confusion by suggesting that, "spirituality is a manifestation of human existence and, therefore, prior to and different from religiosity" (p. 274). Knowledge development of spirituality needs to be considered in two ways. First, the confusion between spirituality and religiosity should be attended to and, second, there needs to be a greater understanding of the spiritual dimension of people. Such knowledge development would benefit both health care professionals and clients.

Gaining a greater understanding of people's spiritual dimension would mean incorporating knowledge development from different philosophies of health and healing, particularly Eastern philosophies. Western medicine has, for the most part, ignored these philosophies and therefore much

knowledge development would be required to become familiar with these differing philosophies and their effects on health and healing.

To conclude, the results of this study point to a need for an expansion of knowledge for health care professionals. This knowledge expansion should include the study of Eastern philosophies, different healing modalities and an greater understanding of the spiritual and transcendental dimensions of health and healing.

Implications for Research

Knowledge development is sparse on the spiritual and transcendental dimensions of health and healing. More research needs to be conducted to better understand the healing effects of the human spirit. Chapman (1987) suggested three questionnaires, (a) How's Your Spiritual Life?, (b) Spiritual Wellness Assessment, and (c) Life Map, to measure spirituality and well-being. Although these measures could provide an assessment of a person's degree of spiritual health and well-being, they would not lead to a deeper understanding of the spiritual and transcendental dimensions of health and healing. Studies should be undertaken by nurses which attend to the experiences of spiritual health and healing.

Similarly, there has been little research done on the efficacy of different healing modalities. The comparatively new science of psychoneuroimmunology could provide exciting new insights into the efficacy of different healing modalities (Adler, 1984; Groër, 1991; Lyon, 1990; Pelletier, 1992). Groër (1991) describes psychoneuroimmunology by dissecting the word; psycho refers to cognitive and emotional processes and mood states, neuro refers to the neurological and neuroendocrine

systems, and immunology to the cellular and humeral immune system. Adler (1984) suggests that psychoneuroimmunology is the study of a complex, communicative and interactive system between the brain and the immune system. The theory of this new science suggests that this complex interaction between the psychological, the neurological and the immunological systems can affect health and ill health. Many of the different healing modalities affect the psychological and neurological systems and therefore may effect the immune system. Research is underway to study the effects of different healing modalities on health and healing, however this is in the early stages and more research needs to be done.

In this present research, the experiences of feeling healthy were explored and described for people with stable chronic conditions. It is important to know how (or if) people with unstable or declining conditions also experience feeling healthy. Does the experience of health within illness exist for people with unstable or declining chronic conditions? If the experience of feeling healthy does exist, how is health experienced by this client group? Also, what are the circumstances that allowed for the experiences of feeling healthy? Research into these phenomena would augment the results of this present study.

One of the participants in this study, Malcolm, did not experience the healing journey. Malcolm explained this by suggesting that because he had been disabled since infancy, and therefore had known no other reality, he did not see his disability in any way effecting his experience of feeling healthy. For the other seven participants, they talked of a synergistic connection between healing and their experiences of feeling

healthy. Also, although Malcolm's experience of feeling healthy had some similarities with the other participants, he equated feeling healthy with physical fitness. Perhaps the experience of feeling healthy is more profound and expansive for people who have come to terms with their chronic condition and to change their perspective to include the experience of health within illness. Other authors have posed similar considerations. Tillich (1961) and Leonard (1989) suggest that the conception of health cannot be understood without the essential possibility and the existential reality of illness. Tillich (1961) goes further by suggesting that it is not the conception of health that is important, but rather the meaning of health which only becomes meaningful when confronted by illness. Similarly, Sutton (1991) suggests that the feeling of health is acquired only by sickness and Leonard (1989) contends that it is only when our health fails that we can develop insight into the taken-for-granted understanding of health. If this is the case, then this study is an important contribution in conceptualizing health.

Limitations of the Study

This study was conducted on the West Coast of Canada in 1993. This fact makes the study inevitably time and space bound. Also, by inviting eight participants to be involved in this study, the results reflect the experiences of those eight participants. I make no claim that these findings can be generalized to all people with chronic illnesses/disabilities. Instead, the results of this study are "phenomenologically informative" (Hycner, 1985, p. 295) in that they provide guidance for understanding and caring for people with chronic

illnesses/disabilities. The fact that other people with chronic conditions found a fit with these reported experiences is encouraging. However, no such claim of generalizability is made. In fact, Charmaz (1983) in studying the illness experience of the chronically ill, found very different results. In her study, peoples' sense of self identity were diminished, relationships with others became more strained and problematic, and the subjects in her study "seldom talked of gaining a heightened consciousness of the world, revelations about self or insights into human nature from their experiences" (p. 191). Charmaz's (1983) study focused on the illness experience of the chronically ill, whereas the present study focused on the experience of feeling healthy within illness. There are profound differences between the results of Charmaz's research and findings of this study, and these differences point to a critical issue. Although health can be, and is experienced by the chronically ill and/or disabled, no claim should be made that all people with chronic conditions experience feeling healthy. The research of Stuifbergen, Becker, Ingalsbe, and Sands (1990), and Health and Welfare Canada (1987) point to the fact that between 60-73% of people with chronic conditions consider themselves healthy, however, the assumption cannot be made that the findings of this study would accurately reflect the health experiences of these studies respondents. The danger would be in assuming that people with chronic illnesses or disabilities either conform to the experiences outlined by Charmaz (1983), or to the experiences described in this present study. The essential notion here is that health and illness experiences are individually defined and therefore should be explored fully with each person with a chronic illness or disability. This research

provides for another perspective of living with a chronic condition, and as such it is an important contribution.

Another question raised in this study is the issue of the elite bias described by Miles and Huberman (1984). Although I had no difficulty in finding eight participants for my research and therefore I assume that the experience of feeling healthy while living with a chronic condition is not unusual or unique, these participants were very articulate and self reflective about their experiences. The participants had all read extensively and had been through some profound experiences of introspection and self reflection. Because of this extensive exploration they all spoke eloquently of their experiences of feeling healthy. I do not consider this to be an elite bias, but rather a reflection of how health is experienced by this client group. That is, the healing journey and the experiences of feeling healthy arise from deep reflection and introspection.

Conclusion

The purpose of this study was to explore and describe the meaning of the experience of feeling healthy for people with chronic illnesses or disabilities. The participants in the study described and explored their *healing journey* which involved the beginning phase of shock, anger, denial, frustration and resentment. These emotions lead to a bleak despair and a *hitting the wall* when suicide was either contemplated or attempted. From the shock of this intended action the participants talked of *turning around* and *letting go* of their debilitating emotions and the desire to be their former selves. As they let go of these emotions and desires they

experienced an *opening up* to new possibilities and new horizons, and a *letting in* of new opportunities and experiences. Finally, the participants regarded their chronic illness/disability as *a gift*.

The experience of feeling healthy included an *honouring of the self*, an experience of self definition, self love, self nurturance with a sense of empowerment. Participants also spoke of *seeking and connecting with others* at a deep and meaningful level. This connection involved both giving and receiving of care and support. The experience of feeling healthy also involved *creating opportunities*, which included feeling challenged, seeking new learning, being courageous and creating change. The participants also talked of *celebrating life*, of feeling joyful, with a sense of vitality, energy, humour and passion. As well, the participants spoke of *transcending the self* which portrayed an expansionist feeling, with a sense of escapism, fantasy, visualization and freedom. Finally, the participants spoke of *acquiring a state of grace*, which included a deep sense of connection within themselves, with a sense of profound inner knowing and trust. They also talked of a sense of their own spirituality, and of being at one with their Creator. These experiences resulted in a sense of harmony, rhythm and peace.

This study is an important contribution to the conceptualization of health within illness. In exploring and describing the experience of feeling healthy while living with a chronic condition, this study provides a language for the health experience. If the conceptualization of health within illness is attended to by health care professionals, this may contribute to a change, or a shift in perspective. This shift in perspective provides an opportunity to expand the focus of client care to

include health and illness. Such an expanded focus could contribute to the promotion of health.

I will conclude with the words of Parse (1990):

Health is a personal commitment--only I know me. Health is my own living values. I constitute my health with my mutual interconnectedness with the world. The nurse's true presence with me calls me to learn the meaning I give to situations, but in me and my world is 'the way'--I know it in my tacit-explicit--I know it at all levels of my universe, in ways I cannot say and that no others know. Health is how I live my life--my own personal commitment to being the who that I am becoming . . . Listen to me nurse, when I tell you how I am, and what I will do--since that is how I am going to be me (p. 140).

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APPENDIX A
INFORMED CONSENT

Informed Consent

Investigator: A. Elisabeth Lindsey, BSN, M.A.

I, _____, consent to being part of this study investigating the experience of feeling healthy for people with chronic health challenges. I understand that there are no known risks involved for participants, and that anticipated inconveniences include only the time required to participate in two or possibly three 50-90 minute interviews.

I understand that my involvement in this study is completely voluntary and that I may decide to withdraw at any point without negative consequences. Should I decide to withdraw, the tape recorded interviews and transcriptions will be returned to me.

I am aware that I will be interviewed by the investigator on two, possibly three occasions to fully explore the meaning of feeling healthy while living with a chronic health challenge. I understand that the interviews will be exploratory and open-ended, and that they will be tape recorded and transcribed. I also understand that the investigator will analyze the interviews before subsequent interviews take place, and that I will be asked to participate in the interpretation and analysis of the original and possible second interview.

I am aware that my involvement in this study will be kept strictly confidential by the investigator. This confidentiality will be maintained by assigning a code number to the tapes and transcriptions. The list of names and identification numbers will be kept in a locked drawer and will be destroyed upon completion of the dissertation. The anonymous transcriptions will be retained and audio tapes will be destroyed at completion of the study. I also understand the results of the study, published or unpublished, will in no way identify me.

Signed: _____

Date: _____